Dying in a rural residential aged care facility: an action research and reflection project to improve end of life care to residents with a non-malignant disease

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Dying in a Rural Residential Aged Care Facility:
An Action Research and Reflection Project to Improve
End of Life Care to Residents with a Non Malignant Disease

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A thesis submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy

April, 2010
THESIS DECLARATION

I certify that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and the material has not been submitted, either in whole or in part, for a degree at this or any other University.

I acknowledge that I have read and understood the University’s rules, requirements, procedures and policy relating to my higher degree research award and to my thesis. I certify that I have complied with the rules, requirements, procedures and policy of the University (as they may be from time to time).

Name: Joanne Rowley

Signature:

Date:
ACKNOWLEDGEMENT

I would like to take this opportunity to express my immense gratitude to all those persons who have given their invaluable support for this thesis.

In particular, I am profoundly indebted to my supervisor, Emeritus Professor Beverley Taylor, who was always generous with her time and knowledge and assisted me in each step to complete this study and thesis.

I would like to extend my thanks to the participants of the residential aged care facilities for their generosity in sharing their insights and time to improve end of life care.

Special thanks, is reserved for my husband Greg, whose loving, extensive support helped me to achieve completion. In addition, to our children Dylan and Amber, who lovingly supported me throughout this journey.

This thesis is dedicated to the memory of my father, Donald Raymond Riley.
ABSTRACT

This qualitative research explored end of life care provided to people dying with a non malignant disease in two Australian rural, residential aged care facilities. Residential aged care facilities provide end of life care for many people dying from non malignant diseases. The illness trajectory in non malignant diseases can be difficult to predict and symptom management can be challenging. Further, as the Australian population ages, the demand for optimal end of life care for frail, older people is anticipated to increase. Therefore, this study aimed to explore issues as identified by nurses and relatives of residents dying from a non malignant disease in order to examine ways in which nurses can provide nursing care that maximises the likelihood of a good death, identify the barriers nurses perceive to prevent optimal end of life care to dying residents, and explore the relationships between nurses and relatives of the dying resident, with the intention of improving care.

Following ethical clearance, 14 aged care staff overall within both facilities were recruited to the project. Participants included Registered Nurses, Enrolled Nurses, Assistants in Nursing and other aged care staff personnel, all of whom were in a carer relationship with a dying resident. In addition, eight relatives of dying residents were interviewed, using individual, face to face, semi structured interviews.

Taylor’s (2006) 13 step action research and reflection method was incorporated into five main phases, including foundation building, reflection on practice
stories, identifying thematic concerns, action plan creation, implementation and critical reflection. In both facilities, group meetings were held weekly for up to 19 weeks. Data were gathered using combinations of reflective drawing, practice stories, interviews and surveys. Relatives’ interview transcripts were incorporated into the nurses’ group meetings, so that end of life care issues of importance to relatives were shared, with the intention of assisting the nurses to examine the nature of aged care nursing and relationships that occur with relatives of the dying resident.

Thematic analysis was conducted and through group consensus, themes and subthemes emerged from the practice stories indicating aspects of end of life care requiring further improvement. Major thematic concerns were prioritised for action, which included considering the possibility of addressing staff debriefing and better pain management. Through collaborative processes, action plans were created, implemented and evaluated, with participants reporting varying degrees of success in attempting to improve these aspects of care.

This project demonstrated that the delivery of end of life care to residents in these rural, residential aged care facilities was inconsistent and of varying quality. Grief and loss permeated aged care work and affected both staff and relatives of the dying resident. Some of the barriers identified in delivering effective end of life care included hierarchical structures, poor staff attitudes, doctors’ prescribing practices, lack of communication within the team and limited palliative care knowledge and services. Poor pain management practices at end of life were related to numerous issues, including the demands of managing more complex conditions, a lack of implementation of evidence based recommendations, and staff knowledge deficits.
Although this project highlighted care deficits within two specified Australian aged care facilities, literature supports the contention that issues exist nationally and internationally within other aged care facilities and systems, in relation to caring for people dying from non malignant causes. The failure to adequately address dying in older people is reflective of aged care industries, which are challenged to meet the increased complexity of delivering optimal end of life care. Further, when end of life care guidelines are available, they are not being enacted effectively. This action research and reflection project suggests that the enormity of these problems requires sustainable practice changes, which will embed and facilitate effective palliative care within aged care institutions.

This project demonstrated that it is possible to establish a working relationship with aged care nurses, with no prior knowledge of action research or reflective processes, to influence end of life care nursing practices. The gains achieved in this action research and reflection project can be sustained in practice, if these specific aged care facilities continue to prioritise grief and loss issues, and implement a range of strategies to address pain management, such as standardised assessment tools, end of life clinical pathways, and ongoing audits and case reviews. Critical to the success of these initiatives is the support for staff, who deliver end of life care, to believe they have a voice and feel supported by their facilities, to constantly examine clinical practices and plan and implement strategies to improve care. The practical strategies generated and used in this project can be utilised in other aged care facilities by nurses, educators, managers and other health professionals, with whom they resonate.
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EXECUTIVE SUMMARY

This Executive Summary provides an easy reference, 13 page overview of the project, for the benefit of the research sponsors and clinical stakeholders.

Acknowledgement

The project was commissioned through collaboration between the University of New South Wales School of Rural Health (now known as the Faculty of Medicine Rural Clinical School) and Southern Cross University Aged Services Learning and Research Collaborative (ASLaRC). The mission of the Rural Clinical School is to provide education to medical students who may choose to practice in rural Australia. The primary aim of ASLaRC is to enhance community capacity in providing services for older people. Funding for this research was secured by ASLaRC in 2004 from a local community credit union, Bananacoast Credit Union, which supported Dr Jim Curran’s focus for ASLaRC to improve palliative care in non cancer dying.

Background

Australia’s ageing population is anticipated to increase over the next two decades (Australian Government, 2007; Department of Health and Ageing, 2008; Gartrell, 2003). The proportion of people aged 65 years and over in Australia has tripled, from 4% in 1901 to 12% in 2001. It is projected that this growth will continue and by 2047, 25% of the population will be aged 65 years and over,
while the over 85 year age group growth rate is expected to increase, from 1.7% of the total population in 2007 to 5.6% by 2047 (Australian Government, 2007). Frail older people are the population group who are most likely to enter residential aged care facilities, requiring end of life care for a range of chronic illnesses.

In Australia and internationally, residential aged care facilities are increasingly becoming the place of care and site of death for ageing populations (Kristjanson, Walton & Toy, 2005; The Myer Foundation, 2002; Teno, 2003). Aged care facilities are structured to meet the needs of large numbers of people by the most efficient means, using regulated care systems, and often with limited resources (Eley, Hegney, Buikstra, Fallon, Plank & Parker, 2007; Quadagno & Stahl, 2003; Wowchuk, McClement & Bond, 2006). While the demand on residential aged care facilities is increasing, palliative care service provision is undergoing a change in direction with the anticipated explosion of demand for the specialty services. Access to palliative care for the dying older person remains limited and regulated within a framework of guidelines, standards and strategic planning (Gadzhanova & Reed, 2007; Kristjanson, Toye & Dawson, 2003; Teno, 2003; Wowchuk, McClement, Bond, 2006). It is important, therefore, to question the assumption that end of life care guidelines and frameworks are being implemented effectively into residential aged care.

Further, people dying from non malignant diseases in the residential aged care setting have been historically under-represented in research literature (Rosenwax, Blackmore & Holman, 2005; Wowchuk, McClement & Bond, 2006). The management of symptoms related to non malignant diseases presents
numerous challenges to those who care for the dying resident (Janssen, Spruit, Wouters & Schols, 2008).

The Research Objectives and Approach

This study aimed to explore issues as identified by nurses, associated staff and relatives of residents dying from a non-malignant disease, in two, rural Australian residential aged care facilities, in order to:

- Examine ways in which nurses can provide nursing care that maximises the likelihood of a good death;
- Identify the barriers nurses perceive to prevent optimal end of life care to dying residents, and
- Explore the relationships between nurses and relatives of the dying resident, with the intention of improving care.

To develop an understanding of the context in which nurses in the residential aged care setting provide end of life care to people dying from non-malignant diseases, the issues that prevent optimal end of life care delivery were examined in this project. A participatory, collaborative action research and reflection approach, which encouraged participants to reflect on their practice issues, was used in order to improve their healthcare practices. Action research is a research approach that engages people in their work contexts, to identify issues, influence practice and facilitate positive changes. The reflective component of the process requires participants to identify issues that are relevant to practice, to develop solutions or strategies to change practice or improve situations (Taylor, 2006).
Following ethical clearance, 14 aged care staff overall within both facilities were recruited to the project. Participants included Registered Nurses, Enrolled Nurses, Assistants in Nursing and other aged care staff personnel, all of whom were in a carer relationship with a dying resident. In addition, eight relatives of dying residents were interviewed, using individual, face to face, semi structured interviews.

Taylor’s (2006) action research and reflection method was incorporated into five main phases, including foundation building, reflection on practice stories, identifying thematic concerns, action plan creation, implementation and critical reflection. In both facilities, group meetings were held weekly for up to 19 weeks. Data were gathered using combinations of reflective drawing, practice stories, interviews and surveys. Relatives’ interview transcripts were incorporated into the nurses’ group meetings so that end of life care issues of importance to relatives were shared, with the intention of assisting the nurses to examine the nature of aged care nursing and relationships that occur with relatives of the dying resident.

**Research Highlights**

Residential aged care facilities are a recognised place of dying (Hall et al., 2002; Wowchuk et al., 2007) and will be more so in the future, therefore, it is important for managers and staff to acknowledge this aspect of their service delivery and determine ways in which end of life care issues can be addressed, in a proactive approach to care. It is noteworthy that both facilities needed to improve various aspects of end of life care and that both groups identified similar concerns in end of life care, however, each facility prioritised their thematic concerns differently.
Identifying end of life care issues that can make a positive difference to a person dying from a non malignant disease in a residential aged care facility is more likely to occur when the facility is committed to constantly improving care, and is willing to reflect and act on thematic concerns related to end of life care. This project demonstrated that when participants explore practice issues using an action research and reflection methodology that encourages a safe, supportive group environment and acknowledge the issues relative’s raise of importance in end of life care, a proactive approach to finding solutions results.

The participatory nature of action research provided participants with an opportunity to engage in and belong to a process that facilitated the identification of barriers, which prevent optimal end of life care and the approach assisted participants to examine ways in which they could provide nursing care, which maximised the likelihood of a good death. Through the collaborative and reflective research processes, hierarchical structures, poor staff attitudes, pain management knowledge deficits, doctors’ prescribing practices, a lack of communication within the team, grief loss and bereavement and limited palliative care education and services were identified as some of the barriers to delivering effective end of life care. It became apparent in these facilities, and it is also documented within national and international aged care literature, that improvements are required in how residential aged care facilities address end of life care issues, including pain assessment and management, supporting relatives and staff to cope better with dying and death and addressing grief, loss and bereavement. Practical suggestions for improving end of life care as identified in the research are as follows:
Pain Assessment and Management

Pain was the primary symptom discussed by participants including relatives, in both facilities and inadequate pain management practices in end of life care were highlighted. Identifying staff pain management knowledge deficits enables early detection of key deficiencies and can demonstrate areas for improvement to staff. An important research insight was that many nurses may fail to address knowledge deficits and remain unaware of the impact those deficits have in contributing to the complexity of a dying resident’s care. The implications of this insight are:

- Be prepared to manage pain related issues in end of life care before they develop;
- Promote effective pain practices as everyone’s responsibility in the organisation;
- Communicate and share pain information with all facility staff;
- Avoid staff working outside of their scope of practice, and utilise palliative care experts when necessary;
- Eradicate labelling residents’ “behaviours” until pain assessment is comprehensively documented, and pain, as a cause of the behaviour, is excluded;
- View untreated or inadequately treated pain as a reportable, critical incident;
- Avoid pro re nata (p.r.n) or administer as necessary prescribing of pain relieving medications in end of life care;
• If p.r.n. or administer as necessary analgesics are prescribed, request the doctor produces evidence that a pain management plan is in place and the resident is being monitored closely;

• Confirm that staff are aware of the requirements of the prescribed pain management plan;

• Incorporate pain assessment and management into staff performance review;

• Assess staff to identify gaps in pain management knowledge and attitudes, present survey findings, target education to address identified knowledge gaps and highlight how knowledge deficits contribute to the complexity of end of life care;

• Encourage allied staff to participate in sharing educational information with nurses;

• Provide resources for educational information, using a variety of formats, for example, one on one education sessions;

• Standardise pain assessment tools for cognitively competent and cognitively impaired residents, provide access to them at the bedside, and integrate them into routine daily care;

• Discuss pain scores and medications at orientation and handover, include difficult to manage pain assessments as a group exercise and include pain management issues on meeting agendas;

• Embed pain assessment into a regular schedule for all residents, including those not reporting pain;

• Educate staff on medication absorption times and provide access to drug information;

• Engage staff in conducting audits, that include pain relieving strategies and report audit findings back to staff;
• Revise or develop facility pain management policies; and
• Perform regular case reviews to recognise effective pain practices and identify pain management and other symptom problems.

The action plans created by participants highlighted the necessity for standardised pain assessment tools for cognitive and cognitively impaired residents to be easily accessible to staff at the point of care. Participants agreed that pain scores must be discussed at each shift handover and regular pain assessments should be integrated into routine daily care. Also, untreated or inadequately treated pain must be viewed by all staff as a critical incident and addressed in the same manner as a fall or other accident.

Coping better with dying and death

• Offer relatives verbal and written information on grief and loss as part of the admission process and periodically reassess their needs;
• Encourage the admitting doctor and director of nursing/care to meet with new residents and relatives early in the admission process to formalise ACD requests and document residents’ expectations for end of life care;
• Have end of life care plans in place before the final stages of dying;
• Acknowledge grief and loss are issues in aged care and facilitate opportunities for staff to debrief;
• Clarify who in the facility is responsible for informing a relative that a resident is dying;
• Educate nursing and support staff on communicating with family members of the dying resident;
• Acknowledge that relatives can provide valuable information about a resident and can contribute to end of life care planning;
• Access specialist palliative care services early;
• Request RNs or ENs complete a palliative care course, as a prerequisite to employment;
• Acknowledge a lack of palliative care knowledge may impede optimal end of life care and offer palliative care education to existing staff;
• Establish connections and facilitate in-reaching of palliative care services;
• Assess knowledge and educate staff on the use of a palliative approach to care, including symptom management such as pain;
• Raise the profile of pain assessment and management for dying residents within the facility;
• Prioritise and share the responsibility for assessing and managing end of life symptoms;
• Establish or reinforce the organisation’s philosophy for end of life care;
• Share the organisation’s end of life care philosophy with residents and relatives and provide both verbal and written information;
• Be aware of whose wishes are being met in end of life care, and confirm that staff are fully informed of a resident’s wishes;
• Provide dedicated time for educational sessions to build team processes;
• Improve communication within the team through inter-professional respect and contact, use of appropriate assessment tools, professional language, accurate documenting, and being accessible in a timely manner, especially when new treatments are implemented, or a resident’s condition is unstable and deteriorating;
• Maximise doctors’ visits to the facility, by encouraging comprehensive prescribing of end of life care medications;
• Support and provide comprehensive information to doctors, to assist them in their prescribing decisions; and
• Consider adopting and adapting an end of life care pathway as a component of education, a systematic approach to end of life care, and as a means of effective documentation of palliative care delivery.

The action plan created and implemented in Facility One, to improve the likelihood of a good death included the following strategies to address grief issues and engage staff in debriefing opportunities:

• Acknowledge grief and loss in aged care work and prioritise the importance of staff self care;
• Be mindful that some staff may not have witnessed death prior to working in the facility;
• Assist staff to appreciate the potential impact of unresolved grief on end of life care;
• Provide regular, scheduled opportunities for staff to debrief;
• Use a variety of formats for debriefing;
• Acknowledge debriefing opportunities may assist staff in their grief and strengthen team bonds;
• Avoid a quick turnover of residents into vacated beds following a death, as a show of respect for the deceased resident, their relatives and staff, who have cared for them;
• Acknowledge and allow time for the packing up of a resident’s belongings following death, as this can be part of the grieving process for relatives and staff;
• Encourage all facility staff to participate in memorial services if they wish to attend; and
• Conduct regular case reviews and use this as an opportunity to discuss end of life care issues, so that grief resolution and debriefing become integrated into the organisation’s training program.

The action plan created and implemented in Facility One to improve the likelihood of a good death consisted of offering staff a debriefing session using a role play format. The following strategies are important when role play is used as a debriefing method:

• Use role play as a method of lightening the topic area of death and dying, to encourage discussion in a nonthreatening, informal group environment;
• Actors in the role play should plan and rehearse together, before appearing in front of an audience;
• Use props and diverse roles to mimic a real scenario, for example, include a relative and an undertaker role;
• Provide a relaxed atmosphere for the session by including refreshments for the audience;
• Advertise and offer session attendance to all facility staff and integrate it into the regular training schedule;
• Keep attendance optional, by informing staff that session attendance is not mandatory;
• Avoid videotaping sessions, but if videotaping is used, be sure to check the video batteries and ensure the person taping is experienced;
• Introduce the role play clearly, by introducing the actors and the characters they are playing;
• State the group’s ground rules prior to the discussion time, for example, not to interrupt each other;
• Be prepared for a range of issues to emerge in discussion time;
• Be prepared to ask staff to clarify issues or statements they are raising during discussions;
• Advise staff to be prepared for criticisms of care delivered;
• Invite management staff to the discussions, so they both gain insights into issues of concern to staff and contribute to possible solutions or strategies, to address issues;
• Consider inviting palliative care service providers, to add value to discussions and offer possible solutions to end of life care problems; and
• Value everyone’s opinion and contribution to the discussions following the role play.

Study Limitations

Action research and reflection provided a methodology, which assisted participants to examine and expose practice issues, identify barriers and facilitate changes in aspects of end of life care, in these two residential aged care facilities. The literature in aged care also suggests that similar issues exist in other aged care facilities, so the insights and implications of this project are useful for other nurses, with whom these ideas resonate.

Although the process was comprehensive, the study sample size was small and limited specifically to a group of nurses working in two Australian rural, aged care facilities, who nominated themselves to participate in the project. Therefore, in line with a standard critique from a quantitative viewpoint, the findings in
these facilities are not generalisable to other aged care facilities, but they are transferable in a qualitative research sense, if they resonate as ‘local truth’ and are accepted as pertinent and useful to nurses in other aged care facilities. A standard quantitative critique of this project is that the participants in the research facilities may have had a bias to participate in a project on end of life care issues, thus they were unable to remain objective. However, this criticism is counterpointed by the qualitative research assumption that the participants had ‘lived experiences’ and thus they were willing to participate in a collaborative project dealing with practice issues of interest to them, and as such, the insights and implications of the research process provide many practical strategies to improve end of life care for residents dying from non malignant diseases.

**Future Research**

As this is an important and complex research area, there are many opportunities for future research, including:

- the questions: If end of life care guidelines are available to staff in aged care, what aspects of those guidelines are of most use to aged care staff, and do facilities resources support the use of evidence based guidelines?
- repeating this action research methodology, to ignite change, while at the same time developing leadership skills in staff of aged care facilities;
- expanding this project, by exploring and comparing the strategies used in pain management across an increased number and a diverse range of aged care facilities, to identify those strategies that best meet medical and nursing care delivery needs and that demonstrate the best residents’ outcomes;
• exploring issues, which doctors with visiting rights to aged care facilities identify, that impede or enhance their decision making in pain management at end of life;

• an observational study using an ethnographic observation/participation methodology focusing on RN - resident interactions in end of life symptoms, such as dyspnoea, restlessness and so on, to shed light on the qualities and activities required to enhance the decision making processes nurses require to effectively address these symptoms;

• examining how grief is identified and managed in aged care facilities. This research may provide insight into the contribution grief and loss has on nurses’ decision making at end of life, staff turnover rates and care delivery in general; and

• a critical ethnography project to explore how an organisation’s end of life care philosophy is experienced by nurses working in residential aged care.

Conclusion

A key aspect of the collaborative, participatory methodology is for participants to feel supported and, therefore, engaged in examining their practices, participating in identifying possible solutions and as facilitators in the change processes and evaluations. In this project nurses were educated in the processes that can be used for any clinical problems that emerge in their future practice. The project focussed on the necessity for aged care nurses caring for dying residents to be cognisant of the needs of the resident and their relatives. This project helped the participants to provide optimal end of life care, by examining issues of importance in end of life care in their practice context including pain management practices and grief and loss issues. During the course of the action
research and reflection project barriers to prevent optimal end of life care including knowledge deficits and poor communication were highlighted so that these skills could be improved upon and used more often in future care. The relationship between nurses and relatives of the dying resident were explored and demonstrated that participants were willing to acknowledge each others challenges and the importance of optimising communication. Additionally, this study supported the use of action research and reflection by residential aged care facilities, as a beneficial research process for improving end of life care.
CHAPTER ONE: INTRODUCTION

Title

Dying in a Rural Residential Aged Care Facility: An Action Research and Reflection Project to Improve End of Life Care to Residents with a Non Malignant Disease

Introduction

This thesis used action research and reflection to explore the end of life care delivered in two Australian rural residential aged care facilities to people dying from non malignant diseases. This chapter provides an overview of the research and an outline of the contemporary issues surrounding aged care. The research problem, aims, significance, background, and justification for the research are summarised. Finally, an explanation of the key terms used and a brief overview of the research methodology are presented, with an outline and diagrammatic representation of the structure of the thesis and the literature in the thesis.

A logical starting point of end of life inquiry in residential aged care facilities is to develop an understanding of the context in which care is delivered.
Ageing and Aged Care

Australia’s ageing population is anticipated to increase over the next two decades (Australian Government, 2007; Department of Health and Ageing, 2008; Gartrell, 2003). The proportion of people aged 65 years and over in Australia has tripled, from 4% in 1901 to 12% in 2001. It is projected that this growth will continue and by 2047, 25% of the population will be aged 65 years and over, while the over 85 year age group growth rate is expected to increase, from 1.7% of the total population in 2007 to 5.6% by 2047 (Australian Government, 2007). Frail older people are the population group who are most likely to enter residential aged care facilities requiring end of life care for a range of chronic illnesses.

An ageing population impacts on government economic planning. The Australian government’s strategies to address the ageing of the population have included “superannuation and retirement income support, workforce, housing, social inclusion and life long education, as well as medical, health and aged care services” (Department of Health and Ageing, 2008, p.2). In Australia, funding, administering and providing care for the aged is shared by government, consumers and non government providers of care (Department of Health and Ageing, 2008). The demand for an expansion of options for aged care that provides choices for place of care, inclusive of community support for older people in their homes, has reformed the Australian government’s funding and policy position.

Aged care services are governed by legislation including the Aged Care Act, 1997 and the Home and Community Care Act, 1985 (Department of Health and Ageing, 2008). The Aged Care Act governs issues inclusive of the “planning of services, the approval of service providers and care recipients,
payment of subsidies and responsibilities of service providers” (Department of Health and Ageing, 2008, p.10). In addition to regulation under the Aged Care Act 1997, residential aged care facilities are regulated by the accompanying Aged Care Act 1997 principles, which provide guidelines and structure to care delivery (Dawbin & Rogers, 2006). The significance of providing appropriate care and service provision to the aged is reflected in the legislation pertaining to aged care (Australian Government, 2009a).

The quality of care delivered in government funded residential aged care facilities is monitored by a system of accreditation. To maintain acceptable standards, residential aged care services are delivered within a quality assurance framework inclusive of “monitoring of approved providers for compliance with accreditation standards and other specific responsibilities to protect resident safety, a complaints investigating scheme and support for users’ rights” (Department of Health and Ageing, 2008, p. 31). Accordingly, a residential aged care facility is awarded accreditation if the standards are achieved. However, the question of how facilities sustain optimal service standards following accreditation, and implement and maintain compliance with recognised treatment guidelines is of interest, and these matters will be explored later in this thesis.

**The Concept of Control in a Good Death**

The foundation of end of life care delivery is that in a good death, dying can be controlled and delivered in such a way that the physical, spiritual and emotional needs of dying are attended to. However, given the premise there is limited evidence to define what a ‘good death’ comprises and the question as to in whose perspective a death is considered good (Clark, 2003; Ellershaw & Ward, 2003; Steinhauser, Clipp, McNeilly, Christakis, McIntyre & Tuisky,
2000), the notion is well supported that the process of dying is controllable (Department of Health and Ageing, 2005a; Jarabek, Jama, Cha, Ruegg, Moynihan, & Mc Donald, 2008; Lorenz et al., 2008; Qaseem, Snow, Shekelle, Casey, Cross & Owens, 2008).

For dying to be controlled, for the maximal benefit of the dying person, the depth of knowledge and skill of the care provider is critical. David Kuhl, a medical doctor with 15 years experience in palliative care, wrote about what people wanted, who were dying from terminal illnesses, such as cancer or AIDS. Kuhl (2005) suggested dying people “want to be heard and to be understood simply for who they were in the world – in their families, in their work, in their pain, in their isolation, in their grief, suffering and hope” (p. xxvi). Similarly, Steinhauser et al (2000, p. 829), suggested dying patients “need to participate in the same human interactions that are important throughout all of life”. Further, they contended that dying people “feared bad dying more than death” and were “terrified of waking in the middle of the night with intense pain or air hunger” (p. 829). For them, a good death includes providers, who anticipate these fears. In addition, Carlson (2007) reviewed the literature on end of life care in nursing homes and reported dying residents in care did not want their lives prolonged in vain, but did want their symptoms both physical and emotional to be adequately controlled.

The disconnection of Australian culture from witnessing death and the care of the dying, has contributed to the sanitising of the process (Ahmad & O’Mahony, 2005; Goodridge, Bond, Cameron & McKean, 2005). Frequently, providers of end of life care entrusted to deliver end of life care in residential aged care facilities are strangers to the resident and their family. There is a presumption that these strangers are healthcare professionals, who know
what they are doing and will deliver an appropriate, pain free, peaceful death (Denham, Meyer, Rathbun, Toborg & Thornton, 2006; Edwards, Courtney & Spencer, 2003; Wetle, Shield, Teno, Miller & Welch, 2005). However, the reality is that some providers of end of life care have limited training in the delivery of care and there are few supports available for them to access during the process (Kristjanson, Walton & Toye, 2005; Wetle, Shield, Teno, Miller & Welch, 2005). For many staff in the aged care workforce, the skills associated following death can be more familiar than the aspects of end of life care that support the dying resident while they are still alive (Denham, Meyer, Rathbun, Toborg & Thornton, 2006; Nay, 1998). As a resident’s care is surrendered to others, power is entrusted in healthcare professionals. Ownership of power features prominently in the provision of end of life care in aged care (Clark, 2003; Matzo & Sherman, 2001). With power comes responsibility and decision making. In residential aged care facilities, authors suggest that the dying resident is the least powerful person in the hierarchy and their involvement in controlling the process is minimal (Clark, 2003; Kayser-Jones, 2002; O’Connor & Pearson, 2004).

While it can be argued that a good death encompasses all of a dying resident’s needs, controlled care of the dying is a good death if it anticipates a resident’s needs, is strategically planned and closely monitored. To achieve control over the distressing symptoms of the dying process, the role, knowledge and expertise of the care providers should not be underestimated. With these considerations in mind, for the purposes of this project, a good death means achieving a well-controlled dying process, for the maximal benefit of dying people, by anticipating their needs and monitoring their health status, in order to attend quickly and appropriately to their physical and emotional symptoms.
Delivering End of Life Care in Residential Aged Care Facilities

In Australia and internationally, residential aged care facilities are increasingly becoming the place of care and site of death for ageing populations (Kristjanson, Walton & Toye, 2005; The Myer Foundation, 2002; Teno, 2003). Aged care facilities are structured to meet the needs of large numbers of people by the most efficient means, using regulated care systems, and often with limited resources (Eley, Hegney, Buikstra, Fallon, Plank & Parker, 2007; Quadagno & Stahl, 2003; Wowchuk, McClement & Bond, 2006). While the demand on residential aged care facilities is increasing, palliative care service provision is undergoing a change in direction, with the anticipated explosion of demand for the specialty services. Access to palliative care for dying older people remains limited and regulated within a framework of guidelines, standards and strategic planning (Gadzhanova & Reed, 2007; Kristjanson, Toye & Dawson, 2003; Teno, 2003; Wowchuk et al., 2006). It is important, therefore, to question the assumption that end of life care guidelines and frameworks are being implemented effectively into residential aged care.

To maintain the comfort and dignity of dying residents, it is necessary for the people working in aged care facilities to determine if the resident has entered a dying phase and is in need of end of life or palliative care. Delivering end of life care can be challenging, as residents dying from non malignant diseases present numerous symptoms. Symptoms can be difficult to manage, illness trajectories can vary, and death can be unexpected. One aspect of end of life care, which has not received much attention, is the impact on the aged care workforce of unresolved grief and how this can impact on how end of life care is delivered (Lugton, 2003; Strom-Gottfried & Mowbray, 2006). This is a
surprising issue, as this workforce has continued exposure to death and dying.

In Australia, family members’ participation in end of life care is overseen by an aged care workforce with limited end of life, palliative care, or gerontology training (Holloway & McConigley, 2009; Paterson, Xiao, Mitchell, Henderson, DeBellis & Kelton, 2007). The aged care workforce has much exposure to the practical aspects of delivering end of life care. However, to meet the needs of families by listening to them, effectively communicating with them and supporting them during the process of impending loss requires specialised training (Lowson, 2007). In a task focused working environment, the expectation that families needs can be adequately catered to, places yet another demand on a time pressured workforce.

Aged care facilities provide a unique environment in which to study end of life care and they present interesting and challenging issues. Due to the complexity of end of life care there are few strategies to address common issues, but the accessibility to guidelines has stimulated the development of ways to implement evidence based care. Although the research on how best to care for people dying from non malignant diseases is still evolving in aged care (Janssen, Spruit, Wouters & Schols, 2008; Stevens, Payne, Burton, Addington-Hall & Jones, 2007), the environment encourages detailed qualitative studies to be undertaken.
Aims and Objectives

This project used action research and reflective practice processes, with an aim to explore issues as identified by nurses and relatives of residents dying from a non malignant disease, in two, rural Australian residential aged care facilities, in order to:

- Examine ways in which nurses can provide nursing care that maximises the likelihood of a good death;
- Identify the barriers nurses perceive to prevent optimal end of life care to dying residents; and
- Explore the relationships between nurses and relatives of the dying resident, with the intention of improving care.

Significance

The project is significant in identifying end of life care issues that can make a positive difference to a person dying from a non malignant disease in a residential aged care facility. Further, participating nurses are now educated in the processes that can be used for any clinical problems that emerge in their future practice. The project focussed on the need for aged care nurses caring for dying residents to be cognisant of the needs of the resident and their relatives. This project helped the participants and other aged care nurses to provide optimal end of life care, during the course of the action research and reflection project and to use the knowledge and skills more often in future care. Additionally, this study supported the use of action research and reflection by residential aged care facilities as a beneficial research ongoing process, for continually improving end of life care for all residents, including those people with non malignant diseases.
Acknowledgement

The project was commissioned through collaboration between the University of New South Wales School of Rural Health (now known as the Faculty of Medicine Rural Clinical School) and the Southern Cross University Aged Services Learning and Research Collaborative (ASLaRC). The mission of the Rural Clinical School is to provide education to medical students who may choose to practice in rural Australia. The primary aim of ASLaRC is to enhance community capacity in providing services for older people. Research priorities include:

- researching problems of recruiting, training and retaining staff in aged care;
- research into introducing computer prescribing and medication tracking in residential accommodation for the aged; and
- research to address the issues of non cancer dying in our community (Curran, 2003).

Funding for this research was secured by ASLaRC in 2004 from a local community credit union, Bananacoast Credit Union, which supported Dr Jim Curran’s focus for ASLaRC to improve palliative care in non cancer dying.

The Research Approach

This project required a participatory, collaborative research approach, which encouraged participants to reflect on their practice issues, in order to improve their healthcare practices. Action research is a research approach that engages people in their work contexts, to identify issues, influence practice and facilitate positive changes. The reflective component of the process
requires participants to identify issues that are relevant to practice, to develop solutions or strategies to change practice or improve situations (Taylor, 2006). Kemmis & McTaggart (1990, p. 5) agree that action research is a “form of collective self-reflective enquiry” to equalise aspects of social situations in order to transform those situations.

Action research is participatory in nature, with no or minimal power differences between co-researchers. Equalising power relationships between the researched and the researcher assists in building bridges across the theory-practice gap, to implement theories into practice and create an action focus (Charles and Ward, 2007; Meyer, 2000; Minichiello et al., 1999; Polit and Beck, 2006; Taylor, et al., 2006). A crucial element of action research is the collaboration of group members to engage in the process and form bonds of trust with group members (Minichiello et al., 1999).

Reflection is integral to action research. The Australian originators of the action research approach, Kemmis and McTaggart (1990), suggest a process of initial reflection to analyse a situation in order to locate a thematic concern. Reflection is then followed by a process of planning, to implement an action, such as a change or adopting a new practice. The implementation of the plan and the ongoing observation of how it worked in practice culminates in the research participants returning to the process of reflection. Reflection encourages participants to review achievements and examine limitations of changes to practice. The analogy of a “spiral” that incorporates the four Plan, Act, Observe, Reflect steps of action research, demonstrates action research is a “dynamic process that can be engaged in several times before a problem is resolved” (Minichiello et al., 1999, p. 256).
In this research, the combined action research and reflection approach suggested by Taylor (2006) is used. This 13 step process is discussed in detail in Chapter 4: Methods and Processes.

**Key Terms and Writing Style**

As this project is intended for academic and professional readers, methodological and clinical terms are not defined here, but they are described within the relevant sections of this thesis. The key terms defined in the following list relate to the Australian aged care context.

**Assistant in Nursing (AIN):** also referred to as a personal carer, certified nursing aide, nursing assistant, care assistant. An Assistant in Nursing generally receives on the job training, but an increasing number of AINs are undertaking aged care training at the Certificate 3 Level, offered by the Vocational Education Training (VET) sector and a number of private providers (Pearson, Nay, Koch, Ward, Andrews & Tucker, 2001).

**End of life care:** for the purpose of this research, is the care delivered when a resident in an aged care facility is in the final days of life.

**Enrolled Nurse (EN):** ENs’ scope of practice varies substantially between the States and Territories of Australia. The major differences relate to the administration of medication, which in turn influences the educational preparation for ENs. Enrolled nurses typically undertake a Certificate 4 in nursing through Vocational Education Training (VET) and some private providers (Pearson et al., 2001).
Residential aged care facility: in this research, is a facility providing personal and/or nursing care, plus accommodation that includes meals, cleaning services, furniture and equipment (Australian Institute of Health and Welfare [AIHW], 2009a).

Relative: any person viewed by the staff of the residential aged care facility as the next of kin or person for contact.

Resident: a person residing in a residential aged care facility.

Rural: classified from the Rural, Remote and Metropolitan Areas Classification (RRMA) system developed in 1994. The classifications are based on Statistical Local Area (SLA) and allocates each SLA in Australia to a category based primarily on population numbers and an index of remoteness. A rural zone R1 is a large rural with an urban centre population of 25,000-99,999 or R2 small rural centre with populations between 10,000 and 24,999 (Australian Institute of Health and Welfare [AIHW], 2009b).

I have written most of the chapters in an informal, first person pronoun writing style, to indicate my personal involvement in the research as a co-researcher. Participatory action research highlights the collaborative nature of co-researchers working together on common issues, therefore, it is appropriate for me to indicate my presence in the research through "I" and "me", rather than to objectify myself as "the researcher". Exceptions to this informal writing style are the Literature Review and Methodology chapters, which maintain an impersonal academic writing style, to feature other authors’ research and ideas, as they relate to this project.
To acknowledge my position in the action research and reflection process, my participation has been made explicit by the incorporation of reflective journal notes. The font style has been changed to Papyrus to indicate my critical reflections, for example, in Chapters Five and Six, relating to Facility One and Facility Two respectively. My journal reflections have been included as a co-researcher, to demonstrate how I participated and contributed in the action research and reflection processes and facilitated the groups in the research cycles. In particular, I journalled to make sense of the taken for granted assumptions within participants’ stories and I discussed my reflections with a critical friend, who coached me to reach deeper levels of reflection, by asking questions and encouraging me to challenge my personal and practice assumptions.

My role in the research process is indicated in Chapters Five and Six, for example, I asked particular questions of the participants in meetings and of the relatives in interviews. I have purposefully attempted not to focus on my voice as an ‘expert’ in the research, but instead I have focused on participants’ voices and encouraged them to depict their unique events, situations and circumstances. The participants’ stories and the relatives’ interviews have been transcribed verbatim and their spoken words have remained unchanged, even if they contained contentious content, for example, participants’ unexamined assumptions and opinions.

The past tense has been used throughout this thesis document and within the minutes of meetings, to conform to the requirements of a research report. Pronouns have been ‘split’ in the meeting notes (for example, s/he) to hide the identity of a male participant, who joined the group in Facility One. Pseudonyms were used and identifying material was omitted or renamed, to
protect the identities of research participants and the people within the transcripts of the practice stories and interviews. These and other ethical safeguards are explained in detail in Chapter Four: Methods and Processes.

Participants’ reflective drawings are included in Chapters Five and Six. Reflection can take many creative forms including drawing; therefore, it is appropriate to link the participants’ de-identified dialogue with the images (Taylor, 2006). Also in these chapters, an adapted diagrammatic form of Taylor’s model of reflection (see Figure 1.1) has been used to lead the reader through the phases of the research process.
Figure 1.1: An adapted diagrammatic form of Taylor’s model of reflection depicting the phases of this research process

Due to the vast amount of data generated in this qualitative project, the Appendices include examples of facility’s session plans, meeting minutes and relatives’ interviews. Session plans were developed to plan for each group meeting, to ensure meeting time frames and objectives were achieved and to give me increasing confidence in facilitating the groups. Detailed meeting minutes were taken to record group discussions and to verify the accuracy of discussion with the groups each week. The transcripts of relatives’ interviews are included to honour their contributions and as verification of the discussions.

Tables and Figures are used within the thesis document, for example, Table 3.1 in Chapter Four: Methods and Process demonstrates research group demographic information for each facility. A conceptual map of the literature is also included at the end of this chapter to depict the structure of the literature inclusions and to provide a rationale for the areas (Table 1.1).
The format and style guidelines of the Australian Psychological Association (APA) have been followed throughout the thesis.

**Overview of Thesis Chapters**

**Chapter Two** of this thesis examines the literature associated with delivering end of life care for people dying from a non malignant disease in residential aged care facilities. The literature reviewed includes areas relating to how the residential aged care industry will meet future demands of an ageing population, and deliver appropriate end of life care in the changing aged care workforce. Additional literature relating the identification of thematic concerns raised by the action research and reflection groups appears in Chapter Seven: Discussion and Conclusion.

**Chapter Three** examines literature pertaining to the methodology for qualitative research, specifically action research and reflection, the application of the methodology and methods of interview analysis. Within the context of nursing the active engagement of reflective processes in the workplace are explored, to bring about change.

**Chapter Four** discusses the methods and processes used to conduct the research. It describes the ethical ramifications, study sites, process used to gain entry to the facilities, recruitment of participants, participants’ profiles, participants’ and relatives’ data collection and analysis, and trustworthiness measures used in the research.

**Chapters Five and Six** provide in-depth detail of the action research and reflection processes conducted in Facilities One and Two. These chapters use a systematic meeting by meeting approach, to share the experiences of the
nurses, allied staff and relatives during the action research and reflection cycles. The cycles identify the issues in end of life care, and describe the negotiated action plans and the varying degrees of success in attempting to improve end of life care in both facilities. Both chapters provide insights into the experiences of healthcare workers and relatives relating to the constraints in delivering end of life care and into the action plans for making the necessary changes to provide appropriate end of life care.

**Chapter Seven** concludes the thesis by discussing the findings of the research, highlighting insights and implications for future practice. This chapter discusses the themes and refers to recent, relevant literature for debriefing, grief and loss and pain management issues encountered in the care of dying residents. The limitations of the study and suggestions for further research are considered.

**Chapter Summary**

This chapter provided a synopsis of contemporary issues surrounding the delivery of end of life care in Australian residential aged care facilities. The research problem, aims, significance, background, and associated research questions were described, and the chapter concluded with an overview of the research approach, key terms, writing style, and chapter summaries.
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Pain Management

Facility Two

Reflection

Associated Issues: Communication Nurses’ language / Palliative care education Rationale: Influences on end of life practices.

Pain Assessment
Rationale: To highlight the challenges of assessing pain Maas et al (2008)

Facility One

Reflection
Rationale: Outlines the framework for facilitating reflective practice groups and implementing reflective processes Taylor (2006).

Strategies for resolving grief Rationale: To support aged care workers in workplace Elkington (2000)

Pain Assessment
Rationale: To highlight the challenges of assessing pain Maas et al (2008)
CHAPTER TWO: LITERATURE REVIEW

This chapter describes the literature related to end of life care within the context of dying from a non malignant disease in residential aged care settings. Literature related to non malignant diseases, end of life care in residential aged care settings, the aged care workforce, and tools to support end of life care delivery are discussed in this chapter, as they relate directly to the key concepts within the research objectives. The areas of literature raised by the action research and reflection process, specifically, the particular issues nurses faced in delivering end of life care within the respective residential facilities, are located within Chapters Five, Six and Seven.

A search was conducted of the literature related to the subjects of end of life care delivery in residential aged care facilities and non malignant disease. Databases included CINAHL, Ovid Medline, PsychINFO, EMBASE, PubMed, Expanded Academic ASAP and Proquest and various keyword combinations including ‘end of life care/non malignant disease/residential aged care/nurs*/palliative care/dying’. In view of the exceedingly high number of articles (8000+) identified that were linked to these topic areas, I restricted the search terms to ‘non malignant disease’ (Title and Abstract), ‘nurs*’ (Title and Abstract), ‘end of life care’ (Title and Abstract), ‘dying’ (Title and Abstract) and ‘residential aged care’ (whole document). The rationale for limiting the search was to identify primary research papers related to dying from non malignant dying in residential aged care. The search generated 1500 articles, of which a total of 130 papers had the
most relevance to the research aims and objectives. Journal article alerts were also used to identify the latest released publications related to the keywords.
Non Malignant Diseases

People dying from non malignant diseases in the residential aged care setting have been historically under-represented in research literature (Rosenwax, Blackmore & Holman, 2005; Wowchuk et al., 2006). Also, the management of symptoms related to non malignant diseases presents numerous challenges to those who care for the dying resident (Janssen et al., 2008). To develop an understanding of the context in which nurses in residential aged care settings provide end of life care to people dying from non malignant diseases, the issues that prevent optimal end of life care delivery are examined in this section.

Non malignant diseases cause most deaths in Australia. Non malignant progressive, incurable diseases include heart failure, advanced respiratory diseases, such as chronic obstructive pulmonary disease (COPD), renal failure, advanced neurological diseases, such as motor neurone disease, multiple sclerosis, the syndrome of dementia and other neurological conditions, rheumatic diseases and HIV/AIDS (Ahmed, Bestall, Ahmedzai, Payne, Clark & Nobel, 2004; O’Brien, Welsh & Dunn, 1998; Rosenwax et al., 2005). In 2007, non malignant diseases represented three of the top four leading causes of death in Australia. The leading non malignant causes of death included ischaemic heart disease, dementia, stroke and Alzheimer’s Disease (Australian Bureau of Statistics [ABS], 2009).

The malignant disease of cancer is a major cause of death worldwide. Murray and Sheikh (2008, p.958) reported that cancer accounts for “13%” of worldwide deaths, as compared to “47%” for other long term conditions. In comparison,
29% of Australian deaths result from cancer, with trachea and lung cancer rated as the third leading cause of death (ABS, 2009).

Non malignant diseases are diverse in type and are the primary causes of death. Unlike malignancies, the progression patterns of the non malignant diseases are unique and present a number of challenges in end of life care.

Non malignant disease dying trajectories

The implications and trajectories of dying from non malignant diseases have been discussed in academic literature in recent years. The significance of these studies reflects the need to refocus on non malignant diseases, the primary diseases from which people die, and to assist health care workers who deliver the care to understand and manage the various courses these diseases may take in the dying phase. For example, people dying from non malignant diseases typically die over a long period of time. Murray et al (2005) described the process of dying for three non malignant conditions; dementia, heart and lung failure and compared these with the decline associated with dying from cancer. Murray et al described dying from cancer as “a predictable decline in physical health over a period of weeks, months, or, in some cases, years” with an illness trajectory depicting a plateau phase following diagnosis and ending with a rapid decline to death (p.1007). Kafetz (2002) agreed, suggesting that in cancer dying, there was a “terminal phase” that was often apparent and identifiable, however, the dying phases in old age were not as clear (p.96). In comparison to cancer, chronic organ failure such as heart failure and chronic obstructive pulmonary disease, were described by Murray et al. (2005) as long term illnesses with intermittent “acute, often severe, exacerbations” or unwell episodes, frequently
requiring hospital admission and potentially being the time when an unanticipated death may occur (p.1008).

An interesting aspect of the trajectory of dying from a chronic illness is that following each acute exacerbation, functional ability is less than prior to the event, resulting in poorer health after each episode. A consequence of this in residential care can be that the loss of function can increase the resident’s illness acuity and, therefore, the care required for that person following the hospital visit. An example of this was demonstrated in a study by McGhan, Radcliff, Fish, Sutherland, Welsh and Make (2007), who statistically analysed 51,353 Chronic Obstructive Pulmonary Disease (COPD) patients’ records from the Veterans Affairs health-care system databases in the United States. The authors found that patients with COPD had an increased incidence of rehospitalisation and death following a hospital admission for an acute severe exacerbation of COPD. The outcome measures in the study were “time to death, and time to rehospitalisation for COPD” (p. 1749). The incidence of death was “21% at 1 year” and the risk of rehospitalisation was “25% at 1 year” (p. 1751). The study had some limitations including the cohort being largely male veterans and the presumption that the medical record coding was accurate, however, the data reflected the challenges faced in caring for people suffering a non malignant disease, such as COPD.

A third illness trajectory, of dying from dementia syndrome or Alzheimer’s disease, was described by Murray et al. (2005) as “prolonged dwindling”. The effect of dementia is that there is a decline in health of frail, older people resulting in a gradual decline in their functional ability. End of life care challenges associated with dying from dementia include “communication
difficulties, managing adequate nutrition and hydration, and ensuring that pain does not go unrecognised and undertreated” (Department of Health and Ageing, 2008, p. 186). A degree of expertise is required to care for and recognise when a person dying from dementia has progressed through the illness trajectory and has entered into the final phases of life, because “prolonged dwindling” and the progression of dementia mask deterioration in the overall health status.

The gradual, progressive decline of people suffering dementia compounds the difficulties health care workers face in identifying when a person has entered a dying phase. Lennon (2009), a social worker, expressed concern following a review of the literature on providing palliative care to people with Alzheimer’s Disease. The author claimed that “people with terminal illnesses are hidden away in institutions, nursing homes being one of the main places, especially people suffering dementia” (p. 14). Further, she asserted that as the disease progressed for those people with Alzheimer’s Disease placed in nursing homes, there was no direct access to palliative care services.

Interestingly, Teno, Weitzen, Fennell and Mor (2001) used next of kin “proxy interviews” in a study that examined the differences in patterns of decline for cancer and non malignant deaths (p. 463). The authors found that people dying from cancer “were less functionally impaired than were other decedents at a similar point in time”, twelve months prior to death (p. 459). Further, the patient dying from cancer was more likely to have access to palliative care services.

The significance of these studies reflects the need to refocus service provision and be inclusive of non malignant diseases, the primary diseases from which people die. The trajectory of dying from non malignant diseases is different to
cancer. Understanding dying trajectories provides insights into disease progression. A broader understanding of dying trajectories can inform nurses to plan for end of life care and access appropriate services in a timely way, so that appropriate end of life care can be provided to all dying people, regardless of diagnosis.

Predicting the Dying Phase in Non Malignant Diseases

Predicting when residents are likely to require end of life care features in current literature on dying and has been suggested to be useful in improving the identification of dying and the initiation of specialist palliative care service provision (Grbich, Maddocks, Parker, Brown, Willis, Hofmeyer, & Piller, 2005; Mitchell, Kiely, Hamel, Park, Morris & Fries, 2004; Porock, Oliver, Zweig, Rantz, Mehr, Madsen & Petroski, 2005; Wright, Zhang, Ray, Mack, Trice, Balboni, Mitchell, Jackson, Block, Maciejewski & Prigerson, 2008). Predicting when a resident has entered a dying phase in a non malignant disease can be challenging (Miller, Teno & Mor, 2004). In a study of six month survival rates in nursing home residents, Porock et al (2005) calculated the risk of death using a minimum data set with a range of variables, such as gender, age, cancer, congestive heart failure, shortness of breath, treatments and activities of daily living. The purpose of the study was to identify those indicators that best predicted six month mortality and to identify those residents “who may benefit from specialist palliative care or hospice services” (p. 497). The findings of the study were that “many residents were at high risk of dying in 6 months” and the tool predicted that “overall 23% of the residents died within 6 months of their first full assessment in 1999-2000” (p. 497).
Similarly, Mitchell et al (2004), in a study predicting death at six months in nursing home residents suffering advanced dementia, developed a risk of death score using a group of 12, similar variables to the Porock et al., study. The authors found that 35% of those people with dementia died within six months of assessment. This study validated the continued development and the use of risk assessment scores to estimate life expectancy in nursing home residents, as a method of assisting aged care staff in care planning.

This line of thought has been echoed by Matzo (2004), who argued that the difficulty in determining “the course that disease will take and, ultimately, when death will occur” is a barrier to optimal end of life care (p. 44). Combining ongoing nursing assessment with tools, such as Mitchell’s Mortality Risk Index, were suggested as methods of overcoming this barrier, to assist nurses in the accurate prediction of death, “plan clinical strategies”, deliver appropriate end of life care and overcome the “conspiracy of silence” surrounding death in chronic disease (p. 48).

The incidence of terminal disease and the time frame for commencement of end of life care can be relatively short and, therefore, many residents can be overlooked as being in the dying phase of a terminal disease until very near their death. Ongoing assessment of residents’ health has been recommended by Kesler, Mowers, Griffie and Prochnow, in Sheehan and Schirm (2003). The authors proposed an unvalidated Death and Dying Critical Indicators Checklist could be useful in supporting residential aged care teams to reflect on residents’ deterioration over time, by periodically questioning residents’ health status and triggering the implementation of appropriate care.
Murray et al. (2005) highlighted the importance of understanding the variations of decline in non malignant diseases, to facilitate a realistic approach of offering appropriately timed care for “preventing unnecessary admissions to hospital or aggressive treatments” (p. 1009). Tailoring care to illness trajectories was supported by Dy and Lynn (2007), who suggested it “offers a promising way to improve outcomes for patients sick enough to die” and that it assists in planning service provision (p. 512).

It is important that managers in residential aged care facilities acknowledge that many residents enter these facilities to die. Predicting the dying phase, particularly in non malignant diseases, in which assessment of dying can be difficult, needs to be acknowledged as important and considered within the context of ensuring the dying phase is not missed. Using available tools to skillfully assess and intervene and determining residents’ wishes can assist aged care staff to plan for appropriate end of life care delivery in a timely way.

Potentially, people can suffer unnecessarily if they are unrecognised as being in a dying phase, as failing to recognise dying can delay the initiation of appropriate end of life care. Ellershaw and Ward (2003) suggested that “recognising the key signs and symptoms is an important clinical skill in diagnosing dying” (p.30). This line of thought has been echoed by Murray, Boyd and Sheikh (2005), who surmised that the practice of observing patients’ deterioration without intervening before death, denied patients and their families the opportunity to “plan for a good death” (p. 612). Therefore, nurses’ abilities to recognise symptoms can be critical and mean the difference between a death associated with untreated pain, severe breathlessness and other suffering, or a death associated with planned, appropriate care and effective symptom management.
End of Life Symptoms in Non Malignant Diseases

Symptom management is a challenging aspect of end of life care in people dying from a non malignant disease. Palliative literature has predominately been related to symptoms and symptom management in people dying from cancer (Brandt et al., 2005; Hall, Schroder & Weaver, 2002). Interestingly, symptom management in non malignant disease was highlighted in the literature of the 1960s, but it did not gain the recognition it deserved. Solano and Higginson (2006) found that one of the first studies that compared dying from cancer with dying from a non malignant disease was conducted by Hinton in the late 1960s. Hinton’s work influenced other reports that urged for palliative care to be extended beyond cancer dying, but this did not gain momentum until much later. Appropriate care for people dying with a non malignant disease is important as they often have a high symptom burden and equivalent needs to people dying from cancer. The demand for equivalency in service provision to those dying from a non malignant disease has only gained momentum in recent years (Ahmed et al., 2004; Janssen et al., 2008) and inequities need to be acknowledged in view of the predicted ageing of the population and anticipated demands for service provision to the dying.

Non malignant diseases carry a high symptom burden. Janssen et al (2008) reviewed a broad range of literature related to observational studies of symptoms in adult patients dying from heart failure, chronic airway limitations and chronic renal failure. The value of the study was that the authors identified, regardless of the disease, the symptom burden at end of life was increased. Prevalent symptoms in all three diseases were firstly “fatigue” being “the most
“common symptom”, followed by “dyspnoea, insomnia and pain” (p. 941). Even so, the prevalence of symptoms in non malignant diseases have been reported to be under-assessed and under-treated (Miller & Miller, 2003; Solano & Higginson, 2006).

In comparison, Borgsteede, Deliens, Beentjes, Schellevis, Stalman, Van Eijk and Van der Wal (2007) statistically analysed the prevalence and number of symptoms in palliative care patients who died at home, including those who died from non malignant diseases. The authors used data obtained from a nation-wide survey of general practices in the Netherlands and found that prevalence of symptoms was higher for people who died from cancer and also for younger patients. They concluded that symptoms were concentrated in the last two weeks of life and that general practitioners required continuous education and access to specialist palliative care services. Interestingly, the symptoms in the survey were reported by general practitioners, who the authors acknowledged may have underestimated the symptom burden patients suffered at end of life. Further, the study sample included only three COPD patients. This may have influenced the results, as COPD patients typically suffer numerous, end of life symptoms, including severe breathlessness, fatigue, nutritional and functional problems (Ambrosino & Goldstein, 2007).

In malignant and non malignant diseases, end of life symptoms are numerous and require expertise to manage. Symptoms associated with dying from heart failure have been reported to be similar to end stage cancer. O’Leary, Murphy, O’Loughlin, Tiernan and McDonald (2009) compared symptoms of 50 terminal heart failure patients with 50 cancer patients with “most common malignancies” and who were receiving palliative care (p. 407). The researchers used the
Edmonton Symptom Assessment Scale and found “the prevalence and intensity of individual symptoms differed between the two patient groups”, however, statistically, symptoms were indistinguishable between the groups (p. 408). Patients with terminal heart failure experienced an increased prevalence of reduced well being, dyspnoea, tiredness, anxiety and depression. In comparison, patients with cancer experienced a higher prevalence of reduced appetite, drowsiness and pain. Regardless of the type of symptoms, this study showed the patterns of distress experienced in declining health, and confirmed that regardless of the actual disease and symptoms, people dying from any diagnosis suffer in various ways and require adequate and appropriate care.

The American College of Chest Physicians identified the same prevalent symptoms in cardiopulmonary diseases and included nausea, vomiting, constipation, diarrhoea, anorexia and oedema as distressing end of life symptoms. These authors suggested barriers associated with effective symptom control included “inadequate assessment, deficiencies in technical skill, and persistent unfounded fears by physicians, patients, and families about opioid overdose and addiction” (Selecky, Eliasson, Hall, Schneider, Varkeey, ACCP & McCaffree, 2005, p. 3604). Further, Ellershaw and Ward (2003) suggested most heart failure patients in the United Kingdom had “poorly controlled symptoms – notably breathlessness and chest pain, but also mental distress and a range of non-cardiac symptoms that are helped very little by conventional hospital care” (p. 31).

The purpose of treatments for non malignant disease symptoms are generally not curative, but focused on the management of the symptom burden. Heart failure symptom management is representative of the challenges health professionals
can face in re-orientating care to quality of life, as compared to disease elimination (Kolb, 2008). Kolb suggested heart failure patients were disadvantaged by not receiving a palliative approach to care and that nurses needed to be at the forefront in encouraging open dialogue and well informed decision making before aggressive treatments were continued. If nurses are to adopt a palliative approach to the care of people dying from non malignant diseases, the knowledge, skills and training for palliative care delivery must be addressed.

Dying from a non malignant disease in a residential aged care facility and receiving adequate symptom management remains unpredictable in the 21st century (Goodridge et al., 2005). Numerous factors are thought to contribute to inadequate symptom management, such as not anticipating death, the rapid decline in residents’ health and multiple symptoms at end of life contributing to insufficient time to implement appropriate end of life care (Brandt et al., 2005).

In a review of 23 qualitative and quantitative end of life care studies specific to nursing homes, Carlson (2007) found that “poor symptom control at the end of life often is caused by inadequate knowledge and skill levels” (p. 40). In addition, Carlson identified that nursing home administrative staff “views are incongruent with the staff providing this care” and that the situation existed because administrators fail to acknowledge the barriers nurses faced in delivering appropriate end of life care and “appear overly optimistic” of the care delivered (p. 39). Kovach (2007) acknowledged the complexity of managing end of life symptoms in the older people and gave the example of having to “escalate analgesics for an 85-year-old” (p. 4). Kovach suggested that American society needed to be challenged to overcome “fear and denial of aging and death”,

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which is an issue that the author concluded influenced end of life care at all levels (p. 3).

Fear and denial of ageing and dying are not unique to residents and their families. Hancock, Clayton, Parker, Walder, Butow, Carrick, Currow, Gherzi, Glare, Hagerty and Tattersall (2007) performed a systematic review of the literature pertaining to “truth-telling in discussing prognosis with patients with progressive, advanced life-limiting illnesses and their caregivers” (p. 507). The authors identified that reasons health professionals withheld information, or were reluctant to discuss prognosis or end of life care issues, included discomfort in either raising the topic or responding appropriately to the patients’ requests, insufficient training in communication skills, the unpredictability of life limiting illness trajectories, limited time to discuss issues, concerns that disclosing information may negatively impact on the patient, failing the patient by not having curative treatments and requests by family or caregivers to withhold information from the patient. Failing to address prognosis or discuss end of life care issues has the potential to impact on the patient their family and the health team (Clayton, Hancock, Butow, Tattersall & Currow, 2007).

*The End of Life Symptom of Dyspnoea*

To appreciate the complexity and under treatment of symptoms at the end of life, the symptoms of dyspnoea and delirium is explored. Firstly, dyspnoea has been identified by a number of authors as occurring frequently in dying people (Brown, & Von Roenn, 2004; Goodridge, Bond, Cameron & McKean, 2005; Hall et al., 2002). For example, Goodridge et al (2005) identified dyspnoea in most of the 15 deaths the authors reviewed over a six month period. Dyspnoea was
considered to be a “far more common symptom in this group than was pain” and concerns were raised that there was limited documentation of interventions to treat the symptom in residents’ records (p. 230). The authors’ concerns were reiterated by Von Gunten (2005), who estimated “1.4 million persons” in the United States die with undertreated dyspnoea (p. S93). Similarly, Hall et al. (2002) performed a retrospective chart audit of 185 residents’ notes, who had died in five Canadian long term care facilities, focusing on the last 48 hours of life. The authors identified “almost one-quarter of those with dyspnea, the most prevalent symptom in this study, had no documented intervention” (p. 505). They surmised that this situation existed because of “the high prevalence of cognitive impairment in the patient population” and a lack of a palliative care education strategy (p. 501). Wotton, Borbasi and Redden (2005) identified Australian nurses reported difficulties in managing dyspnoea in end stage heart failure (ESHF) patients. The authors reported dyspnoea “caused considerable trepidation for nurses who were not experienced in using morphine for patients with ESHF” (p. 22).

In the United Kingdom, a qualitative study with a small sample size of 18 COPD patients, identified breathlessness to be severely disabling in the terminal stages (Gysels & Higginson, 2008). The management of breathlessness was identified as complex due to a number of factors, including the symptom was not always apparent when the patient was at rest, and there was a lack of measurability of breathlessness. Further, patients attempted to hide their breathlessness from others, due to the stigma of being associated with cigarette smoking and the socially unacceptable coughing of phlegm, a problematic symptom, associated with the disease. Gysels and Higginson (2008) found services failed to respond to breathlessness in a number of ways, including failing to provide sufferers with
advice on symptom management and in offering limited effective treatments. The researchers surmised that the failure to manage the symptom was related to a “low level of expertise” of the clinicians and “failure to assess or recognise it” (p. 458). A critical recommendation by the authors was to treat the symptom of breathlessness or dyspnoea the way pain is treated, that is, it is a subjective experience to be believed as reported by the patient.

Similarly, it was identified in a large survey conducted in Australia by Firth (2004), that shortness of breath was a major complaint in people suffering from COPD, significantly impaired their functional ability. It is important to acknowledge the frequency of breathlessness and dyspnoea in the COPD population and the potential impact of this symptom at the end of life. These important terminal symptoms require nurses to be skilled in their recognition and detection, so that appropriate treatment is provided.

The End of Life Symptom of Delirium

Delirium extends the complexity of managing and treating end of life symptoms. Delirium is reported to occur in up to 85% of people toward the end of life and it is recommended that “to manage delirium in terminally ill patients, clinicians must be able to diagnose it accurately, undertake appropriate assessment of underlying causes, and understand the benefits and risks of the available pharmacological and non-pharmacological interventions” (Brietbart & Alici, 2008, p. 2898; Brown & Von Roenn, 2004).

According to Inouye, Foreman, Mion, Katz and Cooney (2001), when nurses’ recognition of delirium in hospitalised older patients was compared with
researchers’ recognition, nurses only identified the condition in 46 of 2721 assessments, as compared to researcher recognition rates of 239 of 2721. The study findings had important implications, as nurses were viewed as a key component in detecting delirium early and their lack of recognition of the disorder limited the effectiveness of intervention strategies. Of further concern was that nurses were found to “overlook symptoms of delirium in patients with dementia” (p. 2472). This is problematic, given that a significant proportion of residents in the Australian aged care setting have a diagnosis of dementia syndrome, either as a primary condition, or in combination with other diseases (Australian Institute of Health and Welfare [AIHW], 2009a).

End of life symptom management in non malignant diseases is complex. A key component of translating available research evidence to the end of life care at the bedside is that those people delivering the care need to be appropriately educated and skilled. It is especially important that nurses’ assessment skills and comprehension of symptom treatments is advanced, as each resident is an individual, who may require treatments that need to be tailored to their individual needs, thus preventing under-treatment, over-treatment and unnecessary suffering.

Suffering

There is general agreement in the literature that the concept of suffering associated with dying is still prevalent in health care in the 21st century and presents a challenge for carers and researchers (Bingley, McDermott, Thomas, Payne, Seymour & Clark, 2006; Connelly, 2009; Emanuel, 2006; Hickman, Tilden & Tolle, 2004; Kellehear, 2009). Kellehear, an Australian sociologist, who
specialises in death and dying, views the concept of suffering as a topic area to “deepen our understanding of dying” and to value the dying person’s experience (p. 388). Kellehear compared and contrasted literature related to social studies of both dying and human suffering, to identify major reoccurring themes. Themes related to human suffering to dying included: addressing suffering may shorten the experience of dying; total pain as a reflection of the moral experience and predicament of dying; the ethical balance between silence and violence; the fundamental characteristic of suffering is loss; and confirming the value of pastoral and social interventions for people who are dying and their carers.

Themes related from dying to human suffering included: a broader view of dying can deepen our understanding of human suffering; human suffering and the problem of open-awareness; suffering as loss is not best described as a ‘wound’; the dying person as ‘hero’ is only one cultural script about suffering; and the distinction between clinician, researcher and those who suffer is artificial and divisive. Kellehear differentiated the themes to highlight that the issues surrounding suffering and dying, although different, have similar interconnected insights within a context of social and political environments that influence the time in which the suffering and / or dying occurs. Further the author argued that even though there are differences in the literature findings in the two areas, the account provided by the person who is experiencing suffering and dying is critical to knowledge in the area.

Suffering, particularly at the end of life, is a concept to which trained and untrained people can identify and relate. In a Canadian study, Hickman et al (2004) explored the experience of suffering through family members’ accounts. The authors conducted a retrospective telephone survey of 63 family members of
people, who had died two to five months previously in a community setting defined as “e.g., nursing home or private home” (p. 21). The researchers used a survey tool designed for the study, entitled ‘Worries at End of Life Survey’. The majority of family members reported their relative who was dying had experienced suffering in the last months of life, with 55 per cent reporting the deceased relative experienced moderate or severe suffering. Acknowledging that Hickman’s et al work had some limitations due to the potential for family members to interpret a deceased relatives’ suffering, within the context of their own grieving and witnessing a family member dying in distress (LaPorte Matzo & Witt Sherman, 2006), the study nevertheless represented the difficulties researchers face in exploring the concept of suffering and conversely, the reality that people can identify with a term, such as suffering.

Suffering associated with dying is not the sole domain of those who die from a malignant disease (Schroepfer, 2007). People dying from cancer and non-malignant diseases have been shown to share similar physical and psychosocial suffering. In a United States (U. S.) study, Schroepfer interviewed 96 people aged 50 years or older, dying in a range of settings, including hospices. The subjects had been given a prognosis of six months or less to live. The researcher identified 15 of the subjects had wished to die early and this request was related to an event that had increased their suffering. Four events were identified by Schroepfer as ‘critical events’ and increased suffering. The critical events included “perceived insensitive and uncaring communication of a terminal diagnosis; experiencing unbearable physical pain; unacknowledged feelings regarding undergoing chemotherapy or radiation treatment; and dying in a distressing environment” (p. 136). Translation of these findings into the Australian context is possible, despite the U. S. health care system being
different, because of the element of common humanity when people are suffering. The critical dying process events identified in this study have the potential to transfer into the care of the dying, regardless of illness type or geography, therefore, nurses need to understand those issues that improve end of life care and reduce suffering.

In contrast, DeSpelder and Strickland (2005) identified the suffering of cancer patients as a unique experience compared to dying from non malignant diseases by stating “it is important to distinguish between pain and suffering, especially with cancer patients, whose suffering may be due as much to loss of function and fear of impending death as to pain” (p. 210). While DeSpelder and Strickland’s work raises an important aspect of pain associated with cancer, Connelly (2009) in a critical essay on the avoidance of human suffering, argued that peoples’ fear of death and dying represented a form of suffering at the end of life, regardless of the triggering disease.

Extending the focus beyond the experience for the dying person and their families, there is general agreement that health professionals struggle with the concept of suffering (Emanuel, 2006; Lesho, 2003; Maas, Specht, Buckwalter, Gittler & Bechen, 2008a). Of concern is that dying people suffer due to health professionals’ knowledge deficits in end of life symptom management (Janssen et al., 2008; Kazanowski, Perrin, Potter, & Sheehan, 2007). Non identification of suffering has been linked to health professionals’ limited life experiences, poor history taking, practice of discounting the importance of suffering, education and training focusing on scientific analysis and staff having an inability to directly ask a patient if they are suffering (Lesho, 2003).
Health care in developed countries has dramatically advanced in many aspects of disease management, however, knowledge deficits continue as to how to relieve suffering at the end of life. Janssen et al (2008) examined the daily symptom burden in people dying from end stage chronic organ failure and found that there was a lack of evidence related to symptom burden and symptom management in people dying from non malignant diseases and suggested this contributed to unnecessary suffering. Emanuel (2006) highlighted that in an age of technology and advanced health care that can relieve suffering, the focus on curative medical approaches to care disengages the medical fraternity from addressing the suffering of the dying. The inability to acknowledge the importance of relieving suffering at end of life could be reflective of the inability of services to engage with the dying process and acknowledge the importance of the care of the dying in the health care spectrum.

Task focused care performed by staff, who have limited end of life care knowledge, has the potential to create a workforce that performs duties, without acknowledging the images of suffering that may surround them. Health professionals have been identified as adopting a “self-protective approach” to people’s suffering. Witnessing suffering has been suggested to trigger an avoidance of situations associated with suffering (Kazanowski et al., 2007; Lesho, 2003). Potential witnesses of suffering are those who care for the dying. Connelly (2009) argued that personal experiences of suffering, for example, the loss of a loved one in childhood, can create an inability to connect with those who are suffering, thus influencing a person’s reaction to loss as an adult.

Personal beliefs can influence end of life care decision making. Meisel, Snyder and Quill (2000) suggested that legal myths surrounding dying can “undermine
good end of life care and ethical medical practice” (p. 2495). Further, “when a terminally ill patient’s suffering is overwhelming despite palliative care, and he/she requests a hastened death, there are no legally permissible options to ease suffering” (p. 2495). Therefore, it could be assumed that the complexity of influences on end of life practices can be as variable as the people who are delivering the care.

Exploration of health professionals’ reactions to suffering were conducted by Kazanowski et al (2007), who argued that educating student nurses to assist them to understand suffering can prepare them to “better understand the suffering experience” (p. 195). In the post course evaluations students reported “feeling better prepared to intervene in difficult situations involving suffering” (p. 195), although a critique of the apparent success of the responses is that end of course evaluations may not reflect what each nurse will actually do, in the face of suffering in clinical situations. Even so, the concept of empowering those who care for the dying is an important aspect in delivering appropriate end of life care, as the quality of care and the barriers to providing optimal end of life care are impacted by a number of factors in the residential aged care setting, including understaffing and undertraining (Maas et al., 2008a) and limited access to palliative care services.

Palliative Care Access in Non Malignant Diseases

Despite the increased symptom burden, the complexity of treatments and the potential for suffering associated with dying from non malignant diseases, the palliative care service provision to the residential aged care setting in Australia is limited (Cooper & Glaetzer, 2004). Historically, palliative care services have been
focused on cancer care. The expertise and skills required to deliver appropriate end of life care can be readily dismissed when the discussion of care relates to a silent majority, such as older people dying from non-malignant diseases in residential aged care facilities.

In Australia, accurate figures for palliative care data including service needs and site of care have been difficult to determine, due to inadequate data and non-standardised collection. The variability in data collection has been suggested to be due to “services using a variety of definitions and collecting different data items” (Phillips, Davidson, Jackson, Kristjanson, Bennett & Daly, 2006, p. 373). As a result, the access to palliative care, the equity of service distribution, and the concentration of resources and focus for service provision, have been relatively unchallenged.

In 2004, the Australian Government funded palliative care information for the residential aged care sector. The information was released in the form of a guideline, entitled ‘Guidelines for a Palliative Approach in Residential Aged Care’. The guidelines were distributed “with the intention of assisting clinicians to apply a palliative approach” to residents in care (Allen et al., 2008a, p. 175).

Interestingly, in 2006 the National Health Service (NHS) in the United Kingdom published an ‘Introductory Guide to End of Life Care in Care Homes’, to support care homes as part of an ‘End of Life Care Programme’. The NHS program trained staff in using three key tools, the Gold Standards Framework, the Liverpool Care Pathway and Preferred Place of Care (Henry & Fenner, 2007). Badger, Clifford, Hewison and Thomas (2009) evaluated the Gold Standards Framework by surveying 44 care homes. The authors found “there were
statistically significant increases in the proportion of residents who died in the care homes and those who had an advanced plan” (p. 502). They concluded that “appropriately funded structured programmes have the potential to assist nursing homes improve the provision of end-of-life care to older adults” (p. 502).

Allen et al (2008a) argued that the Australian palliative approach guideline had not been adopted and remained unknown to RNs and ENs delivering care, despite being provided and that there was no evidence of a palliative approach being offered to residents in a multi-purpose service in Victoria. The authors used a critical ethnography methodology and found the intent of sharing palliative care information with residential aged care facilities had not translated to the bedside of dying residents. The authors used “participant observation with field notations, key informant and focus group interviews and documentation analysis” (p. 178). These failures were attributed to the poor implementation of the guidelines to the facilities and the facilities were described as having a ‘reactive’ approach to care. There was non compliance with the nurses’ registering authority regarding supervision and delegation, an absence of policy and procedure, failure to promote, adopt and implement a palliative approach to care, and a lack of understanding by the organisation of what a palliative approach actually represented. This finding may apply to any aged care facility that does not have the infrastructure, staffing profiles, funding or workplace culture required to provide a palliative approach to care, thus, providing guidelines does not guarantee implementation.

This line of thought has been echoed by Grbich et al (2005), who found inconsistencies in palliative care service delivery to residents in residential aged care. The authors conducted a cross sectional study of 51 residential aged care
facilities in South Australia using a questionnaire and found the majority of deaths were from “non-cancer diseases” and that “up to two-thirds of all deaths occurred away from low care facilities, usually in an acute care setting” (p. 108). The authors identified the situation existed due to residents requiring transfer for specialised care. Palliative care service consultations were minimal, with an average of only four residents per facility receiving a visit. Further, rural facilities had less contact with palliative care services than their metropolitan equivalents.

The challenges of providing access to palliative care services in the Australian rural setting were outlined by Phillips et al (2006). They suggested that a scarcity of resources underpinned the failure to provide services or access. Reasons included an absence of designated palliative care beds in rural hospitals, limited resources to provide aged care facilities with educational and consultancy visits, and chronic shortages of doctors and nurses in the region. Rural needs for access to palliative care are no less important than metropolitan needs and in Australia a high proportion of older people retire to regional coastal towns (National Rural Health Alliance Incorporated in Australia, 2005).

An important aspect of managing symptoms at end of life in people dying from a non malignant disease is identifying when the disease trajectory has reached an advanced stage. Failure to recognise a person is in the advanced stage of dying can contribute to people not being referred to palliative care services for symptom management (Solano & Higginson, 2006), potentially leading to suboptimal end of life care delivery. Ellershaw and Ward (2003) suggested dying residents can be moved to side rooms or staff may adopt avoidance behaviours that fail to address the resident is dying. Limited knowledge and understanding
of the stages of dying can contribute to inappropriate end of life practices and is a critical focus if residents are to be referred for specialist care.

Nurses have been identified as the primary care givers of the palliative care team in the final 48 hours of life (Hall et al., 2002). Advanced practice palliative care nurses in the United States facilitate a palliative approach to care. Kuebler (2003) defined the advanced practice nurse (APN) as “either a clinical nurse specialist (CNS) or a nurse practitioner (NP)” and suggested when palliative care service provision is unavailable that the APN can integrate palliative interventions into frail, older residents’ care by assessing residents, the situation and collaboratively planning and/or referring care (p. 708). In contrast, United States authors, Matzo and Sherman (2001) suggested nursing as a profession is “still in its infancy in the dialogue” of competent end of life nursing care and that there is a need to “openly discuss” nurses’ practices in relation to requests for assisted suicide and euthanasia (p. 293). Nurses play a crucial role in delivering appropriate end of life care and, therefore, need to be supported in delivering care to dying people, regardless of their level of expertise.

Assumptions are incorrect that people dying from a non malignant disease will receive similar access to palliative care services as someone dying from cancer. For example, studies have demonstrated that COPD patients are not offered palliative care services. Ambrosino and Goldstein (2007) outlined the range of treatments available to manage symptoms associated with COPD and highlighted that there was a gap in palliative care service provision to COPD patients, as compared to patients with lung cancer. Other authors have claimed that COPD patients have a worse quality of life and “more anxiety and depression” than end stage cancer patients and yet, COPD patients were not
offered palliative care (Fitzsimons et al., 2007, p. 314). Spence et al (2009) suggested one reason people with advanced COPD did not receive palliative care was the difficulty in “accurately predicting prognosis”, highlighting again the challenge of expertise in timing in caring for people dying from a non malignant disease (p. 126).

Studies show that marginal groups in society do not access palliative care services (Ahmed, et al., 2004; Currow, Agar, Sanderson & Abernethy, 2008) For example, Currow et al., (2008) hypothesised that certain groups of people with life limiting illness do not access palliative care services. In a large South Australian survey, including 18,224 interviews of people who had someone close to them die in the previous five years, the authors identified that people with a non malignant disease diagnosis, caregivers with English as a second language, and those from a lower socio-economic status, were less likely to access palliative care services. While Currow’s et al. (2008) work had some limitations, in that the authors acknowledged caregivers’ views may have not correlated with the needs of the dying person, its main value was in demonstrating that services, such as palliative care, must look beyond service provision and seek the groups of people who are not accessing their services.
Summary

In summary, the literature supported the need for research to improve the end of life care for people with non malignant diseases, because non malignant diseases are diverse in type and are the primary cause of death worldwide. Disease trajectories in non malignant disease are variable, making the dying phase more difficult to predict, leading to unrecognised suffering from lack of timely and appropriate symptom control. Although palliative services are prompt and effective for people dying from cancer, there is a need for improvement in equalising opportunities for palliative care delivery, to people dying from non malignant causes, especially older people within aged care facilities.

Knowledge of key aspects of care for the dying that palliative care service providers offer, has the potential to alleviate suffering from complex, distressing symptoms associated with non malignant diseases. Even though some strategies are in place in aged care facilities nationally and internationally, the literature suggests that the single act of providing residential aged care facilities with access to guidelines does not mean that they will be enacted effectively, nor does it necessarily provide access to palliative care services. Therefore, the literature reinforces the need for nurses working in residential aged care to have comprehensive, well-resourced strategies that will develop their skills and expertise, to ensure optimal end of life care is delivered when residents are in need and when palliative care service access is inadequate. Accordingly, this action research and reflection project responded to the need identified in the literature for improved end of life care for residents in aged care facilities, who are dying from non malignant causes.
Residential Aged Care Facilities as a Place of Dying

There is general agreement in the literature that aged care facilities are a place of dying (Miller, Teno & Mor, 2004; Travis, Bernard, Dixon, McAuley, Loving & McClanahan, 2002). An anticipated ageing of the population and, therefore, increased demands for appropriate end of life services, could potentially exceed aged care facilities’ ability to provide adequate end of life care (Australian Government Second Intergenerational Report, 2007).

Estimates in a study of 544 residents in 16 nursing homes (NH) in the Netherlands predicted that “for every 3 beds, an NH can expect 1 patient per year” to reach a terminal disease phase that requires palliative care (Brandt, Luc Deliens, Ooms, Van der Steen, Van der Wal & Ribbe, 2005, p. 319). Similarly, in the United States, it has been estimated that nursing home deaths accounted for more than 1 in 3 deaths (Miller, Teno & Mor, 2004). Travis et al (2002) identified nursing homes in the south west of the United States had a high proportion of deaths per year estimating “approximately 29 deaths a year” (p. 3). These figures represent the challenges residential aged care facilities face to meet the demand for appropriate end of life care.

In Australia, Grbich et al (2005) in a survey of 30 residential aged care facilities, found that 7% of the facilities’ current residents were requiring palliative care and of those residents, 78% had a non malignant disease. Further, the Australian 2007-08 residential aged care death statistics, as reported by the Australian Institute of Health and Welfare [AIHW], revealed 3,357 or 7.1% of residents died within four weeks of admission to residential care (AIHW, 2009). People aged 85 years and over were the highest users of permanent residential aged care in 2007-
08, however, the rates of usage have been decreasing in Australia since 1998, in proportion to the number of people per 1,000 (AIHW, 2009). Despite the apparent decline in usage of residential aged care in Australia, Catholic Health Australia reported that residential aged care facilities currently accommodate 200,000 Australians per annum, with a projected increase to 300,000 by 2019 (Laverty, 2009). A substantial number of people entering residential aged care facilities are going there to die, therefore, planning delivery of appropriate end of life care is essential if residential aged care facilities are to prevent suboptimal care delivery.

In comparison, an important paper by Gomes and Higginson (2008) analysed 30 years of figures to determine the place of death and national trends in England and Wales. The authors found that for the majority of the population, home, as the place of death, had declined. This meant that the future demand for “institutions (including NHS hospitals, nursing home and hospices)” to become the place of death would increase in line with the anticipated increases in the ageing populations (p. 37). The authors surmised this would result in less than 10 percent of people dying at home in the United Kingdom by 2030.

Similarly, Ahmad and O’Mahony (2005) examined death certificates in Wales over a 20 year period and found that although palliative care services in the community had increased, there was an increase in the number of people who died in hospitals and care homes, particularly for those people 85 years and over. Problems in providing end of life care for potentially large numbers of people dying from non malignant diseases is further compounded by predictions of a dramatic increase in the aged population in the Western world over the next 30 years (Clare, De Bellis & Jarrett, 1997; Australian Government Second
Intergenerational Report, 2007; Gadzhanova & Reed, 2007). In Australia, there are predictions of an increasing aged population, in particular, the very old (85 years and over) “will more than quadruple” by 2047 (Australian Government Second Intergenerational Report, 2007, p. 12).

Similarly, the United States is predicted to see an increase in the ageing population. DiBartolo (2008) used the 2004, Merck Institute of Aging and Health figures to challenge gerontological nurses to advocate and become proactive in preventive health programs that will assist the predicted “20% of the total U.S. population”, who will be older than 65 by 2030 (p.3). Similar to Australia, the United States population of 85 year olds is predicted to be the fastest growing population.

The potential problem of an increasing ageing population is acknowledged by the National Rural Health Alliance Incorporated in Australia (2005), who focused a report on the impact of the predictions for rural and remote areas. The authors suggested rural centres would be particularly challenged by increases in the ageing population requiring care, as large numbers of older people predominately reside in rural and remote centres.

To be aged does not necessarily mean to be unwell. Johnstone and Kanitsaki (2009) challenged the assumption that an ageing population is an increased burden on health service provision. The authors argued that increases in the older population do not necessarily mean older people will require health care. Nurses are considered by the authors to be best placed to defend older people in Australian society both in policy debate and to advocate on behalf of “older Australians”, particularly against those who label them as a “costly burden on
society” or “counting for nothing” (pp 90-91). Challenging the stigma of ageism, while commendable, does not negate the reality that for many frail, older people a lack of progressive service planning now, may result in inadequate care when it is needed most at the end of life. Many people may live healthy lives, but any form of protracted dying will require care.

The place of dying from a non malignant disease has implications for residential aged care facilities in providing optimal end of life care to an increasing ageing population. The predictions for an ageing population will present numerous challenges for residential aged care facilities. Many older people will die in residential aged care facilities from non malignant diseases. Residential aged care facilities need to examine their end of life practices to identify barriers and to engage staff in optimising care delivery, as specialist palliative care service provision is limited and demand is increasing.

Delivering Palliative Care in Residential Aged Care Facilities

The foundation of palliative care was built on caring for people with cancer (Department of Health and Ageing, 2008; LaPorte Matzo & Witt Sherman, 2006; Murray & Sheikh, 2008; Clark, Maddocks, Lynn & Lewis, 2009) with a focus on relieving “pain associated with cancer” (Clark et al., 2009, p. 1). This is a problematic concept in view of more people dying from non malignant diseases and there being a general agreement in current literature that palliative care services need to effectively broaden the focus of their care to address dying from non malignant diseases (Duggleby & Johnston, 2006; Hookey, 2004; Murray, Kendall, Boyd, & Sheikh, 2005; Rosenwax & McNamara, 2006; Palliative Care Australia, 2005).
Dame Cicely Saunders is credited with being a founder of palliative or modern hospice care, which originally developed in Britain with the opening of Saint Christopher’s Hospice in London and then spread throughout the world (DeSpelder & Strickland, 2005; La Porte Matzo & Witt Sherman, 2006; Tishelman, 2007). In Australia, the specialty of palliative care developed from an acknowledgement of the value of care for the dying (Clark, Maddocks, Lynn & Lewis, 2009). A key event in the development of palliative care in Australia was the appointment of the first medical Professor of Palliative Care, in the world, appointed at Flinders University in 1988. It is considered that this academic appointment, combined with the influence of nursing and community sectors lobbying governments to fund palliative care services, advanced the discipline of palliative care. Further, Maddocks (2003) suggested Australia is a world leader in the “relatively new medical discipline of palliative care” (p. S4). While it is tempting to credit palliative care in Australia with being an advanced discipline, it must be viewed within the context of palliative care being a relatively new discipline in the health sciences and that it has not before faced the many challenges an ageing population will present.

Palliative care literature is littered with a considerable variation in terminology to describe care delivery to the dying. The bewildering array of terms, such as palliative care, end of life care, supportive care, hospice care, perideath care, palliation and terminal care, are used and interchanged, potentially confusing those who are required to access the care providers or to understand the phase of dying (Allen, Chapman, O’Connor & Francis, 2008b; Dawbin & Rogers, 2006; Hanks, 2009; LaPorte Matzo & Sherman, 2006; Palliative Care Australia, 2008; Pastrana, Jünger, Ostgathe, Elsner, Radbruch, 2008).
Problems with the language around care of the dying have been identified by Palliative Care Australia, who developed a Glossary of Terms. The purpose of the glossary was to “seek clarity and consistency” to describe end of life care (p. 1). The National Quality and Standards Director for Palliative Care Australia acknowledged “the lack of consistency in our use of terminology has created and will continue to create confusion” (Palliative Care Australia, 2008, p. 3). Consistency in terminology is important in end of life care, to ensure those who are caring for the dying communicate information accurately and effectively.

Palliative care is defined as care of the dying, having a focus on quality of care and interdisciplinary care. The World Health Organisation defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organisation [WHO], 2009, p. 1).

Palliative Care Australia [PCA] defines palliative care as having both a short and a full definition, in accordance with the WHO. The short definition is “palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life”. The full definition of palliative is:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and
impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications”

(Palliative Care Australia, 2008, p. 11).

Regardless of the number of words, definitions of palliative care suggest the discipline is a specialised field of health care and as such, requires a team approach to care by professionals, who have expertise in delivering end of life care. For example, Pastrana et al (2008) suggested palliative care “demands specific knowledge, skills and attitudes, which should be acquired by specific education and training” (p. 228).
Tishelman (2007) commented on care for the dying and suggested the inconsistencies of the language around dying may have impacted on service provision and the care that is delivered. Hanks (2008) a senior United Kingdom medical physician, suggested the problems associated with the language of delivering care at various stages of life limiting illnesses is “that there are many different ways to describe to the same thing” (p. 109). Further, he suggested that the terminology of the care for the dying appears to avoid the fact that the service provision is linked to death (Hanks, 2008). The questioning of the language of delivering care to the dying must be viewed within the context of the questions those who care for older people with non malignant diseases, face each day. For example, carers face the challenges of deciding when a resident is considered to have entered a dying phase, what type and level of care is required, at what stage of dying, and which of the services are resourced to assist in care provision.

The term ‘end of life care’ appears to have been adopted in the literature as a subcategory of palliative care. Henry and Fenner (2007) described end of life care as that which “requires an active, compassionate approach that treats, comforts and supports individuals who are living with, or dying from, progressive or chronic life-threatening conditions” (p. 5). In comparison, Janssen et al (2008) reviewed current literature related to symptoms in end-stage organ failure. The authors criticised the lack of a clear definition, stating “there is no clear and commonly accepted definition of end-of-life or end-stage” (p. 945). Separating terms, such as end of life care from palliative care, even by definition, can be problematic, because the ownership of responsibility for the service provision can be unclear.
Though subtle, definition differences are important, as end of life care is closely linked to the definition used for palliative care. Arguably, terms such as hospice care, described by DeSpelder and Strickland (2005) as a “a specialized form of palliative care for dying patients” further adds to the dilemma of which form of ‘care’ is best for the dying (p. 136). Hospice care is considered different to supportive care in that it is provided when a patient has a life expectancy of less than six months and not seeking further interventional treatment (LaPorte Matzo & Witt Sherman, 2006).

For over a decade, delivery of palliative care services for people dying in Australian residential aged care facilities has been an issue. Palliative Care Standards were developed for the first time in Australia in 1994, by the group Palliative Care Australia, known at that time as the Australian Association for Hospice and Palliative Care (Palliative Care Australia, 2005). The standards were revised in 2005 to better reflect the “level of care that the Australian community would expect, when faced with a life limiting illness” (Palliative Care Australia, 2005, p. 8). People living in residential aged care facilities are considered to be a “special needs population” in the standards (p. 14). The standards recommend people living in residential aged care facilities “have access to the same range of community and inpatient based services available to people residing in their own homes” and state that palliative care service delivery will be either through “consultative support and/or direct care from specialist palliative care services” (p. 16). However, the proposal within the standards indicate service provision is delivered at an arms length, to where protocols and processes will be developed to support and guide the health care provider. This approach fails to address how the delivery of palliative care will be facilitated in residential aged care,
therefore, the responsibility remains with the aged care provider, who may choose not to progress the implementation of the standards.

Authors agree that residents dying from non malignant diseases in residential aged care facilities require palliative care service delivery (Grbich et al., 2005; Kristjanson, Toye & Dawson, 2003). Winn and Dentino (2004) suggested little benefit is gained by aggressively treating older people in long term care, who may return from a hospitalisation episode in a worse condition than they entered. Rather, shifting to a palliative form of care that is dignified, “humane and compassionate” is recommended (p. 197). Care inclusive of open communication with the resident and their family and where advanced care planning is established, is considered optimal. Interestingly, while palliative care is recognised as a right, the provision of end of life care is recommended by the National Health and Hospitals Reform Commission (2008) in Australia to be “everyone’s affair’, not just the job of specialist palliative care services” (Department of Health and Ageing, 2008, p. 189). The idea that palliative care is provided by “all health professionals” reduces the likelihood that dying older people residing in a residential aged care facility will receive specialised, optimal end of life care (p. 182). A substantial number of people working in residential aged care facilities are not health professionals and due to the trend toward reduced working hours and the use of deskilled labour in aged care, the accessibility to qualified health professionals is limited (Hodgson & Lehning, 2008; Holloway & McConigley, 2009; Kristjanson, Walton & Toye, 2005; O’Connor & Pearson, 2003; Wowchuk, McClement & Bond, 2007).

Timely access to palliative care services for dying older people can be challenging. In a United States study, Travis, Bernard, Dixon, McAuley, Loving
McClanahan (2002) performed a retrospective chart review and identified a number of reasons why palliative care was not utilised in long term care. The obstacles included “failure to recognize treatment futility, lack of communication among decision makers, no agreement on a course for end-of-life care, and failure to implement a timely end-of-life plan of care” (p. 342).

Further, Wowchuk et al. (2007) identified a number of factors that impeded palliative care provision in nursing homes. Factors included:

“i) lack of care provider knowledge about the principles and practices of palliative care, ii) care provider attitudes and beliefs about death and dying; iii) staffing levels and lack of available time for dying residents; iv) lack of physician support; v) lack of privacy for residents and families; vi) families’ expectations regarding residents’ care; vii) hospitalization of dying residents” (p. 345).

Similarly, Hodgson and Lehning (2008) identified barriers to nursing homes delivering palliative care services. The authors compared barriers in six, high and low level nursing homes in the United States, using an ethnographic methodology where nursing home administrators were interviewed. The primary barrier identified was the nursing home culture, where staff were reported as placing an emphasis on “task completion, versus a person-centered care approach” to care. The primary barrier, “traditional nursing home culture of care”, when analysed further into subthemes, included problems with the model of care used in the facilities, the role of hospice by the facilities and the formalisation of partnerships with hospice providers as contributing to reduced palliative care access (p. 40). Further, staffing issues were identified as barriers to palliative care, which included “skill level, training and perceived roles”. The
authors acknowledged the limitations of the study, including a “small and select sampling”. A major deficit in the study was the failure to interview those people, who delivered the end of life care, because staffing levels and junior to senior staff ratios were issues administrators chose to ignore.

People dying from a non malignant disease in Australia have been shown to have limited access to specialist palliative care. Rosenwax and McNamara (2006) studied a large number of deaths in Western Australia and found that “one-tenth of people with selected non-cancer conditions received SPC” (Specialist Palliative Care) (p. 441). The authors highlighted how certain people were disadvantaged including, single, widowed or divorced people, those aged 85 or over, who were more likely to reside in aged care facilities, and those people who lived outside a major city.

General Practitioners (GPs) were identified by Watson (2008) as “the main providers of palliative care for most patients” (p. 251). GPs’ concerns regarding palliative care delivery have been identified as “not knowing enough about controlling symptoms, being reluctant to use powerful drugs in effective doses, worrying about the time commitment involved, and being afraid to expose oneself to painful emotions” (p. 251). In Australia, limited palliative care provision by GPs in residential aged care facilities is attributed to “a lack of financial incentives, the time required, and difficulty in advising patients about the treatment they may require in advance of need” (Gadzhanova & Reed, 2007, p. 94).

The barriers to delivering palliative care in residential aged care facilities are multifaceted and cross into all disciplines. Additionally, the responsibility to
find ways to deliver optimal end of life care is a shared responsibility. The call for palliative care services to meet end of life care delivery for increasing numbers of people dying from non-malignant diseases in residential aged care facilities highlights the difficulty the specialty will face in meeting the demand for services if changes are not made to the system. Murray and Sheikh (2008) suggested the lessons learnt from delivering palliative care to cancer sufferers highlight some of the problems that may be encountered as a consequence of needing to provide palliative care to a wider population of people dying from non-malignant diseases. The authors suggested the extension of the services to meet these needs could be impeded by “prognostic uncertainty; funding difficulties; lack of palliative care clinicians with expertise in non-malignant diseases; and a hitherto relatively weak evidence base in relation to appropriate models of care” (p. 958). If palliative care clinicians are struggling with delivering specialty care to people dying from non-malignant diseases, how can the aged care workforce be expected to provide the service when their workforce is already struggling to meet day to day care delivery?

Variations exist in defining both the forms of palliative care delivery and the people skilled in delivering palliative care. Periyakoil and Von Gunten (2007), in describing the integration of palliative care into mainstream care, identified “a wide variance” in what was considered to be offered as a palliative care service (p. 42). The authors used an example of what could be considered to be a palliative care service stating “this can mean that these facilities have a part-time massage therapist on staff or it can mean that they have a sophisticated multivenue palliative care program or anything in between” (p. 42). Therefore, the authors called for “standardization, quality” and consistency in palliative care service provision (p. 42).
García-Pérez, Linertová, Martín-Olivera, Serrano-Aguilar, and Benítez-Rosario (2009) conducted a systematic review that attempted to compare non-specialists in palliative care, labeled as those groups who provided “conventional care” and those who were ‘trained in palliative care’, stated to be providing “specialist care” (p. 17). In their review, the authors stated that the lack of studies and lack of definitions of palliative care teams in the studies reviewed, contributed to an inability to draw a comparison of the two forms of care to determine if either was superior. The challenge of defining the models of palliative care and ascertaining the levels of care delivered, contribute to the difficulty in determining those aspects of care that most benefit the resident dying in a residential aged care facility.

Miller, Teno and Mor (2004) suggested there is a reluctance of managers and staff to integrate palliative care into nursing homes beyond accreditation requirements. Barriers contributing to the integration included nursing home regulations, funding structures, a task focused approach to care, training deficits and difficulties with accessing external competency assessment. Further, the authors claimed that “education alone has not been successful in improving quality palliative care processes and outcomes, in part because of the high staff turnover” (p. 722). Multiple factors may be operating when attempting to improve care of the dying and these factors have the potential to impact on the sustainability of practice changes.

For palliative care to successfully translate into the residential aged care sector and to provide effective care to people dying from non malignant diseases, it will be necessary to look beyond the barriers to service delivery. Separating
palliative care services from residential aged care serves only sustains an exclusivity of the discipline, favouring people dying from malignancies. Residential aged care facilities need to highlight the challenges they face in caring for vulnerable groups and identify solutions that will work to optimise end of life care delivery. The literature attests to a need for a new appreciation of the ‘power within’ residential aged care facilities and a crucial need for aged care nurses to personally engage with the contemporary issues surrounding end of life care delivery. Identifying the supports and guidance necessary to plan for optimal end of life care will assist nurses to meet the dying residents’ needs, thus these findings confirmed the need for participatory processes, such as action research, to empower nurses to improve the care of dying residents.

Advanced Care Directives

Advanced care directives complement the process of planning for end of life care. Documenting residents’ wishes, requested degree of medical intervention and specific needs, assists those who care for the dying to meet those requests. While the principles of advanced care planning are academically sound, the translation into practice can be challenging and the processes to allow informed decision making need to be structured carefully.

Advanced care directives are used to document preferred medical treatment, end points of treatment, patients’ wishes, preferred substitute decision makers and other issues of importance to end of life care delivery beyond medical care, for example, resolution of family issues (NSW Department of Health, 2004). Clayton, Hancock, Butow, Tattersall and Currow (2007) suggested an important
aspect of end of life discussion is in determining residents’ wishes by the use of advanced care directives.

Determining residents’ care preferences and the degree of medical intervention, particularly in anticipation of a person one day not being able to be involved in the discussion, is considered important. Treatment decisions by health care workers are purported to be informed by advanced care directives and tailored approaches to treatment can be developed, to prevent aggressive treatment or under treatment at the end of life (NSW Department of Health, 2004). For example, Caplan, Meller, Squires, Chan and Willett (2006) demonstrated that a system of educating “residents, their families, staff and general practitioners about the terminal nature of dementia, advance care planning (ACP) and hospital in the home (HITH)” lead to a decrease in hospital admission and mortality of nursing home residents (p. 581). Even so, a study by the Department of Health and Ageing (2008) on the Respecting Patient Choice Program, which analysed “a model of advance care planning initially implemented across 17 residential aged care services and two palliative care services”, identified that “67 per cent of people without an advance care plan were transferred from their residential aged care facility and died in hospital” (p. 188). This situation may not be due to resident or the aged care facility factors, as doctors have reported reasons for not completing advance directives, including insufficient time and a lack of reimbursement (Brunnhuber, Nash, Meier, Weissman & Woodcock, 2008).

Some authors disagree with the use of advanced care directives and suggest that they are not a workable solution for end of life care decision making. For example, Perkins (2007) suggested the concept of using advanced care directives in end of life planning was “fundamentally flawed” (p. 51). In using advanced
care directives at the time of need, the author identified issues, such as incomplete documentation, consumers’ limited understanding of medical treatments, a “patient’s preferences changing”, accessibility to the document at the time of crisis, “poor proxy representation”, ambiguity, failure of families to reach a consensus and physicians overriding the directives (pp. 53-55). This study exposed the limitations of the projecting advanced care directives when used during real-time care.

Doctors’ understanding of the legalities of advanced care directives are thought to hinder their use in practice. Meisel, Snyder and Quill (2000) found doctors in the United States had a lack of understanding of the legality of advanced care directives and suggested they often resorted to myths, such as “advanced directives must comply with specific forms, are not transferable between states, and govern all future treatment decisions; oral advance directives are unenforceable” (p. 2495). A poor understanding of the law and a reliance on myths to guide end of life decision-making fails the rights of the dying to have a choice or preference in their end of life care service provision.

A lack of understanding of the laws related to advanced care directives are not confined to the United States. In Australia, the National Health and Hospitals Reform Commission convened to “transform the Australian health system” reported that advanced care plans were not widely used in Australia (Australian Government, 2009b, p. iii). A barrier identified to their use was “confusion about differences in the legislative framework across states and territories” (Australian Government, 2008, p. 188).
Advanced care planning initiatives have progressively gained momentum in recent years. The movement to initiate advanced care planning in the United Kingdom is suggested by Horne, Seymour and Payne (2009) to not be coming from the patient, but “mostly health or social care professionals” (p. 62). Further, the authors argued that the process of discussions and matching of choices is as important as the documentation of the plan. People may choose not to have advanced care plan discussions despite government policies stating that “all patients should have an advance care plan” (p. 60). Identifying peoples’ end of life choices is important, however, the dynamic circumstances of non malignant diseases and the methods used to inform people to facilitate informed decision making are critical components of the process and are not always easily defined in non malignant diseases.

In summary, informed end of life care choices are important at the time of need. Confusion or lack of understanding of legal issues can directly impact on the dying person and their families, as health professionals may fail to meet their last wishes for care. End of life care is a specialised area of practice and planning for end of life should be inclusive of the resident and their families. Providers’ lack of understanding of issues surrounding end of life care planning can result in residents suffering a less than optimal death or a hastened death. All of these findings attest to the need for further research to improve end of life care in all aspects, including informed end of life planning that increases the likelihood of a good death.
The Aged Care Workforce

Residential aged care facilities have a history of facing challenges in the provision of care for an ever-increasing ageing population. Since the early 1800s there has been a demand for aged care in Australia. According to Braithwaite, Makkai and Braithwaite (2007), the New South Wales (NSW) government provided funding for an ‘asylum’ construction in the early 1800s, which over time provided shelter to residents, who eventually aged. Care provision at that time was not provided by trained nurses, as it was not until the 1920s that nursing training was regulated in Australia (Nelson & Godden, 2007). Caring for older people until their death continues to challenge the systems providing the end of life care. The demands to provide a trained, professional aged care workforce are projected to increase to unprecedented levels in the near future (Department of Health and Ageing, 2005b; Eley, Hegney, Buikstra, Fallon, Plank & Parker, 2007; Hogan, 2004; Jackson, Mannix & Daly, 2003; Martin & King, 2008).

In 2003, the Australian Commonwealth Department of Health and Ageing commissioned the first major independent report of the aged care workforce. The report profiled the workforce and the 2003 data were compared with a repeat survey compiled in 2007. Data comparison demonstrated that the number of direct care employees in aged care homes was 175,000, which was a 10% increase from 2003 (Martin & King, 2008). The growth in the aged care workforce is representative of the demand for aged care services for an increasing ageing population, however, the aged care workforce mix is changing.
Registered Nurses

Contemporary literature indicates that the number of Registered Nurses (RNs) working in Australian aged care facilities is progressively decreasing (Chiarella & Duffield, 2007; Elliot, 2008; Karmel & Li, 2002; Scott, 2000). RNs accounted for 22,400 people in the 2007 aged care workforce report (Martin & King, 2008). Elliot (2008), commenting on the workforce, stated “Registered Nurses in aged care homes decreased by four per cent from 21 per cent in 2003 to just 16.8 per cent in 2007” (p. 1). The author suggested the decline in the number of RNs working in aged care was the result of a lack of encouragement to nurses to work in the aged care industry. A reduction in trained nurses is problematic, as optimal end of life care delivery is dependent on nurses being familiar with the principles of palliative care, including advanced medication knowledge.

The decline in nursing numbers in Australia is a worrying trend. In 2008, the Labour Government offered incentives to nurses to return to the aged care and public hospital workforces. The incentives included payment to facilities and cash bonuses to the nurses (Elliot, 2008). Enticing nurses back to the workforce with cash bonuses was criticised by the Australian Nursing Federation (ANF), the national union for nurses. Offering incentives to nurses only if they returned to the aged-care or public hospital sectors and paying the incentive at six months was viewed as decreasing workplace flexibility for nurses. Interestingly, the incentive scheme had a poor response with “less than 7 per cent of its five-year target” achieved in 12 months (Bloom, 2009).

The rural and remote setting has unique challenges in recruiting and retaining nurses. Hegney, McCarthy, Rogers-Clark & Gorman (2002) identified in a cross
sectional survey of nurses employed by Queensland Health, Australia, that a number of factors influenced nurses’ decision to remain in the rural and remote setting. Factors such as high job satisfaction related to role autonomy and practice diversity and personal issues, such as having family and friends in the area, or having had previous exposure to a rural and remote lifestyle. Attracting and retaining nurses in the workforce is challenging and is reflective of more complex issues than financial reward, with the rural and remote setting needing to be innovative and creative to sustain workforce numbers.

Nursing staff shortages in aged care have been attributed to failing to address a number of aspects of the work environment. Jackson et al (2003) attributed nursing shortages in aged care to the industry being an “undesirable work setting”, “isolated from mainstream nursing”, rife with “workplace assault” and job dissatisfaction (p. 43). Similarly, Lu, White and Barriball (2005) identified in a review of the literature published on nurses’ job satisfaction, that the work environment can have an impact on nursing shortages and high turnover rates. The authors identified, among other factors, that nurses’ job satisfaction was linked to: the working conditions; interactions including relationships with patients and co-workers; workloads; challenging work; abilities and skills to perform the work; professional training and opportunities for advancement; autonomy and decision making. Nurses’ workplaces have the potential to influence how nurses deliver or fail to deliver optimal end of life care.

The erosion of the RN numbers in the aged care workforce has implications on the extent to which those RNs who remain in the workplace, can readily engage in practice changes. Decreasing RN numbers and the problems the aged care industry is facing in attracting new RNs do not assist in challenging existing RNs
to be compliant with practice changes, or address deficiencies in end of life care. These findings show that more research is needed, specifically action research, because the opportunities it can provide to reflect on practice improvement can empower nurses to connect with the care that is delivered and to develop the skills necessary to facilitate improvements, therefore, this project is timely and important.

As RN numbers have reduced in aged care facilities, so also have nurse-resident ratios decreased (Karmel & Li, 2002). A progressive increase in assistants in nursing and personal carers have filled the nursing void, however, it has been suggested there are limited data to demonstrate this change in skill mix (Karmel & Li, 2002). While Karmel and Li focused on numbers of staff employed in aged care, Bita (2009) in an interview with the Australian Medical Association (AMA) Chair Peter Ford, argued there is a lack of quality care in aged care facilities, as a consequence of changing staff profiles. The AMA Chair protested that “it was unacceptable that some homes employed just one nurse to care for up to 120 elderly residents” and that “one registered nurse per 100 or 120 patients, with carers who are struggling themselves, is a formula for ensuring a reduced standard of care”. Interestingly, as the RN workforce has decreased in aged care, the literature on resident suffering has increased (Connelly, 2009; Emanuel, 2006; Kellehear, 2009), although cause and effect factors have yet to be identified by controlled studies.
Enrolled Nurses

Enrolled Nurses (ENs) in Australia are the second level of nurses in aged care, who practice under the supervision, either directly or indirectly, of a registered nurse (National Aged Care Forum, 2001). ENs account for 16,000 of the aged care workforce in Australia, which is a slight increase, but an overall decrease in the four years from 2003 to 2007, reported by Martin and King (2008). ENs provide support to RNs and play an important role in the delivery of care to older people including monitoring, assessing and addressing residents changing health care needs. The scope of practice and role of the EN varies across Australia and has evolved over time to include medication administration (National Aged Care Forum, 2001). ENs are assuming more responsibility in the aged care setting with new models of care being implemented and additional, less trained, levels of carers are employed.

Personal Carers

In their workforce report, Martin and King (2008) detailed the substantial increase in the number of personal carers employed in aged care in Australia. In 2007, personal carers represented 85,000, or 48% of the workforce. Scott (2000) suggested the increase in personal carers in residential aged care in Australia was a consequence of increased workload demands, related to higher acuity of residents. In comparison, Martin and King (2008) suggested the increase reflected a decline in the number of nurses providing direct resident care. A workforce that is comprised of predominately personal carers presents a number of challenges to residential aged care facilities in the management of that workforce.
Personal carers have been identified as being more likely than other aged care staff to leave the workforce. In Australian aged care, the casualisation of the workforce has been increasing, with 23.4% of personal carers being employed casually in 2007, as compared to 20.5% in 2003 (Martin & King, 2008). Further, personal carers earn less than nurses (Martin & King, 2008). The increased numbers and casualisation of personal carers in aged care presents a challenge to the nursing profession, because personal carers are a subset of workers, who have limited educational levels and are cheaper to employ, yet they are performing the work of nurses (Holloway & McConigley, 2009) and are involved in end of life care delivery.

Doctors

General Practitioners (GPs) are the main providers of medical services to residential aged care facilities in Australia. Worldwide, the service provision by doctors to aged care facilities has been reported to be limited (Back et al., 2009; Gadzhanova & Reed, 2007; Watson, Hockley & Dewar, 2006; Wetle, Shield, Teno, Miller & Welch, 2005). A number of factors have been identified as contributing to a lack of service provision and a number of barriers have been identified that limit effective palliative care delivery by doctors to dying residents in residential aged care settings.

There is general agreement that GPs can identify a number of barriers in providing services to residential aged care facilities (Brazil et al., 2006; Gadzhanova & Reed, 2007). Gadzhanova and Reed (2007) define the barriers as low levels of reimbursement and time consuming paperwork, resulting in some
aged care facilities relying on “an established cohort of older, predominately male GPs who themselves may soon be reaching retirement age” (Gadzhanova & Reed, 2007, p. 92). Brazil et al (2006) identified inadequate financial reimbursement and time commitment. The authors acknowledged that their survey of Canadian medical directors of long term facilities had limitations, including a response rate of 57% of 302 facilities, and that only medical directors were surveyed, however, important barriers identified by doctors in end of life care included inadequate staffing and equipment in the aged care facilities. Barriers to optimal end of life care in aged care facilities are multifactorial and each one contributes in some way to prevent adequate service delivery to the dying. Developing a reliance on older doctors can also be problematic, if those doctors are not using current evidence and their practices are based on preconceived ideas of how dying should be managed.

Von Gunten, Ferris and Emanuel (2000) argued that many physicians did not receive training in end of life care skills, including “skill in communication, decision making, and building relationships” (p. 3051). Brunnhuber, Nash, Meier, Weissman and Woodcock (2008) agreed that a lack of training resulted in doctors being reluctant to communicate with patients and their families and doctors blaming a lack of time for this poor communication. The authors also suggested if a doctor’s palliative care knowledge was lacking that patients were under referred to palliative care specialists or services and that doctors could be uncomfortable with the subject of palliative care (Brunnhuber et al., 2008).

Similarly, Australian doctors have been shown to fail to deliver a palliative approach to those in an advanced stage of a life limiting disease (Kristjanson et al., 2003). Kristjanson et al (2003) identified barriers including:
“the belief that a palliative approach should only be offered in the final stages of an illness, difficulty recognizing when patients are terminally ill, therapeutic “ennui” (disengagement or difficulty in imaging alternative approaches when active treatment is not available), discomfort in discussing end-of-life issues, the belief that symptoms are acceptable or inevitable, and ignorance about palliative care” (p. S43).

Doctors are charged with the responsibility of providing medical services to residential aged care facilities. In order for dying residents to receive a palliative approach to care, consideration by doctors to respond to the need, regardless of the challenges, and support the delivery of optimal end of life care.

Aged Care Workforce Education Levels

The provision of optimal end of life care is closely linked to nurses having knowledge, training and education, including a range of end of life symptom management strategies. There is general agreement that few nurses working in aged care have gerontology or palliative care post graduate qualifications and that post basic education is declining in the Australian aged care workforce (Martin & King, 2008; Maas et al., 2008b; Paterson, Xiao, Mitchell, Henderson, De Bellis & Kelton, 2007). For example, Martin and King (2008) identified that only 10% of nurses working in aged care had post basic aged care nursing qualifications.

In a report commissioned by the Australian Commonwealth Department of Health and Aged Care, Pearson and Nay (2002), identified:
“the highest attained educational qualification for aged care nurses were Certificates (Registered and Enrolled Nurses) and Undergraduate Degrees. Only 3.2 per cent of aged care respondents had completed a Masters or PhD, however 11.4 percent had obtained a Diploma or honours degree” (Department of Health and Ageing, 2002, p. 27).

These figures compared “similarly to 13.2 per cent of non aged care respondents, who had completed a Diploma or honours degree” (Department of Health and Ageing, 2002, p. 27). Paterson et al (2007) proposed Australian aged care facilities should improve their linkages with the tertiary sector, to promote education to practising nurses and thereby improve care.

Similarly, Maas et al (2008b) highlighted the deficits in older residents’ quality of care in nursing homes in the United States and recommended it was preferential for RNs working in nursing homes to have gerontological training. The authors argued that the advanced skills, leadership and knowledge gerontological training gave RNs, was necessary to provide the quality of care that chronic, complex older residents require.

In contrast, Nolan et al (2008) reviewed the literature on education and training and the relationship to change in care homes in the United Kingdom and argued that education was one component of improving care and sustaining change, however, it was not the only solution to address the problems aged care facilities faced in caring for residents. Rather, for Nolan et al (2008), keys to succeeding in raising the standards of care were in improving the image of aged care as a discipline, adopting a “relationship-centred approach to care” and incorporating a holistic approach to care (p. 412). Overall, the changing profile of the
Australian and international aged care workforce to a predominately, less qualified staffing profile, highlights potential areas of concern regarding the quality of care being delivered to older residents in residential aged care facilities (Badger et al., 2009; Holloway & McConigley, 2009; Maas et al., 2008b; Tuckett, 2007; Winzelberg, 2003).

Impact of the Aged Care Workforce on Quality of End of Life Care

Aged care workforces internationally and within Australia are charged with the responsibility of delivering quality end of life care to high acuity residents dying from complex diseases. Achieving quality of care is dependent on numerous factors, including the commitment of the service providers; constraints to practice; the workers ability to perform within complex environments; workers functioning within their scope of practice and feedback through the use of evaluating service provision (Allen et al., 2008a; Brazil et al., 2006; Courtney, O’Reilly, Edwards & Hassall, 2007; Holloway & McConigley, 2009; Miller, Teno & Mor, 2004; Winzelberg, 2003).

Shield, Wetle, Teno, Miller and Welch (2005) argued that the absence of doctors and insufficient staff numbers in American nursing homes impact on the quality of care provision for dying, nursing home residents. The authors interviewed 54 family members or close associates of dying residents, between one and two years after their relative’s death and found that participants expressed they were “worried when low staffing levels seemed to prevent the proper administration of basic care”; “that physicians were rarely seen in the nursing home”; and they were concerned “insufficient numbers of staff as well as their lack of compassion; problems with symptom management and other end-of-life treatment” (pp. 646-74).
The qualitative aspect of the study was a follow-up of relatives, who had previously participated in a national survey. Recommendations from the study included improved funding to supply adequate staffing, improved end of life training for all staff and encouraging continuity of medical care. The authors acknowledged that the use of narrative interviews up to two years following the residents’ death was one of the limitations of the study, however, the length of time was considered appropriate to allow some respondents to gain perspective on the events. Further, the generalisability of the findings beyond the qualitative sample size were partially addressed by “comparing the qualitative data against the full sample from the quantitative survey, which indicated similar characteristics between the two groups” (p. 649).

In Australia, it has been previously identified that workforce issues are influencing end of life care. The worldwide shortage of nurses, combined with an increasing ageing population, is impacting on the ability of health services, including the residential aged care sector, to provide palliative care. Alternative models of care have been recommended and a focus on future workforce planning and palliative care education has been recommended (Chiarella & Duffield, 2007). In 2009, the Australian Nursing Federation launched a campaign to improve the equality and quality in aged care. Ged Kearney (2009) the Federal Secretary of the union, stated the aged care industry “desperately need nursing staff with the right mix of nursing skills and increased Federal Government funding, with greater accountability for that funding” (p. 12). The campaign focused on the issue that Australian aged care nurses receive less pay than nurses working in the public or private sectors. Pay inequity was identified as a major reason why the aged care industry fails to recruit or retain nursing staff.
Studies also suggest that qualified aged care workers are operating at “an arms length” to the facilities they serve (Gadzhanova & Reed, 2007; Holloway & McConigley, 2009; Wette et al., 2005). For example, the impact of qualified professionals disconnecting with end of life care provision was highlighted by Back et al (2009), who conducted a longitudinal, qualitative study including “31 physicians, who identified 55 patients with incurable cancer or advanced chronic obstructive pulmonary disease, 36 family caregivers, and 25 nurses” (p. 475). The authors found patients and family caregivers expressed concerns that their “their physician” would abandon them in the dying process and recommended reducing system barriers that prevented continuity of care (p. 478).

Similarly, in a study conducted by Wette et al (2005), physicians were described by families as “missing in action” (p. 647). Participants reported needing more communication with the doctors, not knowing the doctor’s name, or not seeing the doctor at any stage. In this American study, nurse practitioners and physicians’ assistants were regarded by the authors as “physician extenders” and more likely to interact with the families on behalf of the physician (p. 647). This American funding model had a physician “non payment” for services to dying patients, and the authors recommended this model be abolished (p. 649).

The changing nature of the aged care workforce to a less qualified workforce is gaining momentum in Australia and may be contributing to staff accepting responsibilities beyond their scope of practice. Holloway and McConigley (2009) conducted a descriptive, exploratory qualitative study in three Australian residential aged care facilities, where six nursing assistants were interviewed using a semi-structured narrative style, to determine their experiences in caring for aged residents, particularly their experiences with pain management. A
A common theme identified from the interviews was that the nursing assistants were being required to extend their role. Additional responsibilities were defined as “making clinical decisions, initiating clinical care and advocating for residents” (p. 71). The authors concluded that nursing assistants’ care provision had exceeded basic care, such as bathing and feeding and had, therefore, impacted on the quality of resident care. Further, in some instances the nursing assistants were the only people delivering care and they stated “supervision is often available off site, with most support available through an ‘on call’ nurse only” system (p. 72).

Employment of less qualified staff in aged care is not unique to Australia. Nursing assistant numbers are increasing in the United States also and are reported to number 1.3 million workers (Denham, Meyer, Rathbun, Toborg & Thornton, 2006). A study by Denham et al (2006) aimed to assess the end of life care training requirements of a total of 63 nursing assistants. The authors identified that 61% of respondents were found to have never had formal training to care for the dying and further that “51% of the participants reported that talking with supervisors about concerns in care of dying persons was a problem” (Denham et al., 2006, p. 233).

The quality of care delivered in residential aged facilities is measurable and important (Achterberg 2004; Courtney, O’Reilly, Edwards & Hassall, 2007; Winzelberg, 2003). In Australia, Courtney, et al. (2007) suggested that until their quality indicator tool was developed, there had been no formal systems to measure quality of clinical care in residential aged care systems. The authors argued that current tools used to assess residents were focused on administrative outcomes and represented the minimum standards of quality. The Clinical Care
Indicators Tool was acknowledged to have limitations, however, its main value was that it attempted to measure the quality of resident clinical care.

To demonstrate the importance of measuring care, the United States Congress, concerned by the poor quality of care in nursing homes, made a recommendation for a “uniform assessment instrument” to measure quality of care and quality of life in American nursing homes (Achterberg, 2004, p. 13). As a result, Achterberg (2004) developed the Minimum Data Set: Resident Assessment Instrument (MDS:RAI), which is now used as a mandatory measuring tool in United States nursing homes. The tool measures the domains of physical, mental and social functions and incorporates quality indicators that provide information on which to base quality improvements. An assessment is performed on admission and at 12 monthly intervals (Achterberg 2004; Courtney et al., 2007). The MDS:RAI is used internationally and has been found to improve the quality of care in USA, Sweden, Japan and the Netherlands, however, the developer of the tool states he was surprised by the lack of studies that identified the pitfalls of implementing the tool (Achterberg, 2004). The international uptake of the tool may be more reflective of nursing home administrators’ desire to be seen to measure and report on quality, than to changing or improving care, because pain assessment and management in the MDS:RAI have not been shown to be a reliable or valid measurement in the cognitively impaired (Achterberg, 2004).

The workforce and the workplace culture influence the quality of care delivered. Workplace culture is linked to numerous factors, as identified by Winzelberg (2003), who suggested that quality in United States nursing homes was difficult to achieve, due to regimented institutionalised care structures; a hierarchical nature of staffing with the resident having the lowest status; poorly paid staff; a
hazardous, high injury risk work environment; high staff turnover rates; unstable organisation financial status; and for those facilities who are required to make a profit, financial pressures eroded their ability to administer a quality to the care. Other factors impacting on quality included a higher acuity of patients admitted into nursing homes and an increasing number of high care, frail, older residents requiring increased assistance. Therefore, Winzelberg (2003) asserted that the negative workplace cultures prevent optimal end of life care delivery.

Employing more staff does not necessarily improve the quality of care. For example, in a United States study, Castle and Engberg (2008) demonstrated through surveying and interviewing nursing home administrators that “resident care is dependent not only on how much is done (represented primarily by staffing levels), but also on consistency of care, coordination, and care practices” (p. 475). The study had a high response rate with 2,946 (74%) respondents to one survey and 3,939 (66%) to a second survey. The authors acknowledged the study limitations including data omissions, quality measure bias and unknown factors that may have influenced care. Identifying issues impacting on quality of care is important as management strategies can be focused on optimising and enhancing the workforce in a way that improves the quality of the care, rather than simply having sufficient numbers to complete the tasks.

In a review commissioned by the Australian Government, Warren Hogan (2004) reviewed the funding and pricing arrangements for the aged care industry in Australia (Hogan, 2004). In his review, the author stated “an adequate and professionally trained workforce is critical to improving quality and level of service now, and to lay the groundwork to meet increasing demand in the future” (p. 284). Interestingly, further research commissioned by the Australian
Government four years later identified that quality of care in the aged care setting is difficult to achieve when “funding is inadequate” (Productivity Commission, 2008, p. 109).

End of life care is complex and support for the workforce can be provided in a number of ways inclusive of education and training. However, when systems or people divulge themselves of the responsibility for care due to inadequate incentives, hierarchical structures, workforce casualisation or a lack of training, the weakest and most vulnerable person, the dying resident, is not heard. If the delivery of optimal end of life care is a goal, then consideration by the aged care workforce is required to find ways to meet residents’ needs and use available methods to deliver optimal care.

End of Life Care Tools to Support the Aged Care Workforce

The aged care workforce can be supported in delivering end of life care by utilising various tools currently available, including clinical pathways, charts and policies guiding end of life care. In addition, providing evidence at the point of care is important to allow staff easy access to the evidence to assess, monitor and evaluate care as it is delivered. While tools do not guarantee care will be managed well, it is important to continue to determine those tools that nurses find useful and support them in delivering end of life care.

There is no definitive tool that prescribes the best way to deliver optimal end of life care. However, a clinical pathway to guide care of the dying patient was produced in 1997, the Liverpool Care Pathway for the Dying Patient (LCP). The pathway was developed to improve the care of patients at the end of their lives
and to assist in translating hospice care into the hospital setting (Preston, 2007; Veerbeek, van Zuylen, Swart, van der Maas, de Vogel-Voogt, van der Rijt & van der Heide, 2008).

Ellershaw (2007) described the Liverpool Care Pathway (LCP) as providing

A comprehensive template of appropriate, evidence based, multi-disciplinary care for the last days and hours of life. It provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. It focuses on the physical, psychological, social, spiritual and religious aspects of care, together with the information needs of patients and carers (p.365).

A number of studies have focused on the LCP as a tool to assist staff in delivering end of life care (Preston, 2007; The Marie Curie Palliative Care Institute and Royal College of Physicians 2008/2009; Veerbeek, et al., 2008). For example, Veerbeek, et al. (2008) studied the LCP in a range of care settings, including “the hospital, nursing home and home care setting” and found “a modest” improvement in the documentation of care during the dying phase and “the symptom burden for patients decreased” (p. 148). Components of the pathway were studied and compared including “documentation, the symptom burden and several aspects of communication before and after the introduction” of the pathway (p. 146). One third of the people enrolled in the study were people dying from non cancer diseases. The authors acknowledged good documentation did not necessarily reflect good care, however, a positive finding was that the symptom burden of the dying decreased when the pathway was
Symptom burden reduction is important to prevent unnecessary suffering and relief of distressing, unnecessary episodes of pain, breathlessness, secretions, nausea or delirium.

Although there is some support for the LCP, other health professionals do not support its use. Kmietowicz (2009) reported doctors had written to a national newspaper in the United Kingdom regarding the use of the LCP. The doctors claimed that “families and friends of patients were angry at witnessing the denial of fluids and food to patients” and that the pathway was “causing a national crisis in care” (p. 653). Shortly after this media release, a national audit of hospitals report was released by the “Marie Curie Palliative Care Institute Liverpool, in collaboration with the clinical standards department of the Royal College of Physicians”, demonstrating the pathway improved care to the dying (p. 653). The second national audit of the LCP was conducted in 151 hospitals and included a total of “3893 patient data sets” of which 61% were patients who had a diagnosis other than cancer (The Marie Curie Palliative Care Institute, 2008/2009, p. 7). Overall audit findings suggested by Johnathan Potter, the Clinical Director of the Royal College of Physicians, London, were that where the pathway was used for the dying patient “people are receiving high quality clinical care in the last hours and days of life” (The Marie Curie Palliative Care Institute and Royal College of Physicians 2008/2009, p. 2).

The positive results associated with use of the LCP have been echoed by Preston (2007), who endorsed the implementation of the pathway in conjunction with two other tools used in the NHS End of Life Care Programme. This programme was funded by the Department of Health and aimed to “offer patients more choice in relation to their health needs” (Henry & Fenner, 2007, p. 56). The “Gold
Standards Framework and Preferred Place of Care” complete the NHS End of Life Care Programme. The implementation of the pathway into the workplace was identified as critical to its success (Preston, 2007). Preston recommended that keys to successful implementation include a 10 step education strategy, ownership of the tool by those clinicians using the tool and before an organisation adopted the tool that auditing be conducted pre implementation.

Just as the LCP has made inroads into improving end of life care, Edvardsson, Katz and Nay (2008) demonstrated in a pilot study that the Aged Care Pain Chart is a “valid, applicable and clinically helpful” chart to use in pain assessment for older people (p. 96). Despite the limitations of the chart requiring further evaluation for interrater reliability and sensitivity, the tool provides another option for aged care staff to assess and manage pain in people with cognitive impairment. However, for residents to receive optimal care, aged care staff must follow protocols and comprehensively document all tools that aid in the assessment and management of residents’ care.

Simpson, Stevens and Kovach (2007) demonstrated the complex relationship between aged care staff agreeing to follow protocols and residents receiving evidence based care. The authors explored nurses’ experiences of implementing research based nursing protocols known as The Serial Trial Intervention (STI), aimed at achieving the best outcomes in comfort and care for people with dementia. The process consisted of assessing, then trialing interventions with residents. Through semi-structured interviews nurses identified a range of barriers in using the protocols. Barriers included physicians’ lack of follow through in escalating pain relief, nurses’ lack of time and “disengaged staff” (p. 1026). The authors concluded that for the protocols to work in clinical practice,
the nurses needed to engage in practice change. This was viewed as critical to the success of the project. Further, improvements were necessary to the “regulatory atmosphere, workload structure and interdisciplinary collaboration”, to support the nurses in using the protocols (p. 1027). Nurses are a critical component in improving end of life care practices. Organisational and professional support can influence and assist nurses to engage, examine and improve their practices.

Brumley, Fisher, Robinson and Ashby (2006) suggested that nurses require access to accurate, current, easily accessible patient information out of hours to deliver end of life care. The authors argued that when nurses were given access to information, improvements were seen in both their confidence and their communication of clinical information, which also saved the nurses’ time. This line of thought has been explored by Cohen-Mansfield, Lipson and Horton (2006), who found that when there was a change in a resident’s clinical condition, nurses were regarded as playing a minor role in the decision making processes, as compared to a doctor. This was despite nurses being more familiar with the resident and their families’ advanced care directive requests. The authors surmised that this situation existed because of differences in medical and nursing language when reporting a change in a resident’s condition, the limited role and influence nurses had on decision making in the clinical setting, and the infrequent opportunities staff had in attending multidisciplinary meetings. The constraints to nurses’ end of life care practices are influenced by many factors including the historical, political and culture barriers the profession has inherited from a profession rooted in a military foundation. When positive influences are combined with participatory processes, it is possible to support the delivery of optimal end of life care to residents dying from a non malignant disease.
Chapter Summary

This chapter described the literature related to end of life care delivery to residents dying from a non malignant disease in residential aged care facilities. Issues were described that may be encountered when attempting to address symptom management in residents dying from a non malignant disease. Delivering optimal symptom management with limited or no palliative care support or expert guidance can be particularly challenging when the prediction of the dying phase is unclear. A lack of symptom management expertise can be a haphazard process for those attempting to meet dying residents’ needs and can result in the resident experiencing unnecessary suffering in the dying phase. Although the contemporary focus is on living well in aged care, residential aged care facilities are nonetheless a place of dying and an increasing number of people enter aged care facilities to die, ultimately.

Advanced care directives are featuring as an important aspect of admission to a residential aged care facility, however, the focus has been mainly on the administrative processes, rather than the translation of their use into effective clinical care. Palliative care is focusing on building professional caregivers’ skills and confidence, and engaging all the other people involved in the care of the dying. It is proposed that staff are then better prepared in many ways to deliver optimal end of life care. However, if a resident’s symptoms are not managed well, then the responsibility is on the nurse to check where omissions to appropriate care have occurred.
Exclusive time dedicated to developing palliative care knowledge and skills of nurses working in Australian residential aged care facilities is critical, however, substituting the nursing workforce with unskilled labour has the potential to undermine these initiatives. Active guidance in care initiatives is more important in the final stages of life and the nurse must be prepared to watch for warning signs and symptoms and know when to intervene and manage symptoms as appropriate. There is no one best way to deliver end of life care, just as there is no single formula to prevent suffering. End of life care tools are available and are designed to support aged care staff responsible for delivering end of life care. Supporting aged care staff responsible for delivering end of life care increases the likelihood that the majority of residents dying from a non malignant disease will die a peaceful death in the residential aged care facility in which they have lived. Overall, the literature suggests nurses and allied staff within Australian residential aged care facilities need to be empowered to recognise the requirement for palliation in a timely fashion and effectively care for residents who are dying from non malignant diseases. Therefore, the literature pointed to the need for this action research and reflection project, which is timely and important in contributing to fulfilling that aim.
CHAPTER THREE: METHODOLOGY

This chapter describes the methodological approach used to investigate the issues nurses and relatives identified relating to end of life care for residents with non malignant disease, in two rural Australian residential aged care facilities. It describes action research and reflection, the two processes used in combination in this project, and a range of nursing examples of the application of the methodology.

Action Research

Action research has been described as developing and changing as a “continuing, process of historical and cultural change” (Carr, 2006, p. 425). Charles and Ward (2007) credit John Dewey’s work in the 1920s as building a “foundation for Action Research”, due to his interest in encouraging people to be engaged in the societies in which they lived (p. 4). Action research was formalised through the inquiry of Kurt Lewin, a social psychologist, who is recognised internationally, because he “produced a theory and practice” (Carr, 2006; Charles & Ward, 2007, p. 5). Lewin conducted social experiments with post world war Americans to explore the social aspects of communities and to foster group decisions and commitment to improvement (Kemmis & McTaggart, 1990). The vulnerability of communities in the post war 1940s provided opportunities for Lewin to demonstrate that “the use and production of knowledge can be political and can be used to exert power” (Meyer, 2000; Polit & Beck, 2006, p. 226).
Action research has moved in and out of favour with the research communities. Carr (2006) suggests the rejection of action research and the eventual decline of its use by the “American social scientific community in the 1950s” was due to the insistence that a quantitative methodology be applied for the “collection and analysis of data” (p. 423). Stout (2006) is of the opinion that, as a methodology, action research was dismissed as it was considered “soft and impure”, because it has a history of being a controversial method of inquiry (p. 195). Action research experienced a revival in the early 1970s and is now recognised as a legitimate form of research (Carr, 2006; Roberts & Taylor, 2002). An educator, Lawrence Steinhouse, is credited with the 1970s resurgence of action research in the United Kingdom, where he encouraged teachers to use the methodology as an opportunity to become engaged in researching “their own practice” (Charles & Ward, 2007, p. 5).

Over time, action research has evolved into a practical change process and has been adopted by disciplines other than the social sciences, such as education, health, agriculture and industry (Charles & Ward, 2007; Hope & Waterman, 2003). Nurses are the major users of action research in healthcare, however, within nursing the research has been “mainly focused on organisation/professional development/education settings” (Munn-Giddings, McVicar & Smith, 2008, p. 476), not specific clinical practice issues (Reed, 2005).

The diversity of professions using action research has been identified as problematic for the development of “cross-sectoral dialogue between practitioners” on the origins of the research (Charles & Ward, 2007, p. 3). Action research has evolved to serve these disciplines, originally from a process to provide “access to participant understandings and meanings of their situations”,
to develop into a “method for addressing ideological and power-related issues in social situations” (Charles & Ward, 2007; Hope & Waterman, 2003, p. 123). Hall (2006) suggests that the substance of action research is that the methodology is “situational and firmly rooted in human values and behaviours”, which provides opportunity and responsibility, for example, for nurses giving care, to generate solutions to problems in which they have an interest (p. 196).

Kemmis and McTaggart (1990) suggest a process of initial reflection is used to analyse a situation in relation to a thematic concern. Reflection is then followed by a process of planning, assessing and observing, to implement an action, a change or adoption of a new practice, validated by further reflection. The implementation of the plan and the ongoing observation of how it works in practice, culminate in the research participants returning to the process of reflection, which encourages participants to review achievements and examine limitations of changes to practice. The analogy of a “spiral” that incorporates the four steps of action research demonstrates action research is a “dynamic process that can be engaged in several times before a problem is resolved” (Minichiello, Sullivan, Greenwood & Axford, 1999, p. 256).

Even though action research is clearly delineated, as a dynamic four step process, Minichiello et al (1999) explains that action research and the use of the methodology has created debate as to “the proper conceptual designation of action research; is it philosophy, theory, methodology or technique?” (p. 249). This theoretical uncertainty is not surprising, given that qualitative research in a general sense can be defined broadly, may not be well understood, and is “criticised for lacking scientific rigour” against quantitative criteria (Mays & Pope, 1995, p. 109). I assert that action research has aspects of philosophy, theory
and methodology, referred to in this project collectively as methodology, meaning the theoretical assumptions underlying the choice of research methods and processes (Taylor et al., 2006), and it is also a technique, referred to in this project as methods and processes (See Chapter 3).

According to Meyer (2000), action research does not fit within the traditional confines of a research methodology. Meyer (2000) suggests action research is a research “style”, rather than a method (p. 178). There is flexibility within the style for researchers to be the focus of the research, or that researchers outside of the research setting can be engaged to facilitate the process. I argue that action research is more than a style alone, as suggested by Meyer (2000), who is confusing style with process. The participatory nature of action research as a process is at the same time methodological, because it consists of a set of sound, well debated epistemological assumptions underlying the choice of research methods and processes. Action research as a methodology with congruent methods and processes is well suited to the increasing demand for “clinically-focused research”, because the collaborative and reflexive nature of the research engages participants in the process (Munn-Giddings et al., 2008, p. 475).

Regardless of the terminology to describe the approach, underpinning action research is its flexibility, which enables users to identify and solve problems. This aspect of the methodology sets it apart from traditional research methods, because in action research, the people directly involved in the context explore the issues, for example, nursing issues can be explored by nurses and, therefore, the theory practice gap can be addressed directly by the people for whom it has most relevance.
Engagement of participants in the research tends to be within three categories of action research – technical, practical and emancipatory (Kemmis & McTaggart, 1990; Taylor et al., 2006). According to Taylor et al (2006) technical action research promotes the improvement of previously unexamined practices, by using a collaborative approach to test the feasibility and applicability of a well-considered instrumental change. The communicative focus of practical action research is on participants using the cycles of the action research process for identifying a practice issue, generating solutions and sustaining changes in interpersonal relationships. The cycles lead to group decisions that result in an action being taken, which improves communicative aspects of practice (Minichiello et al., 1999). Emancipatory action research facilitates critical collaboration between the co-researchers, to identify oppressive issues that constrain their practice, to ultimately deconstruct and transform them into new possibilities and solutions (Polit & Beck, 2006).

Although technical and practical forms of action research are useful, emancipatory action research holds the greatest promise of cultural change in hierarchical organisations, because it is overtly political in its intent. A consistent finding identified in the action research literature is that action research combines well with critical theory as emancipatory action research, because the methodology encourages liberation from oppressive forces, and the methods and processes encourage critical analysis and exploration of behaviours and practices in hegemonic social situations (Hope & Waterman, 2003; Foreman-Peck & Murray, 2008; Taylor et al., 2006). For example, Charles and Ward (2007) claim that the values of feminism and action research match, as “the non-neutrality of the researcher and analysing power relations involved in the research process” can be complementary (p. 90).
In contrast, Minichiello et al (1999) argues that society has moved on and that oppressive, patriarchal systems no longer exist, making social justice issues less relevant. I argue that oppressive, patriarchal systems may be less overtly evident than those studied by Lewin in the post war period, however, the dominance of other social control agents and oppressive hierarchical forces continue to exist overtly and covertly, and they demonstrate that emancipatory forms of action research are still relevant. Therefore, critical methodologies, such as feminism and action research can be complementary to each other, provided the accompanying feminist agenda is acknowledged (Charles & Ward, 2007). This position is supported by Reinharz (1992, in Stout, 2006), who claims that feminist social researchers have called for “more knowledgeable action...not just more knowledge of the problem” (p.178). Whether linked to feminism, or to any other critical theory, action research has a place in present day research, when it is acknowledged that politics as contestation and power plays underlie human interactions, and that there is value in people working as co-researchers to identify and reverse oppressive forces in their workplaces.

At its heart, action research engages people to influence practice or facilitate change. Kemmis and McTaggart (1990) explain that action research is a “form of collective self-reflective enquiry” the purpose being to equalise aspects of their social situation, in order to improve those situations (p.5). The process requires participants to identify issues that are relevant to practice or situations and develop solutions or strategies to change practice or improve clinical situations (Taylor et al., 2006).
Action research is participatory in nature, equalising power relationships between the researched and the researcher, thereby building bridges between the implementation of theories into practice and the action focus (Charles & Ward, 2007; Meyer, 2000; Minichiello et al., 1999; Polit & Beck, 2006; Taylor et al., 2006). Minichiello et al (1999) indicates that a crucial element of action research is the collaboration of group members, to engage in the process and form bonds of trust with group members. Thus, trust is achieved in action research by incorporating foundational processes that support the group in working together. The processes include co-researchers committing to work together on workplace situations until practice issues and improvements are realised, providing opportunities to share personal and professional reflections, in a comfortable, collegial, non-judgement environment (Taylor et al., 2006).

**Action Research in Nursing**

According to Meyer (2000, p. 180), the discipline of health is engaging in action research as the result of a need to “facilitate closer partnerships between staff and users” of health. As a healthcare discipline, nursing uses action research mainly in the hospital setting (Munn-Giddings et al., 2008), where it is conducive to solving clinical questions, because both the nursing process and action research assess, plan and implement ideas as part of a systematic approach, ultimately to problem solve issues (Taylor et al., 2006). Hope and Waterman (2003) agree that the problem solving approach of action research “mirrors that of the nursing process” (p. 121).

Some of the appeal of using action research in nursing is based on this research approach having “ethical and action-oriented principles” that address any
validity concerns of research purists (Hope & Waterman, 2003, p. 121). Even so, Reed (2005) suggests that action research can be problematic regarding the “ownership and commitment” of nurses involved in action research (p. 598). These concerns are attributed to nurses’ perception that the project may involve “extra work that they could not see the purpose of” (p. 598). Reed (2005) also suggests “if nursing is to engage in action research, this must be done critically and reflectively and careful attention paid to developing an inclusive and collaborative approach to knowledge and practice development” (p. 600).

Nurses have used action research in a variety of ways. For example, Cook, Deeny and Thompson (2004) used an action research approach to examine nurses’ roles in fluid management and hydration of patients, who had suffered a subarachnoid haemorrhage. The nurses who participated in the study were employed in two, 29 bed acute neurosurgical wards. A participatory action research design was used, to collect data through a technique of triangulation, which is a qualitative method to ensure data validity (Mays & Pope, 1995). The researchers triangulated a focus group, nurses’ documentation audits, and objective data, including the examination of patients’ vital signs, fluid status, fluid management and blood tests.

Cook et al (2004) were interested in the application of theoretical knowledge into everyday practice and they found that nurses were knowledgeable of fluid and hydration in subarachnoid haemorrhage, but that there was some “ambiguity about their role” that required further clarification and exploration (pp. 845-847). Although action research was viewed as a vehicle to “generate ownership within the clinical team” of the patient care and related issues in the management of subarachnoid haemorrhage, at the time of publication the ongoing action
research cycles required in the methodology had not been completed, and the results were to be taken by the clinical education facilitator “back to the nursing and medical staff with the researcher to develop ways forward to improve the care” (p. 847).

Booth, Tolson, Hotchkiss and Schofield (2007) used action research to identify a suitable approach to inform nurses through “Best Practice Statements” of the optimal nursing care required for older people (p. 946). Participants in the project were “recruited to achieve a geographical spread and role diversity” of nurses involved in gerontology practice in Scotland (p. 947). The researchers used a range of data collection methods that included telephone interviews, focus group interviews and “analysis of text based interactions within a virtual college” (p. 949). Researchers’ notes also contributed to the data collected. The participatory nature of action research was credited with the success of the project in “capturing and melding tacit nursing knowledge together with the experiences of older people and their carers” (p. 952). This resulted in a broadening of the credibility of the evidence that was to be used in the best practice statements. Further, the cooperation of academics with “practice communities” was viewed as a way of closing the theory practice gap (p. 952).

Grainger, Castledine, Wood and Dilley (2007) used an action research approach to improve the management of constipation of residents in long-term aged care settings. The authors engaged staff from nine homes in the United Kingdom to participate in education and training sessions for bowel care. Those nurses who received the training described as “constipation link nurses” then educated staff in the facilities in which they worked and disseminated information and resources for use in bowel care (p. 1212). The researchers were able to
demonstrate through questionnaires that identified core components of bowel care knowledge, that bowel care management practices were influenced and improved following the intervention. Questionnaires completed by patients or their relatives/carers and staff demonstrated the staff members’ holistic knowledge of prevention of constipation including the psychosocial aspects of constipation had changed for the better.

In summary, action research as a methodology comprises theoretical assumptions about the nature of knowledge, which can be generated from collaborative technical, practical and emancipatory approaches, within recurring spirals of planning, acting, observing and reflecting processes. Although there has been some blurring of definitions in relation to agreed action research terminology, action research engages people to influence practice or facilitate change, by processes of collective self-reflective enquiry, which develops solutions or strategies to change practice and improve situations. Although reflection is already a phase within action research cycles, its importance and use within nursing practice is such, that action research emphasising reflection has also been used in this PhD project.
Reflective Practice

John Dewey is credited with being an early writer on reflection (Kenny, 2003). Dewey used reflection in the discipline of education, to demonstrate that personal growth develops from combining reflection with experience (Graham, 1995; Kenny, 2003; Posner, 1989). According to Mackintosh (1998), in the 1980s, Mezirow, a theorist in education, suggested seven subcategories of reflection that included, “reflectivity; affective reflectivity; discriminant reflectivity; judgemental reflectivity; conceptual reflectivity; psychic reflectivity; and theoretical reflectivity” (p. 554). These subcategories depicted reflection as both a conscious process and an exploratory process of “critical consciousness” (p. 554). Another key writer on reflection in education at that time was Donald Schön (1983, 1987), who “acknowledged the working intelligence of practitioners” (Taylor, 2006, p. 8). From its genesis in the practice discipline of education, the concept of reflection has been embraced in healthcare, by nursing and social work (Clegg, 2000).

Posner (1989) defined reflective thinking as a process of “turning a subject over in the mind and giving it serious and consecutive consideration” (p. 21), while Atkins and Murphy (1993) suggested that reflection “must involve the self and must lead to a changed perspective” and these components “distinguish reflection from analysis” (p. 1191). They also suggested that there is a lack of definition of reflection that contributes to the difficulty in comparing those authors who have defined reflection. In agreement, Duffy (2007) proposed that reflective practice as a concept “has been poorly defined” (p. 1405), however, she suggests that as other disciplines use the process of reflection for “professional development”, definitions will inevitably change over time (p. 1406).
In Schön’s (1983; 1987) view, reflection is a process, which facilitates learning. Schön proposed that professionals learn, using “reflection-in-action” and “reflection-on-action”. This means that professionals may not be “consciously aware of the knowledge used, while reflecting-in-action” and they need coaching to understand the complexity of their practice knowledge after practice (Atkins & Murphy, 1993, p. 1188). Thus, given the sophistication of practice knowledge, Schön differentiated between reflection-in-action, as a process of seemingly effortless functioning without apparent awareness during work, and of reflection-on-action, as making sense of embodied practice knowledge after the work events.

Atkins & Murphy (1993, p. 1191) interpret Schön’s idea of reflection-in-action as practice in which professionals “can deliver without being able to say what we are doing”. They further explain that after the practice event, reflective writing and discussion “illuminate the knowledge used” (Atkins & Murphy, 1993, p. 1191), so that through reflection-on-action the professional “is consciously aware of the knowledge used” (p. 1188).

A working definition influenced by Rodgers (1989), concept analysis model, assisted Duffy (2007) to define reflective practice as:

an active and deliberate process of critically examining practice where an individual is challenged and enabled to undertake the process of self-enquiry to empower the practitioner to realise desirable and effective practice within a reflexive spiral of personal transformation. (p. 1405)
Reflection is interpreted as multifaceted, especially as demonstrated in reflective practice models. For example, Johns is credited with being one of the key British developers of reflective practice models (Taylor, Freshwater, Sherwood & Esterhizen, 2008, in Freshwater, Taylor & Sherwood, 2008). Todd and Freshwater (1999) interpret John’s (1995) definition of reflection as being “a developmental process by which an individual explores everyday aspects of practice with a critical eye, while simultaneously engaging in self-evaluation and the evaluation of the experience” (p. 1384).

Kenny (2003) considers reflective models are “too simple or too complex” and offers an alternative model based on Edward de Bono’s “thinking game” (p. 107), which involves using a range of coloured hats that represent the various ways of thinking (p. 107). Kenny suggests this alternative model spares practitioners confrontations during group sessions and assists practitioners to develop empowerment in the process.

Taylor’s (2006) REFLECT model is an easy guide to successful reflection, by using a mnemonic device to represent Readiness, Exercising thought, Following systematic processes, Leaving oneself open to answers, Enfolding insights, Changing awareness and Tenacity in maintaining reflection. She describes technical, practical and emancipatory reflection, based on Habermas’s (1973) “knowledge constitutive interests” (Taylor et al, 2008b, p.76). Each of these types of reflection has a purpose and a linkage to a “paradigm of knowledge” (Taylor, 2006 p. 101).

Technical reflection is a critical thinking process, which can produce measurable data that can be used to influence instrumental work related practices or tasks.
Practical reflection examines the complexity of human communication and the personal use of language that influences interpersonal actions. Emancipatory reflection is a form of transformational reflection, which problematises the status quo, and asks reflective practitioners and researchers to deconstruct their practices and belief systems, to transform practice norms and behaviours (Taylor, 2006).

Reflective processes can be formal or informal, to explore experiences and issues that are raised by an individual or in groups. Reflection can take various creative forms, including journal writing, audiotaping, creative music, dancing, montage, painting, poetry, pottery, quilting, singing, videotaping, or drawing (Cruickshank, 1996; Taylor, 2006). Even though writing seems to be the most accessible and easiest form of inspiring and recording practice reflections, a systematic review of action research from 2000-2005 conducted by Munn-Giddings, McVicar and Smith (2008) revealed reflective diaries were used in only 15 of 162 action research studies reviewed. The authors described reflective diaries as a “more diverse” form of data collection and included “creative arts, repertory grid, Q-methodology and written narratives” in this category (p. 472). Further, the authors identified in the action research studies they reviewed that there was a reliance by researchers to use “traditional research tools” including interviews, focus groups, questionnaire and observation to collect data (p. 472).

Reflection in Nursing

Reflective practices in nursing have been adopted throughout the world. According to Taylor et al (2008b, in Freshwater et al., 2008), in Australia, the uptake of reflection started from the scholarship activities of the Faculty of
Nursing at Deakin University, Geelong, where reflection was used initially within the discipline of education to develop “reflective practice for teachers” (p. 74). At that time, reflection in North America was predominately in the field of nursing education, however, the focus for reflection was on the development of student critical thinking skills (Taylor et al., 2008b). In comparison, the United Kingdom has accepted reflection into nursing as a means of integrating theory into practice with a research focus on developing reflective practice in post registration nurses (Taylor et al., 2008b). Globally, reflective practice remains in a state of evolvement and researchers continue to be challenged to prove the benefits of nurses developing reflective skills in the nursing profession (Freshwater et al., 2008).

Nursing research has adopted reflection as a means of exploring the constraints nurses face in delivering patient care (Edward & Hercelinskyj, 2007; Freshwater et al., 2008), nursing experiences of undergraduates or newly graduated nurses’ (Horton-Deutsch & Sherwood, 2008; Lasater & Nielsen, 2009) and the work of nurses (Mantzoukas & Jasper, 2004; Taylor, Edwards, Holroyd, Unwin & Rowley, 2005).

Taylor (2006) recommends using reflection to assist nurses and midwives to better understand the influences of the past on their current practices, while exploring a way forward to improve or change the care they deliver to patients. Taylor (2006) suggests “our present nursing dilemmas” are a result of nursing’s history, for example, nursing being a female dominated workforce, the demanding work, lower pay, less education and increased responsibility (p. 27). Therefore, reflection can help nurses to contextualise the practice issues that affect their daily work and develop an understanding that their work is not
performed in isolation, but influenced by a range of constraints, including historical, economic, cultural and political issues.

Glasson, Chang, Chenoweth, Hancock, Hall, Hill-Murray and Collier (2006) used reflective processes to assist nurses to discuss the possibilities of changing a model of patient care. Informed by a number of data collection methods, including three assessments of medical patients’ activities of daily living, medication regimens knowledge assessments, patient and staff satisfaction surveys and researchers’ field notes, the nurses addressed aspects of their current model.

Using a process of facilitation, Glasson et al (2006) encouraged the nurses to reflect on issues they experienced in caring for their older patients by inquiring, examining and exploring meanings that patients had previously identified as important to them. The barriers to change the nurses identified included “issues concerning time constraints and nursing staff levels that reduced their ability to perform nursing care procedures” (p. 594). Through a process of consultation with other nurses and managers, the co-researching nurses worked toward owning the new model of care adopted and they were empowered to sustain changes to their practices. This research demonstrated that by acknowledging constraints, such as staffing shortages within a context of a profession shortage, sufficient insights can be developed to change constraints within nurses’ immediate power (Taylor, 2006).

Forneris and Peden-McAlpine (2007) used reflection to analyse new graduate nurses’ development of critical thinking. The setting was an acute care facility in the United States that used a preceptor program to support new graduate nurses
in clinical practice. The researchers used a reflective case study design structured around a “contextual learning intervention”, described as “(a) narrative reflective journaling; (b) individual interviews; (c) preceptor coaching; and (d) leader-facilitated discussion groups” (p. 413). As a result of using the model, the researchers established “sharing narratives on practice experiences, so that novice nurses were not only able to explore their own thinking, but also to gain perspectives from others. This helped them engage in critical questioning focused on context” (p. 419). The findings suggested that nurses’ understanding of the care they were providing was more important to them, than knowing the correct answer to questions they could be asked to assess their clinical knowledge.

Kazanowski, Perrin, Potter and Sheehan (2007) focussed on the topic of suffering, to broaden student nurses’ understanding of the suffering of others. Several classes were held, using content based on research models that emphasised the “impact of a suffering experience on an individual” (p. 197). Reflection was used to encourage students to explore their thoughts and feelings related to the suffering experience and to “later apply the theory to their practice” (p. 197). Several assignments were given to the students, each requiring them to discuss, share and explore the assignment topic. For example, in the fifth assignment students were asked to reflect on a case study of a patient suffering. The students’ responses “described how they often felt inadequate and sometimes wanted to run and hide from the suffering” (p. 199).

The researchers’ participation in the discussions was described as “fellow journeyers instead of experts”, as they assisted the students to feel safe to share their thoughts and feelings on the suffering experience (p. 200). The intent of
exploring suffering with the students was to encourage them to intervene “more effectively with patients who were suffering” (p. 202). Student evaluations of the course were positive with a student commenting that “this course challenged me to think outside the box and look at the nursing profession in a completely different light” (p. 202). Reflecting on issues in nursing practice can be an especially useful tool in encouraging learners to broaden their thinking, and to place issues such as suffering in context of the human experience and thereby influence nurses’ attitudes and behaviours.

The benefit and relevance to patients of nurses translating reflection into their practice is not without controversy, when judged within a framework that demands measurable outcomes (Freshwater, 2008; Hannigan, 2001). For example, Mackintosh (1998) suggests the benefits of reflection are broadly unaddressed by researchers and that claims of relevance are made without evidence that it improves nursing care, rather, anecdotal reports are relied upon to substantiate claims, or reflection is taught in isolation from practice.

Bailey and Graham (2007) also acknowledge the limitations of being able to demonstrate that any changes to practice have occurred as a direct result of teaching reflective practices and suggests participants’ use of the skills “inferred a positive outcome” for their professional development (p. 559). In their study, palliative care nurses participated in a project where reflective skills and the processes of group reflection were taught. The researchers scheduled education sessions over a one-year period and guided the nurses’ learning of reflective practice techniques and utilisation in their work. The research achieved the aim of facilitating the development of reflective practice into the palliative care unit and group discussions on practice stories were reported by participants to
provide “valuable learning opportunities” (p. 557). Despite the lack of evidence supporting the direct translation of learning into practice, participation and acquiring the skills of reflection can be a catalyst for change (Driscoll, 1994), because the very act of reflecting intentionally brings about positive, incremental changes in the reflective practitioner.

In summary, reflection has been shown to benefit nursing practices (Forneris & Peden-McAlpine, 2007; Freshwater, 2008; Glasson et al., 2006; Taylor, 2006; Taylor et al., 2008a). This viewpoint is based on reflection having the potential to change or improve practices, while at the same time challenging the individual to question their participation in delivering care. Nurses have been provided with numerous definitions, descriptions, interpretations, forms of, methods and processes to use for reflection. Constraints to practice that prevent optimal care can be examined and explored within the contexts of care. By encouraging nurses to use reflective processes in their practice, they can be supported to identify their attitudes, influences, experiences and concerns, for example, in end of life care in residential aged care facilities, while establishing a foundation on which they can examine future care for the dying. Because of these distinct possibilities, this PhD project featured the use of reflection within the phases of action research (Taylor, 2006), so this combined approach is described in the next section.

**Action Research and Reflection**

Taylor (2006) advocates that action research and reflection combine well. The qualitative research design processes of action research integrate reflection into the “planning, assessing, observing and reflecting” on clinical practice issues (p.
Reflection is featured in this combined approach to collaborative research, because “this distinction gives more importance to the role of reflective processes in helping practitioners to make sense of their practice and to bring sustained improvements to it” (Taylor, 2006, p. 178). For example, Taylor (2008a) used a 13-step approach (see Chapter Three) with a group of palliative care registered nurses, combining action research and reflection to:

- Raise critical awareness of practice problems they face every day; work systematically through problem-solving processes to uncover constraints against effective nursing care; and improve the quality of care given by hospital nurses in light of the identified constraints and possibilities (Taylor et al., 2008a, p. 326).

In this project, the co-researchers shared their experiences of palliative care nursing, culminating in the generation of an action plan in Phase Four of the project. The nurses worked together to “improve the possibility of getting it right more often under pressure”, by collectively developing “creative strategies”, to address issues of concern (pp. 330-331). Participants shared practice stories and reflected on practice issues following implementation of the developed action plan and used the plan to assist them to function effectively more often under pressure in delivering their nursing care. This process involved preparing themselves for their work, caring for their needs as well as the patients, and appreciating the constraints under which they worked. In adopting this approach the nurses developed a proactive approach to improving care to dying people and their families. Reflection on practice was an integral component for the nurses and enabled them to develop an understanding and
appreciation of the complexity of the work they were performing (Taylor et al., 2008a).

In a recent study, Lee (2009) provided a comprehensive overview of how incorporating group reflection into an action research study enhanced the project, within a community hospital setting. Workshops were facilitated by the researchers, to determine satisfaction with care in a nurse-led unit, to explore care improvements and to develop research capacity within the team. The research team were described as “inter-professional” and included previous patients of the unit (p.32). The use of reflection in the study was identified as assisting the team to “review strengths and weaknesses of the approaches chosen”, and as a means of exploring, learning and to “enhance the participants’ voices” (p. 33). Group reflection was used to broaden the opportunities for discussion and increase the available time for reflection. Lee (2009) suggested that group reflection facilitated learning, for example, in developing “skills for conference presentation, writing abstracts”, practice improvements, such as investigating “patient-tracking systems” and skill development, “particularly in relation to research and professional practice” (p. 37-41).

Vallenga, Grypdonck, Tan, Lendemeijer and Boon (2008) used an action research and reflection project to assist nurses, who support people with epilepsy and intellectual disability. The aim of the project was to share and improve nurses’ decision-making processes regarding “risk-bearing activities” in which their clients engaged and to develop skills in empowering the clients to mitigate those risks (p. 268). The project was conducted over a 22-month period that involved interviews, group meetings, a questionnaire and focus groups. Risk activities were defined as common every day tasks, such as cooking and “navigating
village traffic” (p. 268). The actions were evaluated and observed, and then the findings of the project were discussed at “action research group meetings and, on the basis of this reflection, new goals were set” (p. 266). The use of an action research model facilitated the development of a systematised approach to client risk assessment and resulted in the development of a decision making tool.

Jones, Auton, Burton and Watkins (2008) used an action research and reflection approach “to identify and prioritise issues raised by stroke service users to guide the development of services” and to “facilitate service user involvement in the process of stroke service development” (p. 1272). Using semi-structured interviews and focus groups, the researchers explored the experiences, views and life journeys of stroke patients, their carers and professionals. The planning and acting phase of the research involved the formation of a number of working groups to address specific related issues. The authors reported the strength of the study was the ability to collect “real time” data of experiences of stroke services and to demonstrate it was possible to involve service users in service development activity (p. 1273). Planning the transfer of patient care was identified as an especially important aspect of stroke care. The success of the study was in the engagement of the stroke patients and carers to identify issues of importance to them and to empower those people to influence and implement the action plans for priority issues, such as transfer of care. Further, the researchers highlighted that action research as a methodology provided “a useful framework for involving service users and staff and ensuring that activity is meaningful and tangible” (p. 1278).

Dickinson, Welch and Ager (2008) used an action research and reflection approach to improve older patients’ experiences of mealtimes in hospital.
Concerns were expressed regarding older patients receiving poor nutritional care and potentially suffering malnutrition as a result of their hospitalisation. Observation of meal times, staff focus groups and patient interviews were conducted to collect data and to determine why practices, such as using unqualified staff supervising meal times, worked or did not work. The researchers reported “reflection in and on practice were central” to the project (p. 1497). Reflection was used as a component of Phase One of the project, in which focus groups were held with a range of staff including nurses, to capture their views and engage the group to discuss mealtime care.

In Phase Two, during the change of shift time period, action learning groups were used as a means of negotiating, planning, evaluating and revisiting actions, and gaining group consensus on planned actions or changes to practice. Action learning groups used in the study had a flexible group membership, due to “variations in working hours and the pressures and demands of the clinical environment” (Dickinson et al., 2008, p. 1498). The changes to practice were documented by the project team by “recording fieldnotes and reflective diaries” (p. 1496). Themes for action were developed that included “nursing care and priorities and the mealtime environment on the ward” (p. 1497). For example, staff in the facility changed the rushed meal times, reflecting that “if you sit and be patient and have the time to do it, then that person will actually eat. (PG4)” (p. 1500). The researchers reported that changing the nursing practices at mealtimes resulted in older people receiving the assistance they required and “that patients eat when nurses see mealtimes as important” (p. 1501).

Reed (2005) used action research and reflection in a study that explored the development and implementation of a “Daily Living Plan” (DLP) for older
people moving from hospital to care homes in the United Kingdom (p. 596). Discussions in the project revealed some hospital nurses had negative views on care homes. These views were reflected upon and resulted in some nurses “thinking differently about care homes and the experiences of older people moving into them” (p.598). Reed claimed that “the DLP had a positive impact on those hospital nurses who used it, but that involvement in the study was limited”, which resulted in concerns of project ownership, commitment and project sustainability (p. 598). Reed (2005) suggested a contributing factor that resulted in the lack of ownership or commitment by some nurses to using or completing the DLP tool, was that the study and the tool had originated from outside of the organisation and that “for the nurses it may have seemed like an imposition involving extra work that they could not see the purpose of” (p. 586).

Wallis and Tyson (2003) incorporated reflection into an action research project in an Australian hematology/oncology unit. The nurses’ meetings explored patient care issues, staff workloads and work satisfaction. During the three phases of action research, reflection was embedded into the early phases of the research cycles, for example, in phase one a medication guide was developed, however, the nurses identified through reflection that further improvements in the unit were still required to improve the efficiency of the service. Although not detailed, the reflective processes used in the study were cyclic in that nurses’ awareness of issues increased during the project, critical analysis of the situation resulted in ongoing improvements and actions, such as individual nurse/patient allocation was implemented, demonstrating a new perspectives on practice was achieved (Freshwater, 2008).
In summary, action research and reflective practice approaches are combined in participatory, collaborative research projects, to feature the role of reflection, allowing practitioners to make greater sense of their practice, thereby bringing sustained improvements to it. In this combined action research and reflection approach, nurses are assisted as reflective practitioners to be co-researchers in their own work settings, by using reflective processes to identify and solve their clinical issues, in order to bring about sustained practice changes.

**Chapter Summary**

This chapter described the action research and reflection methodological approach used to investigate this PhD research problem. Action research can be used in a variety of practice settings to examine and facilitate practice improvements. Reflective processes are also beneficial in improving nursing practice. The relevance of practice change, however, is broadened and enhanced when reflection is incorporated and featured in the action research process.

Action research and reflective practice supports collaborative improvements that rely on reflective processes, to involve participants to work on their own issues (Taylor, 2006). By engaging nurses in their work and encouraging exploration of clinical practices, the patient care environment can be transformational and empowering, to build capacity in nursing leadership, in the face of challenging work contexts (Sherwood & Horton-Deutsch, 2008).

By reflecting on their current practices and views, and constraints and influences on practice, nurses can be supported through a combined action research and reflection methodological approach to explore options for change, using
structured methods and informed processes that help them to develop an understanding of the context of their work and their workplace and the potential for improvements in practice. Combining the action research and reflection methodology as a method and process to examine nursing practices and to improve care have been described in Chapter Four, and applied to end of life care in Chapters Five and Six of this thesis.
CHAPTER FOUR: METHODS AND PROCESSES

This chapter describes the methods and processes used to conduct action research and reflection in two rural Australian, residential aged care facilities. The processes relating to the research settings, recruitment of participants, ethical considerations, data collection and analysis are described, within the framework of Taylor’s (2006) method for combining action research and reflection. The chapter concludes with the methods and processes I used to ensure trustworthiness in the research.

Combining Action Research and Reflection

Taylor (2006, p. 179-184) describes 13 basic steps for incorporating action research and reflection in clinical settings. These steps informed and guided the project:

Step 1: Find enough nurses to form a research group.
Step 2: Ensure the nurses are ready to make a commitment to the research group.
Step 3: Decide on a venue and a regular meeting day and time.
Step 4: Write a brief research proposal.
Step 5: Check on ethics approval processes in your organisation.
Step 6: Get the project underway and decide on who facilitates meetings.
Step 7: Share the business of the first two meetings.
Step 8: Share the first reflective task.
Step 9: Share the practice stories.

Step 10: Identify the thematic concern(s).

Step 11: Generate the action plan and begin the action research cycles.

Step 12: Write a research report.

Step 13: Disseminate the findings.

Even though this method was written mainly for nurses seeking to undertake collaborative, reflective research in their own workplaces, as a researcher/clinician seeking to improve end of life care for residents in aged care facilities, I found that Taylor’s (2006) method, adjusted to allow for the requirements of a PhD project, was sufficient to guide me as a facilitator and co-researcher in this project. The adjustments were necessary, because Universities require researchers to gain full ethics clearance prior to the commencement of a project, so this process began in Step 1, not in Step 5, as suggested in Taylor’s (2006) clinical research method. Also, even though nurses formed the core of the action research and reflection groups, some allied staff participated, and relatives’ interview accounts contributed to the research groups’ discussions about improving end of life care.

**Step 1: Find Enough Nurses to Form a Research Group**

This section describes the processes for the selection of the research settings and the recruitment of participants, including nurses who were willing to form a research group focusing specifically on improving end of life care for residents with non malignant disease, and residents’ relatives, who contributed to the research group processes through interviews.
The Research Settings

After ethical clearance (see Step 5), this study was conducted in two rural residential aged care facilities situated within the same geographical region of the mid north coast of New South Wales (NSW). The two facilities were similar in size and provided similar medical and nursing services. For example, the bed capacity in both facilities ranged between 60 to 65 beds, both facilities catered to high and low care resident needs, and were managed by a Director of Nursing. One facility was responsible to a religious organisation and the other operated as a not-for-profit community owned company, run by a Board of Directors. The Board of Directors consisted of unpaid, voluntary members of the community.

This action research and reflection project was qualitative research, not constrained by the strict, objective considerations that apply to quantitative research designs in setting and sample selection, because of the different epistemological assumptions underlying quantitative and qualitative approaches. As qualitative research assumes that ‘truth’ is subjective and relative to time, person and place (Taylor et al., 2006), there was no attempt to control the variables relating to setting and sample characteristics, even though the facilities willing to participate had similarities in their size, care provision and management. Therefore, this action research and reflection project did not seek to compare or contrast, to make cause and effect statements, or to generalise findings to other aged care settings. Instead, it sought to identify specific practice issues within the two participating facilities and create appropriate strategies to improve end of life care, which may be identified by other nurses of being of help to them, while working within other residential aged care settings.
The rural setting within the same geographical region for both settings was chosen for convenience, because funding for the project was provided through a rural aged services and learning collaborative, whose research priorities specifically addressed the issues of non-cancer dying in that rural region. Two facilities were chosen to increase the number of participants overall, to increase the likelihood of a wider coverage of practice issues and to enhance the richness of the action research and reflection processes. Although not selected intentionally, one religious and one non-religious facility offered potentially different insights into approaches to end of life care.

Gaining Entry to the Facilities

After I gained full ethical clearance, I contacted five facilities in the geographical area by telephone, and an appointment was organised to meet with the Directors of Nursing or their delegate, to discuss the proposed study. Three facilities I contacted initially, declined to be involved in the study. One facility’s general manager stated, through the Acting Director of Nursing, that the nurses would be better utilised preparing for accreditation and that he personally considered it unethical to interview relatives of dying residents. Difficulty in gaining facility participation became further evident when a religious facility in the geographical area was experiencing a change over period of management and, therefore, declined to participate in the study, and a non-religious facility declined to participate, due to preparing for accreditation and a self-reported limited number of deaths in the facility. After two months of negotiations, two of the five facilities agreed to participate in the study.
Recruitment of the Participants

Participants included the nurses and allied staff in the action research and reflection groups, and relatives interviewed from the two facilities.

The Action Research and Reflection Groups

I presented an overview of the project to staff in both facilities, using a PowerPoint presentation (CD 1). The presentation provided prospective participants with insights into the research problem, aim and objectives, a brief overview of the action research and reflection processes, expectations of each participant’s involvement, and my contribution as the researcher. Staff interested in participating in the research were then invited to attend a meeting, to be held either the following week, or when organised by the Director of Nursing. Plain language statement, consent and demographic data collection forms, were distributed to the staff attending the introductory sessions (Appendix A). Staff not wishing to participate were exempt from the next arranged meetings, and in both facilities, even though Registered Nurses were identified as the primary staff group, many chose not to attend.

To enable the objectives of the study to be met, the inclusion criteria included a maximum of 10 participants working in each facility, living within a 50 kilometre radius of the residential aged care facility, who had experienced providing end of life care to dying residents, or who had cared for a resident who died from a non malignant disease.
All research group participants completed a demographic data collection form and signed the consent form (Appendix A). (The ethical considerations for the project are described in Step 5). The sample consisted of five participants in Facility One and nine participants in Facility Two. The research group participant demographics are presented in Table 3.1. Of the 14 participants; 13 were female and one was male. The sample size was sufficient for the co-researchers to be able to fully explore participants’ experiences and attempt to answer the research questions (Russell & Gregory, 2003), because the collaborative inquiry nature of action research and reflection provides rich data sources for thorough exploration and resolution of practice issues.

Participants included a range of nurses, including Registered Nurses, Enrolled Nurses, Assistants in Nursing, and a cleaner and also a laundry worker. Participants’ ages ranged from 25 years to 64 years. Basic education levels ranged from School Certificate to University qualifications. Participants marital status ranged from single, married to divorced. The majority of participants had been in their current position for more than 15 years, however, one participant had only been in the position for seven months and one other only one year.

Participants self identified as being in a carer relationship with a dying person and some participants also self identified as having experience of caring for close family members. The cleaner and laundry worker were included as participants, because they self identified as being in a caring relationship with dying residents, coming to know them and their families over time through undertaking their respective roles. In research of a collaborative nature, the learning experiences of the participants involved in the process is as important as the research outcomes (Taylor et al., 2006), so any person who self identified as caring for residents was
included for their own value and benefit. The mixture of participants was appropriate for the project, as the variations in staff had potential to generate rich data from important sources of knowledge of end of life care practices within the facilities, and because of the assumption that in qualitative projects, the research insights and implications are always considered within the context of the participants’ experiences (Mays & Pope, 1995; Taylor, 2006).
Table 3.1 Research Group Demographics for Both Facilities

<table>
<thead>
<tr>
<th>Facility One</th>
<th>Facility Two</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
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<tr>
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<td><strong>Time in current position</strong></td>
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<tr>
<td><strong>Basic education level</strong></td>
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</tr>
<tr>
<td><strong>Gender</strong></td>
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<tr>
<td><strong>Occupation</strong></td>
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<td><strong>Time in current position</strong></td>
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<tr>
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<td>SC/TAFE</td>
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<tr>
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<td><strong>Age</strong></td>
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<tr>
<td><strong>Gender</strong></td>
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<td>AIN</td>
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<tr>
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**Key:** SC = School Certificate, HSC = High School Certificate, TAFE = Tertiary and Further Education Certificate
The Relatives

Relatives’ recruitment to the project was discussed at the initial staff introductory sessions. I provided an information flyer inviting relatives to participate and plain language statement for relatives’ sheets to the directors of nursing for distribution (Appendix E). Facility One displayed in the facility foyer a flyer inviting relatives’ participation (Appendix E). Facility Two chose to approach and personally invite the participation of relatives of dying residents, or those relatives whose family member had recently died in their facility.

The relatives’ inclusion criteria included a maximum of five adult relatives of residents, who had died, or were dying from a non malignant disease in the residential aged care facility participating in the research. The relatives needed to self identify as a relative, be willing to be interviewed about their experiences of witnessing the dying of their family member, live within a 50 kilometre radius of the residential aged care facility, and be English speaking.

The relatives’ participant sample consisted of three participants in Facility One and five participants in Facility Two. Four participants were female and four were male. Participants’ role relationships to the residents included husbands, wives, ex-wife, a son and daughters. The mixture of participants was appropriate for the project, as the lived experiences of participants had the potential to contribute rich data as important sources of knowledge to the research groups’ discussions, to improve end of life care practices within the respective facilities and to influence changes in work practices (Mays & Pope, 1995; Taylor, 2006).
Step 2: Ensure the Nurses are Ready to Make a Commitment to the Research Group

In this research, nurses, allied staff and relatives made a commitment to the research and to the research group.

Nurses and Allied Staff

I outlined the full details of the research group participation, including the time commitment to the research, in the initial presentation and I reiterated the same information at the first research group meeting. After I described the project’s aims, objectives, and processes in full, I reiterated the need for participants to participate actively, by reflecting and contributing to the group and working together through their practice issues. Participants indicated they understood the intentions, methods and processes of the project, and they agreed to meet regularly, for as often as required, to work through the research systematically, until practice insights and improvements were achieved. After full explanation of the research and their involvement within the project, the nurses and allied staff in the research groups demonstrated their willingness to make a commitment to their research group by signing the consent form (Step 5).

In Facility One, two new members joined the research group in the tenth meeting. The new members were provided with the same information, however, in an abbreviated format. Plain language statement for nurse participants, and demographic data collection forms were provided and consent forms were signed, when the participants had sufficient time to understand the research process (Appendix A).
Relatives

The second group of participants were relatives, who showed their commitment to the project and to the research group, by being willing to be interviewed, and by consenting to be part of the project (Step 5), knowing that the de-identified accounts of their experiences about their family member’s end of life care would be conveyed to the research groups’ meetings.
Step 3: Decide on a Venue and a Regular Meeting Day and Time

Due to the sensitive nature of the topic, and the importance of maintaining confidentiality, trusting disclosures, research group meetings were held in a quiet place in the facility, generally separate to the resident care areas, or out of hearing range of any other person. The groups agreed to meet weekly, at a regular time, to discuss clinical issues raised by participants, relating to end of life care of residents dying from a non-malignant disease.

The relatives were interviewed individually on one occasion only, for an average of one hour, at a time and in a quiet, confidential place to suit each of them.

Step 4: Write a Brief Research Proposal

Copies of the research proposal submitted to the ethics committee (Step 5) were made available at all meetings, to provide participants with an overview of the intentions, methods and processes of the research.

Step 5: Check on Ethics Approval Processes in your Organisation

As explained previously, as a University requirement for human research, this step preceded all of the research activity in this project, because access must be gained to enter research settings, such as clinical areas. In Taylor’s (2006) method, this step may be delayed until Step 5 in a clinician’s own workplace, until the researcher/clinician can be assured of sufficient interest by potential co-researchers in forming an action research and reflection group. Also, in some
clinical settings, projects may fall into the category of Quality Assurance projects and may not need formal institutional ethical clearance.

Ethical Considerations

Full ethical clearance processes preceded the research and permission was sought and granted from Southern Cross University Human Research Ethics Committee prior to the commencement of the study, Approval Number ECN-05-75 (Appendix B). The ethics committee application included a detailed research proposal, the plain language statement for nurse participants and relatives, consent forms, demographic data collection forms and counsellor details (Appendix B, Appendix A, Appendix E).

A number of processes were used to ensure the ethical standards of the project. Research participants in both facilities had the right to full disclosure and to consent freely without coercion. Participants received a detailed explanation of what the research involved, both verbally and in writing. Participants were given a plain language statement that included the aims, purpose and processes of the research, anticipated duration of the participant’s involvement, a description of the procedures, assurance of confidentiality of records, and names and numbers for contacts, if the participant had any queries, or required further clarification (Appendix A). The detail in the statement provided to participants was relative to their comprehension. Participants were offered the right to refuse to participate, or withdraw at any time from the research, without penalty of any kind. The measures used to ensure that participants had the capacity to understand the research project were to ascertain that each participant could comprehend English, and appropriate healthcare terms were used for nursing
and non-nursing participants. Participants were given the opportunity to ask questions, make comments, and voice any concerns that they may have had concerning the project. Each participant was then asked to sign a consent form (Appendix A).

Privacy, confidentiality and anonymity were ensured throughout the research by the use of pseudonyms, and the omission of personally identifiable information in meeting minutes and relatives’ interview transcripts (Appendix G, Appendix H, Appendix F). Pseudonyms included Agnus, Eileen, Celeste, Keith and Susie. One facility chose a celebrity theme for pseudonyms including Georgia, Liz, Lindsay, Jackie, Kara, Britney, Marie, Katherine and Drew. Nurses’ education programs teach the moral imperative to uphold residents’ confidentiality and these principles are mandated by a healthcare organisation’s code of conduct, so the nurse participants were conversant with the need for confidentiality in relation to the research, and the allied staff within the research groups also upheld these principles. The relatives who participated were assured that all of the information they provided in the interviews would be de-identified before the stories were shared at the research groups’ meetings.

Strategies were used to alleviate the potential harm of breaking confidentiality, including my assurance that all participants’ anonymity and privacy would be maintained at all times. Open access to the research information was provided to allow participants opportunities to comment upon, and to validate, the end of life care accounts, so the stories shared in meetings and interview transcripts were devoid of any information, which could identify the specific facility, residents, staff or relatives. Also, any identifying material was omitted or renamed to protect the identities of people within the written transcripts of the
stories. Reflective journals remained the personal property of participants and they were not read or sighted by the researcher, unless it was a participant’s expressed wish that this occurred. Reports and published material from the research will highlight the participants’ practice improvements, and they will not identify specific people and places within the research.

Encouraging openness and trust, especially in relation to participants divulging their perceptions about their end of life care practice problems and how they experienced loss, equalised potential power relationships between the researcher and participants. The researcher accepted the responsibility for the safety and security of all data collected and stored the data in a locked filing cabinet for a period of five years, according to NHMRC requirements.

As this research encouraged participants to share their stories related to end of life care, likely risks were that the privacy and confidentiality of residents may have been breached and that participants may have felt vulnerable in sharing their experiences, leading to embarrassment or possible emotional catharsis, such as tearfulness or anger. As described previously, nurses are educated in the need for resident confidentiality and they practice it in their daily work. Even so, the researcher ensured that privacy and confidentiality measures were instituted and maintained at all times. Support was offered and provided to all participants by the researcher, who was an experienced nurse with skills in communication and counselling. No participant in the research became emotionally upset beyond the ability of the group’s or the researcher’s ability to support them, and although the project offered professional counselling at no cost to themselves, no participant used the service.
Step 6: Get the Project Underway and Decide on Who Facilitates Meetings

Following ethics committee approval and the initial presentation to research group members, the project commenced the following week in Facility One and this time frame was also used in Facility Two. I facilitated most of the research groups’ meetings, using the skills of action research and reflection methods and processes I had gained in previous projects (Taylor, Edwards, Holroyd, Unwin & Rowley, 2005). By the participants’ choice, I facilitated all of the meetings in Facility One, and in the final five meetings of Facility Two, participants opted for a ‘rotating chair’ system, to allow everyone to take a turn at guiding the agenda (Taylor, 2006). Chapters Five and Six of this thesis describe each research group’s experiences, in relation to getting the project underway.

Step 7: Share the Business of the First Two Meetings

During the early stages of the research, the research group reiterated the business of the first two meetings. This phase is referred to in this project as the foundation building phase, because it determined the meeting structure and processes.

I recorded detailed minutes at each meeting, which were shared at the commencement of each meeting, to confirm they were a faithful account of co-researchers’ experiences, and if necessary, the details were corrected. In this way, minute sharing and correction not only served as a trustworthiness method of member checking (Taylor et al., 2006), but it also ensured that the project stayed ‘on track’ in a systematic method, using processes congruent with the action research and reflection methodology.
The foundation building phase of the first two meetings included clarification of the details of the project and setting group rules, to ensure the group processes worked well, emphasising the importance of participants respecting the stories shared at the meetings, allowing each person telling a practice story the silence and time to speak, and avoiding discussion of the stories outside of the privacy of meetings.

In the first two meetings, participants also discussed strategies to equalise the potential power differences in the group, given the different roles group members occupied in the research facilities. Participants agreed that every person had ‘a voice’ to be heard with equal respect, because the groups acknowledged that power comes from different amounts of knowledge and status, and for everyone to feel equal and empowered, they needed to respect each other’s knowledge within the workplace (Taylor et al., 2006).

The purpose of sharing the business of the first two meetings was to build an informed, trusting and confidential foundation, on which participants felt safe to act as co-researchers, through sharing their practice stories, working actively towards identifying issues, and ultimately improving end of life care for dying residents.

**Step 8: Share the First Reflective Task**

The foundation building phase of the research also included sharing the first reflective task. At the first group meeting in both facilities, participants were ready to share the first reflective writing task (Appendix C). I gave each
participant a copy of the guide for reflective writing, so they could take them home and reflect on their life experiences. Using the structure of the first reflective task, at the respective group meetings, I encouraged participants to reflect on their own personal, social and historical contexts, and share them with group members, so that they could develop an understanding of how their espoused values influence their personal life and their actual work practices (Taylor, 2006).

These early discussions of personal stories and their links to professional values and issues were important for participants, to initiate and begin to develop their reflective abilities, create trusting, collegial bonds, and to practice the agreed group rules of listening attentively and having non-judgemental, supportive attitudes to other co-researchers. Further details of this part of the foundational building phase are described in Chapters Five and Six of this thesis.

**Step 9: Share the Practice Stories**

The next part of the research was to encourage participants to reflect on their past or present practice experiences. In this project, practice stories were shared in research groups’ meetings and relatives’ accounts of their experiences were shared in individual, face to face interviews.

The Research Groups

The research groups shared practice stories of issues surrounding end of life care, during the normal course of their daily work. To reflect on these issues, I provided Taylor’s (2000) Practice Reflection Guide (Appendix D) and
encouraged participants to use any method of reflection with which they felt comfortable, for example, journaling, drawing or storytelling, and to share and collectively analyse those reflections within the group meetings.

Participants in both facilities had a preference for drawing images representing end of life care and providing a detailed commentary on issues of importance in delivering that care, rather than commit to writing practice stories in a journal. Most participants had difficulty in maintaining a written journal, despite being provided with a paper-covered exercise book. Reasons for not journaling included limited time to write, never having kept a journal previously, having difficulty writing about the issues, and being unfamiliar with reflective journaling processes. Barriers to maintaining a written journal are common, and issues identified previously in the literature have included journaling being time consuming, “exhausting” (Hancock, 1999, p. 39), difficult to sustain and repetitive (Cruickshank, 1996; Johns, 2002; Williams & Lowes, 2001).

The research aim and objectives were reiterated at the beginning of each meeting for sharing practice stories, to allow participants to keep to the research focus, and to use the process of reflection (Taylor, 2006) that encouraged the reconstruction of the meaning of the practice situation. The emancipatory reflective process involved a series of questions posed to examine the taken for granted assumptions in the stories, and to explore the cultural, economic, historical, political, social and personal constraints operating in the situation, in order to identify and overcome them (Taylor, 2006). This approach encouraged a wider exploration of the practice issue and a fuller description of the stories (Taylor, 2006). Further details of phase of reflection on practice stories are described in Chapters Five and Six of this thesis.
The Relatives

Relatives shared their experiences of witnessing end of life care of their family member in a residential aged care facility, through a conversational style, individual, face to face, audiotaped interview. I used the first interview in Facility One as a pilot interview, to allow me to practice using the audio-recording equipment, and to further develop my confidence and skills in interviewing. After the pilot interview, I reflected on the strengths and weaknesses in the interview, including the appropriateness of the semi-structured interview questions to the research objectives, and the duration of the interview and my role as interviewer.

In the pilot interview I identified excessive problems, such as extraneous noise when interviewing, for example, from lawn mowing outside, our tendency to ‘wander off the track’ and the potential for the interview to be too lengthy. These reflections assisted me to refine my interview approach and to suggest more conducive environments for future interviews. I included the pilot interview transcript in the analysis to value the first relative’s contributions, and because no changes were made to the content of the research questions.

The interviews were conducted when a relative initiated contact with me. A mutually agreeable time and place were arranged for the interview and they were conducted either in the relative’s home, a quiet office space, or in one instance, for the convenience of the relative, who was also a volunteer, the interview was at the residential aged care facility. In all cases, a quiet
environment was chosen to ensure privacy and confidentiality for the participants.

All the face to face individual interviews were approximately 60 to 90 minutes in duration. At the beginning of each interview I introduced myself, thanked the relative for participating and checked the relative had received a plain language statement for relatives information sheet (Appendix E). For a detailed plan for relatives’ interview structure please see Appendix E.

The interview questions were semi structured, to encourage a conversational interview. The reason this approach was used was to guide the participant to stay on the topic, while encouraging them to feel comfortable enough to share personal details of this sensitive topic. During the interviews, participants were asked to discuss issues around end of life care that they considered important to the care of their dying or deceased relative. Specifically, the relatives were asked the following questions:

What are the issues that are important to you in the care of your husband/wife/partner now, or when they were dying?
Think about an instance where you were pleased with care. Tell me about it please.
Think about another instance where you were not pleased with care. Tell me about it please.
What might be done to improve care?
How important is it for you to develop a caring relationship with the nurses?
How well have you been supported during this time?
What is optimal end of life care for you?

During the interviews, I periodically prompted the relative, to guide and focus the conversations. Various prompts were used, according to the appropriateness of the prompt in extending and enriching a particular conversation. Prompts included:

You were saying before... Tell me more about that please.
Let’s get back to the subject of...
Are there things you would like changed?
Was the dying process discussed on admission to the facility or since?
Are there others in the facility with whom you have developed a caring relationship?
Why are these relationships important to you?
Would you have felt vulnerable if you complained about care issues?
Is support from the nurses important to you?
How do you think the support could be improved?

In summary, this interview structure assisted me to facilitate a conversation, keep the interview on track, address the research questions and expand and enrich the information.

Each interview was transcribed verbatim as soon as possible following each interview and rechecked against the audiotape for accuracy. I also mailed the interview transcript to the relative for a member check for verification of the accuracy of statements. The mail out included a relatives’ covering letter (Appendix E), requesting relatives to check their interview statements and
change any statements, if necessary. The consent form (Appendix A) was also included and if a signed consent form was returned in the stamped, self addressed envelope, the interview was incorporated into the research groups’ meetings. My contact details were included in the mail out, to enable the relative to return either a corrected interview, or contact me to discuss corrections, or verify statements. All relatives signed the consent form. Some relatives returned the transcript unchanged, while others preferred to discuss minor changes by phone. The phone conversations were of a short duration, lasting no more than 15 minutes. Commonalities in relatives’ responses were occurring by the sixth to seventh participant’s interview.

**Step 10: Identify the Thematic Concern(s)**

Multiple data sources were used to collect data for the study, including detailing recording and sharing of minutes in group meetings, the practice stories, reflective notes and drawings, the sharing of sections of relatives’ of dying residents interview transcripts, and my reflective journal. Each facility’s research group met separately, attending 19 to 20 meetings. The research groups identified their particular thematic concerns, informed by all the data sources, including the relatives’ contributions. The integration of these data sources into the group meetings is described in detail in Chapters Five and Six.

Recording and Sharing Minutes

Descriptive records of the practice stories within the action research cycles were documented in the form of groups’ minutes. Each week the minutes from the previous week were identified by date and shared with group members, who
checked the accounts to confirm they were an accurate representation of individual and collective recounts of the meetings discussion. The minutes formed the data source from which thematic concerns were identified and were cross referenced against the research objectives.

The Practice Stories

When accounts of end of life care practices were reaching saturation, in that common themes were recurring in participants’ practice stories, and as their accounts developed in depth within the minutes, the group members carefully read and re-read the descriptions of end of life care practice issues. Initially, a process of asking critical questions was used such as: “What is this about?” These sections of stories were highlighted within the text, followed by searching for explicit and implicit themes (Taylor et al., 2006). Explicit themes were obvious practice issues, for example, the knowledge and use of medications, whereas implicit themes were those issues hidden within the story, for example, participants’ feelings of powerlessness in the workplace. During this phase, sections of stories including a potential theme were highlighted using coloured block fonts on the computer. I used the cut/paste computer function to cut each colour coded key story out of the full transcript and collated each example into Practice Story Themes Tables (Appendix I, Appendix J). I took care to ensure the section of the story was kept in context, as told by the participant (Burnard, 1991).

By meetings six or seven, participants were asked to carefully read the relevant stories in the Practice Story Themes Table (Appendix I, Appendix J) and ask themselves the question: “What is this story about?” With one or two word
descriptors, participants were asked to label each story, to identify a theme or themes related to the account. In the following meetings, participants grouped themes and placed them into sub-categories and common, major themes, using a process of group consensus (Appendix I, Appendix J). Using this process, themes were identified, refined and confirmed, or they were discarded, depending on their relevance to the research objectives.

The major themes were prioritised into end of life care practices that focused the group on key issues for action, and the groups realised that these contextual issues contained constraints to be identified. Participants were encouraged to address issues that would allow the group to go beyond present constraints, to become empowered to act more effectively in these and similar situations (Taylor, 2006). For example, Facility Two participants identified pain management as a first priority issue to address. Participants identified the historical and cultural constraints of unquestioned rituals and practices around pain management. One of the actions used to overcome the constraints was academic detailing, to share their new knowledge of pain management with other staff.

Reflective Notes and Drawings

Participants used practice stories collated into thematic tables to analyse end of life issues. For example, participants in Facility One chose to focus on addressing staff debriefing. A participant had told the group that their drawing of a naked alien figure crouching down in a “cringing” fetal position represented how the nurse can: “Go into your own space” but that withdrawing does not “make
issues go away”. Further, the nakedness represented how “everything is ripped away”.

Drawings were also used by group members to facilitate discussion on end of life issues. For example, the challenges of providing optimal end of life care were illustrated by a participant in Facility Two. The participant described the central and dominant figure of a palm of a hand as “touching all the areas of life”, and also “a happy death, a painful death” describing some residents who “beg you to let me (them) go”.
Due to time constraints within the group meetings, I analysed the relatives’ transcripts for themes relating to issues of importance to relatives in end of life care and relatives’ relationships with staff caring for their dying family member. I critically analysed the content of all the relatives’ interviews by carefully reading and cross checking transcripts with the audiotapes. Over time, themes were identified, refined and confirmed or discarded by the relevance of the statements to the research objectives and the value the statement would make within the research groups, for further exploration of end of life practice issues. For example, one relative’s statement used as a basis of discussion with participants in Facility Two was: “Make sure they’re (the dying residents are) pain-free first, and then clean. They can’t make him pain-free, after he dies”. This and other key end of life care and relative/carer relationship statements extracted from the relatives’ interviews featured in the research groups’
meetings, to inform practice by sharing relatives’ perceptions of issues in end of life care that were important to them.

These key statements were used to challenge the research groups to reflect on the reasons why the relatives would make these statements, to challenge the myths about providing the end of life care, and to examine specific issues of care important to the research groups and relatives. At all times, I de-identified relatives’ accounts to maintain their privacy and ensured that relatives’ stories were kept in the context of what had been said by a particular relative (Burnard, 1991).

My Reflective Journal

I maintained a reflective journal throughout the research in the form of a type-written file. I kept a reflective journal to acknowledge my part within the process of action research, while maintaining an element of observer self-scrutiny, and to keep myself visible and transparent in the research process. My interconnectedness in the group meetings and the sharing of relatives’ interview statements with groups added depth to the research, by assisting in identifying thematic concerns. For example, as an experienced Registered Nurse with 15 years of critical care nursing and five years of clinical nursing research, I shared my nursing skills, understanding of evidence based care and end of life care knowledge with the group. I also reflected on how to sensitively inform the group of relatives’ views of their end of life care practices, to help participants, in some instances for the first time, to question their philosophies of care and their care delivery assumptions. For example, my reflective journal assisted me in developing personal insights into how to help the research group participants to
understand that, for some relatives, the staff were their only support, that relatives prioritise a resident’s pain relief over being clean and that relatives tend to rely on the staff, rather than the doctor, to manage end of life care.

Through keeping a personal reflective journal I was able to break down the issues raised during conversations I had with the groups and the relatives. This process focused the problems being identified and raised my awareness to the constraints that were possibly operating within the facilities (Taylor, 2006). I raised issues, such as the language some participants were using in describing end of life care, and asked important questions to gain insight into the assumptions being made. To achieve this, I used ‘Challenge Statement’ sessions, where confronting language or behaviours were identified and discussed with the research groups, with a view of exposing myths surrounding practices, examining judgemental attitudes and exploring options for change (Taylor, 2006).

I discussed the interpretations of my reflections with a critical friend, who used constructive questions to assist me to provide fuller descriptions of the research processes, to use and explore each step of the research method thoroughly, and to learn from the research (Taylor, 2006). For example, when a senior nurse participant involved me in a potentially difficult situation with a junior nurse in a research group, my discussions with my critical friend helped me to unpack the event, to explore how people can use a position of power in the workplace, and how that power can be misused to silence and control others, not only in the workplace, but also within the group meetings.
Another example was my discussion with my critical friend on my concerns about the method of recruitment of staff into one of the facilities. I knew from talking in meetings with group members, that staff were employed primarily from the immediate vicinity, the positions were not advertised, and basically, people were employed, who “just walked in the door”. My critical friend and I discussed the effect of these recruitment methods on staff morale and how it might influence the culture of an organisation. Through reflection and critical friend discussions, I came to the realisation that it is possible that the culture of an aged care facility may be linked to low remuneration for work, lack of prestige, oppressive hierarchical structures, and unbalanced skill mixes, thereby influencing end of life care practices. These reflective insights have been previously identified in the aged care literature as challenges to meet, as resident care needs become increasingly complex and maintaining an adequate workforce more difficult (Eley, Hegney, Buikstra, Fallon, Plank & Parker, 2007; Jackson, Mannix & Daly, 2003).

Reflective journaling challenged me personally and professionally, and assisted me to further develop my reflective skills, coach participants in reflection, learn from the research and research processes, examine my own assumptions in interpreting what was happening in end of life care in the facilities, and assist the research groups in examining the influences on their end of life caring practices.

In summary, in this section I described multiple data sources to collect data for the study, including detailed recording and sharing of minutes in group meetings, the practice stories, reflective notes and drawings, the sharing of sections of relatives’ of dying residents interview transcripts, and my reflective
journal. The integration of these data sources into the group meetings is described in detail in Chapters Five and Six.

**Step 11: Generate the Action Plan and Begin the Action Research Cycles**

The action cycle of planning, assessing, observing and reflecting motivated the groups to generate an action plan (Minichiello, Sullivan, Greenwood, & Axford, 1999; Taylor et al., 2006). The groups explored and discussed the identified common themes to attempt to: uncover any root causes of the issues; determine why the themes were an issue in end of life care in their facility; identify the work previously attempted to address the issues; and to identify the constraints in their practices around the issues and what should be considered for change, to improve end of life care practices in their facility (Taylor, 2006).

Prioritising issues of importance to action research, and developing practical and useful action plans to implement were achieved through collaborative reflection in group discussion and consensus on how to proceed (Appendix I, Appendix J). Discussions about power relationships and skill mix in the groups, including member trust and openness, were revisited when necessary during these planning activities. Participants discussed the appropriate actions to be taken and carefully and thoughtfully implemented the plan, mindful that flexibility and being open to change according to real life situations would be necessary (Taylor, 2006). Following implementation, participants observed the effects of the critically-informed action, by being observant and mindful to see the effects of the action and observe issues that may be influencing the outcomes of the action (Taylor, 2006; Taylor et al., 2006).
The action plans focussed on specific thematic concerns, for example, in Facility One the research group identified that opportunities for staff debriefing needed to be developed and in Facility Two the research group identified major themes that included pain management, education and communication, as areas for improvement.

The Action Plans

Following the identification and prioritising of thematic concerns for action, the groups were ready to explore through a process of group consensus, the main phases of action research: Plan, Act, Observe, Reflect (PAOR) (Taylor, 2006). Participants planned to choose thematic concerns that were related to improving end of life care, so that participants could see the issue was resolved/acknowledged/challenged, and improved (Taylor, 2006).

Facility One

Participants in Facility One decided it would be valuable for staff to pursue as the issue of concern, opportunities for staff to debrief. The group decided strategies to address the issue would be to:

- develop an introductory session that would be presented as a case scenario to staff in the facility;
- in the scenario acknowledge grief and loss in aged care and prioritise the importance of staff self care;
- highlight with staff to appreciate the potential impact of unresolved grief on end of life nursing care;
• incorporate the issue of avoiding a quick turnover of residents into vacated beds following a death, as a show of respect for the deceased resident, their significant others and staff, who have cared for them;
• incorporate and allow time for the packing up of a resident’s belongings following death, as this can be a part of the grieving process for significant others and staff and;
• obtain a debriefing structure.

Facility Two

In Facility Two participant’s explored three themes for prioritising for action, including pain management, education and communication. Following discussion with senior staff, the research group agreed that education and communication would be addressed, as a result of pain management being actioned.

Strategies for improving pain management practices included:

• conducting a Staff Knowledge and Attitudes to Pain Survey;
• auditing for specialist involvement to identify actual pain management practices/assessment chart completions and documentation;
• using case scenarios as an educational tool and to assess staff pain knowledge;
• determining the availability of access to the specialist palliative care team and;
• trialing a bedside aid to knowledge, for example, a hand held computer.
The groups reformed for further reflection, to assess the success of the action plans in influencing practice changes. The action plans were revised if necessary during these discussions, to ensure their effectiveness in influencing practices, within the constraints within the identified thematic concerns (Taylor, 2006; Taylor et al., 2006). Full details relating to generating action plans and beginning the action research cycles are described in Chapters Five and Six.

**Step 12: Write a Research Report**

The research report is in the form of a PhD thesis, which includes a 13 page, Executive Summary for the research sponsors and clinicians. The full thesis document and abbreviated forms of the report, e.g., referred journal publications, will be made available to the funding body and for local dissemination, and also to national and international readers (see Step 13).

**Step 13: Disseminate the Findings**

Progressive research findings have been disseminated throughout the project in each facility, to inform the facility staff on the progress of the research in their facility and to engage staff in broader discussions. For example, the images created by the participants in Facility One, added richness to the data collected and became a catalyst to create a role play DVD, for the purpose of educating other staff and triggering broader discussion on end of life care practices in the facility.

Dissemination of the findings has also been through annual presentations at the Southern Cross University School of Nursing and Health Care Practices Research
Seminar, the monthly ASLaRC PhD student group meetings at Southern Cross University, and the local public hospital monthly research seminar.

Conference presentations include the annual, ‘Emerging Researchers in Ageing National Conference’, shared between Brisbane, Sydney and Melbourne, and the St Francis Hospice 8th Annual Kaleidoscope International Palliative Care Conference, held in Dublin, Ireland, where I was awarded first prize in the poster competition (CD 1).

Future journal publications planned include at least four peer-reviewed articles on the overall project, action research and reflection as a methodology, applying the action research and reflection methodology, and the insights and implications for aged care facilities. The thesis will be available through Southern Cross University library’s thesis collection.

Future conference presentations planned include the St Francis Hospice 10th Annual Kaleidoscope International Palliative Care Conference, and the 43rd National Conference of the Australian Association of Gerontology.

Summary

This section described the research methods and processes I used to conduct action research and reflection in two rural Australian, residential aged care facilities. I described the processes relating to the research settings, recruitment of participants, ethical considerations, data collection and analysis and the integration of the relatives’ transcripts within the framework of Taylor’s (2006) method for combining action research and reflection.
I adjusted Taylor’s (2006) method, to allow for the requirements of a PhD project, and this revision is suggested below, as suitable for researchers undertaking academic research within healthcare settings.

**Step 1:** Gain ethics approval prior to accessing the healthcare setting.

**Step 2:** Find enough participants to form a research group.

**Step 3:** Decide on a venue and a regular meeting day and time.

**Step 4:** Prepare a brief research proposal, from the full proposal in Step 1.

**Step 5:** Complete the ethics processes with participants prior to beginning the clinical research, including plain language explanations and signing of consent forms.

**Step 6:** Get the project underway and decide on who facilitates meetings.

**Step 7:** Share the business of the first two meetings.

**Step 8:** Share the first reflective task.

**Step 9:** Share the practice stories.

**Step 10:** Identify the thematic concern(s).

**Step 11:** Generate the action plan and begin the action research cycles.

**Step 12:** Write a research report.

**Step 13:** Disseminate the findings.
Rigour as Trustworthiness

Rigour is described by Kitto, Chesters & Grbich (2008) as the “thoroughness and appropriateness of the use of research methods” (p. 243). The authors describe three types of rigour: 1). procedural rigour is “the transparency” or “explicitness” of the description of the way the research was conducted”; 2). interpretative rigour “as full as possible demonstration of the data/evidence”; and 3). evaluative rigour refers to “ensuring that the ethical and political aspects of research are addressed” (Kitto et al., 2008, pp. 244-245).

Qualitative research has been criticised as lacking scientific rigour for a range of reasons, including the findings are:

“merely an assembly of anecdote and personal impressions, strongly subject to researcher bias; secondly, it is argued that qualitative research lacks reproducibility – the research is so personal to the researcher that there is no guarantee that a different researcher would not come to radically different conclusions; and, finally, qualitative research is criticised for lacking generalisability” (Mays & Pope, 1995, p. 109).

Mays and Pope’s (1995) criticisms of qualitative research reflect the scientific community’s, preference for objective knowledge, which is gained through quantitative research methods and validated by scientific methods for judging rigour. The authors highlight how there is a lack of awareness and value placed on the epistemological assumptions of qualitative research, which suggest that subjective knowledge, derived from and validated through people’s lived
experiences, can also inform researchers of the nature of human existence (Taylor et al., 2006).

Data quality is important, regardless of whether the research is qualitative or quantitative. According to Polit & Hungler (1999), methods to enhance the credibility of data quality in qualitative research, include “prolonged engagement”, “persistent observation”, “triangulation”, “peer debriefings” and “member checks” (p. 434). Qualitative research credibility is assured when the research findings “reflect the true state of human experience” (Polit & Hungler, 1999, p. 426), which is a problematic imperative, given the uncertainty of the meaning of ‘truth’ and of any knowledge being ‘true’, in a postmodern era (Rosenau, 1992).

The standards for qualitative research are described variously, in terms of rigour, credibility, trustworthiness, and believability (Russell & Gregory, 2003). According to Taylor et al (2006), rigour in qualitative research is the “strictness in judgement and conduct that must be used to ensure that the successive steps in a project have been set out clearly and undertaken with scrupulous attention to detail, so that the results/findings/insights can be ‘trusted’” (p. 400). Just as there are many types of qualitative research, there are many methods for judging the extent to which trust can be placed in the research.

Quantitative research “aims to count and measure things”, in contrast to qualitative research, which seeks to “capture people’s meanings, definitions and descriptions of events” (Minichiello, Sullivan, Greenwood & Axford, 1999, p. 36). Various methodologies are used in qualitative research. For example, in grounded theory “attempts to make sense of what people say about their
experiences” are converted “into theoretical propositions that form middle-range theory” (Taylor et al., 2006, p. 330). Close scrutiny of the data is necessary in grounded theory, so “the data is read and reread to identify and index themes and categories”, until “key themes or categories for further investigation” are identified (Pope, Ziebland & Mays, 2000, pp. 114-115). Phenomenology is a methodology used in nursing that encourages the exploration of the “lived experience of any person in their care and also the people with whom they work” (Taylor et al., 2006, p. 336), while ethnography “is the study of a group of people whose beliefs, material aspects, actions and artefacts are influenced by their culture’s implicit or explicit ways of being” (Minichiello et al., 1999, p. 124). Ethnographic data are “examined to identify and to categorise themes and key issues that “emerge” from the data” with an aim to “generate tentative theoretical explanations from their empirical work” (Reeves, Kuper & Hodges, 2008, p. 513).

This qualitative research project used action research and reflection to go to the site of an issue of interest, and work with the people there, as reflective co-researchers, to generate solutions to problems, which they agreed to address. In this section, I address the rigour as trustworthiness, by making explicit the theoretical framework and methods I used at every stage of the research, informed by Sandelowski’s (1986) categories for rigour in qualitative research - credibility, fittingness, auditability and confirmability. These criteria for trustworthiness have been explained for researchers by Taylor et al. (2006).

Credibility is the degree to which the participants and readers of the research recognise the experiences of others as similar to their own (Taylor et al., 2006). Credibility in this project has been achieved to some extent by the positive
feedback I received from aged care professionals, who were present at seminars and conferences, where this research has been disseminated. Also, other non research group staff working in the research facilities recognised participants’ experiences and joined in actively in the action plan activities, to improve end of life care. The research has the potential to gain further credibility when the findings are disseminated widely (see Step 13 in the previous section). This research also aligns with previous findings, for example, the issue of poor pain management practices are not unique to these facilities, or to only residential aged care facilities. Poor pain management practices at end of life are detailed in the literature and are found in many forms of healthcare (Holloway & McConigley, 2009; Jones et al., 2004; Wilson, 2007).

Fittingness of qualitative research is defined as to how relevant the research is to those who read the findings (Taylor et al., 2006). In Australia and internationally, residential aged care facilities are increasingly becoming the place of care and site of death for frail, ageing populations (Kristjanson, Walton & Toye, 2005; The Myer Foundation, 2002; Teno, 2003). Delivering appropriate end of life care to people dying from a non malignant disease has been acknowledged as challenging for residential aged care facilities (Department of Health and Ageing, 2008; Kristjanson, Walton & Toye, 2005; Lennon, 2009). Further, residents dying from non malignant diseases in residential aged care present numerous symptoms that can be difficult to manage and illness trajectories can be variable with death occurring unexpectedly (Ellershaw & Ward, 2003; Hanson, Eckert, Dobbs, Williams, Caprio, Sloane, & Zimmerman, 2008; Murray, Kendall, Boyd, & Sheikh, 2005). It is anticipated that the findings of this research will resonate with a range of health care providers, who intend to
improve end of life care for residents in aged care facilities, who are dying from non malignant diseases.

According to Sandelowski (1986) the third category for determining rigour in qualitative research is auditability. Taylor et al (2006) describes auditability as a “decision trail”, to allow others to replicate the study and “possibly arrive at similar or comparable conclusions” (p. 402). The auditability of this research is ensured by many strategies congruent with the research approach. For example, detailed accounts of group planning, acting, observing and reflective discussions were chronicled through minute taking. The minutes also outlined the specific details of the methods and processes used to conduct the research and this thesis document represents the complete account of the research undertaken, including de-identified supporting information in the Appendices. Other publications in progress, such as articles for peer review, and future presentations at professional seminars and conferences, will describe the decision trails taken in this project, to present the research for peer scrutiny and make the project’s methods and processes transparent and accessible to other researchers.

Further, the progressive development of how the thematic concerns were identified and prioritised are described in Chapters Five and Six of the thesis and excerpts from my personal journal are integrated into the thesis document. Other important data available in the thesis and Appendices include relatives’ interviews transcripts, participants’ end of life care drawings, nurses’ pain knowledge survey results and a role play DVD. These data sources provide a comprehensive decision audit trail for readers and other researches, to judge the extent to which this project achieves auditability.
The definition of confirmability is “when credibility, auditability and fittingness can be demonstrated” (Taylor et al., 2006, p. 402), therefore, the confirmability of this project rests on the extent to which the criteria described already within this section, can be demonstrated. Extra to the measures already described, I was aware that I had not used an action research and reflection methodology previously, so I used Taylor’s (2006) 13-step method for using action research and reflection in clinical settings. This collaborative, participatory approach assisted me to learn how to be a research group facilitator and to build on my facilitation skills, to enhance the research processes and outcomes.

As a co-researcher/facilitator, I used congruent research processes, such as using session plans for the group meetings and exploring the research processes through personal reflection. I maintained a reflective personal journal to critically explore and deconstruct assumptions I held regarding my end of life practices, and my beliefs about nursing, nurses and aged care nursing, hidden meanings, power relationships, and issues relating problem solving clinical practice issues and change processes. I also discussed my personal concerns and the developing research insights with a critical friend, who is experienced in qualitative research and reflection.

No exact measure of the trustworthiness of this project is possible at this stage, because the research findings are yet to be disseminated widely. To date, participants’ and conference attendees’ responses to this project, and the extent to which this research can show an audit trail of its methods and processes, suggest that this research is achieving the criteria of credibility, auditability and fittingness, and that confirmability is assured.
Chapter Summary

This chapter has described the methods and processes used to conduct research in two residential aged care facilities. The processes relating to the research settings, recruitment of participants, ethical considerations, data collection and analysis were described, within the framework of Taylor’s (2006) method for combining action research and reflection. I suggested an adjustment to this 13 step action research and reflection method, designed initially for clinicians undertaking projects in their own work settings, to make it more relevant for researchers from academia undertaking research in clinical settings. The chapter concluded with the methods and processes I used to ensure trustworthiness in the research.
CHAPTER FIVE: ACTION RESEARCH AND REFLECTION IN FACILITY ONE

This chapter describes the action research and reflection process in Facility One. The action research process of collectively reflecting, planning, assessing and observing with continuous reflecting, to generate and action plan (Minichiello, Sullivan, Greenwood & Axford, 1999; Taylor et al., 2006), assisted aged care nurses in Facility One to examine ways in which end of life care can be provided that maximises the likelihood of a good death for residents with non malignant diseases and to ensure that improved care strategies are applied in practice. The relationships between the research group and relatives of the dying residents were also explored, to identify relatives’ expectations in the care of their dying family member, and to inform and influence optimal nursing practice in end of life care.

As explained in Chapter Four, I approached the Facility Director of Nursing and extended an invitation for staff working in a 60 bed aged care facility, referred to in this project as Facility One, to participate in the action research and reflection project. The day to day operations of the facility were managed by a director of nursing and regional manager, who were responsible to an Aged Care Ministry Team. The services provided by the facility catered for both high and low care residents’ needs and included a 10 bed dementia unit.

This chapter describes the six phases of the project and provides a condensed overview of the progression and outcomes of action research meetings. Due to
the length and collaborative, participatory nature of the research process, detailed session plan and minutes are included in the Appendices of this thesis.

The Six Phases of Action Research and Reflection

The research period of 19 weeks was informed by Taylor’s (2006) action research and reflection method described in Chapter Four, and occurred in six main phases: 1) Foundation building, 2) Reflection on practice stories, 3) Learning from the relatives 4) Identifying thematic concerns, 5) Action plan creation and implementation and 6) Critical reflection on action.

Figure 5.1: The phases of the research process
Adapted from Taylor’s (2006, p. 72) model of reflection

*Foundation building* refers to the first phase, in which the project was promoted in the facility, to recruit nurses and allied staff, who were interested in improving
end of life care. During this phase, the group determined the meeting structure, including the meeting frequency, time and venue. Action research processes were outlined and the first reflective task focused participants on understanding how their childhood experiences influenced their personal and work values.

Reflection on practice stories occurred in the second phase. Group rules were discussed and participants shared work stories of end of life care situations, with which they were pleased or not pleased, and in which they were a central character. Collectively discussing these stories assisted the research group to identify commonalities in practice, form bonds within the group and discuss ways to improve nursing practices relating to end of life care.

In the third phase, Learning from the relatives, I shared sections of the transcripts of de-identified relatives’ interviews that I conducted and analysed during the project. Key statements from the relatives’ stories were used to assist deeper reflection by the nurses into their work practices and to consider the issues relatives identified as important to them in end of life care.

Identifying thematic concerns, in the fourth phase, included the development of analysis sheets, on which the practice stories had been copied from our meetings. Each story was analysed collectively for common themes, which were then further prioritised into key themes or thematic concerns.

Action plan creation and implementation, the fifth phase, included the group developing an action plan to address the thematic concerns. In this phase, the group decided on the themes to address, planned actions for changes, discussed
various strategies for moving beyond the identified contextual constraints, and implemented and observed the actions.

*Critical reflection on action,* the sixth and final phase, included research group discussions for plan revisions and evaluation of the effects of the actions taken, so that, in Facility One, the end of life care for residents dying from nonmalignant diseases improved.

Throughout the research I maintained a journal to reflect on my role as the research group facilitator and researcher. A critical friend, who was someone I trusted and respected, assisted me in “making sense of my reflections throughout the research process” (Taylor, 2006, p.64). The six phases of the research, including my reflective approach to the project’s processes, are described in the next section.
Phase One: Foundation Building

The foundation building phase was held over the first three meetings. I facilitated the introductory meeting at the facility in the staff tutorial room, using a PowerPoint presentation. This session provided prospective participants with some insight into the research problem, research aim and objectives, a brief overview of the action research process, expectations of each participant’s involvement, my contribution as the researcher, and an opportunity to ask questions related to the project. Nurses and allied staff interested in participating in the research were invited to attend a meeting to be held the following week.

Four females and I attended the first group meeting, which was held in a lounge area of the facility at the agreed time of mid morning. The nurses attending were a Registered Nurse (RN), who was also a senior staff and patient co-ordinator, an Enrolled Nurse (EN) and two Assistants in Nursing (AINs). I distributed participant information sheets, and consent and demographic forms to the group. I reiterated the PowerPoint presentation from the introductory meeting and provided a brief overview of the major points of the research, with an
emphasis on the definition of non-malignant disease and the need for research into improving end of life care in aged care settings. Relatives’ recruitment to the project was discussed and an information flyer recruiting relatives’ participation was provided to the RN, who offered to display it in the facility foyer.

I provided a verbal overview of the first reflective task, in which I asked participants to think about childhood influences on their personal lives, including memorable people, events, organisations and institutions. This invitation prompted a participant to recall people, of whom she had not thought for a long time. One of those people was her father and she told the group she remembered being “very happy until Dad left”. Later, in the discussions, the participant described her father as a “beautiful, caring man”, who had taught her skills for life, such as swimming. This initial opportunity to reflect, gave all of the participants a foundation on which to build their reflective expertise during the project.

A paper copy of a reflective writing task was provided to the group for discussion the following week (See Appendix C). The intentions for sharing this reflection were to firstly, introduce the nurses to an exercise in reflection, and secondly, to give them opportunities to reflect on their insights. Taylor (2006) suggests reflection is not for the purpose of deep psychoanalysis, but that it encourages participants to develop the skill of being open and honest in their responses to themselves, and to better understand their own behaviours. The sharing of personal details of childhood memories and events in the reflective task assisted the group to share background information with each other, as to who they are now as an adult and a clinician, and assisted the nurses to identify some of the values and rules for living that continue to influence their practice.
(Taylor, 2006). The writing task also assisted the nurses to feel safe and confident to work toward sharing future reflections that would explore openly and frankly in future meetings, positive and negative end of life nursing care outcomes.

Journal Entry 16.11.05

I held my first meeting with nurses at Facility One. One Registered Nurse (RN), 1 Enrolled Nurse (EN) and 2 Assistant in Nursing (AIN), (one of whom is leaving in December) attended. I felt really nervous going to the first meeting, but the nurses were excellent and received my presentation well. I detected the EN was very quiet and withdrawn. As it turned out, it was because she was having issues with the AIN, who is leaving. The EN promises to rejoin the group when the AIN leaves.

Researcher’s Note, March 2008

On reading this entry I can now see as a facilitator, that the EN not wishing to participate in the group until the AIN left was an important issue to address. The influence this conflict may have had on the group could have resulted in participants being reluctant to share stories, or focus only on issues of conflict. Taylor (2006) suggests successful reflection requires spontaneity, free expression and openness to ideas. I can now see that the power differences in the group may have silenced participants.

In the second meeting, including myself, three of the original group returned and a new member was welcomed to the second meeting. The minutes from the previous week were confirmed and the group discussed how participants’ identities would be hidden by the use of pseudonyms in meeting minutes.
Participants then shared reflections on their childhood influences and how their childhood values as “rules for living” had influenced them to become nurses. For example, a participant spoke of being a “shy child” and being “unable to speak to others”, yet, despite this setback, she described herself as “adventurous” and was “always looking for excitement”. Living next door to a hospital, using the hospital grounds and exploring, were happy memories for the participant and may have influenced her decision to become a nurse.

Another participant described a need to belong, depicting herself as an insecure child, who was raised in an orphanage with an older sister, until they were fostered. She recalled being hungry enough to “suck on white shoe cleaner” in the orphanage and being cared for by nuns. The participant reflected on having issues with “abandonment” and separation from her sister. As an adult, this person was advised to “try nursing” by an employee at a training centre, after her own children had left home. She told the group: “I needed a job and a direction”.

In this meeting, participants identified the rules of living that formed the values they held as being important in interpersonal life. Participants identified the need for honesty, valuing self, “the right thing”, telling the truth and admitting fault. When asked why they wanted to work in aged care, participants spoke of “needing a job”, “needing a direction” and “enjoying the job”. At the end of the meeting, I presented participants with a covered exercise book to use as their own journal, in which to record their reflections. In preparation for the next meeting, I asked the group to reflect on an incident at work, in which they were not entirely happy about the outcome, using the Practice Reflection Guide (Appendix D).
Journal Entry, 23.11.05

The second meeting was good, except the nurses did not journal beforehand. I was disappointed, as we had all agreed last week they would write in their journals. They prepared morning tea – coffee. I feel a bit awkward. I am an acute care nurse doing research in an aged care facility, so I think I am doubting my ability to be a critical friend to these nurses and most likely feeling a little unworthy in my role. The RN was nervous, I could tell by her forward sitting posture and rapid responses to questions. I tried really hard to put her at ease by taking a relaxed posture myself, sitting back in the chair, maintaining eye contact with all participants in turn and sharing the conversation around. Perhaps I am worthy to facilitate!

We all talked and they covered their personal backgrounds. It was good, because the nurses were open and candid in their responses. At times it was confronting for me, as I soon came to realise these nurses were discussing really personal aspects of their lives, some with tears in their eyes, and I was listening to how bad some of their backgrounds were for them. I felt tense, hoping I was maximising the listening and not interrupting too much. I wondered to myself: “Can I run these meetings?” I thought I was more self-confident than this, but I am now doubting myself. I think this comes from me thinking I don’t know aged care nursing. What am I doing here? Instead, I need to sit back and take in the information and learn and grow as a group facilitator.

I followed up one AIN after the meeting and offered her counselling assistance, if she needed it. Her sad background of separation from her family, being placed in an orphanage, Indigenous background, and alcoholic stepmother and so on, was not what I had expected to
hear in the group and it caught me off guard; I felt I had to offer some assistance to her. She cried in the meeting, but the nurses had obviously heard the story before and rallied around her. I think this is going to be harder than I thought! If I am to be honest, I feel way out of my depth. Even though I invited them to reflect only at a level with which they feel comfortable, I am surprised by the depth of their disclosures. I think I need to understand these nurses' lived experiences will be reflected in their future stories and I need to acknowledge their stories, and to learn to move forward with them to gain a better understanding of their practices.

This section described the foundation building phase of the research where details of the project were clarified, and research formalities, such as consent form signing and participant information sheet distribution, were accomplished. In this phase, group processes were agreed upon, to ensure the group worked well. Participants’ demographic details were outlined and responses to the first reflective task detailed. My personal reflective journal accounts highlighted some of the personal and professional challenges I faced in conducting the research.
Phase Two: Reflection on Practice Stories

The second phase, reflection on practice stories, lasted from meetings three to 10 inclusive. A key aspect of this phase of the research project was to encourage and share with participants the value of using journaling to express and explore clinical practice issues and analyse their own practices in relation to caring for older people, who are dying.

Three members of the group assembled for the third meeting and were each given a journal and a ‘Practice Reflection Guide’ (Appendix D). The guide provided a structure of questions for reflecting on practice stories. According to Taylor (2006, p. 71), the use of systematic questioning creates a flow of “seamless connections between the reflective processes”.

Unexpectedly, the Director of Nursing (DON) appeared and requested the meeting be postponed, as the facility was currently undergoing accreditation. The meeting was disbanded and the group agreed to meet the following week.
Journal Entry, 30.11.05

The third meeting was all ready to go, I had given the nurses a journal – freshly covered in pretty paper, thanks to my husband - and out of the blue, the Director of Nursing (DON) interrupted the meeting, only speaking to Celeste. She did not acknowledge me in any way, and informed the group, through Celeste the RN, that she did not want the meeting to go ahead, as the accreditors were on site and the nurses were to be available to answer questions.

I leave disappointed, but only see one journal! My disappointment is a result of my feeling progressively confident in facilitating the group and then, the power of the DON stops the meeting in its tracks. I understood the DON’s reasons for wanting staff available; however, I feel the way she handled the situation showed a lack of respect for the meeting and its participants. The power! Wow, the power is something I should reflect on a lot more!

The RN is very apologetic; which may turn out well, as perhaps she will try to make this role power dynamic work over the next meetings. I feel I need every bit of support I can muster to keep this project on track and progressing, so that the group are given the opportunity to share their stories and practices. I hope the RN assists, because this is turning out to be a rollercoaster ride for me. I had a magical project planned out in my mind, each section flowing smoothly; instead, I feel I have been rejected. I was welcomed initially and then swept aside. I guess I thought as a researcher there would be a degree of respect shown toward me. As a nurse who trained in a hierarchical structure, I still hold respect for authority, even though I see that sometimes those who have that authority use it without respect for others.
Researcher's Note, April 2008

Reading back over this journal entry, I remember the mixed emotions and how I felt, grappling with the power imbalance in the group and the DON's power to stop the meeting. My disappointment was short lived, as I found the insight I gained from witnessing the power struggles within aged care were relatively no different to the imbalances I frequently witness in the healthcare setting in which I work. I have learnt to speak with assertion and attempt to negotiate with those people who choose to use their power over others. This strategy is not always successful, but at least it exhibits the behaviour to those who recognise the display as “power over” others.

I reflected on my feelings of the disappointment I felt at the time and I have reconciled to myself that in my enthusiasm to commence the project, I was unprepared for all of the unforeseen difficulties in the early stages of the project. The DON was acting in a power position when she abruptly interrupted the meeting in that way. I now understand that I value respect and equality, and that everyone does not necessarily share my values for treating others with respect and equality and that sometimes they actually take advantage of those who do value these ideals. If the circumstance was to occur again I would risk speaking up, to gain the DON's attention, so we can be direct and open in our communication. I may feel vulnerable in trying to communicate assertively; however my attempt to open up a dialogue with the manager could model mature adult-adult communication to the group and perhaps influence the use of this open, assertive communication approach within the group.

The fourth meeting commenced with participants discussing why each meeting would involve the reading of the minutes from the previous meeting. I
explained that the minutes would be confirmed as an accurate account, and if necessary, statements would be removed at a participant’s request. We discussed participants’ rights for privacy and anonymity again, and how the minutes of the meeting are research data for analysis and interpretation, thus they need to be confirmed as accurate by participants throughout the action research phases, as a means of ensuring the trustworthiness of the project.

I suggested that reflections on practice stories could be represented using any creative medium, including drawings. The rules for the group were agreed upon, including allowing 10 minutes of uninterrupted time for each participant to share a practice story, so they could maintain their train of thought and express how they honestly felt. It was at this point that participants were invited to share their stories that related to an incident at work, in which they were not entirely happy with the outcome of their involvement.

Each participant shared a practice story with the group members. For example, a participant spoke of an incident that she had “never forgotten”. The resident she remembered was described as “a large, forceful person”. The group was told that the resident “forced” the doctors and nurses to allow her to walk, so that she could go home for Easter. The participant reflected that the resident “was desperate to get home”, and stated that “she wanted to walk out of here”. A RN had directed the participant to “make it happen”, even though the participant did not feel comfortable with mobilising the resident, due to concerns over her safety. The participant expressed her concerns to the group repeatedly while relating her practice story, stating: “I was against it”. The resident fell and suffered a gash on her leg and died two weeks after the fall. The participant blamed herself, because she was present at the fall, and she inferred she could
have prevented the resident’s death, if she had been more assertive in refusing to mobilise the resident at that point in time.

The participant reflected that her present level of expertise would help her to feel comfortable in refusing the mobilisation order, or to argue rationally why she felt it was not prudent to mobilise the resident at that time. The participant said she was “new” to the facility at the time of the incident, and she was “too weak to say no”. A little later, the participant spoke of how “death is a blessing” and said that, if the resident’s death had not been precipitated by the fall, it would have been more prolonged due to her obesity and general poor condition. The participant concluded: “She died better (then) than she would have (later)”.

At the conclusion of the story the group remembered the resident as the “Lady in 27”. A participant stated there was “totally no shame or fear to be blamed” and encouraged the participant recounting the incident “not to feel guilty”. The participants agreed this resident at the time was expressing “what she wanted to do”, to “walk out of the facility” and that she was determined about “going home for Easter”. A participant stated it was important to “allow people to do what they wanted to do” and reassured the participant that, in her opinion, the resident may not have died from the fall. The group agreed a carer’s role is to support residents’ requests. The group then discussed the circumstances that may have contributed to the resident’s fall, including that the facility was new at that time, and staff were described as being “under stress”. The group remembered the resident, who they agreed was not very old and was going through her own “grief and anger” at being placed in a residential aged care facility.
Despite these assurances, the participant relating the practice story still expressed feelings of personal responsibility. The participant stated she had never had a problem with death before this incident and that she was confident in mobilising residents prior to this event. Another participant agreed it is important that nurses show a resident they are confident, as this confidence is transferred to the resident. The participant relating the practice story spoke of placing residents’ safety first and if she had any doubts regarding residents’ safety now, she prefers not to mobilise them.

The participant went on to tell the group she had shared her concerns regarding the incident with senior staff, stating she wanted to “just to get it off (her) chest”, even though she knew it was not her fault that the resident fell and died two weeks later. The participant ended her story, by reflecting that she has a practice of farewelling residents when they are dying, but she stated, in this instance, she felt sad, because there was “no chance to say goodbye”.

Another participant’s reflection related to a resident with dementia, who she believed did not want to die, so “he fought to stay alive”. The participant remembered that the resident had a habit of climbing “over the rails”, so she had to take him with her to where she was working, to “keep an eye on him”. She told the group: “I put him in a chair and he was safe”. She remembered that his eventual death was a “traumatic death”, describing it as a “difficult, difficult death”. The participant reflected that the resident died looking like a “battered, bruised man”, because he had “steri-strips on his eyes and arms”, as a result of various injuries he sustained from climbing out of bed. The participant said the resident died over an 18 month to two year period, and added that he was “an amazing” man, who had a “beautiful voice”.

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Another participant recalled the resident as encouraging her to sing, because he taught her how to sing by “breathing and sucking” air rhythmically. The participant then reflected that Christmas was “special”, because a week before the resident died, she recalled how, even though the man was demented, he sang a duet with his son. She spoke of being very moved witnessing this and of having a “strong bond with him”, as they both enjoyed singing. However, the same nurse described the resident as being a “pig headed man” at times. She recalled that “he would always listen” to her, and she also described having an occasional “shouting match” with him.

Researchers Note, March 2008

I recall at the point this story was discussed, that I decided to wait and challenge the language later, to allow the participants, time to gain confidence in sharing their stories. Words such as “pig headed man” and “shouting match” are problematic. When I discussed this negative language with my critical friend, we considered how negative language persists and becomes entrenched, because it remains unexamined and uncorrected by nursing peers. At that early point in the project, although I was surprised at the negative language some participants used, I was aware of the necessity for the stories to be shared freely within the group. Also, the aged care environment was unfamiliar to me, so I felt it wise at that time, to allow the practice stories to flow to gain an idea of the patterns of language the nurses used when they were describing clinical incidents. Later in the project, I addressed the issue of participants using negative language to describe clinical contexts by using Challenge Statements (Appendix G).
In continuing the discussion, another participant stated that the resident “didn’t like being told anything by women”. During the resident’s physical decline, the participant telling the story remembered an occasion when the resident was taken to the dining room in a wheelchair, and she recalled “the look on his face”. The participant described the resident’s look as a mixture of embarrassment and horror, which prompted her to take him back to the office. The participant felt the resident acted in this way because the other residents were looking at him and that she knew the resident well and believed she could tell how he was feeling. She described the resident’s loss of dignity, because “other people were looking at him” and “you could see (the embarrassment and horror) in him”.

The participants then reflected on his death and one participant said: “I knew he was dying – (the resident) didn’t”. Another participant felt the resident was “not willing to give into the death experience” and said the resident’s death affected staff. She stated: “It was a hard death for us girls” and she said: “I still miss him”. The participant stated the family had been “supportive of the staff and resident” and on the day he died “he waited for the daughter to come”, so the participant remembered needing to phone the daughter to tell her “to come straight up”.

I asked participants to reflect on what they thought was ‘a good death’. The group then spoke of a good death as being about a “patient’s acceptance” of dying, “the family goes with the flow”, and we (doctors and nurses) “work as a team”. One participant said death could be like a “cauldron type storm for the staff”, saying that she needs to know “you can’t do anything” about the fact that a resident will die.
When speaking of family involvement, participants recalled some families questioning the nurse’s involvement in an accusatory way, for example, in asking: “What have you done to him or her”. At other times, nurses needed to explain to the family what they could do after the death, suggesting: “You might like to say goodbye to Mum”, or “You can touch Dad”. This prompted discussion by the research group on nurses’ training for facing death. Participants made various statements at this point, such as: “There is no training in helping one another with death”, “nobody has ever told me how to do it” and that staff have to “get used to death”. Another participant spoke of giving new staff an “initiation to death” and how she sometimes shows new staff/RNs how “massage can bring back a patient’s colour”. Other points for new nurses to recognise were being “able to identify death” and, for new staff death “can be scary”.

Journal Entry, 09.12.05

I felt out of my depth again this week, as I was unsure what to do when issues arose, such as the language the nurses were using to describe residents, and when they felt they had insufficient training for death. My phone conversation with my critical friend reminds me I am not the ‘rescuer’. She says: “You don’t have to have all the answers”. I know at one level that I don’t have to have the answers, but why do I feel like I do? Is it because people always start their conversations with me, with: “You’ll know”? Acute care nurses tell me they know I am an expert and that I have the answers they need. I think this is the acute care nurse in me, who is used to providing a quick response with authority to other nurses. I think the acute care nurse in me is wanting to surface in these meetings, when, in fact, I know I have very little experience
of death in an aged care setting. Also, as a co-researcher in this group, I have a lot to learn about myself and how I see myself in this role of group facilitator.

Attendance at the fifth meeting was small, as only three of the group arrived to share a positive outcome of their involvement in an end of life incident. There was agreement that “family support of staff” and “understanding what is happening” are important aspects of a good death. To demonstrate this, a participant recalled how a daughter had accepted her mother was dying. She said the mother was in bed dying and the daughter was clearing out the cupboard. The participant said that “only the bare necessities had been left”. The group agreed that families minimising belongings toward the end of a relative’s life was common and described this time as a “waiting game”, so having something to do, such as clearing out the resident’s cupboards, gives the relatives something constructive to do. The participant described the relative as “connected to her mother”, and the daughter “knew everything that could have been done, was done”, so “this made it easier”. The participant described the dying resident as being kept “comfortable”, which made the family “feel at ease”. The group described this resident’s illness trajectory as “bouncing”, stating: “She wasn’t going to bounce back like she had before”. When I asked what the resident had died from, the participant replied: “Old age, just died, maybe a UTI” (urinary tract infection).

Another participant said that the family were Jehovah Witnesses with “different religious beliefs”. She recalled asking the daughter if believing in resurrection made her mother’s dying any “easier to accept”. The daughter told the participant: “It does, but it still doesn’t stop the grieving”. The daughter
continued to visit the aged care facility where her mother had died, for months following the death. When the daughter arrived at the facility the staff would often say: “Here comes the cyclone – grab hold of your chair”, because the relative was known to them as being very organising and busy.

Researcher’s Note, March 2008

In this instance, the nurse was invited by the daughter to the resident’s funeral. It was evident that the nurses respected the relative’s connection to her mother, yet they called her a ‘cyclone’. I reflected on the way the nurses described the relative. I hope the nurses were not being intentionally unkind by saying: “Here comes the cyclone – grab hold of your chair” to the daughter, however, it did reflect a lack of understanding of the grieving process and the support families should be offered following the death of a relative. Now, I am more aware of the language the nurses use and I have spoken up and asked for clarification. In this case, I could have asked: ‘Could you please tell me how you think this relative would have been feeling while visiting the facility where her mother recently died, and why do you describe her behaviour as a cyclone?”

Participants agreed “making residents comfortable” and “supporting the family” are important aspects of dying. They said that some families “turn to us and we offer them support and make them feel comfortable”. I asked the group what they would describe as a non peaceful death. A participant described a non peaceful death as “laboured breathing, gurgling, dreadful sounds”, stating this made it difficult for the staff and family.
The group agreed it is important to be “totally honest” with the family regarding the possible time of death and prepare the family by saying: “To be honest, I think it will be ...” (time period to death), or “It looks like it will be in the next few hours”, or “It could be today, but it might not be”. The intention was to offer some indication of the time remaining, so the relative would have a general idea of the particular resident’s condition, knowing the prediction was according to the nurses’ tentative guesses.

A participant said that families are often not told their relative is dying, saying: “No-one will tell them”. She recalled a RN saying to her: “It is the doctor’s job to tell them” and described a RN being angry at the participant for telling the family, because “the RN refused to tell them”. Participants felt it was important to prepare families, as “the families have to get kids in”. A participant felt RNs in the facility were generally not challenged on their decision to not notify the family of impending death.

Researcher’s Note, May 2008

I’ve been reflecting on why some RNs may decide to not even give tentative guesses about the time remaining in impending death. Looking back on the nurse’s indecision and avoidance of speaking with the relatives regarding how long a resident may have left to live, I wonder whether she might act differently in a different context. What would happen if that same nurse was supporting a carer, as a friend, in a home environment? If the nurse was supporting a neighbour, would she be so reluctant to share information? Would that nurse be so guarded? Would that nurse be thinking about getting into trouble, if she said ‘the wrong thing’? I think not - I think she would most likely make a tentative guess, based on her nursing
experience, to provide information to their friend, to be of comfort. So what happens in the work environment, such as an aged care facility, where patients are regarded as residents? Most probably, nurses will do what they think best in a situation, within the legal and ethical constraints on their practice. I know that challenges with communication of prognosis are not unique to aged care facilities. I have seen a reluctance of health teams in approaching the subject of impending death, even in critical care where life can hang on a string. When I have witnessed doctors raising the issue of poor prognosis I have seen how it can help the patient (if able), their family and the team, to prepare and plan for optimal end of life care.

The act of challenging clinical decision-making led to discussion regarding a RN being challenged to provide pain relief to a resident. Medications prescribed pro re nata (p.r.n.) were seen as problematic, and a participant said that the de-identified RN in focus would say: “We will give them a couple” of pain relievers, however, RNs can be “too scared, afraid to give them too much of a drug” or they were “frightened to give them too much, as allowed by the doctor”. One participant spoke of giving residents adequate medication and asked when a resident is in their 80’s or 90’s whether it matters if the dose turns out to be too much. She said: “The resident has most likely had a healthy life”. This led the group to discuss that those nurses who were not RNs were in control of the residents’ care and that they needed to go to the RN if a medication was required. One participant described having to explain to a RN why she thought it was important to initiate pain relief before the morning routine care was given to a resident, having to explain to the RN how she knew the resident was in pain.

The focus of the discussion changed to the difficulties encountered in accessing a doctor on behalf of a resident. A participant recalled: “Only at a resident’s
daughter’s insistence” did a doctor see the resident, describing doctors as “reluctant to attend” the facility. The participants felt doctors did not listen to or look at the resident, and only thought of residents as they seemed to be, at that point in time when they were making hasty visits to the facility. A participant commented that a permanent resident could be “as crook as”, but when the doctor sees the resident, the resident has a “smiley face”. This resident was known well to a participant, who said: “He grunts and groans in pain, but displays a big grin” when a doctor visits. The participants spoke of subtle changes happening that are not extraordinary, but yet they are important changes, and because of regular contact, as the carers, they felt they noticed the changes. One participant said she had “no trouble ringing a doctor”, if she was worried or had a question about a resident’s care.

Researcher’s Note, March 2008

Looking back on the statements the nurses made in this meeting, I can see that the nurses touched on a number of issues, including the power relations shared within the team caring for the resident. Power issues were raised when the AIN had to ask the RN for medications for a resident, and when the RN had to ask a doctor. These seem to be differences between RNs in regards to perceiving their rightful power to administer nursing care i.e. some RNs don’t have a problem contacting a doctor and some are reluctant or have difficulty following up with a doctor. These communication problems had the potential to impact on appropriate medication regimen for a resident, so they were considered fully by the group, in later discussions.
The discussion moved to referring residents for hospital care at the end of life. A participant reflected on a resident, who had been sent to hospital and he had told staff at the hospital that he wanted “to go home”. The participants felt proud he called the facility “home” and said: “He died here, (in the facility) that was the most important thing”. Calling the facility home was seen as important to the staff, who commented that few residents were going out of the facility for the upcoming Christmas holiday. The group then discussed their plans for Christmas Day at the facility, including the organisation of the drinks, music and decorating the hall area.

The meeting concluded with the group agreeing when the nurse, the family and the resident worked together for the good of the dying resident, it was more likely to be a ‘good death’.

Journal Entry, 16.12.05

I am concerned that the group still has not formalised their journaling. I am worried that I cannot control that aspect of the process and I am disappointed. Control seems to be important to me. I think it is the intensive care nurse in me wanting to have everything predictable, just right. This may be the result of the pressure I am placing on myself to show I can do this research. I think my disappointment reflects my need to produce something, some tangible evidence, as again I am pushing my boundaries of comfort and challenging myself to perform in a completely different arena. To encourage interest in journaling, my strategies for the January group will include:

- Impress on participants early, the importance of the actual journaling/reflecting
• Considering alternatives each week e.g. one week I will ask for a picture/drawing, the next week I will ask for a story.

Researcher’s Note, March 2008

Looking back at this journal entry I can now see the importance I placed on participants’ journaling, and in producing tangible reflections on paper. I can now see that I was not valuing participants’ contributions at the meetings enough, nor my ability to concisely capture and document their statements in the meeting minutes. My experience now with successfully completing two groups in two facilities demonstrates to me that I need to trust the process and myself more. My recording of discussions in the minutes has been meticulous and I am reading the minutes back to the group the following week with few adjustments. The knowledge I have gained from facilitating the groups has assisted me to add another dimension of trust to my teaching repertoire and to my nursing knowledge – trusting myself and trusting a valid research group process – and I intend to share this personal learning experience in the way I teach and supervise postgraduate students in practice areas in the future.

In the sixth meeting, discussion revolved around the management of pain in older residents. Following confirmation of the minutes, a participant commented on RNs being separated from the care of low care residents, due to the administrative duties RNs are required to perform. She described herself as a RN, who, when allocated paperwork duties, only had an opportunity to “breeze in if there is a problem” and ask if “everyone is well today”. She stated RNs “have so much on their plate”, thereby being unable to “responsibly cover low care residents, as well as their other high care residents”. The RN spoke of
having to develop a sense of being able to “accurately gauge” the residents and their care requirements, despite limited time with those residents.

The discussion then focused on the complexity of assessing pain in aged care residents, including those residents with cognitive changes. A participant expressed the importance of “never ignoring pain” and stated: “We deal with the pain”. Pain was spoken of in the context of needing a holistic approach to care, with the nurse stating: “If the problem is not pain, we look at the other problems”. The participant reflected on the importance of morphine being ordered and administered in a timely fashion. The timing of medication was described as critical, before the resident is in “dire straits”.

A participant recalled a resident, who was having morphine ordered and administered by the nursing staff. The resident’s family were told by a couple of staff members that morphine was a “dreadful drug”. The participant expressed the difficulties that occur when residents are not given adequate pain relief, describing the process as “trying to catch up” with the resident’s pain. The participant described this resident’s family as “overly defensive” to morphine being administered. She tried to convince the family morphine was a safe drug to administer. Comments to convince the family included telling them: “We do know what we are doing”, saying further that “it can be difficult to source other drugs” and the resident’s needs are in a “high care” category. The participant expressed the importance of all the team being “cohesive” in the information shared with relatives, the importance of using “tact, respect and wisdom” and of being “careful what you say” to relatives. The participant recalled, in this case, that the relatives had been staying day and night with their mother, who was receiving morphine and was “quite settled”. However, one night the resident
became very distressed during the night for an unknown reason and the family’s negative attitude regarding morphine administration resurfaced.

The group then discussed the challenges nurses face in adjusting to residents’ dying processes. A participant reflected: “Even though you know someone is dying, it is still a surprise when they go”. She then stated: “All the residents are going to die, the residents here are not going anywhere else”, but she told the group at times she thought to herself: “Why does one resident die and another resident, who you think would go, is still here?” The participant discussed not having difficulty “accepting death” and that she “takes it as it comes”. She questioned “new nurses’ behaviour” when seeing death and how some nurses cry when residents die. She then recalled crying herself when she first started nursing, on seeing her first death. The group agreed that experiencing death is a personal process and they also described some staff as “buying into the emotions to meet their own needs”. The participant stated: “We can watch this person for three or four years, and there’s no quality of life”; so “when they are gone we say: Thank God”.

The group then discussed developing “detachment type behaviour”, even though they also expressed a connection to residents, such as “love and care” for them. Death was described as a long process, and as a “slow decline”. Death was also described as a “release for the person”. A participant discussed people asking her: “How can you be so hard, so uncaring?” She spoke of the importance of residents to her, stating: “I care for the residents more than my own family”. This participant had spoken of her upfront approach to residents and being a person “who says it as it is”, for example, she might say to a resident: “You look terrible today”. Her belief was that the residents appreciated this approach. A
participant used the word “blunt” to describe this approach. The group then discussed how some people use “polite speak” and “social manners” and how this may or may not be beneficial to dying residents and their families.

Journal entry, 18.01.06

It was good to see everyone, but we are down by one with Mary gone. I felt upset, let down, disappointed, that the group didn’t arrive with formalised stories on paper. I pushed the point and hopefully, next meeting, for once, they will come prepared. Their stories are relevant, but how will they change their practice unless they analyse their stories?

Researcher’s Note, March 2008

I feel I have now moved beyond disappointment with the nurses for not formalising their reflections by journaling in this research. I have developed an understanding there are many reasons nurses choose not to formalise their reflections, such as limited time or literacy skills, or more pressing personal commitments. The research processes of participants sharing their stories verbally in the group can be just as beneficial as journaling and assist the nurses to critically analyse their statements, for example, their negative clinical language.

In the tenth meeting, I presented the first session on challenging statements. I decided to remind them of some of their language used previously and to use challenging statements to show them how they sometimes appear to speak negatively about their work and the people with whom they interact within the facility. Challenging statement sessions assisted nurses to hear their language and discuss why they say such statements. I have found these sessions
assisted nurses to reflect on and explore their statements and the language they have used, and to be ready to make changes to the way they communicate if they are needed.

Three participants and I attended the seventh meeting. This meeting was disjointed, with attendees arriving late, a resident sitting with the group for a short period, and one of the participants having to attend temporarily to another resident. During a brief period when the RN and I were alone, the RN shared her personal experience of the death of a loved one. She described the impact of this loss as a “life changing” experience for her. She spoke of how she attempts to use the lessons learnt from this experience, in her day-to-day nursing practice, but she did not expand on the actual details of strategies she uses to achieve this.

When the group settled into comprising four attendees, we discussed how best to portray a nurse’s experiences of end of life care in a reflective form. I shared my knowledge of various methods, including journaling, drawing, recording thoughts into a recorder, or creating a collage from magazine cuttings. Participants agreed to bring one form of reflection to the next meeting.

Journal Entry, 01.02.08

No drawings or journaling again today, even after their commitment last meeting! Celeste, the RN in the group, said she had started to journal, and then she shared a sad story of caring for a foster child, who died from cerebral cancer, which was way off the research topic of caring for dying, older residents. Celeste was quite emphatic about being a ‘Christian’, repeating it often during our one on one conversation when other participants were absent from the room temporarily in the last meeting, now I am wondering why she was saying that to me.
I look back on this time, when Celeste used this opportunity to share her religious beliefs with me, and I think maybe it was another way for her to connect her religious values to her professional practice. This may also have been her attempt to create a bond with me as a person and as a professional of equal ranking. The personal constraint I needed to rise above with her was my lack of assertion and relatively shy disposition. Even though I felt somewhat overwhelmed by her religious fervor, yet special that she felt she could relate a personal story about dying to me even if it was not on the research focus, it was less confronting for me to remain silent and agreeable, for the sake of the research process continuing. As the group evolved, the drawings did eventuate, led by Celeste, who demonstrated the link of religion to her nursing practice. This turned out to be a trigger for the group, as Celeste’s drawing gave participants the confidence to share and express their thoughts and practices in end of life care.

The eighth meeting was an opportunity to discuss Resident Classification Scale (RCS) funding. A participant commented it was “similar to climbing Mount Everest”. She explained to the group that RCS funding paperwork is documentation that demonstrated a resident qualified for funding assistance from the Australian Government. The paperwork identified the type of care and why the resident needed the care. She explained the complexity of the form and that every detail of care must be documented and detailed, such as explanations as to why a particular resident needs assistance. The paperwork includes 21 questions on aspects of care, subdivided into subcategories. An example is mobility, which is sub-categorised into falls risk, lifter use, and why a lifter is
indicated. This information is documented on a falls risk form. I asked: “Who completes the form?” The participant explained that all staff complete the forms, including the low care staff, senior staff and others. It was explained that the resident’s care is evaluated every two months and backed up in the resident’s notes, to justify the band of care allocated.

The participant explained that different facilities have different paperwork and that an initial assessment can take a full day. The process of evaluation can be streamlined, with an evaluation taking only approximately two hours to complete, provided there are no interruptions and the person completing the form is focused totally on the task.

A participant commented that when she was first introduced to the funding processes, she was surprised how funding was allocated and interpreted it as “the more time staff spent with residents to encourage independence equated to more funding for that resident”. A participant explained this approach maintained the resident’s independence and dignity and felt the purpose of the form was for staff to prove why the resident could not do their own care. The importance of not focusing only on the paperwork was emphasised by a participant, who commented on attaching value to the residents, by stating: “Aged care has moved past treating elderly people with as much value as a 20/30 form”. She emphasised the importance of keeping the paperwork in context, by stating: “These people have served their nation in wars, suffered in the depression, contributed to the community, worked” and, therefore, they should be valued and respected for their contribution to society, rather than being valued for the amount of funding they attract to the facility for their care. The participant seemed to be making a point, to engage the nurses, so they would
remember to treat the residents with respect and as people, who had contributed in various ways to society during their lives.

Discussion then moved to the importance of the staff working as a team. A participant explained that residential aged care facilities are similar to working in a Medical Unit now (in an acute hospital) and that residents had investigations, such as x-rays and scans. She also commented that, because of the acuity of the residents, the staff need to develop a generous attitude to foster a teamwork approach to care. She used the example that a teamwork approach is necessary, so that staff in the side areas (low care) assist those staff in the high care section. She felt the facility must be thought of as a whole, not three separate entities all working separately.

Another participant agreed with the teamwork approach to care, commenting: “The only place I won’t go (to work) is dementia”, although she stated that “a lot of people want to go there”. When asked why she did not work in the dementia unit, the participant commented that she had no patience, and said: “I don’t like kids; I don’t want to work doing little activities, amusing them.” The reason the participant identified for not wanting to work with people suffering dementia, she likened to “kids”, was because she enjoyed the personal conversations she had with other residents and she felt dementia care was “no good for (her), no good for the resident”. She told the group she had previously worked in a facility caring for alcohol related brain injured people, commenting: “I couldn’t be bothered with them”, and that she did not feel busy enough doing that type of work. She remembered previously in a meeting that someone had remarked she was “blunt” and felt this was “spot on”. When asked to describe “busy”, she said: “Busy is talking to the resident, talking about their family history and
providing care” and “talk as you go”. She said she liked to acknowledge the resident as she walked past and she would say to them, statements such as: “You’ve had your hair cut? Wonderful”. The participant went on to say she also lets the residents know she is caring for them, by making remarks such as: “You’ve got me, for three days”.

Researcher’s Note, May 2008

Cognitively impaired older residents provide nurses with an opportunity to apply advanced communication strategies. The nurse’s statements, in this instance, left me wondering whether she had the ability to communicate well with cognitively impaired residents, or whether her practice was based on caring and respect for those residents. I did not challenge the nurse’s statements at that point, but throughout the group meetings, I often reiterated the importance of reflecting on and analysing our nursing rituals and practices.

At times it was difficult to facilitate the meetings, there was a mixture of participants at various levels of nursing experience, I had limited experience as a facilitator, in challenging inappropriate statements and I wanted to ensure a positive relationship was maintained with the research group. To challenge some of the statements at the time they were spoken may have meant I was risking group bonding and perhaps marginalizing the participant or me. Interestingly, no other participants in the group challenged those statements either. I can now see on reflection that it is important for nurses to examine how they communicate with residents and their peers. If we had addressed the ‘bluntness’ at the time in a gentle but earnest way it may have helped the participant to understand that it is not acceptable for nurses to speak about or to residents in such a blunt way. I have learnt from these
experiences that it is possible and more rewarding to address unacceptable language at the
time and that this approach can result in having an effective conversation in a non-threatening
way that allows exploration of inappropriate communication and nursing practices.

Ideally, if, the ‘blunt’ participant had engaged further in the reflective practices, she may have
gained some awareness as to why she had developed these assumptions about the nursing
care of people with dementia and cognitively impaired older residents and begin to own her
attitudes towards these residents. Further, reflective processes may have assisted the
participant to appreciate the complexity of communicating with people and to gain new
insights into seeking other ways of communicating with cognitively impaired residents.

The group then discussed why looking busy was important and I asked them to
think why some nurses value this behaviour in their work. This led a participant
to reflect on allowing or not allowing herself to become “attached” to residents.
She remembered telling a dying resident to: “Let go” and said she often says that
to residents, if she knows they will give themselves permission to surrender to
death. She recalled being “very attached” to a resident, who had lost his wife
and remembered being called at home by the staff, who told her: “Phil’s not
well”. She went to the facility and sat with Phil until 3 am and she remembered
him calling out to his late wife: “Mary, Mary”. The participant believed some
people need permission to die. She remembered giving the resident permission,
by saying to him: “There is nothing left now, Mary’s gone, and you can go”. The
participant was pleased when the family asked her to be one of the pallbearers at
his funeral. She interpreted this as being accepted by the family, adding that the
resident “had heavy feet” and that her place at the coffin was at his feet.
The attachment issues the nurses faced when connecting with residents prompted a participant to reflect on the care of a dying resident with a severe disability. A participant stated she had a child with a disability, not as severe as the resident’s, but recalled being cautious about letting down her barriers and allowing herself to get close to that resident. A participant commented: “We rob ourselves, by not allowing ourselves to fully engage with residents”. This participant felt past experiences and nurses’ own fears were valid reasons for not wanting to engage with residents. She said: “It can be so awful to go there”, saying further: “You can open a flood of grief”. A participant stated the staff go through many stages of grief and denial and felt that when a resident is close to death, some nurses distance themselves, and she described this as taking a “step back a bit”.

The discussion then changed to how nurses influence outcomes with end of life care and the decisions families make. A participant commented on the influence nurses can have on family decisions, stating that the nurses “coach the family”. She stated: “We hope the family call the shots”, but she realised that nurses can be influential. The group agreed that most families will “hang on as long as they can” to their loved one. The group spoke of the role of palliative care and providing the best comfort to the resident and supportive treatment, right to the end of life. The participant said families can be reluctant in accepting the decline of their loved one and often take a day or so to agree with treatment changes, stating: “Families often can’t face the thought of the changes in treatment at that stage. The families will go home and think about treatment changes and then the next day agree with the change in treatment”.

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At this point, a participant produced a drawing, representing her thoughts on end of life care (See Figure 5.2.). In the middle of the drawing a person was standing on a surfboard. The participant described this person as: “The nurse riding the waves, despite waves coming from every direction”. She explained the waves represented all the emotions associated with grief, denial, fear, pain, misinformation, unrealistic expectations, sadness, acceptance, lack of understanding, starvation, dehydration, and nurses’ lack of knowledge experienced by the family, the nurses and the resident. The participant explained the surfboard had the word “love” written on it, representing the nurse as “standing on love to give.” In the drawing, the nurse was wearing a badge of hope, describing hope for the family and the resident. There was a ring of yellow colour, representing light surrounding the nurse and within the ring were the words, kindness, empathy, listening, acceptance, nursing skills and care. The participant explained the yellow in the picture represented God and because of her Christian beliefs, this was drawn intentionally. I asked her why one of the waves was labeled loneliness. The participant said this represented the emotion often experienced by all involved in end of life care; the resident, the staff and the family. The participant stated the importance of the nurse still standing and described this as having “survived the experience”. When discussing how she drew the picture, the participant described her thought processes occur by “thinking in pictures, particularly cartoons.”
At the end of the meeting, I thanked the group for participating and expressed my sense of responsibility, to be sure that I represent the aged care nurses’ love of their work and devotion to the residents’ care in this research.

Journal Entry, 08.02.06

The group went well today. Celeste has such clear explanations and as a personality, Eileen, the ‘blunt one’, is a classic. She keeps the group honest. Her frankness is uncomfortable for me sometimes, but it makes participants stop in their tracks and think about the statement she has made, what the statement says about aged care nurses and how the statements reflect on the people working in aged care. Eileen’s statements are raw and at
times rough. She avoids the politically correct statements, and I'm not too sure why. I don’t think this is intentional I think it is just not in Eileen's vocabulary to be politically correct. Her speech is uninhibited and lays bare her thoughts of working day to day in aged care. Having Eileen in the group demonstrates to me that minimally trained workers are a growing workforce in aged care and research needs to explore how best to develop their potential and determine how best to engage them in the care of older people. If this research can influence Eileen’s work, I think the outcomes will be beneficial and long lasting for her.

Another thing to continue to ponder is Celeste’s role in the group. I sometimes think Celeste knows it all, but why is she calling herself “only an aged care nurse”? This is worth exploring sometime with Celeste and the group.

Researcher’s Note, March 2008

I found Celeste’s personality to be both endearing and challenging. Being a devoted Christian, her beliefs flavoured, even dominated, most of the research group’s conversations and yet her devotion to her work and her articulate explanations of nursing care, were at times captivating. I can see that I valued her collaboration, but I had uneasiness about her frequent references to religion. I’ve reflected on my uneasiness, and I can see that my responses to her show me that I chose to not confront Celeste about her frequent religious references and that I am passive to religious philosophy. My personal religious-based upbringing taught me to respect various religious doctrines. Through reflection on this issue, I now feel my uneasiness was not so much about me reacting to her religious statements, but that I was beginning to sense that it was possible that the religious based statements may have been
used to exert Celeste’s authority and superiority within the group, both as a religious expert and a RN guided “divinely” by religious values.

At that time I was worried that Celeste’s frequent religious references would silence participants within the group. At times, I noticed participants sharing glances or raising their eyes to the sky when Celeste was expressing her beliefs, for example, about the afterlife. I did not confront the non-verbal behaviours of the participants, but I remember thinking at the time of how complex it is to let some things I notice ‘slide’ so the group processes can flow, and how it is important to protect all of the participants ethically, so they feel free to share their practice stories in the group.

Reflecting on my interaction with Eileen, I can see I felt a responsibility to influence her. Why did I feel responsible? Trying to influence Eileen assumed that she was “wrong” in the way she spoke about nursing. Am I responsible for influencing her, or anyone, who might seem to be a “rough diamond” in the way they talk about, and possibly practice, nursing? My feelings of responsibility, although well meant, may have been dismissive of Eileen, who was a self-identified blunt, strong person. Yet all I was seeing of her were what I considered to be her weaknesses, such as her lack of insight into her practices, her apparent thoughtlessness and lack of compassion, defined by her and others as bluntness, and her lack of reflective thought about the harshness of her decisions about who she preferred to nurse, and why.

I realise that I need to look at how I communicate with others, especially those who are not RNs, or not as experienced as me. Maybe, down deep, I suspect that the less “trained” nurses do not have the necessary experience to be discerning in their practices, or in the ways they talk about them. I feel the best demonstration of leadership and facilitation in this action
research and reflection group is in treating all participants as equals, because it embodies a position that minimises power differences in the group. This means that I do not need to feel compelled to confront each and every statement, which unsettles me personally. Some insights are to be gained by each person at their own pace, according to their own ability and willingness to use the structures of reflective questioning to improve their own practice.

The ninth meeting was cancelled due to a lack of people, who were available to attend. The participant who attended and I discussed the importance of sufficient numbers attending the group, for the project to achieve the intended research goals, of identifying the barriers to caring for dying residents with non-malignant conditions. Rescheduling the meeting time or day to improve attendance was discussed, but the participant said this would not be necessary and would discuss the project and meeting attendance with other staff, who had not attended on that day.

Journal Entry, 14.02.06

The group arranged to meet this Tuesday at 1400hrs. I had indicated last week that I had to travel for work reasons, to a town nearby on our usual scheduled day Wednesday. All were okay with the change in time, but I turned up 10 minutes before the time and guess what? Celeste tells me: “No meeting”. Eileen was not coming, Agnus won’t come. Celeste had not even bothered to give me a call. I had a horrendous day at work in the morning, so this was the last thing I needed. It was pouring rain and I had an urgent clinical issue to sort out.
I can’t take the apologies from Celeste much more. I feel I have to smooth things over and say: “That’s okay”, but inside I am screaming. I tried to pin Celeste down this time and say, “Celeste, I need to know if Agnus will be rejoining the group”. Celeste hesitated and said that Agnus just needs some encouragement and asked me whether I would speak with Agnus, if I saw her on my way to visiting a person I had interviewed previously. Agnus made it clear to me she is not interested in rejoining the group and will be on leave next week. Agnus was definitely not trying to sit down and discuss the issue and was walking away as she was telling me. In a way, I felt sorry for her not being able to discuss the issue, and just evade my questions.

I met up with Celeste and suggested we change the day or the time for the meetings. Celeste then told me she did not want to change that day as it suited her babysitting arrangements with her grandchildren. I explained to Celeste that involvement of staff was important to this project, so that the staff could identify the need for change and implement the change. Celeste didn’t get it at all about a change to the day! She told me she would attempt to gather other staff. I think I know what next week will be like.

Researcher’s Note, March 2008

Looking back at this journal entry, I can now see my personal struggles with a busy day and striving to conduct the research influenced my responses in this journal entry. I was not objective in thinking about why the nurses did not attend this meeting, as my focus was on my achievement, and in particular, achieving that meeting. It seems as if I act according to my belief that achievement is the only way I can demonstrate my worth to my peers. My professional achievements have been important to me, as they have assisted me to progress
my nursing career. In light of this, I have reflected on how meetings do not always go to plan, but that does not mean the meetings will not go ahead in the future, or that I will not progress my career by being successful as a facilitator in this research project.

I used some degree of assertion in this instance, so I am pleased about that, but why did I take the non-attendance at the meeting personally and was it reasonable of me to feel so annoyed that Celeste had not phoned me to tell me the meeting had been cancelled? I realised I needed to trust Celeste more, to follow through on her attempt to gather other staff, even though it would have been far more conducive to the research processes, if the same participants attended regularly.

Attendance at the tenth meeting increased, as two new members, one of whom was a male, joined the group, and thereafter, the split pronoun (s/he) was used in the minutes to hide gender identity. The new members were provided with an abbreviated format of research group participation, including the time commitment to the research. I described the project’s aims, objectives, and processes in full, I reiterated the need for participants to participate actively, by reflecting and contributing to the group and working together through their practice issues. Plain language statement for nurse participants sheets, and demographic data collection forms were provided and consent forms (Appendix A) were signed, when the participants had sufficient time to understand the research process. Some adjustments to the last meeting were attended, as requested by participants.

The reading of Week 8 minutes (Week 9 meeting was cancelled), led the group to discuss relatives’ and nurses’ expectations of care. A participant stated: “We
(nurses) perceive care from a medical point of view”. The participant explained: “The conscious thought is that the resident will be alright, but the relatives do not necessarily understand this”. The group discussed nurses acting differently when relatives were present or not present. A participant stated that as a nurse, you should be “true to yourself”.

A participant discussed some of the staff being vocal, strong willed people and that issues around end of life care can “come to a boiling point”. The group agreed that a process of consultation and debriefing with nurses, relatives and medical staff about issues could be helpful and this process occurred some of the time. A participant suggested, in dealing with a work issue, to “take it home and deal with it in another way”. This prompted one of the participants to suggest that being able to share end of life care issues was gender related and that women nurses would tend to talk the issue through, with other women.

In this meeting, I introduced a strategy of ‘challenging statements’, in which I reiterated some statements made previously by participants in the group, as a focus for further reflection and discussion. Cards with selected statements from previous meetings were shown to the group, to encourage them to ask why nurses would make these statements. For example, the first statement was: “Come in crying, go out crying”. It was explained to the group this statement had been made by one of the participants, in relation to dying. I asked the group why a nurse might have this view of the death process and asked what they thought of the language in this statement. A participant related the statement to birth and the different stages of life, stating: “Babies cry to receive oxygen initially and to continue in life” and in death “a cry can be life sustaining, an honest expression of a resident’s emotions, reflective of aspects of their life”. The
group was divided on the interpretation of the statement and differed in their opinions, with one participant stating there was “no match” between a birth and death analogy. Another participant interpreted this statement as relating to “the relief, the uplifting feeling of crying”. Another participant said s/he thought the statement represented the “agony people go through”, but did not elaborate on this point.

Another challenging statement was: “The resident was not willing to give into the death experience”. This statement was made when the group members were discussing a dying resident, who suffered from dementia. The resident was described as dying “a bruised and battered man”, from frequent falls when climbing over his bedrails. I asked the group what would cause nurses to think a resident should “give into death” and to describe their expectations of how a resident “should behave” when they are dying. A participant remarked that death is a summation of life and that some residents are not able to accept changes in life. S/he continued that residents can be “oppositional to everyone” and that the dying process can bring up these responses and a person’s views on life. Another participant felt a person’s temperament can influence their reactions, despite death being a part of life. A participant commented on a resident’s denial of death and stated: “It is hard for staff” and that some people can be helped through the process and others cannot be helped.

A participant described the role families play in a resident’s dying process, describing the families as “hanging on” to their family member. S/he used the example of families encouraging the dying resident to “eat this, and drink that”. The participant felt this was unfair on residents and staff, particularly when s/he thought a resident “needs to go” (die). The participant recalled a family reacting
to a resident’s imminent death in this way and remembered the resident then went through a process of questioning his own beliefs about what happens to the spirit when one dies. The participant recalled the resident sharing and exploring his thoughts with the nurses, because he felt he could not share these thoughts with his family.

The group explored the statement: “We deal with the pain”. This statement was made when the nurses were discussing the complexity of determining and managing a resident’s pain. The researcher asked the group about the constraints nurses encountered in trying to “deal with the pain”. A participant stated that some residents can refuse to take medications and described this as “a huge problem area and quite complex”. The participant stated that there can be misinformation surrounding the drugs by all involved, including the resident, the staff and the family. Another participant shared her/his straightforward approach when administering medications, stating: “If you have been prescribed medication, you take it”.

A participant spoke of attempting to manage a high care resident’s pain. S/he recalled that one Registered Nurse spoke to the doctor to have morphine ordered for a dying resident. The participant recalled the resident’s condition declined rapidly shortly after the morphine administration, in that his respiratory rate decreased, and the resident became drowsy and “almost died”. Another staff member at the time assumed the resident’s decline related to the medication being given and the morphine order was ceased. The participant described the withdrawal of the morphine as “a set back to the resident”, because the resident’s consciousness was roused and he experienced the severe pain again, for which the morphine was originally ordered. The nurses discussed the struggle they
often faced in having a morphine order reinstated in a timely fashion. In telling this practice story, the participant shared with the group the struggles encountered in achieving adequate pain relief for residents and identified that some nurses’ pain management practices were difficult to understand or to justify.

Palliative care specialist review and the issue of doctors prescribing pain relief medication as a p.r.n. order, were then discussed. A participant stated that residents sometimes need the pain relief immediately and confirmed that “only Registered Nurses can give Schedule 8 medication”. Another participant discussed requesting medications to be changed and was told by a doctor: “It will be my decision”. Doses prescribed were viewed as problematic at times, with participants stating when orders were written as 1-2 mg, it varied as to how much was given and that frequently the lower 1 mg dose was administered, rather than the 2 mg dose. This led a participant to state that pain is related to nurses’ levels of perception of how much pain a resident is experiencing. The participant stated there were three pain assessment charts available in the facility, but commented that no chart provides a total assessment and expressed the opinion that knowing the resident assists nurses to determine pain levels. A participant felt the palliative care chart is a more descriptive chart and it identifies a resident’s pain better and assists in relaying that information to the medical officer. The participant suggested the chart could be put to the management committee for approval, but expressed that it can be difficult to have some charts approved.

The group discussed having to work with relatives to maintain a resident’s pain medication regimen, using the example: “A resident may be asleep during the
medication round and the relatives may not want the resident woken for the pain medication to be administered”. Another participant stated that some relatives “don’t seem to care”, but felt nurses have a duty of care to the resident and, therefore, should attempt to resolve the issue of not giving medication to sleeping residents.

Participants then discussed how some families are more willing to speak with the AIN, rather than the RN, and felt the AIN also had an influence on families’ decisions.

The meeting time ended and the group members were encouraged to reflect on barriers nurses experience in providing end of life care in any form, and for example, to draw or make a collage for next week. I explained that I planned to share a relative’s interview with the group at next week’s meeting and discuss the process of exploring themes for the action plan to improve end of life care for residents dying from non-malignant causes. A participant said s/he would try to remember her/his poetry book for the next meeting.

Journal Entry, 22.02.06

We did the Challenging Statements session this week. It wasn’t too bad, except I don’t feel I focused the questions to the group well enough. I left it too broad and open to interpretation.
I now think the problem I had with the Challenging Statements session was related to feeling I did not open up to the nurses and express my real shock at the statements they were making, such as “Come in crying, go out crying”. To me, I am alarmed that a nurse would say such a statement without thinking what that might mean to the family, to other nurses, to the medical community, and to the public. The silencing I have experienced from being subservient to my seniors over the years in nursing has contributed to stifling my ability to speak out in such situations; to say what I was really thinking to those nurses. It has always been important to me to fit in with my peers, to belong to the group, and in being silent or restrained in my responses, I have felt accepted into the profession.

However, I now have more experience; I have grown in confidence; I feel more empowered and can see that ‘silence’ on unexamined negative language allows inappropriate nursing cultures to develop, and inappropriate behaviour to go unchecked. I feel I am not as silent as I was, but I still struggle at times not to let these situations go unchecked. The main thing is I am mindful of identifying opportunities to speak fully to these behaviours, to place a mirror to those nurses, who are still unaware of the destructive patterns and the negative cultures such statements can create. I believe my co-researchers value the contributions I now make in this area and I use those opportunities to lead other nurses, to show it is okay to fully explore and challenge inappropriate statements about residents’/patients’ care.

Reflection has enabled me to ask myself questions and critically analyse how I was facilitating the group. I believe I was failing to acknowledge the complexities of the discussions, the aged care workplace and the issues surrounding end of life care. Through personal reflection I
gained a new awareness that assisted me to transform and act in a more confident role as a facilitator. I needed to reach a point where I broke free of my taken-for-granted assumptions that maintained the status quo and to be prepared for opportunities as they presented to openly address the challenging statements when they occurred. I would describe what I thought I heard as clearly as possible to encourage participants to gain new insights into practice and to allow transformational moments to occur.
Phase Three: Learning from the Relatives

Learning from the relatives, phase three, occurred during the eleventh and twelfth meetings. At the eleventh meeting, I shared excerpts from the relatives’ interviews with the group, which I had analysed previously (see Chapter 4). At the commencement of the meeting, a participant handed me a letter containing a practice story, then apologised for being unable to attend that day. The group then discussed the first issue relatives’ interviews had revealed, which was the reasons families place relatives in care. Relatives’ interviews were discussed that detailed why relatives had placed a family member in care, to encourage participants to see the issue from the relatives’ perspectives and to explore their thoughts on this issue. A participant was of the opinion that placing a person in care was a good decision for both the resident and the family. Another participant commented that “nine out of 10 relatives need care when placing family in a facility”, due to the stigma the relatives attach to themselves and the guilt they carry.
The ability of relatives to cope with family members needing care prompted a participant to wonder how people coped before “places like this” were built. This led the group to discuss the cultural dimension of families and society generally and how the burden of care may fall to an individual in a family. A participant commented that, previously, people’s expectations of life were different, and that “life was simpler”.

I asked participants if nurses ask relatives why they are placing their family member in care. Participants commented the question was not asked directly, however, nurses “ask around it” and attempt to identify the key issues of why the families have made that decision. Another participant commented that it is important for the background history of the resident and this knowledge assisted nurses in determining how to care for the resident in the facility.

Relatives’ thoughts regarding the transfer of a family member from the aged care facility to hospital for end of life care were discussed at this meeting. I asked the group for their thoughts on residents going to hospital to die and why a relative would rather their family member died in the aged care facility. This prompted a participant to express the importance of granting people their wish to stay at the facility to die, describing this wish to be “more like dying at home”.

The needs of the family were discussed and a participant stated the family may be “looking for answers” and “not ready to let go”, therefore, they need the resident to go to hospital, to try to save their life through active intervention. The group generally agreed a resident is happier to die at “home”, likening the facility to home. A participant felt it can be confronting to bring up the topic of end of life with relatives and described times when relatives can be “blind” to
end of life decisions. S/he went on to say s/he thought “life issues and the relationship with the family member can be bound up in a relative’s denial” (of the dying process).

The aspects of care relatives viewed as important in the interviews were then discussed. The first aspect was ‘Trust for the doctor’. I asked the group if it was important that residents and relatives have trust in the doctor. A participant felt it was important and emphasised it as “the most important thing”. Another participant described trust for the doctor as a “generational thing”, describing this type of trust as a “status thing”, in which older residents placed their trust in the status of the doctor. One participant commented that there could be an element of “conflict”, with the nurses sometimes not agreeing with the resident’s trust in their doctor, but they nevertheless maintained a professional approach and did not voice that opinion, when this conflict occurred. The group agreed doctors are all different and most of the doctors are willing to listen to nurses’ concerns about a resident’s end of life care.

The second aspect of care viewed as important by the relatives was their family member ‘being kept clean and comfortable’. I asked the group if nurses view cleanliness as a priority. The group agreed cleanliness and comfort were important, with a participant considering this aspect of care was important to nurses, who “own the job” of clean and comfortable. Participants linked this aspect of care to both the nurses’ and the residents’ self esteem. The group discussed improvements in providing care, comparing the incontinence aids with the methods of care delivered in previous years. For example, a participant recalled as a young nurse assisting at her/his grandmother’s aged care facility and changing beds frequently due to a lack of incontinence aids then. A
participant commented that keeping a resident clean was important to her/him and viewed bathing time as a time to “get to know the resident”. The importance of allowing time for this care was discussed with a participant detailing her/his routine when there was limited time to shower a resident in the morning: “I toilet them, wash their face and hands and dentures and sit them out, so they are comfortable”. If the relatives visit, s/he apologises to the visitor, and asks them to wait because s/he prefers not to “rush the shower”.

The third aspect of care viewed as important by relatives was ‘staff demonstrating they care about the resident’. I asked the group if “showing you care” was viewed as a priority for nurses, as a conscious choice. This led a participant to comment: “It is a natural thing” and that staff: “Treat them as somebody, a mother, a grandmother”, reflecting: “It will be me, one day”. Another participant discussed that “small things can make a difference” and commented: “As you get older you see it differently, totally different”. A participant linked this to personal values and felt the ageing process changed people’s values and described this as a challenge to the individual nurse “to treat them like you want to be treated”.

This led the group to comment on the philosophy of the organisation that drove nursing practice in end of life care. A participant commented on the care as: “Subtle – we are not a regimented place”, and she also said: “Kindness and care are key priorities for staff, not routines”. The participant felt these were practices supported by management in the facility and viewed as important. S/he described the facility’s approach to attracting and recruiting staff and described those staff, who demonstrated a kind, caring attitude to residents and colleagues, who had a “focus on the care we give residents”, saying the facility needs people
with “a nurse’s heart”, “not just a nurse looking for a job”. S/he said also that management “discourage abruptness with residents”. The organisation’s caring culture was developing and was thought to be reflected in the cohesiveness amongst the staff. A participant explained how these practices translated for her/him in daily work and commented: “I don’t care if a bed is not made, it is important to talk to the resident” and then shared a story of having to “catch” a wandering resident. S/he told the group: “I chased him all the way over to another section in the facility and when I caught up with him, I just gave him a cuddle”.

The caring culture they agreed was apparent in their facility, was then compared with organisations, described by the participants as “those facilities that work from a nit picking” culture”, which they defined as a culture of incident monitoring that “creates dramas” and works from a basis of “intimidation and a fear factor”. These organisations were not viewed as having the resident’s best interests at heart. The group asserted the residents enjoy the staff who work in this facility and felt this reflected their notion that “staff must be doing something right”.

Before the meeting ended Celeste read a poem from a book titled “In time of Grief”, given to her following the loss of a special family member. The poem was authored by Connie Harrison, source unknown and titled:
‘I have seen thee’

In the face of a child,  
In the blossoms on bare branches,  
In the moonlight and the sunset.  
I have seen thee.

I have heard thee.  
In the song of a bird,  
In the laughter of children at play  
In the wind and the rain.  
I have heard thee.

I have felt thee.  
In the touch of a friend  
In the warmth of the sun upon my face.  
In the waters and the gentle breeze.  
I have felt thee.  
I have been with thee.

In joy and sadness  
In the long sleepless night  
I have felt thy love and know that all is well.  
I have been with thee.
I asked the participant why she had chosen to share that poem with the research group. Celeste replied that, for her, the poem spoke of death and grief, in a meaningful manner.

*Journal Entry, 01.03.06*

Good meeting today. I incorporated some of the relatives’ interviews in the group today and asked open-ended questions to have the nurses explain what is important to them about care. I think it went quite well, and I will have to look closely at the minutes again. It is so hard to keep a group on track, on the topic.

*Researcher’s Note, April 2008*

Looking back on this journal entry, this being the eleventh meeting, I think I was becoming tired at facilitating. The action research process made me responsible for facilitating the meetings, keeping the minutes up to date, and managing group issues as they arose. I could have taken a different approach and trialled a ‘rotating chair’ system where everyone takes a turn at keeping the group on task. This may have allowed me some breathing space, but would I have felt any less responsible for the group progress and outcomes?

The final relatives’ interview statements were shared with the group at the twelfth meeting. An important aspect of care relatives had identified in the interviews was for nurses ‘To keep relatives informed’. The group were asked: “Do nurses believe it is important for relatives to be kept informed? A participant commented relatives need to be informed “sometimes” and went on
to say: “Sometimes, not too much”. This led the group to discuss the difficulties nurses face when providing information to relatives. A participant commented that the information can be “taken out of context” and that a “bit of information can be used and treated as misinformation”. Another participant spoke of the challenges nurses face in situations where they are sharing information with relatives and stated: “Pressure is put on us by families to tell them what they want to know”. This pressure caused the nurses to be keenly aware of what they say to relatives. Another participant expressed that s/he felt: “They (relatives) are trying to get us to slip up” and linked this to relatives sometimes trying to: “Make us look incompetent”. The same participant said that relatives know: “We can’t always give information” and that “relatives judged” nurses. A participant stated why s/he hesitated in sharing information with relatives, as: “There is a line you draw regarding how much you tell them, as some take it as gospel”.

Researcher’s Note, May 2008

Looking back on the discussions of this meeting, I can now see I had an opportunity to challenge statements, such as “They (relatives) are trying to get us to slip up” and “they are trying to make us look incompetent”. Statements such as this reveal to me the nurses’ communication with the relatives is less than ideal, and is, in fact, non existent or breaking down. Questioning the nurses’ statements at that time would have assisted the nurses to critically analyse their thoughts on communicating with relatives and explore and identify the fears that make them feel threatened when sharing information with relatives.
I am now aware that a pattern emerged in my reflections, that I was unaware of inappropriate 
statements and that I did not challenge them on the spot. Looking back on my journal I often 
asked myself and my critical friend what to do and why nurses would say such things. I gained 
insight into the language but I kept on being periodically disarmed by the nurses’ language so, 
by the time it had to make an impact we had moved on in the discussion and the window of opportunity in that moment was lost.

Why didn’t the group edit or censor each other? In a sense our collective silence was 
condoning these statements. I now think I was caught off guard, surprised and did not expect 
the statements, and perhaps the group felt the same way, or perhaps we were all on autopilot, 
sharing the details, but not deepening our reflections to uncover truths and meanings of the 
details. The participants were unedited in their discussions and I was most likely the only one 
in the group who did attempt to address the statements. This is interesting in that in the 
group there were senior staff and they did not confront the nurses or check their own 
statements.

If we had challenged as a group we could have separated the statement from the person who 
stated it and deconstruct it to what was said, challenge the thinking behind the statement and 
possibly eradicate the tendency to for example, blame the relative.

Participants’ opinions linked closely into the focus for the end of life care research, because 
how nurses speak about their work, and create cultures within aged care settings can have a 
bearing on end of life care. Communication was identified as a theme in the action plan by 
these nurses and these examples of communication breaking down provided insight that many 
in the group felt communication around end of life care was problematic. Challenging taken-
for-granted assumptions and being conscious to stay alert and notice the details of conversations is obviously a skill that is developed over time and then role modeled as a learnt behaviour that nurses should accept responsibility for. There are no easy answers but a lot to be gained by exposing unexamined practices and patterns of communication through reflective practice, particularly in end of life care.

I asked the group: “Whose responsibility is it to inform the relatives, of resident care issues, condition changes, and so on? This prompted a participant (AIN) to say: “I will always pass the buck”. The group discussed the hierarchy of nursing, and the relative prestige that is attached to the various grades of nurses. The group felt it is appropriate for less senior nurses to refer residents and relatives to a RN to answer questions about a resident’s care, but acknowledged that sometimes the RNs do not know the resident as well as, for example, an EN who is responsible to care for low care residents. A participant commented that in “the early years of nursing everything was passed onto the RN”, because “this was how you were trained”. A recently graduated nurse felt this approach is “still taught today”.

The group discussed what they described as “covering your back” and felt that sometimes it is more appropriate to refer relatives and residents to the doctor. The potential for litigation was discussed and providing incorrect information was of concern. A participant stated that nurses can be “out on a limb, by yourself, with a lack of support”. If nurses were unsure of the correct information, they preferred to not pass it on, but relatives had an “expectation” that the nurse will follow up on requests for information. Participants linked information sharing to relatives “trusting the staff” to have answers for their
questions. The group discussed how new residents’ relatives asked for more information than long term residents’ families. A participant stated that providing information to relatives is part of the process of “continuity of care” and that it results in a “nice, restful place”.

The issues with which relatives were not pleased were then raised. I asked the group: “Why would relatives feel they were not being communicated with by health professionals?” and “Why does it depend on which RN is on duty, for issues to be clarified for a relative”? This led the group to discuss the accessibility of staff, with a participant stating: “Assistants in Nursing (AINs) are more accessible” to residents and relatives. This participant stated s/he thought that RNs were not as available, because: “RNs are always busy with two floors to attend to”. This prompted a RN in the group to discuss AINs sharing information with the RN on duty, saying: “It is invaluable when an AIN shares information, even a perception, as I (RN) tuck it away and process it. I may not divulge information to a relative straight away, (pause) sometimes people may think I am reticent, but that is because I am thinking about the information.”

Researcher’s Note, May 2008

This meeting was a breakthrough, with nurses in the group talking to one another openly about their roles. The AIN and the RN spoke honestly about their perceptions of the accessibility of staff for relatives and the extent to which information is shared and acted on. At this stage of the research, bonds of trust had been formed with each other, and power differences had been acknowledged and negotiated sufficiently to allow open discussion and expression of feelings regarding their roles of individuals and within the team. Rather than
being a source of “power over” and silencing, the mixed levels of nurses represented in the group had actually provided an opportunity for the participants to share their thoughts and feelings from their various perspectives. This added depth to the conversations, and as the group adhered to the group rules of respecting each other and allowing uninterrupted time for each speaker, junior staff had an opportunity to speak and be heard by senior staff. I could see that the research process works and that I could trust it to eventually meet the research aim to improve end of life care for residents dying from non malignant causes. I could also see that the ways nurses work together in end of life care contributes to the quality of care residents receive and relatives witness in that facility.

In continuing the group discussion on staff working together, ENs working in low care areas were described as the “go betweens” for residents and senior staff. A participant stated the EN and “the regular, consistent staff, rostered in the low care area”, assisted staff and residents to know each other. This was viewed as beneficial and important by the group, as they thought these staff “get to know these residents well” and they were “able to influence end of life decisions”. Continuity of staff and residents in the low care and high care areas were then compared by the group. When referring to getting to know the residents, a participant stated: “In high care we are behind”. High care residents were thought to be “always new”, and as new RNs are employed to work in high care areas and each has a different approach to care. The group agreed the staff are less consistent or familiar to the residents in high care and a participant stated: “The residents can’t keep up with the staff”, in the sense that they do not get to know them well. This led the group to discuss the differences between RNs and how some RNs “use their authority”. A participant stated: “Some RNs think they know better, so you just don’t bother” and said further: “What they say
goes”. This participant admitted that s/he could not understand why some RNs behaved in certain ways, commenting that s/he has seen some RNs “run around like they’ve had their heads cut off”.

Researcher’s Note, May 2008

The discussion at this point informed me of the expectations nurses had of each other. The frank observations shared by this participant went unchallenged at the time by the group or the RN in the group, yet as a RN myself I imagined that those RNs to whom the participant referred, were most likely trying to meet the expectations of both residents and staff. “Running around like they’ve had their heads cut off” sounds very harsh to me, but it was the participant’s perception, and needed to be heard in the group. Taking the statement on face value, it made me wonder: If the new RN was not coping with day to day care in an unfamiliar environment, how much harder would it be to deliver optimal end of life care in an unfamiliar, unsupportive environment?

As an acute care clinician myself I value team members being supportive of each other, sharing the load in the name of delivering safe, effective patient care. I have learnt over the life of this project that unsupportive statements made in the group must be challenged. My personal value system tells me that nurses, at times, need their unsupportive behaviours identified and confronted in the interests of better patient care. I need to think about techniques we can all use, as co-researchers, to draw attention to these statements when they are made, while at the same time supporting the participant to examine the potential effects of these statements on patient care.
A participant described residents’ symptoms as potentially becoming a “huge crisis of conflict”. S/he spoke of a resident with renal failure, who had severe skin itch and how the itch caused problems for all involved. S/he said: “The doctor was unsure, the RN felt it was a renal itch, another RN treated it as scabies, and another RN believed frequent showering would provide relief”. The participant then discussed how RNs may use their initiative and try various methods to relieve symptoms, but felt that “honest documentation of treatments” did not always occur.

Issues with which relatives were pleased were shared with the group. These included going over and above what might be expected, mutual respect, respect for intellect, moving on issues straight away, and courtesy. A relative’s statement was shared with the group. The relative said during the interview: “One assertive person can make a difference with their philosophy”. I asked the group: “Do you, as a nurse, identify with mutual respect, courtesy, and being assertive?” A participant described assertion as “observation; action comes after”. Another participant offered: “People know if you are being assertive” and “Respect and courtesy are part of the assertive behaviour”. Assertive behaviour by nurses was thought to “give relatives a secure feeling”. Assertion was linked to professionalism, and a participant described assertive people as being able to “take charge” and have “clear boundaries”.

Assertive behaviour was also thought to have the potential to “cause waves”, but a participant felt that usually the nurse had “the resident’s best interests at heart”. Assertive behaviour was also linked to power, when a participant stated: “Power is a risky thing” and s/he quoted the psychologist Adler, who said: “The basis of our will is to have power over others”. Another participant added that
some nurses have not “learnt their way to master their power” and they may view themselves as being leaders, when they are acting as “bulldozers”.

Researcher’s Note, May 2008

The relative, who raised the issue of nurses demonstrating assertion, spoke of nurses not waiting for a doctor’s approval, but acting in the best interests of the resident, and this differed from the nurses viewing assertion in the context of leadership and power. To what extent does assertion play in delivering safe end of life care? When does nurses’ assertiveness play a part in delivering safe end of life care? Do nurses use assertion in the hope of providing a resident with optimal end of life care, and if they do, how does that influence their communication with the team or the family?

The project continues to reveal to me the many layers of complexities in delivering end of life care in this residential aged care facility. The nurses should consider fine tuning their assertive behaviours and to be reflective every day, to maximise the likelihood of giving optimal end of life care. Staying alert to practice by sharing reflections and viewing end of life care practices each time they occur through critique of communications, pondering why something is being performed this way or that, asking is there a better way may permeate practice and demonstrate to other nurses that maintaining the status quo is not always in the best interest of the resident.

The group discussed workplace changes and how staff now work as proactive people, describing themselves as “agents of change”. They described the working environment as constantly “evolving” and explained that their
organisation’s philosophy was to always be “implementing improvements in people’s lives”. The group discussed how staff are encouraged to always be thinking: “How can I do it better?”, to be “constantly learning”, and they described the philosophy as the organisation “moving forward”. The group agreed this proactive process required staff to be “constantly adapting to changes”.

At the close of the meeting a participant spoke of the difficulty s/he faced following the death of a resident and how this became such a problem for her/him at the time that s/he was considering leaving aged care work. S/he spoke of the emotional upheaval of the experience and how s/he had continued working, but felt the memory of the resident’s death made her/his working life so difficult at times, that s/he had to drag her/himself out of bed, just to go to work. The participant spoke of sharing the story informally with another staff member and felt comforted to know other nurses had felt the same.

The reflective practice guide was again shown to the participant and we discussed the value of exploring the details of the situation in more depth through reflective journaling. The remaining members of the group discussed the importance of addressing death and finding some closure, to ensure nurses develop “longevity” in the profession, as the participant would most likely have to deal with similar death circumstances in the future.

Copies of the practice stories in a table format were distributed to the group for theme identification and discussion the following week (Appendix I).
Journal Entry, 08.03.06

Another good meeting - it was held in a lounge room in the low care area. This area was better for privacy and the staff were less on edge, as though they were missing being at their work areas, however, some still wandered away at times, to attend to other things. I noticed especially when a doctor arrived that the RN almost jumped out of her seat to help him. I could not help but think about how RNs have been conditioned to jump to attention when a doctor arrives in the unit.

Three participants came today. I wanted to catch up with a participant regarding that practice story s/he handed me in a letter format. I had collated a number of questions for him/her to use to explore the story more. Celeste told me the participant was known not to handle anything out of the ordinary, especially unwell residents.

Researcher’s Note, May 2008

The practice story in the nurse’s letter was a detailed account of a resident suffering from chronic airways limitation (CAL). The story outlined a comprehensive medical history and medication list. The nurse’s primary concern was the anxiety the resident experienced regarding her debilitated state and the level of emotional support necessary from staff, family, palliative care team and doctor. I asked the nurse to express how s/he felt about the resident’s health problems as I suggested that the practice story read as an expression of the nurse’s anxiety and need for support in delivering the care for this resident. I also asked the nurse about the constraints in the workplace that prevented her/him from giving the care s/he would ideally have chosen for this resident.
My hope had been that the nurse would share her/his thoughts with the group on her/his return. Unfortunately, that was the last time the nurse attended the group. It left me wondering why s/he went to the effort to deliver an end of life practice story in this written format, and then not return to discuss the issues in greater depth. Ethically, s/he has the right to leave the group at any time, without coercion, and I will honour that, but it is frustrating for me, to finally get a written reflection from a participant and not be able to follow through on helping the person to make sense of it.

The group is definitely more relaxed, or maybe I am just used to the group and I’m starting to feel more confident. I did not realise that this type of research took so much effort and was so difficult to do well, and I have this feeling I just want the action research and reflection project to hurry up, and yet I know the most important part is just about to start.

At the end of the meeting, when all but two participants and I had left, a participant started to talk about how a resident’s death had really upset her/him and how s/he had thought of leaving work and s/he was crying at home, not wanting to go to work. I really felt for her/him and wanted to be the rescuer – the disaffected nurse, who keeps a straight, professional face, and yet inside completely understands the impact work can have on one’s personal life and how difficult life can be when caring for the dying. I was relieved Celeste was there as a back up, because I really felt a bit out of my depth, due to her/his openness about the issue. We discussed guided reflection and I gave her/him the reflection to unpack and make sense of the issue. I also reminded the participant that I was always available to help if necessary, and that counselling was available, at no cost to her/himself, if that was required. I really hope s/he
uses the reflective guide. I feel like I keep offering the reflective guide, but I feel it’s a bit like: “You can take a horse to water, but you cannot make it drink”.

Celeste asked for a grief debriefing structure, and I think we have a theme for action emerging!!! I am starting to see the research process unfolding, so that it achieves an action plan for changing end of life care practices.

Researcher’s Note, April 2008

Looking back now at that meeting, I remember feeling overwhelmed by the enormity of the task at hand. The importance of the research topic was making me feel especially responsible and then more so, when the nurse revealed such anguish regarding her/his experience of grief and loss at the facility. I realised how valuable the research group’s contribution to nursing practice would be from conducting this research and I could see the research process working. I knew then, as I know now, that I did not have all the answers for her/him, but I did have a wealth of experience to share and could assist to empower her/him to reflect and explore her/his thoughts on end of life care.

In summary, in this section I described Phase Three: Learning from the relatives. I described how I integrated the relatives’ interview statements into the nurses’ meetings, for the purpose of discussion and exploration of those end of life care issues of importance to these relatives. The challenges of facilitating the group meetings were explored in detail in my personal journal reflections.
Phase Four: Identifying Thematic Concerns

Phase Four was from meetings 13 to 15 inclusive. In meeting 13, I handed out the Practice Story Themes Table (Appendix I), on which the practice stories had been copied from our meetings. The group went through each story to identify the practice issues. When the group discussed each practice story, memories resurfaced of how each participant experienced the situation at that time.

During this meeting a participant suggested that debriefing would provide an opportunity to “off load” and felt that, within an environment of trust and respect, staff would “hear you” and “not miss what you are saying”. We discussed who should attend debriefing sessions and a participant suggested that attendees should include those staff involved when a resident dies, that is, the “close people”.

As enthusiasm for debriefing sessions increased, a participant suggested the death of a resident and the issues surrounding the end of life care could be
“acted out”, using a case scenario approach. We decided that each participant in the group would act a part in the story. The group agreed that would be a good method of representing some of the stories shared in the research and it would assist other staff to “see themselves” in the stories. The group agreed each member would be allocated a task, to contribute to the success of the case scenario. Celeste agreed to write the script and I agreed to write the questions that would be discussed with the audience after the presentation. Agnus had previous experience organising costumes and agreed to attend to wardrobe, Eileen agreed to organise props and Keith took responsibility for the music.

Other issues that arose during the reading and analysis of the practice stories included staff regretting their actions at the time, and they also commented that sometimes there is no chance for staff to say goodbye to a dying resident. We discussed various death and dying training programs to prepare staff for death. The group said these had previously not been useful for them. The group agreed it is best to “learn on the job” and that training “does not prepare you for death”. A participant identified a number of issues of importance in care for the dying, including touch, talking to the dying resident, and giving the resident “permission to go”. A participant spoke of “hating to think of anybody dying alone”. When asked how s/he knew these things, s/he replied that experience had developed these skills. Another participant spoke of the importance of recognising the signs of dying and shared a story of a resident being reviewed by a respiratory specialist, who spoke with her/him following the patient assessment saying: “I think your resident is dying” and that his problem was “not his lungs”.
Participants also discussed difficulties they had in speaking to a resident about death, but agreed on admission that death is discussed more with the relatives, due to the necessary pre-emptive paperwork. Participants viewed death as an important issue, when attempting to incorporate a holistic approach to care.

Journal Entry, 22.03.06

We are at the stage of identifying a thematic concern. The participation of the group in identifying themes and merging them into an issue has been limited. I think I left the group behind at first, in grasping the concept of analysing practice stories to identify themes, then issues. Participants looked quite vague initially, but eventually the discussions started to refocus and we were on our way.

Celeste is such an articulate, interesting person. I am going to speak to my critical friend tomorrow to discuss the possibility of interviewing Celeste on the issue of teams, as Celeste has definitely developed strong leadership on the role and importance of teams. Somehow though, it just seems a bit weird to me, a bit of a brainwashing technique of some sort. Is Celeste using the group for her own agenda? I don't know. How can we really know another person’s agenda anyway!

I am feeling like more is being achieved, but sometimes as the group disbands, staff disclose statements and comments that I so wished they had shared during the meeting. After meeting comments can speak volumes, like additional thoughts, or summarising ideas.
Today, I was somewhat disturbed when Celeste asked me to stand behind her when we went into Agnus’s (EN) office at the end of the meeting. I did not know what was going to happen, and then Celeste put on a formal stance and voice and “eyeballed” Agnus, who looked like she was going to cry, when Celeste asked her for her story/drawing, whatever, for the research group. I was absolutely astounded, but in my shock I tried to add humour and encouraged Agnus, by telling her how much value her stories add to the group. What was Celeste thinking? Why didn’t I ask Celeste why she wanted me to stand behind her? Was it force in numbers: RN + RN? And why stand behind her? This project is not about confrontation and coercion. Participation is voluntary, not forced. Why can’t I learn to expect the unexpected? I really hope we haven’t lost Agnus over this. I feel like I’m back to square one in figuring out Celeste, especially after all my reiteration in meetings about the nature of action research and reflection, and what it hopes to achieve through collaboration in a trusting group environment.

Researcher’s Note, April 2008

Hindsight is a great thing, and my conversations with my critical friend assisted me to identify Celeste as a challenging person, who provided me with an opportunity to develop my skills of assertion. I questioned why some nurses treat other nurses so disrespectfully, as Celeste did to Agnus that day, and why I did not address the behaviour when it was occurring. I can now see I was involved in a power relation, where Celeste was demonstrating to me her superiority and power over Agnus. Celeste was also taking advantage of me, making me an unwilling witness to the superiority display. When I analyse this situation according to the determinants of the situation, I can identify cultural and historical constraints Celeste was
demonstrating, related to the symbols and rituals that separate nurses and the ways in which practices over time play a part in nurses’ interpersonal communication (Taylor, 2006).

While I did not condone Celeste’s behaviour to the E.N, I was nevertheless a silent participant in the interaction; therefore, I attempted to defuse the situation and my own astonishment with humour. Times have changed, but the historical conditioning I have experienced in nursing still causes me to allow such situations to continue, without addressing the person who is using their superiority in such a cruel way. I felt silenced and powerless in the situation, because the oppressive culture and history of nursing also constrained me. It was easier to make light of the situation and less confronting for me, as the stakes were high.

I reflect now on the ambiguity of the situation for me - I could not lose Celeste, as a senior nurse, and key organiser from the group, but Agnus was also important - she was in need of support in that situation and she was also a valuable group member. Fortunately, Agnus continued in the group right to the end.

I never spoke to Agnus about the situation with Celeste. In hindsight, I should have respected my values for open, honest communication. I should have asserted myself the minute I sensed things were not right in Agnus’s office space. It is so very difficult for me to be assertive, every time it is required, especially when situations occur unexpectedly and catch me completely off guard. I know now I should do further work on my assertion skills and apply my values to maintain my self respect and to be a role model to others, so that confrontation does not always have to end ugly.
In meeting 14, the group reviewed a condensed version of the practice stories, themes identified in the previous meeting (Appendix I). The issues that emerged from the group analysis of the story Table included:

**Debriefing Issues**

- Effect of a resident’s death on nurses
- The need for reflective practice
- Strategies for longevity in the nursing profession

**Medication Issues**

- Medication administration
- Pain medication knowledge
- Pain assessment
- Role of palliative care
- Access to palliative care

**Issues with Doctors**

- Doctors’ prescribing habits
- Medical review of residents

**Team Issues**

- Conformity
- Speaking out
- Being heard/Assertion
- Whose opinion is valued?
- Power/Authority
- Self blame
Sticking together

**Communication Issues**
Sharing information
Supporting relatives
Speaking about dying
Connecting with families/relatives
Role delineation/clarification
Nurses’ extended roles
Nurses’ roles after death
Admitting you don’t know

**Staffing Issues**
Continuity of care
Responsibility
Consistency of staff
Staffing ratios
Bullying behaviour

**Education Issues**
Training for death
Fear of litigation
Initiation processes
Peer pressure
The old and new brigade
**Documentation Issues**
Changes in a resident’s condition
Documenting pain assessment and problems with pain medications
Impact of skill mix impact on quality of documentation
Documenting effects of treatments on symptoms

**Organisational Issues**
Organisational culture
Recruitment processes

**Residents’ Issues**
Knowing what people want in death
Disclosure by dying patients
Personal beliefs of death
Stages of grief
Acceptance of death

**Other Issues**
The need for understanding
Perfectionism
Giving of oneself/caring
Clinical judgments

At this point, the group agreed they would work as a whole group, so they required a thematic concern that was sufficiently generic to their practice, so that they could see improvements in that particular area. After much discussion, the group decided the area most common to them all, with the best chance of
creating practice improvement, was the thematic concern of debriefing. According to Taylor (2006, p. 182), the action plan that addresses a thematic concern needs to be flexible enough to manage unexpected obstacles, acknowledges local constraints for example, limited funds, challenges participants to extend themselves and “empowers them to act more effectively in the situation” and uses a collegial, collaborative, exploratory group framework to develop the plan.

Given these criteria, it was agreed that debriefing would be suitable and valuable for the group to explore. We decided that we would plan an introductory session to debriefing, which we would present as a case scenario to other staff in the facility. We then discussed when a session would be held and how to present a case scenario.

I told the group that more than one issue could be addressed and I asked participants if there were any other thematic concerns, for which we should generate an action plan. The issues of pain medication knowledge, pain assessment, and medication administration were identified. The group indicated medication administration was generally handled well within the facility, but they agreed that the medication chart can be problematic, if a medical officer is reluctant to update the chart three monthly. A participant spoke of some doctors faxing through electronic versions and staff just having to “live with it”.

The group spoke of the benefits to the organisation of a six monthly visit by a private pharmacist, who reviewed drug combinations and was thought to be a great resource for sharing medication knowledge. Participants commented that the pharmacist could suggest medication options with doctors and noted some
doctors were willing to work with the pharmacist and some were not. Medication audits were used in the facility and the information was sent to Head Office.

I spoke of a project in which I was involved, that provided nurses with Personal Digital Assistant (PDA) technology. I explained to the group that a PDA is used as an electronic source of medication information, for example, the MIMS can be downloaded into the PDA. The benefits of having access to a PDA are that drug information and drug combinations can be determined without having to leave the resident’s bedside, which reduces medication incidents and assists in improving nurses’ drug knowledge. It was agreed I would investigate this option further and discuss it with the group the following week.

In meeting 15, the group shared their reflections on dying and death, in preparation for the next phase of the project. For example, Agnus produced a drawing that represented her impression of end of life care (See Figure 5.3). Agnus discussed aspects of the drawing, including the central theme, which was a broken heart. Agnus told the group this represented “how people feel” and told the group the heart was her own. Agnus also described death as a “gut wrenching feeling”. Agnus compared people who had not experienced personal or work related deaths with people who had, and she stated that people, who have not experienced death: “Never, never understand the feeling”. Agnus felt training is not of benefit when residents are dying and that people, such as other nurses or family, can be “so scared”. Agnus described her role as needing to “draw them in”. Agnus said the dying resident: “Needs us more than ever at this time”. In the drawing, surrounding the broken heart, were various words on lines that pierced the centre of the heart. Agnus told the group the word “greed”
was to depict that death can bring out greed in people. ‘Flight’ represented how the person, nurse or families want to “run and fast”. Agnus also spoke of someone needing to be an anchor and related this to a personal loss, when the support of her daughter had been her anchor.

Agnus spoke of attending funerals and how this made feelings of loss reoccur, but she reflected that her personal loss had helped her to understand how others may be feeling. Agnus stated the broken heart in the drawing “can be repaired” and that “time repairs”. Agnus concluded that people “learn from experiences”, and that when “one door closes and another opens”.
Looking back at Agnus’s representation and views of end of life care, it prompts me to ask: What happened to Agnus each time a resident died? Does her heart break each time? What then are the cumulative effects of unresolved grief and loss for Agnus, or other nurses, who take residents dying personally and do not, or cannot, address the grief? Why did she use the word, greed, when depicting end of life care? Did that come from watching families of dying residents? Agnus believes because she has experienced loss she can understand the
experience and feelings of loss for others. How important is having lived an experience, to the way we give care?

Another participant produced a framed drawing of her/his representation of end of life care and discussed with the group that the drawing represented the experience of death and dying for her/him (See Figure 5.4). S/he described the figure in the drawing as an alien, crouched down in the dark, but commented there was some light filtering into the picture. S/he described the alien as a nurse having “distortion”, represented by several elbows distorted out of place. S/he described the concept of distortion depicted by the elbows meant “they don’t fit anywhere”. The naked alien figure in the drawing was crouching down in a “cringing” fetal position. S/he described this position as representing how the nurse can: “Go into your own space”, but withdrawing does not “make issues go away”. The nakedness represented how “everything is ripped away”. The participant described how the “heart is ripped out and stomped on”. I asked why one arm of the alien is over the top of its head. S/he said this represented the alien “shielding” itself. S/he commented: “No one else feels the same way after being involved in the death process” and that people can feel “alienated”, describing this as being “a bit out in the dark” at both home and work. S/he spoke of attempting to discuss her/his feelings at home with her/his partner, but felt, as Angus had commented, that: “Unless you go through it, you don’t understand it”. S/he had discussed his feelings previously by chance with a colleague at work and felt this to be a turning point for her/him in understanding s/he was not alone in these feelings of loss and how some deaths: “Hit you hard”.

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I commented the drawings by the group members had similarities, in that each had represented the effect of end of life care and death on them as an individual, or a representation of them as a primary figure in each drawing such as the surfer, the alien. This prompted the participant sharing the alien drawing to comment, that for her/him, flight represents anger and over time when anger dissipates a nurse needs to decide what to do. S/he said flight and anger were not useful strategies and not the answers, when a person has commitments, such as a marriage. This prompted participants to comment that it is best not to leave work until a problem is resolved and that the nurse may want to push the problem back down, but that it is important to obtain help. S/he replied that fortunately s/he had received very helpful advice from a nurse who s/he felt was strong, adaptable and who had a lot of life experiences.
The participant explained this picture had been created shortly before the research project commenced in the facility and it had recently been framed. The participant told me it was framed, because of the quality of the work and as a reminder s/he had moved forward since drawing the picture. I wonder how one conversation with a senior nurse could resolve these disturbing images? Why were the words alien and alienated used by the participant? Was s/he feeling separate and different from the other nurses?

When the discussions on the drawings drew to a close, the group members were deep in thought, following the heartfelt comments made by each participant
when describing their drawings. I recall feeling that each participant had been affected deeply by giving end of life care and they had many memories of residents, who had died.

As we were finishing the meeting, we spoke generally about other aspects affecting end of life care. It was at this point I raised the issue of the facility’s espoused ‘caring team philosophy’, noting that themes of teams and communication had emerged frequently in previous meetings. The group confirmed teams and communication as complex issues, but they agreed that if the desire is to continually improve on these aspects of care, end of life care improvements could occur. I asked the group to state individually to what extent they felt a ‘caring team’ approach was actually happening in their workplace. Answers varied, for example, a participant felt 98% of the time a caring team approach was evident in the facility, but felt this was dependent on who was on the team, and that some team members were “spanners in the works”, because they were “troublesome” and sought acknowledgement. It was agreed that aiming for 100% participation in a caring team would not be unachievable, due to “too many personalities” and staff needing to “learn to compromise”.

The group agreed it would be important for their action plan for a debriefing session, to highlight and demonstrate the difficulties staff could face in providing care to a dying resident when a team is not functional. The difficulties they identified included constant staffing changes, low staffing levels, splitting a team for two nurses to work together when a resident’s care needs were high, and teams not working well in busy times. When attending to a dying resident, some
participants focused on the dying resident and did not attend to other residents, while others left the dying resident’s care to later.

A solution discussed to improve team work was the use of “walkie talkies”, allowing nurses to “track down another nurse” for two person tasks, such as using lifting equipment. Participants also discussed use of the staff assist buzzer, but felt it was not part of the culture in the facility to access other staff using that system. Participants then discussed the importance of new staff to the facility receiving orientation to the team approach to care, as this was important to maintain. A solution offered by participants was for staff to be rotated fortnightly, so that all staff had an opportunity to know all the residents’ care needs.

At the end of the meeting a decision was made to change the debriefing session name to Grief Discussion Group, as debriefing session was thought to be negative and clinical.

Researcher’s Note, May 2008

Looking back on the participants’ decision to change the session name from debrief to grief discussion group, may have been influenced by two documents I had shared with the group. One of the documents was the ‘Managing Loss and Grief in the Aged Care Industry’ (2000), a document published by WorkCover NSW. The purpose of the WorkCover document is to “assist managers and other workers in the aged-care industry to better understand the process of work-related grief and how it can best be managed”. The second document I shared provided a structure for critical incident stress debriefing (See CD 1).
They decided “debriefing session” is negative and clinical. “Grief Discussion Group” does sound more participatory.

In this section I described Phase Four: Identifying thematic concern. I described how practice stories were summarised and the group analysed the stories to allow themes to be explored and meanings to be examined. During this phase the thematic concern that was most common to all staff, and with the best chance of creating practice improvement was chosen for action and to see if some of the other issues such as working as a team could be also addressed along the way.
Phase Five: Action Plan Creation and Implementation

Phase Five commenced with meeting 16 and was completed by meeting 18. In Phase Four the group identified the thematic concern of the need for staff debriefing following a resident’s death and Celeste had offered to write a draft dialogue of a role play to be presented to the facility’s staff. At the sixteenth meeting, participants began to create the action plan by focusing on Celeste’s dialogue for the Grief Discussion Group session, planned for May 2006. The session was to be titled ‘Dying Well in Living Care’. Celeste spoke of wanting facility staff in the audience to be able to identify issues in the dialogue of the role play as themes that had emerged from the group’s practice stories.

The dialogue included demonstrations of a mixture of negative and positive nurse behaviours, such as demonstrating efficiency, but not being focused on the resident, striving for perfection, focusing on tasks, being supportive, connecting with relatives, inhibiting communication by judging, being abrupt and tactless, being directive, the use of power and authority over others, conformity,
admitting you don’t know, sharing information, bullying, nurses’ emotions including self doubt, anxiety, ownership of emotions, courage to speak and assertion.

Dialogical issues in the role play in relation to dying residents included being in denial about dying and death, looking for comfort, missing home, and being unable to express their inner needs. Team issues included in the dialogue included not being cohesive, medical review of residents, not valuing all the team member’s opinions, and communication issues within the team. Relatives’ issues within the role play included missing their family member, being frightened, speaking about death and dying, misunderstandings, and feeling helpless.

Researcher’s Note, May 2008

Looking back on Celeste’s eagerness to take on the challenge of writing the dialogue for the role play, I can now see that to express these complex and contradictory emotions and behaviours was a huge commitment for Celeste. For me, this project has involved so much reflection on how I relate to, and make sense of Celeste. So much of my journal is filled with understanding her role in the research group and dealing with all the unexpected challenges she has put my way! Celeste has been so eager to be part of the group and to make it all happen – sometimes eager in ways that have been confronting for me. Now Celeste has addressed such a huge task of drafting the role play dialogue when she had spoken previously of her increased workloads. What motivated her, I wonder? Was it her personal experiences of loss? Maybe it related to her Christian zeal. Was it her witnessing staff behaviours around end of life care? Maybe the participants’ stories, shared so openly and honestly in
the group, moved her to act. I guess it doesn’t really matter all that much. I have learned a lot about facilitation, we have all moved on to this point of being ready to create an action plan, and Celeste has been an important part in the process. It seems to me that working with these participants and planning incremental changes to practice has been a key to engaging the group and influencing their involvement in planning for practice change.

The group discussed various aspects of the Grief Discussion Group dialogue, including how the session would end. The decision was made that the ending would involve the removal of the resident from the facility, by funeral directors coming to collect the body. Participants spoke of this process as being difficult at times for staff to witness. One participant spoke of a previous facility where s/he had worked many years previously and recalled how a resident’s body was dragged along the floor in a bag to the funeral director’s vehicle. The participant discussed the impact on the staff and the shock and horror of witnessing the event. The participant reflected on how badly staff had felt who had cared for that resident, but nobody stopped the action, or objected to the funeral director’s undignified treatment of the resident’s body.

Researcher’s Note, May 2008

The discussion of a resident being dragged along the floor was very disturbing and the submissive behaviour of the nurse and other staff who witnessed this event, was equally disturbing to me. Why would nurses not object to this inhumane display? Even though it was many years ago, why would nurses at that time not challenge such disrespect to the resident? Haven’t nurses historically viewed their role as patient advocate before and after death? These questions bring me back to the issue of assertion – of how we might know something is
wrong, but we can't find the voice to speak up at the time. Sometimes the most dreadful things can “paralyse” us, and all our good intentions to communicate quickly and appropriately, “for the good of the patient” go out the window.

This issue led participants to discuss the quick turn over of residents, following a death in the facility. Participants acknowledged aged care facilities are businesses, but felt a quick turnover of resident’s “when a bed becomes available”, implied disrespect to the deceased resident. Participants felt it would be useful to include this aspect of death in the grief discussion group, by having the resident “die” in the scenario, be removed, and then have a new resident suddenly appear, ready to occupy the room. The group spoke of using an opposite personality type for the new resident, to highlight the difficulty for staff in moving on, in having to deal with the grief and loss and adjust quickly to the change in residents.

Participants expressed looking forward to, and being interested in, comments from staff who watched the planned role play and the issues that would be raised on the day. Celeste spoke of the possibility of future inservice training being linked to issues raised by that group.

Researcher’s Note, April 2006

I told my critical friend, that the project now feels to me, like it has a ‘life of its own’, in that it feels it is autonomous – running itself - and I think that has come about because participants are empowered, with being able to express their issues within the group. I also think there is a
desire for development of their reflective practice ideas in the workplace. How great it is, to be a catalyst for change through facilitating this action research and reflection project!

At the seventeenth meeting, following the reading of the previous week’s minutes and the issues of how residents’ bodies are managed following death, a participant spoke of her/his feelings of wrapping up deceased residents. S/he said s/he understood why wrapping deceased residents is necessary, but felt the practice disrespects the deceased, stating: “I think they (the residents) should be transported out in a glorious fashion”, not wrapped up and hidden in a sheet.

Participants then spoke of how defining ageing can cause people to miss the point about how interesting a resident and their life can be. Participants discussed how, in the high care areas, nursing staff are less likely to “find out what they (residents) were like, who they were, or what they experienced in their lives”. Participants felt high care aged care nurses often see a “fading, demanding person”, when in fact, these people have contributed to society and are often “so much more than what we see in the final years of life”. The nurses spoke of using time to chat with residents when they were waiting at appointments for tests and how during this time the nurse is able to gain new insights into the resident’s life. The group discussed how they “often don’t know a resident’s age” and how you can be “hard pushed to give a resident an age”. This prompted another participant to state there is value in all ages, whether in the “60s, 70s or 80s”.

We planned for the Grief Discussion Group session with new roles allocated for staff in the facility, for example, one would play a resident’s offspring and
another nurse at the facility would play the role of a nurse role in the session. The group agreed that, at the beginning of the role play, it was important for the staff in the audience to be asked to think about the issues with which they identify, as those issues would be discussed at the end of the training session. A participant suggested that an effective strategy to assist staff to identify end of life care issues would be to highlight each role individually.

Journal Entry, 03.05.06

I spoke with my critical friend about the group videotaping the role play, to be held at the end of the month. She said that was a great idea as it would be a permanent record on which to reflect further, and as a source for auditing the project’s processes.

At the eighteenth meeting, the research group had a practice run of the ‘Grief Discussion Group’ session. We also discussed an action plan for the second thematic concern we had identified previously, of the need to improve medication knowledge. I reiterated the use of the Personal Digital Assistant (PDA) and gave an overview of information to Celeste, to discuss further with the Director of Nursing. Celeste felt the PDA would be adopted at the facility.

The following week, the ‘Grief Discussion Group’ session was presented in Facility One, coinciding with a regular staff training day. The session was held in the main hall of the facility, which was a large room used for training purposes, residents’ activity days and the weekly sing-a-longs. The audience included all staff in the facility, including RNs, ENs, AINs, cleaning and maintenance staff. The Director of Nursing agreed to videotape the role play and
the group discussion time. The role play participants arranged a number of props, including a bed, a telephone, oxygen bottle, and walking stick. Following the role play I was introduced and I led a discussion around the issues the role play raised (Facility One: Role play not attached for confidentiality reasons).

Journal Entry, 31.05.06

I attended Facility One for the grief discussion group role play session today. I felt a bit sick in the stomach, not knowing how things would go. I really felt this was important today, as though all that work in the lead up to the event hung in the balance. The staff were very accepting of the session, contributed greatly by joining in the discussions openly, and raising excellent points. The Director of Nursing, of all people, caught the whole thing on videotape – what a gift!

I made a point of watching the faces of the nurses, who viewed the role play, to see if I could get a feel for how the discussion time at the end would go. The audience laughed, gave directions to the ‘actors’, had shocked looks on their faces, when the nurse spoke bluntly with the resident, thought the RN slamming the phone down after speaking with the doctor was hilarious, and the reference to 50 different charts really cracked them up.

Agnus was missing for the performance today. I was sorry she wasn’t there, but Celeste told me it was unfortunately due to a family issue. I hope we haven’t “stirred the pot too much” in Agnus’s life with the project. Once you become reflective, there’s no going back to being totally unreflective. Nurses’ lives sit within a fine balance of how the job affects us and how we live with the job at home with our families.
Today, I had a sense these aged care nurses had so many stories that could be told and yet they are rarely invited or heard. Caring, respect and a belief they could make the last days of life dignified for people, shone through in the discussion time. I saw this was so, especially when they all shook their heads and agreed the resident in the role play was having a hard time adjusting to this new environment and that she most likely had left her ‘comfy chair’ at home.

In the discussion it became apparent that the role play audience believed it is a family’s responsibility to explain to a resident what is happening when the decision is made to admit them to an aged care facility. It’s odd isn’t it, because the relatives I spoke with in interview conversations, would like the doctors to do this task. We all like to sanitise things. I guess. By sanitise, I mean clean up the ‘dirty work’ of breaking the news to a loved one, that you can’t or won’t be able to care for them in their ageing years. Yet, I suppose caring in our society is often thought to be someone else’s responsibility. I wonder why that is.

A really key point made by the role play audience group was that when staff share information with relatives it must be the same message from all staff – nurses, doctors, etc.

When asked how they would have supported the son or daughter in the role play, the audience discussed how the family often get neglected and that the support is most intense in the pre dying stage, then ‘bang’, suddenly it is all over, and they are out the door. The nurses were saying: “We have our job to do”. Others stated that if the relatives “seek support, they get it”.

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The discussion between the audience and role players led to how quickly the bed is filled after a resident dies - the staff acknowledged that facilities are run as a business, as a company, but there was a sense of regret that there is a lack of understanding that “this was a resident’s home, where they stayed a long time.” This led to a long discussion on when to pack up a resident’s belongings after death and where to store them and who should do this. I had a sense this discussion was critical, as it seemed a bit of a stand off between staff and the Director of Nursing. The Director of Nursing was firm and stated the facts that the next day after a death, the bed must be filled. Yet somehow, there I had sense there was no real closure for relatives or staff. If the relative can’t get to the facility the day of the death - bad luck. No chance to say no good byes, no closure.

The action research and reflection group agreed to have a final meeting the following week, even though I will be back for the rest of the project. I feel a sense of closure with what we experienced as a group and I am so glad the group members are expressing to me that the process was a success, both personally and professionally for them. The debriefing sessions will continue, without a doubt, because it was a valuable session for all.

Researcher’s Note, April 2008

I recall feeling at this time some degree of sadness that the project was coming to a finale. I had formed relationships with these nurses and real inroads were being made into their end of life care practices. The group had progressed to reaching out to others in the facility, to share their new found insights, and put them into practice. I very much felt part of this process and felt extremely proud of the group.
My confidence in my ability to facilitate an action research and reflection group had grown by this stage, but I was about to face another challenge, and that was the facilitation of a really large group at the presentation. I honestly felt sick about that whole next level of facilitation. I really did not want to stand up in front of a large group and lead the discussion. It seems I am always putting myself out there, but do not always feel comfortable being out there. I am a relatively shy person and I was worried I would stumble at the crucial discussion part of the session. I now realise that it wasn’t all on my shoulders - for the discussion section to fail, the whole session had to fail. We were a group and the group rallied and the facility wanted this session to work. I redirected questions when necessary and the group were there to support me, just as I was there to support them. It was a successfully managed action plan, to increase staff sensitivity to issues in debriefing nurses, who care for residents dying in their aged care facility from non malignant causes.
In the final phase of critical reflection on action, in meeting 19, the group reformed to discuss the Grief Discussion Group session. I commenced the meeting by asking participants a series of questions related to the session. The first question was: “Do you think that the plan of using a debrief session achieved its goal?” One participant stated immediately: “I think it did”. Other participants felt the role play approach “lightened people up” and helped the audience to “open up”. A participant commented s/he felt videotaping the session was distracting. Celeste suggested that, in future, the introduction of the play needed to be clearer, by stating who the players were and by giving an explanation of the characters.

A participant noticed how some staff in the audience spoke more than others. All participants commented how well a particular person spoke during the post role play discussions and how her contributions and points were excellent. I asked the group what role this person had in the organisation and was told she was part of the cleaning staff. The group discussed how she had said that even
though she mops the floor, she still cares for the residents. This led a participant to comment: “You can rely on the person who mops the floors” and that some residents “relate to the cleaner more than many staff.”

During this discussion this person was cleaning in the wing of the building where the group meeting was being held. When she passed the door, the group invited her to participate in the meeting. She agreed and discussed enjoying the grief discussion group, recalling some of her comments related to a couple she had spoken with, before one partner had died. She described the couple as not being “a loving couple”, but she recalled saying to the partner: “You are running out of time here, you may not have the opportunity tomorrow to say what you need to say” (to his dying partner). Other participants agreed with the cleaner, that the dying resident’s partner had “not been able to express himself” and was “out of touch with his emotions”, so her facilitation was important.

The second question I asked the group was: “What came out of the discussion that you didn’t expect?” This question caused a participant to comment that s/he was surprised when one of the RN during the discussion session said: “It must only be the RN, who informs the family” of imminent death. A participant in the group reminded the co-researchers of the importance that sometimes, but not all the time, only the RN should inform the family that a resident is dying, and the RN in the presentation discussion group was procedurally correct. The participant linked who can tell the family of a resident’s imminent death to the importance of the quality of the information being shared with relatives and stated that nurses “need to be careful what they say”. A participant stated that Assistants in Nursing (AINs) are often closer to the family and that it depends on whether the AIN is responsible enough to speak appropriately. Celeste
reminded the group of a previously discussed practice story, where inexperienced night staff had spoken with a resident regarding the dangers of morphine and that this situation had created a “fracture” in the care of the dying person and between staff. Celeste described this situation as having “undermined the care” of the resident. Even so, the opposite opinion was voiced by another participant that aged care workers cannot be that “inflexible”, demonstrating that the issue of giving information to relatives was not resolved within the research group.

The cleaner, who had been invited into the meeting, felt she was looking for techniques to be able to cope after a resident’s death. This was related to how she had felt about the “quick turnover” of residents in the rooms, following the death of a resident. She explained it was important to “get your feelings out at the time” and that debriefing shortly after the death would be useful. She asked the group: “What is the correct thing to say?” relating this to when someone next asks her when a person will die. This led the participant to discuss feeling sad for a resident’s partner, who she described as having “never opened up”. The participant recalled the relative wanted to know when his partner would die. She avoided a direct answer, when said she told him to “hold her hand and tell her now” how he felt. She said she had spoken with others, who said: “You just can’t say (a person will die) in the next 24 hours”.

I asked the group: “Do you think the key issues were identified in the role play presentation, such as those relating to the care team, communication, relatives, staff, and residents’ needs?” The group discussed how the issue of residents’ belongings had been raised on the day, due to a recent incident in the facility of a deceased resident’s room being packed up quite soon after their death. This led
a participant to comment there were “inconsistencies” in the management of the issue and s/he said the “goal posts get moved on some issues”. One participant recalled s/he knew the deceased resident’s family and that they had told her/him how important the resident’s belongings were to them, and had commented on the “haphazard way the belongings had been packed”. The group agreed that the packing up of the resident’s belongings is a part of grieving. Participants spoke of ideally, a “day’s grace” between death and the next admission being reasonable, but commented on the quick turnover of residents as “out at 10am; new at 2pm”.

Another participant commented it is important that there is no name placed on the resident’s door until the resident is settled into the room, as previously, family members had been packing up a deceased resident’s belongings when the next resident’s name had already been placed on the door. The group also discussed talking about death processes as “tricky”, when a resident is being admitted, such as funeral arrangements and preferences for packing up belongings following death. The participants felt a time frame for how long the room would be left following a resident’s death would be useful to discuss with relatives, and it should be made very clear to the family that rapid turnovers are commonplace.

The final question I posed to the group was: “What do you think the constraints will be in the future role play sessions, to achieve successful debriefing outcomes?” A participant commented the debriefing session will develop a “life of its own”. Another participant commented: “We are pioneering new ground here no other organisation is trying this (use of role play) and we have found it highly beneficial”.

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We discussed the constraints management staff face, and a participant commented: “Management is prepared to listen to what people say and they see it as a benefit to staff emotionally and practically”. Participants felt future sessions would “bring people closer together as a team” and “speed up the processes for resolution of debriefing issues”.

Future session times were suggested, with one participant stating the session should be part of the lunch break on the training day, and that the atmosphere should be relaxed with staff eating and drinking, and attendance being optional. Other suggestions included holding a training day that focused on team building. A participant also felt staff should be encouraged to attend the religious memorial service. The use of case conferences was highlighted with a participant commenting, that: “They should happen more”.

Meeting 19 was the group’s final meeting, following the series of questions, we discussed plans for the writing of the thesis and future publications. We farewelled each other and the group presented me with flowers and a card.

Journal Entry, 07.06.06

I held the group meeting to critically review the action plan we implemented during last week’s presentation of the Grief Discussion Group session. I had a sense the research group appreciated the group debrief session and the opportunity to share with other staff in the facility all their work they have been doing in this research. When I spoke with my critical friend, she reminded me of the appreciation the staff would have felt for me as a facilitator of
the project and of the debriefing session. I told her they gave me flowers and a really nice card. It felt like all the effort I had experienced previously was suddenly quite effortless.

My critical friend also spoke of how action research values nurses as clinicians and co-researchers. I spoke with her about how the research process is an opportunity to formalise the link with the hospital and aged care facility and that this could result in regular liaison, such as attending monthly meetings as an ongoing link in care of dying patients. She suggested I talk to the nurses and Director of Nursing about how constant evaluation of nursing care becomes a component of end of life care, by keeping care of the dying at the forefront of the nurses’ discussions.

**Ongoing Research Processes**

After the action research and reflection cycles were completed in the form of regular research group meetings, as arranged, a second Grief Discussion Group session was held in Facility One, to coincide with the regular monthly staff training day. This time the session was held in a lounge area near the residents’ dining area of the facility. It was a large room, but had an intimate feel, more so than the training hall we used for the first role play.

The audience were different from the first session’s audience and included mainly RNs, ENs, and AINs. The Chaplain of the facility attended and Celeste arranged to have a person present with experience in videotaping. The role play participants again arranged a number of props including a bed, a telephone, oxygen bottle, newspaper, coffee cup, wheelchair and walking stick. The same
dialogue was used and following the role play, I was introduced and led a discussion around the issues the role play raised.

Journal Entry 21.06.06

I was informed that the videotape from the first training day turned out to be a poor recording. Apparently, the Director of Nursing was waving the camera around a lot and I remember a disturbance when the battery was changed. Anyway, the facility had their second training day today and I attended. In some ways, it was better than the first, as it was held in a lounge room, which meant the audience was closer to the action; bed, phone call, undertaker, and so on.

The ‘actors’ were well rehearsed and introduced themselves first, which set the tone for the audience to understand the role play. Except for the residents’ dogs having a playful fight in the middle of quite a dramatic scene, all went well. Even the facility clergyman attended and gave his nod of approval. Celeste had arranged a more professional approach to the videotaping, so that was great – fingers crossed. The audience participated and raised a variety of issues, of which communication was at the forefront. I felt this group wanted answers on how to do things “the right way”. Oh, if only it was that easy. But, as usual, our little team rallied and openly discussed things that had worked in their practice and all left satisfied, wanting future sessions and ready for lunch.
Journal Entry, 27.06.06

I worked with the video person today, to finalise the video. I will lose my contact temporarily with the facility (5 weeks - Celeste’s annual leave), but I have been redirected to Shirley, who will assist me to introduce the Personal Digital Assistant. Fingers crossed.

Journal Entry, 16.07.06

I have been trying to sort out the Personal Digital Assistant for the facility. I think I am right now that MIMS is downloaded, with only drug calculations and palliative information to go. This is more difficult than I realised and it hasn’t even been introduced yet.

Two of the themes identified in the fourteenth research group meeting, related to medication administration and pain medication knowledge. Following approval of the PDA proposal by the Director of Nursing, a training session was organised by Celeste. The session was held in a training room of the facility. Five Registered Nurses and two Assistants in Nursing attended and I explained one of the change actions from the research identified by participants had been to improve access to end of life medication knowledge.

In the training session, I demonstrated how to use a PDA and how to locate medication information contained in the PDA. Each participant practised the steps of using the PDA and locating the medication information. A print out instruction sheet was provided to each participant that detailed how to use and care for the PDA (CD 1). Participants completed a pre use PDA staff survey and were told a post use survey would also be given at a later date (CD 1).
Attendees agreed to store the PDA in the medication room. A laminated sheet was placed with the PDA, to remind the nurses to charge the battery when the device was not in use. A book to assist in tracking the location of the PDA was also located with the device.

Journal Entry, 29.08.06

Where have I been? Busy, busy, busy. Anyway, I am back, that is the main point. It took some divine intervention, though Celeste returned and contacted me to ask about the Personal Digital Assistant. Fortunately, I had organised the MIMS and palliative care information, so I was able to introduce the device, which I did for those RNs working on the day. It was really well received and my preparation of a book to record the whereabouts of the device and the instruction sheet really helped. I will now hold my breath and wait and see. I left my contact details and plan to return in 6 weeks to survey the staff. I am a little apprehensive that it will be more work, through more requests for additional information, but I will attempt to face that, if and when the time comes. Anyway, Facility Two is just around the corner – oh dear!

Journal Entry, 26.10.07

I went back to Facility One, to find a lot has changed. I was told by the secretary that Celeste had left the facility. I was told by the Director of Nursing to contact her replacement. She was a very rushed, pleasant RN I had met at other meetings we had held at the facility during the project. She seemed to be caring for residents and running an education/project role, and I am unsure if non-clinical time was allocated to this work. I asked
her if there had been any further work on end of life discussions or role plays. She told me, despite there being a number of deaths, that there were no further end of life sessions held.

The RN told me the Personal Digital Assistant was not functioning correctly, because the MIMS Alert kept bringing up the word ‘Alcohol’ as a potential combination. When I checked, the MIMS in the PDA was not operational, as the licence had expired. I took the PDA to register it again and recharge it. The RN took some staff surveys to identify how staff felt about the Personal Digital Assistant.

I returned to Facility One again to return the PDA and collect the staff surveys (CD 1).

Journal Entry, November 2007

I caught up with Facility One and returned a now functioning Personal Digital Assistant, and collected staff surveys. I was disappointed with the limited use of the device. I had a lovely morning tea with the new self identified educator/change agent. I promised to send her the local hospital’s end of life care pathway. We discussed the project I conducted and I told her I was willing to go over the actions with her or return to run a group debrief session. I wonder if we will reconnect in future.

Researcher’s Note, April 2008
Looking back on these journal entries, my return to Facility One taught me a number of things. Firstly, the actions the nurses identified as important and useful, that would assist them to work towards improvements in end of life care, were implemented. However, the sustainability of those actions would only be possible if key staff continued to champion them to others. Unfortunately, each time key staff leave or move into other positions, the improvements stop or move on with those nurses. Improvements can easily be forgotten or not valued by a facility in which they are created.

As an experienced nurse, during my career, I fear nurses continually “reinvent the wheel” and create never-ending circles of new practice ideas. The challenge lies in the sustainability of those new, improved practices. I discussed the issue of sustainability with my critical friend and we agreed it was through the loss of the original members of this group, that there was a loss of sustainability of the project. The tendency toward a casualisation of the workforce, staff moving on, and organisations not valuing staffing continuity increases the risk of the loss of corporate memories and of changed practices being lost. I reassure myself that those nurses who participated in the project now have the skills to use reflective processes in their practice, and may choose to implement the action plan strategies, such as running grief discussion sessions and/or using PDAs in their new workplaces to enhance medication knowledge.

Summary

This chapter provided a synopsis of the main aspects of each meeting taken directly from the Minutes of the meetings, which were verified weekly by participants. This chapter described the six main phases of the research in
Facility One: 1) foundation building, 2) reflection on practice stories, 3) learning from the relatives 4) identifying thematic concerns, 5) action plan creation and implementation, and 6) critical reflection on action outcomes.

During Phases One to Three inclusive, the research group built a foundation of trust and confidentiality within the group, on which to base the collaborative action research and reflection processes. Using their insights from reflection on their own practice stories and from key statements made by relatives, the research group identified thematic concerns about end of life care of residents dying from non malignant causes in the facility.

The primary thematic concern identified by participants for improving end of life care for dying residents was developing opportunities for staff debriefing. The action plan was to collaborate in organising a role play for facility staff, to address the complex issues experienced in the delivery of end of life care. Participants scripted, performed, videotaped and adapted an end of life scenario involving a non-malignant disease into a role play, for a facility training DVD. The role play was performed for facility staff on two separate occasions and incorporated into regular staff training days.

The role play provided a trigger to encourage facility staff to openly discuss numerous end of life care practice issues, such as discussing death and providing support to families, contacting the doctor and obtaining medication prescriptions in a timely fashion, nurses’ communication with each other, nurses’ extended roles in end of life care, nurses working as a team, and the effects on staff of a quick turn over in bed occupancy following a resident’s death. The role play also allowed the group to share suggestions on how issues could be addressed within
the facility, such as knowing what to say to the dying resident and their family, communicating information to the doctor, prioritising care and allowing the family time to remove the deceased resident’s belongings as highlighted by relatives in shared interview transcripts.

Following the role play, the research group critically analysed the action plan, by discussing staff responses to the Grief Discussions Groups. The positive responses related to staff having an opportunity to communicate with each other and openly discuss end of life care concerns. Further, the session provided staff with a forum to suggest various ways the facility could change those practices that do not assist in delivering optimal end of life care, such as not working as a team, and also to identify and value those things that do assist in delivering optimal end of life care, such as communicating well, working as a team and supporting each other in the team.

Interest in continuing the Grief Discussion Group was lost when those research participants, who developed the training DVD, left the facility for employment elsewhere. Loss of knowledge is a challenge aged care facilities face, when trained staff leave and the memory of research projects, such as this one, leaves with them. Even so, those participants in the research group, who gained experience in examining their practice through this action research and reflection project, now have the knowledge and skills to be more reflective in their nursing practice in any facility in which they work, and they are equipped with some strategies to improve end of life nursing care practices in their future workplaces.
CHAPTER SIX: ACTION RESEARCH AND REFLECTION IN FACILITY TWO

This chapter describes the action research and reflection process in Facility Two, which was intent on exploring ways in which aged care nurses could examine end of life care practices for residents dying from non-malignant causes and implement their findings into clinical practices, to maximise the likelihood of a good death. The key processes were undertaken of reflecting, collectively planning, assessing, observing and implementing change with further reflection. Relatives’ expectations in the care of the dying were also used to inform and explore the relationships between the research group and relatives of the dying resident, for the purpose of creating a greater understanding of the issues.

As I explained in Chapter Four, I contacted the Acting Facility Director of Nursing and extended an invitation for staff working in the 64 bed aged care centre, referred to in this project as Facility Two, to participate in the action research and reflection project. The facility was a not-for-profit community owned company, run by a Board of Directors consisting of unpaid, voluntary members of the community. The services provided by the facility catered for both high and low care residents’ needs and included 12 high care rooms, plus one high care respite room. The facility also provided 49 low care rooms, plus two low care respite rooms.

This chapter provides a condensed overview of the progression and outcomes of the research group’s meetings. Due to the length of the action research cycle and
the collaborative, participatory nature of the research process, detailed session plans and minutes are included in the Appendices of the thesis. The research period of 17 weeks occurred in six main phases: 1) Foundation building, 2) Reflection on practice stories, 3) Learning from the relatives, 4) Identifying thematic concerns, 5) Action plan creation and implementation and 6) Critical reflection on action. The key research activities within the six phases are described in Chapter Five.
Phase One: Foundation Building

The foundation building phase was inclusive of the introductory meeting and the first group meeting. I facilitated the introductory meeting at the facility in the staff tutorial room. I reiterated the project proposal, using a PowerPoint presentation. This session provided prospective participants with some insight into the research problem, aim and objectives of the research, a brief overview of the action research process, expectations of each participant’s involvement and my contribution as the researcher. A discussion followed regarding the current needs of the facility, after which the Director of Nursing requested that staff be given some time to discuss their participation in the project and to decide on a meeting date, without my presence. One week later, I was contacted by the Director of Nursing to organise the first group meeting date.

Seven females and I attended the first group meeting. The meeting was held in the staff tutorial room at the agreed time of mid afternoon. The nurses who attended were a Registered Nurse (RN), who was also a senior staff member and Deputy Director of Nursing, a first year graduate RN awaiting university results,
who was employed as an Assistant in Nursing (AIN), an Endorsed Enrolled Nurse (EEN), who was working as an AIN, three Assistants in Nursing (AINs) and the facility’s female laundry worker.

I provided a brief overview of the major points of the project, with an emphasis on the definition of non-malignant disease and the need for research into improving end of life care in aged care settings. Relatives’ recruitment to the project was discussed and relatives’ participant information sheets were provided to the Director of Nursing for distribution. I distributed participant information sheets, consent and demographic forms to the group (Appendix A).

I outlined the steps for ensuring the group worked well, which included the importance of participants respecting the stories shared at the meetings, allowing the person telling the story, time to speak and avoiding discussion of the stories outside of the meeting. The purposes of sharing these steps were to facilitate discussion on the importance of group dynamics and confidentiality, so that participants felt safe in sharing their stories and in building mutual trust between themselves.

Following the group rules, I provided an overview of the first reflective writing task and asked participants to reflect on their own personal, social and historical context and how that had influenced the values of who they were now and how that impacted on them in their workplace. Participants were asked to think of a time in their childhood when they had a good sense of who they were. The group members answered the questions by writing on the sheet provided (Appendix C).
Initially, the group was quiet, but very friendly and enthusiastic to get on with the task at hand. Participants gradually commenced sharing memories of their childhood and events that changed their childhood, such as the loss of a parent and parents remarrying, and the rules of living they had learnt from important people, places and events in their life. Rules they identified included the importance of politeness, manners, respect for older people, education, respect for others and especially for ‘yourself’, and appreciating what you have. A participant, Liz, said she particularly identified discipline as being an important rule for her, but did not elaborate further.

Connections of childhood memories and life rules were then made to adult work life as a nurse. This prompted a participant, Jackie, to describe herself as “always being sick” and she spoke of a link between sicknesses as a child and her eventual career as a nurse, who provided care to the sick.

The participants discussed some of the important people in their life during their professional education. For example, Reece recalled a patient, who was a man in his forties, dying at a facility where she was completing a student placement during her nursing training. She recalled him being worried about his two daughters and she described how the impact of witnessing his dying had not left her memory. A participant who had experienced a recent personal loss became upset during the telling of Reece’s story and left the room (See Journal Entry 13.02.07). The participant returned to the group after a time and before the session concluded was offered support.

I asked the group: “Why did you want to work in aged care?” The laundry worker, Marie, spoke of coming to live in the town and how she had “tried every
place in town” to find work, including the aged care facility. She felt her persistence over a four year period to gain employment eventually paid off, as she enjoyed her work and felt part of the facility ever since.

Reece recalled her trigger for working in aged care occurred when she was 19 years of age and training to be a nanny. A requirement of the nanny training course had been for trainees to experience an aged care placement. Reece described herself as “trembling” and being “scared shitless” at the prospect of attending an aged care facility. A woman described by Reece as a “matron” took her “under her wing during the placement”. Rather than sending Reece to perform the daily personal care work, Reece was taken to the facility’s activities room. She told the group, that four hours later, on leaving the facility, she knew that aged care was where she wanted to work. Reece told the group she still has “goosebumps” when recalling the experience.

Georgia, who had previously left the room, rejoined the group and spoke of hearing “horror stories” of aged care and being “put off” by them. We checked that she felt up to continuing the discussions and gave her our support by acknowledging that it can be difficult sharing life stories. It was important that participants felt supported within the group and I reminded them that participation was voluntary. As many of us in the group had many years experience in nursing, we felt confident the group had the ability to support Georgia, however, the option of free professional counselling was also offered at the end of the meeting.

Jackie told the group that aged care had been a convenient employment option for her, as she was a single parent when she commenced working in aged care.
The facility in which she was employed allowed her to take her baby to work. Jackie described aged care as “being foreign” to her, as she had a critical care nursing background. The group recalled other nurses working in aged care, who had a critical or emergency care background, and they discussed how aged care was not an attractive part of the nursing profession and that it was plagued by negative stereotypes. Jackie spoke of the nurses’ own registration board not supporting aged care nursing, but did not expand on this point. I realised it was not always necessary or appropriate to immediately follow up on broad, opinion based participant’s statements, however, these types of comments were addressed later.

Another participant described her entry into aged care nursing as being “by accident”. She told the group at the time she “could do with the money” and a friend had encouraged her as the facility needed nurses.

When we discussed the influences on their work, Reece said she felt her own children had a great influence on how she worked and related how this increased her compassion and tolerance of residents in her care. Angelina recalled her mother being “a big influence” on how she worked. She recalled her mother preserving food and being a great organiser and felt that this taught her the skills of being able to “work in a team” and to “get on with the other person”, as preserving food required a great deal of coordination and cooperation.

The meeting ended and participants agreed that since Christmas was imminent, the group would reconvene in the New Year. It was agreed that I would contact the Director of Nursing to organise a suitable next meeting time.
The group were really quiet at first, ‘really quiet’ and then slowly, slowly, as the official paperwork got out of the way and we commenced the first reflective task on childhood memories and profiling of the ‘nurse’, the group started to loosen up and talk freely. It was great. Then out of the blue, Georgia started to cry. I was surprised, as the topic was quite light, or | thought it was at that time. The topic may have been light for me, but others in the group may have been at a different stage in their understanding of events or life in a general sense, and as it turned out, Georgia said it was the memories of the loss of her parents that triggered her emotional response to the story.

The participants were all great, very supportive. Georgia recovered quickly and returned to the group, tissues in hand. At the end of the session, Georgia and I had a chat, but | was still not clear what was happening for her, as what she was saying about her coming to terms with the memory of the loss of her parents did not match her body language; hand wringing and nervousness. I offered the opportunity to receive professional counselling, which she declined, then she left the room returning soon after and she asked for the counsellor’s contact details, which I provided.

The group session finished right to time and participants asked for the planning for the next meeting. I gave them a ‘homework’ reflection sheet. Let’s see if they engage! I feel a little anxious about engagement, as my experiences in Facility One have taught me to keep my expectations realistic and wait to see how participants transform their reflections into actions over time.
This section described the foundation building phase of the research where details of the project were clarified, and research formalities, such as consent form signing and participant information sheet distribution were accomplished. In this phase, group processes were agreed upon, to ensure the group worked well. Participants’ demographic details were outlined and responses to the first reflective task detailed. My personal reflective journal accounts highlighted some of the personal and professional challenges I faced in conducting the research.
Phase Two: Reflection on Practice Stories

The second phase, reflecting on practice stories, lasted from meetings two to five inclusive. A key aspect of this component of the research process was to encourage participants to use reflective methods to explore their clinical practice stories and issues, in relation to caring for older people, who were dying from a non malignant disease. In this phase, reflective questions were essential to make sense of the practice stories, because systematic questioning creates a flow of “seamless connections between the reflective processes” (Taylor, 2006, p.71).

Three of the original group and two new members were welcomed to the second meeting held in the New Year. Following the paperwork formalities that included distributing the participant information and demographic sheets, consent forms, and reflective writing task for those staff who had not attended the first meeting, I provided a reminder on where the group had left off at the meeting held prior to Christmas, by reading the meeting minutes. The rules for the group were discussed, including allowing each person time to tell their story, listening to what each other had to say, maintaining confidentiality and the use
of pseudonyms to de-identify participants. Participants were also informed of their right to request adjustments to the meeting minutes if necessary.

Participants who had attended the previous meeting told me they had not had an opportunity to reflect on practice stories during the Christmas break using the Practice Reflection Guide, therefore, the group agreed to share their stories impromptu. I distributed a copy of the Practice Reflection Guide (Appendix D) and briefly refreshed participants’ memories regarding how to build a picture of a practice story in their minds.

This prompted Georgia to recall an end of life care event where things did not go well. Georgia recalled it was not so much the resident, but the relative, who contributed to her remembering this end of life event in a negative way. Georgia spoke of the difficulties in meeting a relative’s needs during the end of life care for the woman’s aged mother. The mother and daughter had lived together prior to admission into the facility. Georgia told the group: “No matter how hard you tried” the care provided to the resident was “never good enough”, for the daughter.

Sharing of this story prompted others in the group to remember the resident and her daughter, as the death in the facility had been quite recent. Jackie said the relative had been “such a hard woman” and said: “She spoke in a demeaning way to staff”. The participants spoke of all the extra time that had been given to placate the daughter. This prompted Jackie to ask other participants if they had seen the resident’s death notice in the paper. The group said they were surprised that the daughter had thanked the staff publicly for her mother’s care, even though the daughter’s behaviour was “always difficult” and “demanding”.

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Georgia said the daughter’s demanding behaviour increased in the last 48 hours before the resident’s death. Georgia felt that spiritually and therapeutically, everything was being attended to for the resident, but that the daughter was still not happy and that there was “always something to deal with from day one”. Georgia told the group: “All staff copped it, even the gardener”.

Participants spoke of the resident being more settled when the daughter was not present, which prompted Britney to ask: “Was it the guilt factor”? Georgia said the situation had made her feel “frustrated” at the time, telling the group that when the “daughter arrived, mum got agitated”. Georgia demonstrated to the group how staff would try to position pillows for the resident, saying: “You would have the pillow here and there”, adding “she looked uncomfortable, terrible”. Participants discussed how the pain management had not been handled well and that the resident was having “all different concoctions”. Jackie, a RN in the group, said: “We can only do what we can do, with what we have” and told the group the resident was having enough medication to “kill an elephant”, but that the daughter wanted “mum to be zonked out”. The group reflected if pain management had been better, they “could have made her (the resident) more comfortable”.

I asked if there had been communication between the daughter and senior facility staff. Jackie said the Director of Nursing had meetings with the daughter, but it was thought that there was limited contact between the doctor and the daughter.
Georgia recalled spending time with the daughter, saying: “I would sit with the daughter for an hour and that was still not enough”. She described the mother’s death, as “a relief”.

Jackie recalled in the final hours of the resident’s life “dreading” the daughter coming to the facility, but said that she had contacted the daughter to tell her of her mother’s imminent death. Jackie spoke of preparing the resident for the daughter’s arrival, saying she checked that “mum was clean”, and the “room was clean”. When the daughter arrived, she “got active” and “packed up Mum’s things”. At this point in the discussion, Marie told the group that when she saw the daughter following the resident’s death, she said: “I’m sorry”, and the daughter said: “That’s very kind of you”.

Researcher’s Note, May 2008

Looking back at the story told by the nurses and their focus on the daughter, rather than the issue of the resident’s pain management, makes me question: Why? Why did the nurses remember their issues with the daughter more than the requirement to ensure adequate pain relief? Were the nurses deflecting their lack of control over the resident’s pain and their inability to obtain further management of the pain onto the daughter’s issues, which were in some way controllable? It makes me wonder why nurses would behave this way. How might they work differently, to prevent this from happening again? Did the nurses not recognise the daughter’s anguish at seeing her mother dying? They didn’t speak of it, if they did. They were so ready to label the daughter’s behaviour as demanding and difficult, and it seems to me that they did not seem to see that she was trying to deal with her mother’s impending death.
Jackie shared an incident that had occurred that day in the facility, when a resident had died. A staff member had said to her: “It was that injection you gave him”, referring to the earlier administration of midazolam. Jackie told the staff member: “He’s at peace” and told the group about the difficulties nurses face when having to use when needed or p.r.n. medication orders, as opposed to standing palliative care orders. This statement prompted participants to speak of the fear some nurses have when administering medications in end of life care, stating: “I don’t want to give the last dose”. One of the participants said to Jackie: “It’s good when you’re around”, referring to how she ensures dying residents receive adequate pain relief.

The conversation changed to superstitions around death, with Britney saying: “Some of the cleaning staff blame the rooms” and that some rooms “had mockers”. Jackie and Paris spoke of having to change a room into a respite care room for a period of time, following a run of resident deaths in the room. Paris recalled two instances where the condition of low care residents had suddenly deteriorated and they were transferred to a particular room and consequently died in the same room. Paris told the group that other low care residents, who had visited their sick friends, eventually realised that both had died in the same room. The other low care residents had told Paris that they did not want to be moved into that room. The conversations ended on superstitions around death, when Britney recalled cleaning staff linking a “soaking bucket” to a series of resident’s deaths. Britney explained the same bucket had been in rooms of residents who had died. Britney told the group the cleaners “got rid of the bucket”, to “break the cycle”.

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The issue of doctors’ prescribing practices and RNs administering end of life pain medications were then discussed, with a participant saying: “Some doctors are reluctant to give anything”. Another participant stated that certain RNs will tell carers, who report a resident’s pain, that the resident “doesn’t need the drug”. This prompted Jackie to add that these nurses who withhold pain relief often did not keep pain charts, even though they were available in the facility.

The group discussed the process of how a RN received information about a resident being in pain. Participants said the RN relies on carers or other staff, for example, cleaners or activities staff, or other nursing staff, to tell her a resident is in pain. In some instances, staff went directly to the RN. The ‘Chinese whisper’ process was thought to be due to the RN rarely delivering the resident’s personal care and in some instances not seeing the resident on her shift. Georgia told the group that some RNs interpret pain as a behavioural issue, stating: “They will blame the behaviour”. When I asked for clarification, Jackie used the example of a resident with dementia and the pain causing the resident to “act out”, rather than complain of pain, and how this can be misinterpreted as a behavioural issue by nurses, who lack an understanding of how pain can be expressed in dementia. Jackie felt misinterpreting pain was not due to a lack of available education and said: “The facility even tried paying staff to attend sessions” and went on to say: “They (RNs) won’t come”.

Journal Entry, 21.01.08

Surprise, surprise! No one had used the reflective practice guide – am I sounding a little repetitious and jaded on this issue? Anyway, we made the best of the time and they were a
really nice group, who shared so openly, even though sometimes I cringed at the ethical ramifications and the legal nature of the issues. For example, the statement, “It was that injection you gave her” referring to midazolam being administered – and an hour later, the resident died. The ethical issues raised within the group provided opportunities for the nurses to discuss the challenges in delivering end of life care and the complexities of pain relieving medications.

Researcher’s Note, May 2008

Looking back on my concerns with the discussions being contentious and open to misinterpretation tells me, just like the nurses in the group, I too have reservations around medication delivery at the end of life being litigious. I am aware of being concerned about expressing some of the issues around end of life care, just in case they are taken out of context or misinterpreted, by people who may not understand.

Throughout this research I have been very aware, at all times, of the researcher / counselor roles I have developed. My awareness of this dual role has helped me to use my reflective discussions with my critical friend whenever potential ethical issues arose. This process has allowed me to challenge assumptions and explore reasons as to how end of life care practices expose nurses to a higher level critical thinking.

Politics influence health care today as much as ever, and political constraints as interpersonal power plays, can be exposed by speaking out and highlighting injustices, to allow nurses’ stories to influence decision makers. This is a strange example of politics, I sense, because it seems it may be linked to the constraint of needing to be silent – of not really “saying it as it
is”. I imagine that anyone who has experienced the responsibility attached to delivering adequate end of life care appreciates the complexity health care workers face in determining the precise and measured adequacy of dosing, to relieve pain and suffering. I even feel challenged writing about it in my journal, and reflecting on it as a co-researcher, worried that my comments will be misinterpreted. What makes me feel nervous about documenting comments, such as “...the last dose given”? Why do I cringe when nurses tell it like it is? What are the real issues behind adequate pain relief at the end of life? I sense I am getting close to the nub of it all, but it is still eluding me. How much pain medication is enough for a dying person, and how much is too much? If a dying resident seems to die quicker, but relieved of pain and distress, after the administration of an analgesic, is that reasonable, in the sense of “just and fair”? Maybe some things aren’t spoken about honestly, for fear they will be misunderstood, yet they are the issues at the very heart of the problem!

Managing residents’ pain in end of life care featured again in the third meeting. Eight nurses attended the meeting, including myself. Following the reading of the minutes, I read out some of the rules for living participants had identified in the first meeting, when they undertook the First Reflective Writing Task. The rules for living identified by participants as important to them were: never argue; never judge; don’t get angry; stand up for yourself and respect yourself. I asked participants to reflect on these statements in light of the previous week’s minutes and answer the following question: “Why do people act the way they do in difficult clinical situations?”

The question prompted Britney, the cleaner, to discuss an instance when a resident was in pain and she had heard “moaning coming from the resident’s room”. Britney told the group she remembered thinking: “I should say
something”. Some participants in the group added that they felt the resident’s medications may have been delayed. Britney told the group: “You know when someone is in pain” and that she asked herself: “Why don’t they give something”?

The group agreed there could be problems behind that particular incident, in addition to the medication being late. Georgia outlined what she would do in those situations, saying as the carer: “You approach the RN”, telling her or him that “the pain is constant, or more than it should be”. Georgia went on to say the carer can “suggest a pain chart”, or ask the RN: “What is the resident on now?”, meaning the current prescribed pain medications. Georgia explained that as the carer “that’s all (she) can do”, stating: “I have made the first step”. Georgia felt that in this way, she contributed to “making a change for that resident”. The group agreed it was a process of one person “passes it on to the next level”, the next level often being the RN. One participant stated: “We can keep harping”. Jackie reminded the group that the staff can speak to the Director of Nursing, or the in charge RN, if they are concerned. Lindsay suggested “documenting and re-documenting” the issue, as a method of alerting other staff to a resident’s pain.

I asked the group: “What are the things in the workplace that influence the way you act in what you perceive as good and bad clinical situations?” I reminded participants of some of the values they had previously identified, including the importance of teamwork, the value of education, ensuring residents are comfortable and taking time to talk to residents. Workloads were identified by Jackie as an important aspect that influenced the way staff act in “good and bad” clinical situations. She went on to tell the group: “You can come to work with a list of things to do”, but she recalled being advised to “never plan anything”,

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especially when relieving the Director of Nursing position. Even so, when relieving the Director of Nursing, Jackie spoke of the benefits of being able to “touch base” in being able to “spend time with residents” and of the relief of having “nothing scheduled”.

Participants agreed that staff “learn to chat” as they work with residents. The group spoke of the stigma of “sitting one to one” with a resident. Marie spoke of this practice not being encouraged, saying it was “not allowed from training” and how this training influenced her to feel guilty, is she was not keeping herself busy. The group agreed that guilt can be a factor for staff, in not sitting and talking with residents. Jackie shared a method she used to prevent feeling guilty when giving a resident “one to one” time, when she said: “I’m better off taking the resident for a wheelchair walk” and spending time talking, while appearing to be busy.

Marie recalled a time when a resident invited her to “sit down for a minute”. Marie said she sat in the chair and the resident encouraged her, saying: “Sit for a while”. Marie said she had to tell the resident: “I can’t”, but the resident encouraged her, saying: “Yes, you can”. On rare occasions when nurses were seen sitting amongst a group of residents, a participant said: “It is nice, because they (the residents) love it”.

Georgia commented that the staff culture viewed a nurse doing nothing if she was sitting in a group of residents and agreed with Jackie that staff were reluctant to sit with residents, due to the staff being “task orientated”. Participants spoke of the importance of “time managing workloads” and said they would “never get the work done” if they sat with residents. I asked what
would happen as a consequence. Georgia responded: “You don’t go home”. I asked if the next shift would complete the unfinished work. Jackie said: “We tried passing (work) on”, but “it doesn’t work”. She explained that the staff had attempted managing residents’ care over two days and found some staff performed all the care in one day, or others “leave all the care to the next day”. Managing care over two days had resulted in an unequal distribution of work for staff. This prompted a participant to state that staff can be ‘dedicated”, but some “work for the pay cheque”. The group agreed that, in aged care, workers “can’t stay (employed) unless you enjoy the work”.

The discussions moved to reflecting on a positive outcome in end of life care. Marie recalled a resident’s death where the positive outcome was attributed to the involvement of the palliative care team, which prompted a participant to remind others that the palliative care team have their workload issues to deal with also. Marie recalled that when the palliative care team were involved in a resident’s end of life care the resident “got a few wishes she wanted”, such as a steak for dinner. Marie could not recall end of life care including granting such requests, saying: “It had never been done before like that”.

A general consensus by the group was that, if issues relating to medication orders were sorted, end of life care was “controllable”. Jackie recalled a resident where “everything was in place”, but recalled for “the last 12 hours, she was restless”. The resident was described as “strong”, “she wasn’t going to go”. Jackie remembered wondering: “Why don’t you settle down?” Jackie felt sometimes a “spiritual issue” can affect dying people. When asked to clarify what she meant by this, Jackie said “everything was in place; morphine, midazolam, maxolon, mouth toilets, second hourly pressure area care, attention”.
Jackie said this resident was considered special by staff, saying: “Everyone loved F”, but remembered her being “troubled in the last few hours” before death. The group felt, as carers, they had “no control” of the experience, to help the dying resident settle down. I asked how spiritual needs are met, which prompted Jackie to ask the staff if anyone asked if she wanted a Minister and they had, but she did not want to see one. The group felt that the palliative care team can “make a difference” in those situations, because they know how to manage terminal restlessness.

I asked who is involved in the multidisciplinary (MDT) meetings. Jackie advised it is the doctor, director of nursing, pharmacist, carer, and nursing staff. The meetings were held monthly, but could occur earlier if issues arose, or a new resident was admitted, or if a number of residents were cared for by one doctor and the one doctor’s only patients were addressed. Staff were able to nominate a resident to be on the list for the meeting, but generally the nominations were discussed with the Director of Nursing or the in-charge RN beforehand.

A third positive outcome of end of life care was discussed by Georgia, who described a death as “peaceful” and recalled it was in the same room, ironically, as F. Georgia remembered this as a “good death”, because the granddaughter stayed with the resident, and she added that staff “can’t stay or talk the same as loved ones”. She remembered the death as involving “not a lot of pain”. Jackie remembered the grandson and granddaughter would sit and go through all the family photos. She said: “Staff would hear them laughing”, and saying: “Remember this or that”. Georgia described them as “a lovely family”.

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Another resident was remembered, who had family (a daughter) with her at the end. A participant commented: “J seemed at peace”. The group discussed it being “nice to see someone die with someone who cares beside them” and how important it was “not to die alone”. A participant commented on the importance of having your own relatives present, saying: “To come this far in life”, the “only important thing left is relationships”. Jackie said a resident loses their material possessions, their home, and the only important thing left is their relationships, commenting that there is “nothing at the end of it”, but those relationships. Jackie recalled in a Queensland facility in which she had worked, a system was used where staff were rotated in the shift, so that there was “always someone with them (the dying resident)“.

Close relatives were not viewed as the only people to have present at the dying resident’s bedside. Jackie recalled J’s death, who was a respite care resident and described him as having had a “traumatic, hard life” and his “children being disgruntled”. Jackie remembered this person having “beautiful friends with him, right to the end”. This resident had spoken to Jackie about “issues with family and friends”. Marie expressed the sentiment that “most parents give so much” and being with the parent at the end is the least children can do for their parent.

The meeting time ended with participants being asked to draw where they saw themselves in end of life care at the facility and to bring their drawing to the next meeting.

At the fourth meeting, participants further discussed a resident’s story that had been told the previous week. Participants recalled this dying resident had been difficult to manage, describing her as “spinning upside down at times in the
The accuracy of the recall of the end of life circumstances told by the participant was questioned by the group, therefore, it was decided it would be advisable to rework the story in the minutes when Jackie (the storyteller) returned from leave, so the group had an opportunity to discuss the account further.

Participants discussed a drawing that each had created depicting where they saw themselves in end of life care at the facility. Georgia told the group her drawing depicted the facility being the “last stop” for residents, saying: “There is nowhere after this”. “This is it, the final stage on earth” (Figure 6.1). A sign on the drawing depicted the ‘last stop’. Georgia recounted the Director of Nursing, who was described by Georgia as “spiritual”, having an alternative point of view and she would tell staff that death “is the beginning of the journey”. Stairs on the drawing depicted going “down stairs”. Georgia described this aspect of the drawing as the resident being on a “descending process”, eventually being bedridden and then dying. Georgia depicted herself or other staff, in the middle of the drawing surrounded by batteries. She told the group: “The batteries are necessary to energise me” and that the staff use the batteries to draw on energy, to help “make their (residents) life enjoyable”. Georgia described the batteries representing laughter, family support, learning for herself, comfort, being pain free, and empathy.

In the drawing a resident in his wheelchair was positioned above a dying patient. Georgia said this was “B”, a former resident, and that he was “in the clouds”. “B” was linked to staff working to achieve ultimate comfort. Georgia told the group that “part of being comfortable is being pain free and enjoying your final days”. Georgia then spoke of the difficulties staff could face after attending a
resident, who had died in Room 3 and then going into Room 1 and enjoying a joke with that room’s resident. Georgia spoke of the staff’s responsibility to keep the residents environment “upbeat”, saying: “We are their outside life, we bring the outside in”. Reflecting further, she said that is why the “batteries are on charge”, as “we draw on the batteries’ energy”. This prompted Paris to comment: “Even if staff have their own personal issues”, they “put on the batteries” and use that energy, saying: “It is not about what happened at home” and that at times home life can be “hard to switch off”. Paris said the workers “rely on work buddies” during these times.

Georgia then showed the group a word to match each letter of “end of life care” on the back of her drawing. Georgia described this thought as coming to her as she was reflecting on the topic. Each word symbolised what she felt end of life care involved.

E – nergy
N – ursing
D – ignity

O F – amily

L- aughter
I-nteraction
F-riends
E
C – ommunication A.R.E.
Paris described her drawing to the group (Figure 6.2), which depicted a large door with the words ‘Welcome. Enjoy your stay’. Paris described the door as the door to the aged care facility and that the drawing was actually depicting a revolving door, with many exits branching from the entry door. Paris explained there was only “one way to exit” the facility. Paris described herself as being “in the middle” and reflected that with all of this “exiting”, she was mindful not to “take on the stress”. For Paris, the end of life process involved residents entering the facility and the staff knowing the resident will eventually “exit” in death. Paris said it was important that staff “do the holistic bit”, describing this as: “Know the family, the history intricately”, as the resident could be with the facility, anywhere from “six weeks to six years”, recalling F, who was with the facility for 10 years. Paris felt it was important staff felt they had done their job and then reflected how “someone else replaces the deceased resident” and enters
the facility. The revolving residents prompted Paris to say: “Everyone you look after passes away” and “you could get depressed about that”. This reflection prompted Liz to say that some residents tell you: “I’m at heaven’s door”.

Figure 6.2: Paris’s drawing used for reflection

Lindsay’s drawing depicted two trees, one with no leaves, representing those residents who had passed away and had not had a “happy passing” (Figure 6.3). Lindsay described these deaths as those people, who she felt had “pain”, saying: “We didn’t help them”. The second tree with leaves and a bird on a branch represented the pain free deaths, with family present. Lindsay told the group the face in the corner of the drawing crying, with rocks around her depicted herself,
“weighed down by rocks, the pressures around end of life”. The sun in the picture represented life, and the angel and the crucifix represented “passing”. In the middle of the picture was an older lady, with an infant rising above her. A single eye, crying tears, represented the “sadness of their (residents) passing”. Lindsay also told the group the tears were also “tears of joy”, as residents were “out of their pain”. The central and dominant symbol in the picture was the palm of a hand, which Lindsay described as “touching all the areas of life”, “a happy death, a painful death”, describing some residents, who “beg you to let me (them) go”. This reflection prompted her to say that she wished “we could do more for them”. 
I thanked the group for their reflections and then read a statement from a relative’s interview transcript to the group. I asked participants to say what they thought the relative was expressing of aspects of end of life care the relative valued. The question I asked the relative at interview had been: “What would you say would be the most critical thing for you about (resident’s name) care in those last stages of dying?” The relative replied: “To keep him pain free”. I then asked the relative: “Who do you see is responsible for making sure that happens”? The relative replied: “The nursing staff. We’ve done an end of life care plan”. Participants responded by saying that the relative was focused on the physical effects of dying when making these statements.

I read the following statement from the same relative’s interview transcript: “I think that in order for (resident’s name) to get the best of care it’s important to have a really good relationship with everyone. It’s not just the nurses; it’s
everyone in the place that makes it tick”. Participants felt some concern over this statement and a participant said she thought the relative was saying: “If I’m not happy, I won’t say anything. Be nice to my family”.

Another question to the relative in the interview was: “Do you feel the facility is equipped to care for (resident’s name) in the last days”? The relative replied: “I do, especially having a Medical Officer on the premises”. A participant felt the relative’s response showed that s/he valued authority and said the response was a “generalisation” by the relative, as the Medical Officer only worked office hours.

The final question to the relative and their response was read from the transcript. I asked: “What is optimal end of life care to you?” The relative replied: “Pain free, give him whatever they need to give him, in order to keep him comfortable, and even if that hastens his death, so be it”. Participants said they could “relate” to this statement.

Journal Entry, 13.02.08

The meeting went well today. Everyone did their homework, on reflections. Group dynamic seemed different though. Jackie, the in-charge RN was absent, on leave. Suddenly, participants were a little less inhibited, spoke of Jackie misrepresenting a resident’s story in the previous meeting minutes. They agreed that Jackie did not know the resident, that is, not like they did. I challenged them on their statements, asking why they thought Jackie did not know the resident. The nurses were not forthcoming on the details, except that Jackie was not as involved in the situation as much as she had represented in the story. Eventually, we
found a compromise to talk further about the story next week on Jackie’s return. Why were
the nurses unable to challenge Jackie when she was recounting the story? I thought we had
decided on how to manage power differences within the group.

I guess it is no surprise really; dissention in the ranks, nurses not speaking up until the senior
nurse is absent. How often do nurses do this to one another? Imagine, after all these years, I
am still witnessing the things nurses did when I trained 30 years ago. What is it? Maybe it has
to do with nursing or women? I have met some difficult men, in and out of the profession, so I
guess the latter is not really the case? I suppose it is a people problem - people are not
honest with each other, people lack assertion, or people dislike confrontation. I’m not sure.
What are the constraints that are operating here? What power relations are playing a part
here?

I thought that the group seemed quick to interpret and make assumptions on the relative’s
responses. For example, when the relative said: “It’s not just the nurses, it’s everyone in the
place that makes it tick”, this was interpreted by a participant as “If I’m not happy, I won’t say
anything. Be nice to my family”. I can’t quite see the connection and I remember thinking at
the time, that I had an understanding and an empathy for the relative. I suppose that’s the
problem with taking a key statement – it tends to decontextualise the speaker. I had the
opportunity to meet the relative and hear the tone of voice, and so on. By jumping to early
conclusions, the nurses seemed to be on the defensive, and they were missing the opportunity
to learn from this relative, to gain insights and solutions into the issues the relative raised. Is it
usual for nurses to jump to conclusions when relatives speak? Why did the nurses interpret
the relative’s statements as essentially non supportive? Did they see the words as coming
from a “power over” perspective?
The fifth meeting was attended by eight participants, including myself. Following the reading of the previous meeting minutes, participants discussed the accuracy of the recount of F’s story in week three. The group reached a consensus to remove the “strong words” from the story. Jackie explained to the group that her recount was meant to be as “holistic as possible”, saying: “When the experience is outside of what is expected, you don’t know what could be causing the problem and I was thinking: What’s troubling you?”

Marie presented her drawing (Figure 6.4), depicting Marie with a smiling face and in the corner of the drawing was a washing machine, that symbolised her role in the facility as the laundry worker. Marie said she saw herself as “keeping the residents nice and clean as possible”. Marie explained the sun depicted in the drawing represented being “happy, helpful, smiling, bright sky and clear days”. This prompted Jackie to comment: “You (Marie) are a ray of sunshine in the place” and the rest of the group agreed.
Figure 6.4: Marie’s drawing used for reflection

Jackie’s drawing depicted a person in the centre, lying on a bed, surrounded by people, who were connected by a chain (Figure 6.5). Jackie said the person in the bed represented a resident, with the staff “circling the resident”. Jackie represented herself as a dominant figure at the top of the drawing, with long arms outstretched to the group. As the Deputy Director, Jackie explained her work was to “pull everybody in to work effectively”. In some sections of the drawing the chain was broken. Jackie said this represented when “people don’t follow instructions”, or she “can’t get a doctor’s order” in end of life care.
The next reflection was drawn by Liz (Figure 6.6), who asked a family member, who could creatively draw, to do the drawing for her and she explained what she wanted in the drawing. The drawing depicted a person sitting in a hunched position, with their head in their hands, and a frown on their face. A lifeless body was draped across the sitting person’s shoulders. Liz said the lifeless body represented “a resident, weighing down the caregiver” and that “all the carer’s energy was so consumed”. She said: “Some days you can be so zapped”. “(You can) give so much of your energy to the resident”, that the resident can consume all your energy. On the drawing, Liz had written “lots of emotional support, physical support, compassion, best quality of life and sometimes I feel the residents can weigh down the caregiver”. This prompted Jackie to add: “Particularly when you haven’t been well”, referring to Liz being unwell on different occasions.
Kara shared the final drawing with the group (Figure 6.7), in which she explained “providing the comfort”. A resident was depicted lying in a semi upright position against a rock. Kara said: “The nurse is the rock behind the person”. The resident in the drawing had long hair, a long beard, a furrowed brow and eyes closed. Kara explained that the long plain covering over the body represented a “body no longer functioning”. A dominant figure of a woman with flowing hair was drawn leaning over the body, arms outstretched, gently fanning currents of air that contained small crosses that looked like sparkles rising from the head of the resident. Kara said this represented the “spiritual journey” and that she was: “helping them (the residents) resolve those issues”, adding that “even despite limited time, I will cry, or laugh with them, hold their hand, share stories, let them tell me things, give guidance”. Kara explained her role was to “help (the resident) through the process of dying”. Kara said she
believed: “It is not the end; it is the beginning of another journey”. She said: “I don’t fear death and I am not afraid to see it”. “You know there’s another journey, or a new path to take”.

Figure 6.7: Kara’s drawing used for reflection

This section has described participants’ reflections on clinical practice issues related to caring for older people, who were dying from a non malignant disease. Taylor’s (2006) ‘A Practical Reflection Guide’ was used as a framework.
Phase Three: Learning from the Relatives

Phase Three, Learning from the relatives, was introduced in the fourth meeting (as in Facility One) and expanded in depth in the fifth and sixth meetings. At the fifth meeting, relatives’ interview statements were examined closely. I asked participants to state the value statement they considered the relative was expressing, by asking them: “What would be the aspect of end of life the relative values, when making the following statement”? The first relative’s account was when a relative was speaking about their life since their partner had been admitted to the facility and her interactions with staff. I asked the relative: “Do you see advice as important” and the relative replied:

“Very much so. If the staff don’t support me I don’t have any support, because I don’t belong to any support groups or anything. I haven’t got a lot of friends, because I’ve been caring for X for … years, so you drop off with friends. I’ve got no true friends who ring me”.

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The reading of this statement prompted Gloria to comment: “That is so sad, that a relative comes to see staff and interact as much with us as to see their relative”. Lindsay suggested that it seemed the particular relative’s “whole life is around care”. Gloria felt the relative’s response demonstrated “they are happy with the resident’s surroundings”. Paris said: “The facility can be an extension of home”, stating further: “What happens when a resident dies is that staff, everyone goes” from that relative’s life. A participant commented they did not realise that they were “that important, that we are part of their life”.

The next relative statement was read to the group. In the interview I had commented to the relative that “it is not just the nurses, who are there for the residents, it’s all those other services”. The relative responded:

“Every service; the cleaner, the nurses aides, the maintenance men, the nurses, the laundry lady, are all important, because without one of them you haven’t got a service, and they all contribute in a great way… they all treat him/her like a person … I’ve seen them treating people, who are practically in a coma the same way, which I think is very important… that’s what I love about out there, they don’t speak down to anyone, they speak as they’re (the residents are) 100% able”.

The group discussed how the relatives are watching their nursing care practices, which prompted a participant to comment the implicit value in this statement was ‘humanity’. Paris said humanity was important, “despite their (the residents’) cognition. Respecting that they have lived their life”. Kara commented it was important to be “non judgmental as a carer, even with
relatives”. This prompted Jackie to remind the group of an elder abuse educational video scene she had seen, in which a nurse “chopped a resident’s hand in the cot rails, resulting in the relative moving the resident out of the facility”. Jackie was making the point that relatives watch nursing care practices, however, she used an extreme case of resident neglect.

In the interview transcript I had asked the relative: “What are the important aspects of end of life care for you”? The relative replied:

“She mustn’t suffer. I don’t want her to suffer. I’ve talked to her about it. She’s on morphine and they must up that dose of morphine as she gets sicker and she’s asked for that as well. When she gets to the end, I hope she has a very peaceful exit with the morphine to help her to go quietly and peacefully. I don’t want her to choke or bleed, because she’s had two bleeds already”.

The comment regarding the bleeding was discussed and Gloria stated: “If the resident does bleed, the relative would be devastated”. Then Gloria asked: “What would his (the relative’s) reaction be? Blame?” The group felt staff had “no control over a bleed” and said they would just have to “hope it didn’t happen”. The group felt, in this instance, the value for the relative was “trusting the nurses”.

The interview with the relative progressed to the issue of suffering, with the relative commenting:
“Every time you look at her, it just breaks your heart. But she’s human and the mother of my children and grandmother of my grandchildren. She’s very loved by her children and her grandchildren. She means so much to everyone and her friends. After three or four months you still can’t sleep, because you hear them calling through the night, and you’re out of bed and into her bedroom, and there’s no one there”.

A participant commented: “It breaks your heart” and felt that this resident was “highly valued by the family”, commenting further that it helped to “know more about the person, the life story”. The group discussed that it was interesting to know about the people for whom they were caring, especially their previous life. Jackie commented how a resident’s “social profile was written up in the monthly newsletter” of the facility. The group spoke of the relative’s value in this instance, as “acceptance and denial” and the “struggle with putting a mother or father in the facility”. A participant commented: “It really is the best place to be loved and cared for”. However, the group agreed that part of the problem was that “people who have not worked, or have been in a facility”, combined with “the negative media portrayal of nursing homes, for example, in gastro outbreaks”, influenced relatives’ negative reactions to having a family member admitted into an aged care facility.

The relative’s interview progressed to the issue of care priorities. The relative commented:

“Make sure they’re (the family member is) pain-free first, and then clean. They can’t make her pain-free after she dies - no, you go for the pain first and then deal with everything else after … make death comfortable”.
A participant commented: “Don’t clean before the Ordine”. The group agreed it was important to prioritise care around pain needs.

During the interview, the relative expressed an appreciation of the nurses’ workloads, by saying:

“I know the nurses are busy and that, but I’m just hoping that at X’s time they’re going to take time, special time for X, that they will help her on her journey to a comfortable exit, even if you have to pay overtime for the carers and all the other things. I don’t care if they send me a bill. As long as they make X comfortable”.

A participant said: “Gone are the days of hold the hand” and said she wondered if the relative realised facilities were often “over budget”. Jackie commented: “We do spend more time, we increase the mouth care, the turns”, at end of life. A participant agreed, by saying: “We are in the room more often”, and we “visit the relatives in the room, chat, see if anything is needed”, saying further that some relatives stay with the dying resident.

The relative said s/he understood the nurses would be told the resident’s and relatives’ requests for end of life care and stated:

“It might only be three or four hours in the end, but they’re there, make it good for her, don’t let her suffer. (A man) screamed up here. He was dying of cancer for about five hours. They wouldn’t give him a morphine injection either. The whole family was out and in the end they just came
and gave him a morphine injection. For five hours that man screamed. Can you imagine the damage they’ve done to that family”? That damage, that’s all they remember, the horror of his death”.

Participants agreed that “death can be traumatic enough, to witness”, without the final hours being as bad as this relative’s account of dying.

The traumatic end of life story told by the relative reinforced the importance of appropriate end of life care. The relative stated:

“You can’t fix something that’s broken totally, can you? We don’t bring them back and put them on ventilators, but we help them on a safe journey. That’s all you need, a safe, peaceful journey to the end. Then you’ve made everyone happy. You’ve made the patient happy, you’ve made the carer, the loved ones and the children and the grandchildren, they’ve all been happy, because X has gone happily, and without pain. You know, without pain. You don’t need to go out struggling”.

This prompted Jackie to state: “Unfortunately, it (death) doesn’t always work like that”. I asked: “Why not”? Jackie stated: “Remember F, had all the right interventions, but was restless and struggled”. She stated further that her thoughts at the time were: “Accept the struggle” and she believed ‘F’ was saying: “No” to death. Jackie went on to say: “We couldn’t do anything else”.

I shared with the group how much the relative valued the staff in the facility.
The relative had stated:

“They’re wonderful out there. We’re so lucky that we’ve got the X nursing home, because Katherine (pseudonym) runs it. You think she’s a softie, but she is steel. She is steel underneath and she makes sure that place runs like it should”.

The group agreed it was important to “keep relatives informed, and to be good communicators”. The group spoke of the extra effort that was made when residents were dying, including “hand massages and soft music”. I asked: “Who for, the dying resident or the relative? A participant responded: “For both”. Jackie said when a resident is terminal, Katherine and Jackie (the Director of Nursing and the Deputy Director) “keep going to the room”, describing this as “playing tag” and making an effort to “keep the relative up to date”, “offer a cup of tea, talk”, and “just being there”.

Journal Entry, 20.02.08

Good meeting! I anticipated a little heat with Jackie back from leave, but all went well sorting out the previous minutes. I never know if the nurses are just quiet and, therefore in agreement, or stewing and unable to speak out. Not just these nurses. I have felt powerless before and I tend to keep my mouth shut. I have found that senior nurses use their position and power to maintain the distinction between junior and senior, by exerting authority and superiority. These nurses in the research group may view their jobs to be on the line. What if they are on a temporary contract? Try as we might, do we really eradicate power differences within the research group, just because we are aware of it and say we will manage it? Is the historical
constraint of senior nurses being put on pedestals by other nurses and other health professionals whose interests they serve, stronger than ever in aged care nursing? Maybe the senior nurses are only too willing to occupy the pedestals. I get the sense that Jackie does not see these nurses as equals, but I may be misjudging Jackie.

I may have reinforced the relative’s stories a little too much today, but I feel a weight of responsibility to be sure the relative’s message is taken to the group in the spirit of which it was related to me. My concern is some of these relative’s statements are a surprise to the nurses. A relative said, ‘I just want someone with her when she dies’. Is that too much to ask? I know nurses can make this happen. Is there a will to make this happen in aged care nursing? Would nurses accept people having to die alone?

My critical friend and I laughed, because here I go again, with a facility where the most senior nurse in the group has revealing she has a religious background and as before, the group are quiet around her. Déjà vu, from Facility One. I told my critical friend I feel more confident with this group and that’s true, so that’s good progress for my confidence and self belief in my ability to run the meetings. We also spoke about the potential changes to practice that could result from the nurses’ practice stories. Change is okay, but it is the sustainability of the change that I am viewing as vital. I feel that I may be able to help nurses to make changes while I am here, but will they be maintained when I am gone? What supports should be in place to ensure positive clinical changes in end of life care are maintained over time?

At the sixth meeting, ‘Challenging Statement’ cards were used with the group. Various statements had been made during the group discussions that needed to be challenged to facilitate a process where participants would extend their
reflections deeper to expose myths about practices, examine any judgmental attitudes, and explore new options and possibilities to encourage the possibility of change. Time constraints around the meetings and the complexity of addressing every single statement limited this approach in the regular weekly meetings. Therefore, challenging statements, specific to end of life care that had been made by participants at previous meetings were collated, written onto display cards and one meeting was set aside to discuss the statements, one by one. The dedicated time for this exercise was provided to encourage deeper reflection and extended discussions, specifically on end of life care issues. The process assisted participants to express their value statements, provided time to coach the group into reflection and challenge the myths about the care nurses were providing and the constraints they were working under, that shaped their attitudes. The broader constraints to practice were written on the whiteboard, such as political, cultural, historical, financial, and personal constraints, to trigger responses from the group on those constraints to practice that resonated with them.

I asked the group: “What would cause a nurse to say this or act in this way”? I showed the first card with the challenging statement: “Some rooms had mockers”. The group discussed that the statement had come from a story where the room number was linked to consecutive deaths. Paris spoke of not only the cleaning staff, but the residents talking about that particular room and becoming upset. Her concern at the time had been related to perhaps having to send one of the low care residents to that room at that time of a number of consecutive deaths. A participant commented the statement may have been the result of a personal issue with the person who raised it. The group also agreed personal
superstitious beliefs could have had a part to play in the person making the statement.

The next challenging statement was: “Some doctors are reluctant to give anything”. It was agreed by participants that this statement had come from the frustration of “constantly trying to get something” (a medication ordered). It was thought the constraint that would have caused someone to make this statement may have been the politics involved. Participants spoke of a particular doctor requesting the “ground work is done before things are changed”. The ground work was various “assessments” of the resident’s physical status. The group agreed it was “easier to blame the doctor”, which prompted Kara to say: “They hold the power” and that the doctor needed documented evidence on pain.

Challenge statement three was: “It was that injection you gave him”. Marie commented the nurse giving the injection would “only be doing their job” and asked: “Why would they say that? It is cruel”. This prompted Paris to say the nurses had been “pushing with that doctor for about a week and then finally gave it” (the injection). The group then discussed that there were other issues around this statement and one of those was an “education gap in pain management”.

Challenge statement number four was: “Battling with doctors”. Participants decided that this statement firstly depended on which doctor was involved and also on what the nurse wanted from the doctor. Gloria said: “This reflected a history the facility had with doctors over the years”. The “Battling with doctors” statement was also thought to reflect the personal and political constraints the
nurses worked under, which prompted a participant to say: “Often the doctor won’t meet staff half way”.

The issue prompted Paris to say the challenging statement demonstrated a “lack of communication”. Paris commented further on the facility’s improvements in communication and attributed this to the formation of the multidisciplinary team (MDT) meetings, where resident cases were presented. Paris felt these meetings had contributed to improvements in communication between the nurses and doctors and said: “Doctors will listen to you” and that the doctor can be “more than obliging, accepting to listen if enough information is provided”. Paris gave the example of a resident’s circumstances being shared by the nurses at a MDT meeting, that resulted in the doctor commenting: “I didn’t know about that different perspective”, until it was highlighted by staff. The group agreed MDT meetings were a “huge step forward” in care and that the meetings “break down the historical stuff” and contributed to the “doctor being more in tune with what’s going on”.

Challenge statement five was: “That’s all I can do. I have made the first step”. The group discussed this comment demonstrated the person was “limited in their role” and “couldn’t go any further” or, they had gone “as far as they are allowed”. It was agreed by participants that the statement was both a personal and a cultural constraint to practice, as some staff in the facility were “listened to and others aren’t”. Kara felt the carer can go to the RNs to alert them to a problem, “but if they didn’t action it, (what then)?” The group felt this problem in any facility could be a barrier created by a hierarchical structure, with a chain of command.
Challenge statement number six was: “It is important, not to die alone”. Participants decided this statement would have come from a resident’s personal circumstances. A participant said: “Some residents have no family or visitors”, and “not having love from family or friends” could result in people dying alone. It was also discussed how the financial constraints nurses work under result in these statements being made. The group agreed it “would be fantastic” if residents could have someone with them 24 hours per day when they were dying. I informed the group of a Silent Visitors program for those people without family or friends, and that as people are ageing, on occasions, there may be no one alive from the person’s family to be there, when the resident was dying. I suggested that there may be many reasons why families do not visit dying residents in aged care facilities.

Challenge statement number seven was: “Even tried paying staff to attend sessions, but they won’t come”. The group discussed how this statement originated from the personal “frustration” of trying to organise staff to attend inservice education. The group discussed how staff had personal issues and lives and the demands on people’s time could result in a reluctance to attend education sessions. A participant said: “Days off, people have other things planned”. Reluctance to attend education sessions during work time resulted in a participant stating: “We have to catch up after” an education session, referring to clinical care left to attend education.

Challenge statement number eight was: “She (the resident) doesn’t need the drug’. Gloria recalled, in this instance, it had been suggested by the RN that it was the resident’s behaviour, not pain, that was causing the problem. Gloria spoke of problems carers encountered when a RN makes a decision that a
resident is not in pain, “without seeing the resident”. Gloria also felt it was a “lack of education” on the part of the RN and it could also be a “personality issue”. The group discussed the importance of RNs having palliative care knowledge and that a recent one hour education session was insufficient time to provide palliative care knowledge. Paris discussed how few RNs had a palliative care background and suggested that aged care RN job positions should include palliative care experience in the selection criteria.

Challenge statement number nine was: “I don’t want to give the last dose”. When this statement was shown to the group, the discussion focused on blame, with a participant saying: “Someone would be saying I don’t want to be blamed” for the resident’s death. The constraint to practice was thought to be related to the statement being based on a personal view resulting from that person basing their judgment on their own fear of giving the last dose. The fear of causing death in this instance appeared to be greater than the desire to relieve pain. Although the value behind the statement was not pursued in the discussion, fear associated with the administration of opioids and accelerating death is a recognised problem and a known barrier to achieving optimal pain management (Brennan, Carr & Cousins, 2007; Good, 2003; Jones, Fink, Pepper, Hutt, Vojir, Scott, Clark & Mellis, 2004).

Challenge statement number ten was: “Spiritual needs are met … staff asked if she wanted a Minister”. Following the reading of this statement, the group decided it was a cultural constraint, with a participant saying: “They (the residents) are either Catholic or Church of England, with some going to services while they are here” (in the facility). Other residents were thought to have a history of having gone to Church and were “confronting things in their life” as
they neared their death. I highlighted with the group the idea that spiritual issues can be more complex than religious beliefs when caring for a dying person and that these issues may be managed by allowing a dying person to talk, rather than to assume it is the sole province of a Minister of religion.

On completion of the challenging statements, a relative’s interview was shared with the group. I read from the relative’s transcript from where I had asked the relative: “Who do you see as your link person to inform you of where X (resident) is at? Do you talk to the doctor a lot? Do you talk to Katherine (Director of Nursing) now?” The relative responded:

“I talk to Katherine more. Dr X, her doctor, is my doctor, but I haven’t had time to discuss X (resident) with him, because he’s too busy with other things. But I get fairly good information from Katherine and Jackie” (Director of Nursing and Deputy Director).

This prompted participants to discuss the MDT meetings and relatives being invited by staff to those meetings. I asked if on admission or at the initial resident review visit, a doctor spoke with the resident’s relatives. Participants did not think this was the usual practice.

I read further from the relative’s interview and asked participants to state what they thought the relative was expressing. The relative had said:

“Over the weekend there’s just as many staff there. Sometimes, when they’re rushed off their feet. They’ve got that many high care people on
that side they could probably do with a few more staff, because it’s hectic work taking care of old people like that, isn’t it?”

Participants agreed with the relative’s statement, with a participant saying: “Relatives see staff running around”. The statement did not surprise the participants, as they felt that “staff running around” was a feature of aged care work. The group also thought this statement was interesting, as they were being “watched” by relatives.

Another relative’s interview statement was discussed. The statement related to the issues the relative prioritised in end of life care. The relative’s statements included:

“Have their quiet music going, a nice environment for them and I think they would turn them. I have seen them do that up there … and I think they get in touch with a Minister and they come in and do the last rites. That is important, my X (resident) believed in all that. That’s what she would like. Some people don’t like that kind of thing, they don’t believe in it, whereas some do. My X (resident) has always been a believer, so I think she would like that” and “Yes, I know that they’ll give good care, because I’ve seen them with other people who are dying that they’re very attentive, and that’s all you can ask for … See, I’m not scared of my X (resident) dying, because I wouldn’t like to be like that. She wouldn’t like to be like that. She’s a Christian, so it’s a blessing for her to go and I don’t think she’d be frightened of dying, because she’ll be ready for the maker. So, you’ve got comfort in that kind of thing”.

The conversation in the relative’s interview changed to discussing whether or not a resident would be transferred to hospital for life support. The relative replied:

“...I don’t see any point in just lying there like a vegetable and even with these people in the home, I don’t believe in euthanasia ... They’ve got no life as it is. I’d hate to live like that. I’d rather take a pill and not wake up ... we’re all born to die aren’t we?”

The group thought these statements were interesting, as the relative seemed to be saying euthanasia for him self was okay, but not for the resident.

The issue of signing and requests within advanced care directives were then discussed during a relative interview, with the relative saying:

“She (the Director of Nursing) said: “You can go home and discuss it with your brothers. I said, “No, I don’t have to think about that one”, because I thought about what my father said. Definitely, not. You see people who’ve been brought back and they’re just vegetables and they’re worse. There’s one lady up there, she’s had a stroke and they revived her, well she’s been a vegetable up there for over 12 months now and there’s no change in her and she still needs all the care and she just lies there. She yells out sometimes, not much, and her family have given up on coming to see her now ... The family used to come to this particular lady while she was okay and once she was brought back from the hospital like that, I’ve never seen anyone around her for 12 months, and I feel sorry for her... I’d hate my X to be like that. So I said, “No way”, to life saving treatment.
The group agreed their perspectives of the resident’s circumstances that had been discussed were actually different to what the relative had recounted, but participants agreed that relatives were watching staff and interpreting or misinterpreting what was happening with resident’s circumstances and their care.

At the end of the meeting I distributed the themes Table to the group and asked for participants to read the themes and complete the section, using a one or two word answer, to the question: What is this about? (Appendix J).

Journal Entry, 01.03.08

I thought the Challenging Statements session went well. In some sections I did not elicit a comprehensive response and towards the end I was very mindful of the time, so we barely had responses to the final relative’s statements. I am hoping next week we will add to those statements discussed today.

I feel so charged with a responsibility toward the relatives. I even raised some of the de-identified/decontextualised issues at an area health service meeting. I was careful to keep the identities of the research facilities and the participants’ confidential and spoke only of the issue in general terms. I don’t think the lack of service availability to carers was acknowledged as much as it should have been at the area meeting, but that is why this research and other research is necessary, so information can be published and find the policy makers.
When I reflect on the problem of why carers/relatives do not seem to have a powerful voice in aged care, using systematic questions in the emancipatory reflection guide suggested by Taylor (2006), I imagine that there are many determinants that could act as constraints. Historical constraints endure over time, and so it is possible that the relatives’ opinions may have not previously been elicited, nor have relatives been seen as legitimate members of the healthcare team, and carers'/relatives' voices are traditionally not heard at senior, political levels.

The political constraints relate to power, so possible constraints are that carers are often women, but not always, and therefore, are less powerful members in Australian society, and they have less power in aged care facilities, because they are perceived to have less aged care and end of life care knowledge. Possibly, carers are too busy to engage politically in the community, to raise the profile of carers.

The economic constraints may include carers being socio-economically disadvantaged themselves, as they cannot work due to their responsibilities of caring, maybe they are ageing themselves, and/or the carer’s pension is minimal. Within aged care facilities, money is directed towards maintenance, care and other costs, so to some extent relatives can offset economic constraints, by staying with their dying family member, alerting staff to any changes.

The social constraints for carers possibly include their inability to engage, due to their caring responsibilities, or that they can become socially isolated or disconnected. In the culture of the aged care facility, nurses and allied staff engage in work rituals, which defer to people with professional power and knowledge, and because they are responsible for care, staff may have also taken over “ownership” of family members once admitted to care, making staff somewhat
defensive or resistant, when relatives witness care and offer suggestions to improve end of life care.

In light of what I have discovered from this emancipatory reflection exercise, | realise there are many possible reasons why carers'/relatives' voices may not have been heard in end life care. | expect that publishing this research on staff/relatives relationships will make some difference to the plight of carers, in being heard in the healthcare team. | will be bringing the carers' views on care of their dying family members to a broader audience and | will continue to advocate for the role of carers in assisting aged care staff to improve the care of dying residents.

Phase Three: Learning from the relatives', has been described in this section. Relatives’ interview statements were shared with the research group, to assist them to explore the relationships between nurses and relatives of the dying resident, with the intention of improving care. The insights provided an opportunity for participants to discuss the complexities of care delivery and to gain insight into issues of importance to relatives in end of life care.
Phase Four: Identifying Thematic Concerns

Phase Four lasted from meetings seven to eight. Meeting seven was extended in time, to focus on the task of identifying the thematic concern. Using the same Practice Story Themes Table (Appendix J) distributed the previous week, on which the practice stories had been copied from our meetings, the group carefully went through each story to identify the practice issues. I asked participants the question: “What is this story about?” Participants slowly and carefully examined the stories further and identified the key themes, which were then rated by importance (Appendix J).

At meeting eight, extra to the task of identifying the thematic concern, as the last participant to do so, Katherine was given the opportunity to share her reflective drawing and interpretation with the group (Figure 6.8). Katherine described seeing herself in end of life care as quite “simple”, but she stressed to the group she had given the drawing a great deal of thought. The drawing depicted a long, straight road running through the middle of three converging circles; at the end
of the road was a crucifix. Katherine described the road as “the journey of life” and said: “For these residents, it is the last part of the journey”. Katherine said the journey takes the resident to the facility where she sees herself, depicted as a figure beside another figure, the resident.

Katherine told the group: “I stand alongside that person to share the last bit of their journey on this earth”. She said: “I stand beside the resident to support, encourage and share my knowledge”. Katherine described the converging circles at the top of the drawing near the crucifix as representative of where this end of the journey becomes “complicated”. Two of the converging circles represented facility staff alongside with family and friends of the resident. Katherine said her “support for the resident and the family” and her knowledge was part of that support for both family and her staff. Katherine described her role as to provide care and support and said: “This privilege is awesome to be able to come along with these people”. She stressed: “We have no right to make judgments at this stage” and that being part of the “last piece of the puzzle in that person’s life is a privilege”. I commented the circles looked to me like Katherine was being pulled in different directions. Katherine then described how a staff member had previously drawn a character drawing of her that depicted “me as the jester, throwing balls up all at one time in the air”. Katherine told the group this was the “greatest explanation of her role”, “always keeping all the balls in the air".
When Katherine had finished describing her reflective drawing, I distributed the completed Practice Stories Themes Table (Appendix J) discussed at the previous week’s meeting and showed the group the breakdown to major themes. The major themes were pain management, education, communication, good death, workloads, staff needs, and relatives’ needs. The group identified the first three themes as priority issues, with Katherine commenting, before having to leave the meeting, that the other issues will be addressed as a result of action in these priority areas.

Journal Entry, 07.03.08

Themes were discussed at the meeting this week. The group had long discussions on the issues identified. I was pleased we were all on the same page, so to speak - the reason being
that the major themes that had emerged from the analysis were primarily pain management and education. I sensed some disappointment by the participants, who I thought may have been thinking, “Well, we told you so”. It is a long, arduous task to eventually have the known themes emerge! Even so, the opportunity to share their stories and be heard will always be useful to them, especially as it assists participants to gain some insight into clinical care and use reflection in their practice.

Why don’t nurses use reflection more to improve their practice? Is it avoided because the issues will be too painful to identify and address? Is it easier to not address the issues, and just bury them? Why did the group appear like: “I told you so”, when the themes emerged? Have they asked for pain management and education to be addressed previously in their organisation, but nothing happened? – maybe they have been ignored previously. Maybe clinicians have sufficient insight that they identify key themes intuitively and find the processes of uncovering the issues arduous and a waste of time. Maybe they just wanted to ‘cut to the chase’ and not go through the process of telling their practice stories – sort of short cuts with minimal effort.
Phase Five: Action Plan Creation and Implementation

Phase Five lasted from meetings nine to 16. In order to create an action plan, the research group discussed the thematic concern of pain management. I explained that the practice stories participants had shared in group meetings were anecdotal accounts. I asked the group: “What evidence is available to validate your practice stories, that demonstrate pain management should be addressed in the facility?” Jackie said the audit that had been completed of the three pain charts used in the facility had demonstrated that the admission pain section was not used or not followed up, to or from the doctor. The Abbey Pain Scale and the Cognitive Pain Assessment charts had also been audited and were shown to have limited completion compliance.

The research group discussed how the target group of staff, who they thought required education on the pain scale, had not been present when the palliative care team had visited the facility and provided education on the use of the scales. I asked how the results of audits were shared at the facility. Jackie said the
results were graphed and displayed on a notice board. Jackie said the audit tools were allocated to staff and were alternated, but that “night staff copped a lot of this work”. I spoke of the importance of not making audit allocations appear punitive. Jackie explained the auditing process included “returned audits” being “double checked” by herself and that the results were then presented back to the auditors.

The group discussed methods of communicating audit results and staff education when time was limited. Gloria suggested it would help: “If you (Jo) could come in on report time and use just 15 minutes, to capture those, who don’t usually attend education”. I shared with the group the process of academic detailing and how this method was used in a recent project in my workplace. I explained that staff are trained to communicate efficiently and target staff one on one, by sharing vital pieces of concise evidence, for example, in this instance it would be key pain management strategies. Jackie spoke of her concerns of taking an increased workload by using this strategy. The group discussed how it would be possible for each participant in the group to target three staff each with an intensive 15 minute education session. Gloria commented: “It would make the work more interesting”.

I shared with the group my understanding of the knowledge and attitudes to pain survey, as an excellent tool to assess staff pain management knowledge and attitudes to pain (CD 1). Jackie requested to see the survey and the group decided that if it was used, it would be best to target no more than five key questions, to ensure staff completion compliance.
The group discussed the theme of access to specialist input and specialist pain management. I asked them how access to the palliative care team occurred in the facility and if it was easy to contact the palliative care team. Jackie said a RN had been nominated to participate in the MDT meetings and that she usually arranged specialist access. They encouraged me to make contact with the RN to determine the processes more fully. Jackie gave me contact phone numbers.

The group discussed the issue of staff using end of life clinical pathways. Jackie said there was an end of life pathway available, but that it had a history of not being used, as it was considered to be of “no use” to the facility. I discussed an end of life pathway with which I was familiar used at a local hospital. The group agreed this would be worth cross checking against the current facility pathway. We planned for the hospital pathway to be sent to Jackie for review.

I asked about staff access to palliative care guidelines. Jackie informed the group the Palliative Care Guideline Booklets were available and that one was in the treatment room. I told the group about the use of hand held computers, which provide staff with point of care access to guidelines. The group agreed it would be useful to see a hand held computer next meeting.

Another idea generated from the discussions was the use of case reviews, to assist staff to relate real time events to outcomes and create opportunities to improve practices. I explained to the group that structured case reviews are often used in root cause analysis investigations. The group decided it would be useful to obtain and share the format structure at the next meeting.
Journal Entry, 12.3.08

The action planning meeting today seemed to go well, and quite a few strategies were discussed. The Director of Nursing sat in on the group longer than expected. The dynamic within the group changed, as it always does when a person in a position of authority visits. Participants were fairly silent, and very agreeable. Overall, the feeling of the meeting was positive though. My critical friend and I discussed the change in group dynamics, which occurs when the DON visits the meeting. I think it is important for me to tell the Director of Nursing how important it is for the group, and the changes that can be made in a practical sense for the ‘higher good’ of the plan, and for the project to be sustained, that she is in attendance at this important stage. The Director of Nursing did tell us her priorities were the same as the group thought were important – PAIN MANAGEMENT!!

We don’t have enough time left to take a multi-pronged attack on themes! We have to stick to key issues to make sustainable changes in practice. I want to leave the facility feeling confident that they can continue without me, so that successive groups of nurses can continue this care.

The end of life pathway I’ve used before is more likely to be sustainable in the facility. I can address compliance issues by asking the key people: How will we make it happen? How will we have an immediate effect? This approach can assist with establishing improved care.

In relation to the RN who attends the MDT meetings, my critical friend suggested I seed to bring her along by recruiting her co-operation. I will stress the importance of the RN’s role as facilitator of the MDT meeting and acknowledge her role. Further, I can highlight that we
have a greater chance of success with her support. I will acknowledge her influential position, showing her how to fully own the importance of her role as an expert, and how this can increase the implementation of the practice changes, for example, the end of life pathway, and I will reinforce that we need her leadership from within the group, especially after I exit the research venue.

Meeting 10 was an education session, to report back to staff the results of the Knowledge and Attitudes to Pain Survey, which had been distributed to all RNs in the facility, to complete following the eighth meeting. I commenced the session by presenting the results of the survey using a Power Point presentation (CD 1). Three RNs attended the session and were very keen to receive the results for the facility and to determine if they had correctly answered the survey. Pain assessment and pharmacological knowledge responses to the survey demonstrated a knowledge deficit by those RNs who completed the survey. Participants were appreciative of the feedback and requested a copy of the presentation to enable other staff unable to attend the session to view the PowerPoint. I offered to provide a ‘voice over’ for the PowerPoint and to copy the presentation onto a CD (See CD 1).

Following further discussion, participants commenced planning how to reduce the identified knowledge deficits from the survey results. A decision was made to book another presentation, to address pain assessment. The group decided it would be useful to introduce staff to this first aspect of pain management and that the inclusion of a brief overview of the survey results would lead staff to understand why pain assessment knowledge needed improvement in the facility. Future pain management related sessions were planned that included the use
and actions of opioids and other medications used in pain management, and the group needed to discuss academic detailing techniques.

Journal Entry, 14.3.08

I presented a PowerPoint presentation to Facility 2 today on the results of the Knowledge and Attitudes to Pain Survey. It was interesting at the end of the session that Katherine and Jackie (the DON and Deputy DON) had long conversations with me about a number of issues. They identified problems with Schedule 8 medications, because they wanted to know about using another patient’s Schedule 8 medications if one resident’s drug ran out. I spoke about having checks in place in a timely fashion, so that the drugs don’t run out for example, on a weekend. Katherine did not blame the doctor as much as the doctor’s secretary for not getting the scripts to the facility in time. Some of the RNs in the facility, it seems, have told Katherine they will administer another resident’s drugs to prevent the patient missing out on a Schedule 8 medication. Katherine spoke of how the ‘resistant’ RNs, who won’t comply with appropriate medication administration, for example, signing after administration, will be “managed”, by going in front of the Board, if the drug audits demonstrate they did not comply (I am not sure if anyone has actually had to face the Board). Katherine also spoke about previously contacting the Nurses Registration Board, to ask what to do about RNs using other residents’ medications.

Katherine was also worried that I had said they - Katherine and Jackie - are the key people in the facility on whom the families reported at interview that they would rely, to make sure their relatives have a peaceful, pain free death. Both nurses put their heads on the table with the weight of the responsibility. I spoke of succession planning and how important it is to share
the responsibility for a resident’s end of life care. They told me they were trying to share the responsibility, but I can’t help but wonder if Katherine’s work is the focus of her life. Jackie works in a part time position, and she told me this is how she copes with the responsibility of her role!!

Katherine then spoke of a ‘good’ RN, who previously complied with medication issues and reported incidents, and who had recently told her at a performance review that she would no longer report incidents as she was given a hard time by the other RNs. To me, this smacked of horizontal violence and I told Katherine this was an important issue to address with the RNs.

We then discussed team building and communication. Katherine spoke about the facility rapidly expanding as new wings were built into the facility and that 20 staff had turned into 70, it seemed, overnight!!

I asked Katherine about showcasing nursing innovations, such as this project. Katherine spoke about how she had wanted to do something like that and present some of the AINs with awards for completing Certificate IV. These AINs would also be receiving payment from the facility to cover their costs as an incentive. Nothing was set solid though and I felt it was regrettable they did not take the opportunity to showcase the good work of the project and the additional learning the AINs had achieved! I think the will is there, but not the energy to find a way.

As part of the implementation of the action plan, in meeting 11, I presented a PowerPoint presentation to all facility staff, on Pain Assessment (CD 1). Twenty
staff attended the presentation including three RNs, and EENs, ENs, AINs, personal carers, support staff and the research group participants. The presentation commenced with an overview of the research project, and brief results of the Knowledge and Attitudes to Pain Survey, followed by in-depth details of evidence related to pain assessment (CD 1).

During the presentation I asked the group a number of questions, including: Were nurses involved in developing pain treatment plans? The response to this question by the group was generally: Yes. A RN, who represented residents’ cases at the MDT meetings, told me that usually she attended MDT meetings and was involved in treatment planning but that any staff member could attend the meetings.

I asked about what stopped nurses from assessing pain. Responses included: “too busy, not educated, RN won’t give pain medication, and a medication order is required”. Asking attendees about what pain policies were available in the facility followed this question. The group did not know of any pain policies being available, with one person in the group saying: “There is the Abbey Pain Scale”. Following the presentation, Jackie said a new government pain manual had arrived and would be made available to staff.

I asked attendees how they would describe pain at end of life. Responses included: “pain at end of life pain can be unrelenting”, and “ongoing and emotional pain”. In the presentation, the impact of pain on a resident was outlined and included pain can contribute to limited mobility, depression, anxiety and sleep disturbances. I asked attendees about the impact of pain at end of life. No one attending the session could answer this question specifically
related to pain at end of life. A limited response also occurred when I asked: “Who are the difficult-to-manage-pain resident groups, at end of life?” One attendee responded: “(Residents with) constipation”.

I asked the group to identify their preferred pain assessment tool in end of life care. A person responded: “Vital signs and body language”. This question was followed by: “Whose responsibility is it to assess pain in end of life?” An overwhelming response from the group was: “Everyone’s”.

One RN was particularly challenging towards me, regarding performing pain assessments. Following further discussion, I interpreted her responses to me as being related to having insufficient time to perform regular pain assessments.

Journal Entry, 10.6.08

Today, I presented the second in the series of addressing pain in Facility 2: Pain Assessment. What a turn out. There were 20 people in the room. A further 4 RNs could have attended, as I was told the facility offered to pay their hourly rate if they attended. What are the reasons for RNs not attending paid education sessions, when they are offered by a facility? Is it simply they are busy in their out of work lives, or is it a show of lack of engagement with the facility, or a lack of their commitment to ongoing learning? Maybe there are other reasons I cannot imagine.

During the presentation I noticed an older RN, who represents residents’ cases in the MDT meetings. Her body language appeared to me to represent resistance; arms crossed and her “nose out of joint” on the whole business. At one point, the RN responded: “Surely a RN
with 30 years experience can just tell a person is in pain, without having to assess using a pain assessment tool!"

Katherine commented on this statement after the presentation ended and when the RN was not present. Katherine said the representative on the MDT meetings was responsible to communicate pain issues and other issues to the doctor, but there had been a lot of discussion of how the doctor tells the staff – such as – “I need more information. I can’t order on you telling me: I think Mrs W is in pain”.

Katherine discussed how a treatment plan would be a great idea for staff and residents and asked if I could provide the facility with a copy of the survey results, pain assessment presentation and any points of care on end of life information. Why did the RN who represents residents on the MDT meeting seem threatened during this presentation? Would it relate to her knowledge of pain assessment/pain management in general? Maybe she felt I was telling her “how to suck eggs”. Was it the presence of the Director of Nursing and Deputy? I wonder about her capacity to learn evidence based information after 30 years of nursing.

The RN who challenged me during the presentation on performing pain assessments came to me after the presentation and asked: “What do you think a QID p.r.n. drug order means?” She asked me if it meant give the drug 1pm, 2pm, 3pm, 4pm. I said I interpreted QID p.r.n. required the drug be administered when needed, with a 6 hour interval between doses. I thought later about why would a RN waited back to clarify prescribing requirements with an outside presenter. It seems she may have perceived me as knowing about the area, or maybe she was checking my knowledge. Either option is interesting, given I sensed her resistance
and defensiveness in the session. What constraints could be operating to prevent her from discussing this issue with the facility’s staff?

It is worrying when nurses in any role, for example, in-charge of a shift, try to maintain a façade of being the ‘expert’ and not ask for advice, when they may be unsure. The consequences can be detrimental to both the people in their care and the staff they are working with. I think workplaces can foster these traits of openness and willingness to learn in nurses. Junior staff can sometimes be rostered to senior positions before they are ready, and peer pressure can prevent nurses from disclosing that they don’t know something. Maybe, when nurses cover up what they don’t know, it is more about their personal insecurities, embarrassment of not keeping up to date, poor self esteem, wanting to please others, or even a result of horizontal violence. These reasons and more, could be why we can become defensive when we are challenged, instead of being honest and engaging openly about the gaps in knowledge.

Is it maturity and/or courage that helps a nurse to speak up to admit knowledge deficiencies, without worrying about what people may think? People may feel more comfortable and confident if we speak up and say we don’t know, because it shows we have confidence and self respect, and the best interests of the patient at heart. Reflective practices can expose these issues and help nurses who ‘pretend’, to be invincible and all-knowing, to explore why they act in this way, and maybe help them to reconcile and transform their habits, so that they can accept it is okay to say: “I don’t know”.

The week after the pain assessment presentation, the research group reconvened for meeting 12, to learn the process of academic detailing. Academic detailing was a method chosen by the group in week eight to share educational
information with staff when time was limited. The plan was to ‘sell’ the pain assessment message to the eight permanent RNs and two casual employed RNs, by engaging them and providing relevant pain assessment evidence using a time limited, one-on-one communication technique. The meeting was well attended and the group was enthusiastic to learn the academic detailing method (CD 1). Initially, Marie and Cathy were unsure if this method of sharing information with RNs was applicable to them, as they were support staff, however, by the end of the meeting, they agreed they would “give-it-a-go”. Before the meeting ended all participants were discussing with whom they would meet to share the academic detailing exercise, as some RNs in the facility were thought to be more difficult to work with than others.

The group reconvened three weeks later, for meeting 13, to share their insights and reflections on the action plan for improving pain management. Five participants attended the meeting and revisited the planned actions. The first action had been to survey RNs in the facility using the Knowledge and Attitudes to Pain survey tool. The results of the survey had revealed key areas for improvement included pain assessment and pain medication knowledge. As a result, a series of three PowerPoint presentations were created and presented to staff. The first presentation was the Knowledge and Attitudes to Pain Survey results for the facility, the second a pain assessment presentation, and the third a presentation by a pharmacist on drugs used in pain management. Each presentation was copied onto a CD with a voice over and the notes of the presentation were printed and collated in a package with the CD for those staff to view, who could not attend the face-to-face presentations (CD 1).
In combination with the pain assessment presentation, an academic detailing exercise was incorporated to share pain assessment evidence with the facility’s RNs. Academic detailing has been shown to be valuable in improving practice, however, the results are variable (O’Brien, Rogers, Jamtvedt, Oxman, Odgaard-Jensen, Kristoffersen, Forsetlund, Bainbridge, Freemantle, Davis, Haynes, & Harvey, 2007). Academic detailing in this project, encompassed the development of a relationship with a RN, through a one on one visit, the purpose being to seek to understand the nurse’s practices and assess any barriers to behaviour change and to overcome those barriers with evidence based information. The participant who approached a RN used a product marketing approach, in this instance, for the product of pain assessment. The participant’s goal was to attempt to convince the nurse why pain assessment was beneficial to the RN’s practice. The participant was required to understand the topic, appreciate why the topic was chosen and deliver a small number of key messages to the RN during the 10 to 15 minute presentation. A package of relevant information had been supplied to each participant at the previous meeting.

In meeting 14, five participants in the group having completed the values and beliefs exercise in the academic detailing package shared their responses. The values and beliefs exercise was used to raise participants’ awareness of how their behaviour impacted on others. Participants were provided with an information sheet, which asked them to explore their beliefs and attitudes about the RN, who was controlling the pain medication.

The first item was: “Most RNs are ...” Marie told the group she felt most RNs were “sympathetic” toward the resident in pain and said: “Sympathy is in the make up of being a nurse”. Other participants said most RNs were caring, they
need a better understanding of drug use, and they find it difficult to keep up with the ongoing changes in medications. Georgia told the group most RNs are accepting of being made aware of appropriate pain practices, but still believed they knew what to do and based their knowledge on individual practices and beliefs. The group then discussed how those nurses, who had not updated their practices, could be using practices from their training days, or for some RN knowledge learnt 30 or so years ago.

The next item in the values and belief exercise was: “A good RN was …” Marie finished the sentence by stating: “A good RN was caring and understanding of how the resident felt”. Another participant responded: “A good RN was knowledgeable about pain management and listened to other staff”. This prompted Jackie to recall the previous evening, when she was required to work on the floor, how she had relied on the carers, who were showering, turning, and making the residents comfortable to tell her about a resident’s pain, and said: “They have seen the transfer (of the resident being repositioned) and the pain”.

“The bunch other than RNs are …” was the third prompt in the exercise. This question prompted Paris to state: “Nurses other than RNs are more knowledgeable”. The group agreed and responded with statements, such as, nurses other than RNs are in tune with the pain of most residents and nurses other than RNs are caring and understanding. Jackie told the group that, as a RN, it is easier to believe the staff rather than just take a quick look, as the resident may have settled following the “turn” (change of body position). Jackie spoke of trusting the carers’ reports and said the RNs were often “attached to the drug trolley”. Participants also discussed how nurses other than RNs are part of the assessment processes and should feel valued in the team.
I thought the EN’s statement that nurses other than RNs were more knowledgeable seemed to be an expression of the disrespect for the RN by this nurse. If this is so, what is the foundation for this disrespect and on some topics this may be correct? What would the RN have to change to receive respect from the EN? In retrospect, I should have asked if the EN was speaking of one particular RN, or all RNs in the facility. I doubt she would be referring to all RNs, however, even one RN who had major knowledge deficits could have a profound effect in a facility. It seems to me that the RNs enjoy a certain role status and that the power of the position of RN goes relatively unchallenged in this hierarchy of nursing in aged care.

It is interesting to me also, that the participants are willing to share their opinions of what they think RN’s knowledge is with the group, even though they are aware of the power differences between themselves and the RNs in the facility. It takes courage to speak out, even in the protected dynamics of this research group, but I trust it is showing that these nurses are feeling safe and are, therefore, willing to expose their opinions and challenge the status quo.

The pecking order of the hierarchy in the facility is encouraging the power to be one sided and seems to be influencing the way the nurses interact with each other. I think this highlights that there is a lack of understanding or respect for each other’s roles and has created an ‘us and them’ mentality. The power of the RN position seems to be working in the day to day working of the facility, to silence the nurses of a lesser rank, but interestingly, it is not silencing them in this group.
The action research and reflection process is really empowering the group to speak out, and challenge and explore their end of life practices. The reflection and collaboration is encouraging the workplace culture to be exposed. I feel a weight of responsibility with each disclosure to do something, as I feel as a rescuer by nature, that I must fix things. I know that this is not possible and, as facilitator, the role I need to perform is to encourage and support the nurses working in the facility to gain their own insights and thereby improve and own as important, their end of life care practices.

I am interested in the responses of the RNs, who have been somewhat defensive. What impact, if any, is this research having on the RNs’ nursing practices in the facility? Are the RNs more aware of their nursing practices, now that their work activities have become more public, and they have begun to feel they are under a degree of scrutiny?

The fourth item in the exercise was: “A good doctor is …” Jackie said: “A good doctor is “teachable” and compared two doctors’ practices in pain management. She described how one doctor was shown all the pain charts for a resident, but the reporting was not believed and thus she said: “The nurses may not get what they want” in pain relief for the resident. Jackie compared this doctor to another doctor, who was thought by participants to have more experience in aged care. Jackie said this doctor did not need to be shown as much information and believed the nurses’ reports of residents’ pain. Britney said: “A good doctor is controllable, just like a puppet”. Paris said a good doctor is: “Having things in place before death”. Jackie told the group of having witnessed an example of peer influence or pressure between two doctors at a multidisciplinary team (MDT) meeting. Following discussion of a resident’s case and review of the charts, one of the doctors suggested medication and as a result, the other doctor,
who was known to be reluctant to prescribe, went on to prescribe his peer’s suggested medication regimen.

The next question was: “What do you think are RNs’ values and beliefs about pain management?” This question prompted Britney to respond that some RNs may be “unaware of current practices” and that they may have “no time to talk or read” about pain information. Marie said the RN to whom she gave the pain assessment information in the academic detailing exercise had said: “There is nothing new” in the information and that she “knew the information”. Marie said the RN said it was: “Good to refresh pain knowledge” and that more “regular palliative care” information would be helpful. Georgia told the group the RN she approached was very receptive and interested in the pain assessment information, which prompted participants to reflect that some RNs were open to being approached and took their professional development more seriously than others.

The final question in the values and beliefs exercise was: “How do you think the RNs’ values and beliefs on pain management impact on their interactions with residents, other nurses and staff?” In response to this question Jackie said: “RN’s should show some concern, listen and try to understand the information that comes from other staff”.

The group discussed how sharing information with senior staff, such as RNs, could be an intense activity, and required attention to communication skills and careful interaction. Participants had been asked to reflect on what they had learnt, from the visits that went well with the RNs, with whom they had shared information, and what factors affected the impact of the message. Also, whether
there were any practical problems they had encountered during the academic detailing presentations. Jackie said since action had been taken to improve pain management practices, there had been an increased awareness of pain assessment in the facility. Jackie used the example that when she had to ring all the RNs to advise them the pain medication presentation was temporarily cancelled, a RN told her that “it was a pity”, as she had planned to attend the session. Jackie told the group that this was a real breakthrough, as the RN did not usually attend education sessions. Georgia told the group the RN she had approached said she was feeling threatened and targeted by the recent pain management activities. Even so, Georgia felt this was a positive outcome, as she had witnessed the RN’s competency improving since the commencement of pain management education.

Journal Entry, 18.6.08

Some of the responses to the questions in the feedback session were interesting, for example, “A good doctor is controllable, just like a puppet”. Why is it about control and pulling strings? Has the ordering of medications broken down to game playing? A game of, who can get the doctor to order the drug? Who wins? I imagine that if the nurses were better informed in pain management strategies, perhaps they would not have to play games to get medications ordered, because their assessments and reporting would demonstrate the need for pain relief.

It was interesting when Britney defended the RNs, when she said they might be “unaware of current practices”, or that they have “no time to talk or read” about pain management. Is Britney saying that the RNs can be excused for not knowing up to date information on what
they are doing? What would have made her assume this? What is she basing this assumption on?

The RN’s reaction to Marie was remarkable. Marie is not a nurse, so I assume the RN was patronising her by saying “There is nothing new” in the information and that she “knew the information”. Was the RN receptive to the information and welcomed the update, but somehow offended that Marie relayed it? The RN obviously had a chat to Marie, sharing it was good to refresh her knowledge on pain assessment. This would have helped Marie, as I know this exercise in approaching a RN was a challenge for her, not being a nurse herself. There would have been a lot at stake in this interaction for the RN, as she could have been defensive and dismissive, but she seems to have engaged. Maybe she was relaying a message back to the group or the facility, when she asked for “regular palliative care” information?

When Georgia said the RN felt threatened and targeted by the recent pain education activities, it was strong language. I wonder whether Georgia was pushing too far and using this updated knowledge as her power. Maybe Georgia is enjoying letting the RNs feel that their practices are under scrutiny, and “not in a good way”. Changing practice is definitely a gradual process. Some aspects of change seem to be pushing people out of their comfort zone. I will keep on encouraging the group to keep paying careful attention, to monitor and observe the effects of these changes. In this phase of the project, we are still exploring and examining practices, testing and feeling the effects of change.

It begs the question, how can we encourage RNs working in aged care to attend education? Is the presenter the key? Is it the time of day? Day of the week? Perhaps RNs choose the caliber of the presenter to match the effort required to attend education on their days off, or
is it the subject area that catches their interest? Why would a shift worker want to come back to work on a day off anyway? Attending education sessions may depend on the importance the RN places on the subject, not what the employer identifies as relevant to the facility or the residents’ care? How do experienced RNs determine their own knowledge gaps, especially if they are feeling defensive and/or threatened and targeted by the push to update their knowledge base?

Jackie shared a recent event where she had come onto a shift and found that a resident with severe dementia had been assessed for pain with the incorrect pain assessment tool. A numerical scale 0-10 had been used for a week, instead of the condition appropriate Abbey Pain Scale. The group discussed the problem that, in this facility, only a RN could commence a pain assessment chart. The group felt this could be rectified by writing into a policy that other staff could commence a pain scale, as staff, extra to RNs, were thought to be capable of identifying the correct tool for a resident’s condition. Georgia said the resident Jackie had discussed was particularly difficult to assess for pain, as she had increased anxiety and confusion and that four staff had assessed her. Jackie suggested that at handover the group observe the resident together and decide on a pain score.

This prompted Paris to say that there was a “link missing” in pain management and that medications were not discussed at handover of patient care and, therefore, staff other than the RN did not know if a resident was receiving pain relief medication. Jackie told the group that changes were coming where pain scores would be reported at handover. Other imminent changes included pain scoring being linked to clinical audits, and pain assessments would be conducted
second monthly for all residents, even if there were no obvious problems with pain. Jackie told the group that the audits would be incorporated into the quarantined resident care days, rather than be additional work extra to clinical care.

The group discussed how the pain assessment academic detailing exercise was found to be a targeted approach to education and “sold the message of pain assessment” to the RNs, as an important aspect of care. Marie said she had noticed when she approached a RN to share the pain assessment information, that the RN immediately folded her arms, so Marie felt that the RN’s body language was defensive. In preparation for the academic detailing, the group had discussed and used practice exercises to demonstrate positive and negative body language. Marie said that she was aware not to mirror the RN’s body language, because of the exercises and, therefore, maintained an open, friendly stance. Britney said she recently noticed a resident with her head in her hands, looking at the floor and she immediately asked herself: “Is she in pain?” Britney said she promptly went to a nurse to ask if the resident could be assessed for pain.

All participants who completed the exercise gave the RNs the pain assessment handout sheet to take with them (CD 1). Britney said she had not sat down with the RN to discuss the information, but gave the RN the sheet to take with her as she had been leaving after a shift. Britney said she would follow up with the RN before next meeting, to determine if the RN had any questions. Georgia told the group a RN with whom she had shared the pain assessment information, told her at the session she would bring in articles linking pain and depression in older people, to share with other nurses.
Paris told the group she had “felt fine” and did not feel “intimidated” by the RN, when sharing the pain assessment information. She described the RN’s response as “good” and “happy to be involved”. However, at first Paris said she thought the RN was suspicious, as she had asked: “What is this about?”, “Why are we doing this?” Paris also said the RN immediately questioned the percentage of residents, who suffer unrecognised and untreated pain in residential aged care, as outlined on the handout sheet. Paris said she responded to the RN by referring to the credible sources for the information that were listed on the handout sheet. Britney found it interesting that the RN was surprised at being approached by a cleaner regarding residents’ care. Georgia said: “I would have liked to speak with another RN”. Georgia was encouraged to speak with other RN, as only five of a possible ten RNs had the information shared with them.

Participants discussed how they had enjoyed the “team effort” of academic detailing and asked each other: “Who did you see?” They also spoke of other nurses in the facility wanting to listen to the conversations and get involved in the one on one discussion with the RN. As the group viewed the pain assessment academic detailing exercise as a success and the information sheet was thought to be of benefit to all staff, Jackie asked participants for the best place to leave the sheet for staff to access the information. The group felt the memo book was often not signed off as being read by staff and, therefore, it was decided the pain assessment sheets should be attached to all staff pay slips.

The next planned action to address pain management issues was for a Consultant Pharmacist to present a PowerPoint presentation to all facility staff on: ‘Drugs Used in Pain Management’ (CD 1). Eight of the facility staff attended
the session, which commenced with the pharmacist providing a brief overview of pain physiology and then covering the specifics of opioid medications.

At meeting 15, the group incorporated the drugs used in pain management presentation into an academic detailing exercise. The meeting had been well attended and the group was enthusiastic to again use the academic detailing method to share pain management evidence with RN in the facility. I asked the group to be mindful of how they interacted and explored the issues of pain management with the RNs and to share those insights at the next meeting. The group discussed how they would approach this subject area, as Georgia said it was “crossing into RN territory”. The group discussed how no specific drug was being discussed, only the facts about pain management strategies in general on the sheet (CD 1). Participants decided that a drug formulation sheet would be useful for the medication trolley and for display on the drug cupboards. Jackie and I decided to draft a display sheet for discussion at the next meeting.

The group reformed for meeting 16, to reflect on the academic detailing exercise about drugs used in pain management. Seven members of the group attended the meeting. At the beginning of the meeting the Director of Nursing requested copies of the Area Health Service patient information booklet for advanced care directives, the actual advanced care directive used and the area health service policy for advanced care directives. Katherine said the current advanced care directive being used by the facility was from Queensland and had not been legally endorsed.

Only one participant had completed the pain management academic detailing exercise. The reasons other participants gave for not approaching the RN
included the RN was going on holidays, or was on days off, or that the participant felt the process was too daunting. The participants said medications were “RN Territory”. I encouraged participants to perform the exercise and reinforced with them that the information was general pain management information, not specific information on individual drugs and, therefore, not to feel intimidated or anxious about sharing their new knowledge.

Georgia, who had completed the academic detailing exercise, told the group she had targeted a different RN, to the previous RN she had targeted for the pain assessment academic detailing exercise. She told the group she found the RN “approachable and receptive” and that the conversation had expanded into the RN and Georgia discussing specific drugs. The RN provided Georgia with product information on the drug midazolam. Georgia said she had enjoyed the opportunity to do the exercise and told the group that “they have the knowledge, a lot more than we have”, referring to the RN. Another participant agreed that the RNs do know the drug information, but said: “They won’t say what they don’t know”. When asked about the information sheet, Georgia said the handout sheet was “okay” and did not require any changes. Georgia promised to bring her written comments to the next meeting.

In summary, this section described the creation and implementation of the strategies in the action plan, including identifying current pain assessment and management practices in the facility, surveying nurses’ pain knowledge and presenting the survey results, trialling academic detailing exercises and reflecting on the RNs’ responses to the sessions and providing pain management and medication education sessions to facility staff.
Phase Six: Critical Reflection on Action

Phase Six lasted midway through meeting 16 to meeting 20. During meeting 16, the group commenced the process of critical reflection on the overall success of the research actions within the action plan. In previous meetings, we had reflected on the progress of the action strategies as they were implemented, and by meeting 16, we were ready to reflect critically on the project’s activities to improve pain management, when caring for residents dying from non-malignant diseases.

Jackie recalled a recent end of life review that she said she would like to think would have been the “best one, we’ve done” referring to a “good death” outcome for the resident. Jackie told the group: “All staff were on the same page” and described this as: “Everyone knew what was happening and followed through”. However, Jackie went on to recount the events that contributed to a deterioration in the end of life care. Jackie told the group that two RNs were the exception; one night shift RN had taken over an hour to provide pain relief to the dying resident, resulting in the family being quite distraught, and the second RN
had not administered the pain relief as prescribed. Jackie told the group she is still yet to speak to those RNs and ask them why they did not follow through with the medication administration. This prompted a participant to say that at handover everyone is so different in how they handover information and how they assess residents’ needs throughout that shift, particularly palliative care needs. Georgia said that RNs’ “pain relief ideas are different”.

The group discussed a recent event, where a resident did not want to go to hospital despite, as it turned out, having a collapsed lung and being very distressed. The group discussed how difficult it would have been for the RN caring for the resident to make the decision to send the resident to the hospital, particularly when the resident had stated in their advanced care directive, the wish for no active treatment. Jackie told the group that the RN who sent the resident to hospital had failed to send the advanced care directive with the resident and that, since the event, the Medical Officer had prescribed end of life drugs. Previous to this event, the resident’s General Practitioner had been hesitant to prescribe end of life medications.

The group reviewed the initiatives implemented to maximise appropriate pain management in the facility and were asked if they had witnessed these initiatives having any effect on residents’ end of life care. Jackie responded by saying: “The Schedule 8 drug cupboard is bulging” and felt this was an improvement in the prescribing of pain relief medications and an improvement in the recognition of residents’ pain by staff. Georgia recommended that the drugs used in pain management handout sheet be included in the facility’s orientation manual. Jackie told the group the sheet would be included in the section on elder abuse, neglect and duty of care in the orientation manual.
Participants discussed the strategies already implemented to improve pain management knowledge, strategies yet to complete, and future planned strategies to improve pain management. During these discussions a list was created on a whiteboard, commencing with strategies implemented to date, which included:

1. The Knowledge and Attitudes to Pain Survey completed
2. The Knowledge and Attitudes to Pain Survey results presentation
3. Knowledge and Attitudes to Pain Survey results burnt to 2 CDs with voice over and an information handout sheet
4. The Pain Assessment evidence presentation
5. The Pain Assessment evidence burnt to 2 CDs with voice over and an information handout sheet
6. The Pain Assessment Academic Detailing, plus a key messages handout
7. A ‘Drugs used in Pain Management’ presentation by a Consultant Pharmacist
8. The ‘Drugs used in Pain Management’ presentation burnt to 2 CDs with voice over PowerPoint and an information handout sheet
9. The exercise ‘Drugs Used in Pain Management Academic Detailing’ plus a key messages handout. At this stage, not all participants had completed this exercise.
10. Standardised pain assessment scales available and accessible to staff
11. The audit tool refined to include pain scoring and assessment
12. The RN were now involved in auditing
13. The Pain Score now shared at handover
14. Pain management now included in new staff orientation
15. The Government Pain Management Kit available for staff
16. A pain treatment flowchart poster located in treatment room

Strategies Yet To Be Completed:

1. Demonstration of the Personal Digital Assistant, with a pre and post survey
2. Preparation of a ‘Drug Formulations Table’ poster
3. Preparation of a ‘Complementary and Alternative Therapies’ poster
4. Formulation of pain policies
5. Dissemination of audit results to staff
6. Graseby syringe driver education

Further Suggestions:

1. An end of life care case study presentation
2. Repeat the survey on knowledge and attitudes to pain
3. A morning tea to be conducted by the Norspan drug representative
4. Discuss and highlight pain management strategies at the RNs’ meeting
5. Consider the adoption of an end of life pathway
6. Newsletter submission

Participants were pleased with the progress of the action plan and were surprised by the number of strategies they had achieved. I asked the group to identify the best time to repeat the survey on ‘Knowledge and Attitudes to Pain’. The group agreed that toward the middle of the following month would be suitable. The reasons given were to allow time for the planned strategies to reach all staff and to provide a comparative report to determine if the pain
management strategies had improved RN knowledge. Jackie asked me to remind staff at the RNs meeting that the group planned to repeat the survey the following month.

Participants made suggestions on what they would like me to raise regarding the project at an upcoming RNs’ meeting. I informed the group my purpose in attending the RNs’ meeting would be to update the RNs on the progress of the research project, to inform them of pain management strategies that had been developed and to outline the planned future strategies to address pain management. Participants suggested I ask the RNs about the education they felt they required and in what form. Also, they requested I ask for the RNs’ response to using an end of life pathway for dying residents. Participants suggested I ask for another RN volunteer to join the group. The meeting ended with participants suggesting the project be advertised in the facility newsletter and they agreed that each participant would complete the academic detailing exercise before the next meeting.

Journal Entry, 19.08.08

I was disappointed that only one participant completed the pain management academic detailing exercise. Did I underestimate the fear nurses have of one another when discussing medication practices? I am a RN with experience and other RNs do not hold any fear for me, as far as I know, but I suppose it is different for nurses and other staff who are not RNs. I imagine it takes courage to speak with a professional of ‘higher rank’.
I remember my training days when my own senior nurses were scary characters. I am asking relatively junior health care workers and in one case, a cleaner, to approach RNs about medication administration practices, so I can see I am asking a lot of them. It is a dilemma for me to find a balance between, on the one hand, listening to the criticism of the RNs’ practice, and on the other hand, getting some real action happening that can change the status quo.

It does take courage to change things in nursing. I can see that. Maybe this reluctance to communicate with the RNs is revealing the effect of hierarchical structures in nursing. If participants are unable to share information, would nurses be willing to challenge a RN in a clinical situation, who is not administering or initiating adequate pain relief for a dying resident? I imagine the same fear of authority would keep them silent. I suppose that is why some things do not change, or change very slowly – it is difficult to speak up and oppose authority figures, changing the status quo.

I attended the facility’s RNs’ meeting to present an overview of the project and outline the activities participants had achieved so far to address pain management. Seven RNs attended the meeting, including the Director of Nursing and Deputy Director. The RNs were very courteous and listened attentively as I outlined the group’s progress. One RN commented that appropriate end of life care would be achievable if the doctors ordered appropriate medications and cooperated with RNs.

During the overview of the project, I shared with the RNs some of the reflective drawings participants had created. The group discussed how aged care workers may carry grief with them after experiencing a resident’s dying. This issue triggered further discussion regarding the need for staff being provided with
death and dying education during their training. Training for death and dying was not thought by the RNs to be incorporated into training for aged care work, which surprised some in the group, who recalled they also had only learned on the job during their training. This created a lot of independent lively discussion, as each RN recalled their first experience of seeing a person die, or seeing a dead body. Katherine shared an experience when one of the support staff did not realise a resident was deceased. Katherine had a facility policy that staff do not cover the face of a deceased resident with the bedclothes. Katherine told the group the staff member was greatly shocked when she realised the person in the room was deceased. Katherine told the group the staff member required a lot of counselling to assimilate the event.

Katherine also told the meeting she recalled being taught in palliative care education to ask: “Whose needs are we meeting in end of life care?” She recalled a resident being given hand massages and quiet music played in the room where the resident was dying. The group discussed how these practices could be reflective of a relative’s or carer’s needs in end of life care. Katherine told the group that when this resident’s advanced care directive was retrieved, it was clear he had specifically requested not to have people with him at the end of his life, which prompted one of the RNs to say: “And definitely no classical music”. Katherine also said she had witnessed some residents waiting for their relatives to leave the room before dying. Katherine thought this was due to some residents not wanting their family to witness their death.

I distributed the assembled RNs a list of the thematic concerns the research group had identified in relation to end of life care and highlighted that pain management was a current priority being addressed by participants.
whiteboard exercise that listed pain management achievements and future planned strategies was on a white board in the room, which had been left from the research group’s meeting the previous day. I told the RNs the strategy of academic detailing drugs used in pain management would be shared with them in the next few weeks and Jackie told the group the morning tea with a drug representative had to be delayed temporarily.

I asked the RNs their thoughts on a planned future strategy of using an end of life care pathway. One RN said the end of life pathway would not achieve what was required, which was the doctor prescribing the required medications and that pathways did not acknowledge what RNs already know, and that they can make end of life care decisions. We discussed how knowledge of what to do at the end of life was not known by all RNs, with the exception of those RNs who had “a good grounding” in pain management and end of life care. It was thought that the pathway may not be useful for RNs with end of life care knowledge, but the pathway would most likely assist them and guide the nursing care of those with less knowledge and experience. Due to the majority of RNs in the facility working part-time shifts, the group agreed that it was more likely that experienced RNs would not be in the facility when a less experienced RN needed to access or discuss end of life care information.

The group discussed advanced care directives and the link to having all end of life medications written up when the directive was finalised. This was disputed by one of the RNs, who felt that just because an advanced care directive was in place, it did not necessarily equate to a need for end of life medications to be prescribed.
The MDT meeting was discussed as an opportunity to explain end of life care medication requirements to the residents’ doctors. The RNs discussed the comparisons between doctors who visited the facility and they said that some doctors will ask the RN “What do you want me to write?”, which was surprising for some of the RNs, who inferred their role was not to tell doctors what to prescribe at the end of life. Doctors’ fears in prescribing end of life medications were discussed, with one RN saying that she understood why a doctor would be fearful of prescribing end of life medications, as she had felt she had “given the last dose" in end of life care and had empathy with the doctor’s responsibilities when prescribing, in particular, opiates.

Katherine discussed how it was important when the doctor was prescribing to “get all (end of life medication prescribing) done at once”. The group agreed the doctors were in the facility for a short time and it could be difficult to obtain appropriate orders if the opportunity was missed and the doctor left the facility. This prompted the group to discuss a recent event where a doctor had visited a resident, who was unwell in the evening. The doctor decided to delay the ordering of opiates for this resident until the following day. The RN, who was present when the doctor was in the facility, recalled being more focused on the doctor’s discussion of ordering antibiotics for the resident, which she felt was inappropriate, than checking appropriate pain relief medications were prescribed. The RN said: “I take responsibility for that. I feel embarrassed, but I could not get over him wanting to order antibiotics”.

Another RN, who had been on the next shift was unaware that that resident had been distressed overnight and was informed by other RN that the doctor had to be contacted a number of times, until the resident received adequate pain relief.
Katherine said: “We kept him up all night”, referring to contacting the doctor overnight about the resident’s condition. The RN who had worked the next shift said the carer had not told her the doctor had been in the facility and recalled telling the carer: “Please let me know, when the doctor is here”, so that she could discuss her concerns and the resident’s needs with the doctor. The group discussed how the resident, who was described as a “cheerful man”, had been observed at the meal table earlier that evening leaning forward, holding his side and grimacing in pain.

Jackie told the meeting when the planned new model of care commenced, RNs, ENs and carers would be responsible to care for both high and low care residents and that it would be critical that pain medications and pain scoring be discussed at handovers, to ensure all staff were aware of those residents receiving pain relieving medications.

A RN then asked: “Do nurses know about therapeutic levels of drugs?” She questioned whether nurses in the facility understood that regular administration of pain relieving medications was important, otherwise the following shifts needed to “catch up” the pain relief if a dose was not administered, missed, or if a RN decided a drug was not required.

Katherine requested I tell the RNs about the relatives’ interviews I had conducted in the project and provide feedback to the RN on each relative’s views on priorities in end of life care. I told the group that the wish for “no pain” was a clear message relatives identified as a priority for their dying relative. Keeping the resident clean was not viewed as a priority by relatives, compared to not having pain at the end of their family member’s life. I also told the group how
highly the relatives spoke of the staff who care for their relative and how they had also told me Katherine and Jackie were the two staff they identified, relied on, and felt were responsible, for making sure their relative did not have pain at end of life. I noticed as I said this one of the RNs raised her eyebrows, but the RN did not follow this up with any further comment except to say: “Your sample size was small, wasn’t it” and she felt that there were a number of relatives who would not provide the same feedback.

The presentation to the RNs meeting was originally planned to be 15 minutes, however, we had discussed issues around end of life care for one hour. It was at this stage of the meeting that Katherine asked if there was anything else I wanted to raise with the RNs. I asked the RNs whether, if the area health service end of life pathway was reconfigured to suit local needs, they would be willing to trial the pathway. The RNs all agreed this would be possible and that they would be willing to contribute to the revision and trial of the pathway.

Before the presentation concluded, a RN asked what would be done to provide staff with opportunities to debrief. I discussed how Facility One in this project had addressed debriefing by creating a role play melodrama, which was used to prompt discussion on issues for staff following the death of residents. Katherine said that in recent times that there had been a dramatic increase in deaths in the facility, which prompted the RNs to discuss how the increased death rate reflected the phenomenon that people live at home longer with more support, so when they are admitted to the facility they are sicker and their care needs are higher, and therefore, their death more imminent. I told the group that Work Cover NSW provided a manual and brochures for grief and loss in the Aged
Care industry. Katherine asked whether copies could be provided, so that they could be made available to staff.

I explained to the group that the demonstration of a personal digital assistant (PDA) was a planned strategy to address pain knowledge in the facility. The PDA contained drug information relevant to end of life care. I asked the RNs if one of them would be willing to volunteer to learn to use the PDA and share the PDA training with other RNs in the facility. A RN was ‘volunteered’ by Katherine and Jackie, as she was a RN who worked more consistent week day shifts. This RN smiled and agreed to meet with me the following week to learn how to use the PDA.

I asked the RNs’ meeting for a volunteer to join the research group and support participants in implementing the next planned actions for pain management, as the actions were medication related and the group had come to the realisation that medications could only be led by those RNs administering the Schedule 8 drugs. The assembled RNs each gave reasons as to why they would be unable to volunteer to join the group. The reasons included an upcoming holiday in South America, an existing appointment as a link nurse in palliative care, already being over committed, and two of the RNs said they worked a minimal number of shifts, which would make it difficult to attend meetings. As a result, the same RN who had previously been ‘volunteered’ by the senior staff for the PDA training was again nominated to participate in the group meetings. The RN agreed to represent RNs in the facility at the research meetings.

I thanked the RNs for their contributions and informed them the research group planned to repeat the knowledge and attitudes to pain survey in mid September.
I enjoyed the RNs’ meeting today. The nurses were challenging and somewhat defensive at times, but overall I had a sense they were interested in making practice improvements and that they were keen to see enhancements to end of life care. There was a definite ownership of their area of expertise, medications, and a genuine concern for each resident’s welfare.

The RN ownership and concerns of these issues, however, were not committed enough to participate in the group meetings, or to take on a trainer role for the PDA. I noticed when I asked for volunteers, the RNs either avoided eye contact with me, or looked at the Director of Nursing. Hierarchical systems can create power struggles; so did the RNs feel vulnerable declining to participate in front of the Director of Nursing? The RNs’ reasons for not volunteering to participate were valid reasons, however, I wonder if more of these RNs worked either fulltime or more than one or two shifts, whether their commitment to practice change would have been more evident.

Is that what happens when the staffing profile is mainly part time or casual? Is it a good excuse for not becoming too involved in practice? Does casualisation of the workforce make it easier for RNs to voice their concerns, but not change their practices, complain about what others are not doing correctly, but not to review their own practices, and expect others to fix the problem? What will happen to that smiling RN who was volunteered by her seniors to participate in all the practice changes? Is this representative of “eating our young”, pushing those staff to burn out? Are casual or part time staff’s requests put ahead of the needs of those staff who work more hours? What is the fall out of these issues for the dying resident?
have so many questions, and many of them cannot be answered easily. I will ‘sit’ with them a while and see what transpires.

Jackie, Drew, Gloria, Paris, Liz, Lindsay and Britney attended meeting 17. Even though we were in the phase of critical analysis on actions, we were also continuing the other agreed research processes. The meeting commenced with Drew, the RN, who was ‘volunteered’ at the RNs meeting, returning a pre use PDA survey. Paris said she found the end of life care guidelines in the PDA useful, for example, in the management of hiccoughs and dyspnoea.

At this meeting, the two support staff resigned from the group. Marie sent a message through Gloria that she would not be attending any further meetings, as she felt the action planning now had a clinical focus and that she preferred to stay with her regular work. Britney also left the meeting before it ended and the participants agreed the tasks were now more clinically focused and that it was probably no longer relevant for Marie or Britney to participate.

Participants reported that they had not completed the Academic Detailing for Pain Medications since our last check in. Marie said she had “half presented to Drew”, Paris said she had not had time to speak to the RN, but that a RN had taken the sheet and said she would read it. The group agreed to compromise and make sure a RN was given the handout and the participants would follow up with the RNs to see if they had any questions before the next meeting. Britney said she would follow up with “C”, a RN. I asked the group if staff had viewed the pain medication CD. Jackie did not think anyone had written it out of the borrowing book and agreed to monitor the use of the CD.
Jackie told how a RN, who was two years out of nursing training, was about to commence in the facility. Jackie told the group the RN was a young mother, who was breastfeeding, so things had to be sorted out. Jackie said it was important to have clinical end of life pathways available for junior staff, as it was most likely that she would not know how to manage end of life issues.

During the meeting, Katherine came to the door and asked if I could arrange a counsellor, who would not charge the facility for staff counselling. Katherine said this request resulted from a number of deaths recently in the facility and the Managing Grief and Loss Booklet had provided a prompt. I said I would try to arrange this for the facility.

The group discussed attending a recent memorial service in the facility. They said it was the first one anyone could remember and it had come about because the family of the deceased resident asked if it could be at the facility, as the family was not religious and this had been the resident’s home. It had been a small service followed by an afternoon tea and participants said it was nice for the staff and family to meet and reminisce about the resident.

I read to the group, sections of the minutes of the recent RNs’ meeting that I had attended. The issue of grief and debriefing prompted the participants to discuss how they would like future debriefing sessions to be organised. Participants said they wanted a regular debriefing, but not too frequently, for example, three monthly would be optimal and that those staff who wished to attend could do so, but that it should not be compulsory attendance. Suggestions for the format of the meeting included a small service, for example, lighting a candle and
informal discussion of issues surrounding the death, or a focus on celebrating a resident’s life.

During the reading of the RNs’ meeting minutes, I told the group the RNs had discussed the issue of “Whose needs are nurses meeting?” when delivering end of life care. This issue prompted Gloria to discuss a resident, who had recently died, over many days. Gloria said she had gone into the resident’s room and saw the resident’s daughter sitting alone with her mother. Gloria said she decided to play music and, as it turned out, it was dolphin music. This action was intended as a kind gesture for the resident and her daughter, as Gloria said she felt sorry for the daughter, as her mother’s death was taking a long time. We discussed reflective journaling and I asked Gloria to think about nurses’ end of life practices and if they are for themselves or the resident and their family. Gloria thought she would examine this further and think about whose needs she was meeting in her end of life care delivery for that relative.

The RNs’ meeting discussions on the MDT meetings prompted participants to assert the RN was charged with the responsibility of facilitating the MDT meeting, to make it more organised. Participants said a RN had a habit of asking staff at very late notice to present resident cases, and also that she did not contact relatives to identify if there were any issues for discussion at the meeting. The RN’s usual workload was thought to contribute to her disorganisation and the facilitation of MDT meetings was thought to create a lot of extra work for her. Gloria said she refused to present a resident’s case, as she received a note on a Sunday to present a resident on the following Monday, and this time frame was too short for her to get organised. Drew said the RN who coordinated the MDT meeting was changing her rostered days and that she would be replacing her in
the meetings. Drew said she did not know what would be expected of her at the MDT meetings. Paris said she had been involved in presenting low care residents at the meeting since its inception and had always followed Katherine’s instructions on presenting, as previously Katherine had been the facilitator of that meeting. The group discussed how a local doctor had said he found the MDT meeting too intimidating and, therefore, did not attend and that another doctor was available on teleconference, but had never participated.

Participants developed a list of goals they felt would be useful to improve the function of the MDT meetings, in particular, those issues relating to end of life care, which included:

Releasing staff to ‘sit in on’ the meeting, to observe how the meeting was conducted, to enable staff to present residents’ cases in the future.

Organising a list of residents’ cases to be presented at the meeting and circulating it at the beginning of the month (MDT was usually held at the end of each month).

Circulating the issues form at least a week before the MDT meeting and ensuring issues were relevant to the MDT meeting.

Improving contact with relatives before the meeting. Administrative staff could perform this function, however, the workload could be problematic (No resolution was reached on this issue).
Critiquing the nurse’s presentations, to determine if the case presentations at the meeting were effective and achieved the desired outcome, for example, in organising end of life medication prescribing, or pain relief.

Approaching the current RN facilitator, to determine if she wished to continue having the responsibility to be a facilitator and organiser of the MDT meetings.

I asked the group how they would know if someone dying is receiving adequate pain relief in end of life care. Following a short discussion, the participants decided to review a deceased resident’s case and present the findings to the monthly group meetings, and if appropriate, to follow up with a facility wide presentation.

Following the reading of the minutes the group agreed the most likely constraint in continuing to achieve good pain management outcomes for residents would be waiting for the RNs in the facility, excluding Drew and Jackie, to become involved in developing practice changes. I asked the group to choose between accepting the status quo and, therefore, no longer meeting, or to continue meeting as a group and progress the planned practice changes. The group discussed the issue and agreed they would like to see further improvements in end of life care continue and to work towards addressing other clinical practice issues into the future. Therefore, it was agreed that to continue to sustain improvements made by the group so far, the meetings would continue on a monthly basis with the role of meeting chair being shared between participants, to enable each to gain some leadership experience. Lindsay volunteered to chair
the next meeting, where the RNs’ meeting endorsed, that the end of life pathway draft would be amended further.

Five participants attended meeting 18, which commenced with Drew informing the group that she had been off work unexpectedly since the last meeting and that the PDA had been in her locker for safe keeping during her leave. Participants discussed the need for the PDA to be accessible to the nurses and Drew agreed in the future the PDA would be left in the treatment room with the laminated instruction sheet. Drew also agreed to periodically check the PDA was plugged into the power and charged when not in use.

The group briefly read over the key aspects of the previous meeting and all participants said they had given a RN the pain management academic detailing handout, but as yet no participants had received feedback.

Improvements for the MDT meeting were discussed by participants. Most of the issues remained unfinished, so it was agreed to revisit the goals in a future meeting. The final versions of the opioid formulations and the complementary and alternative therapies in pain management posters had returned from the printer and Jackie agreed to display the posters in a prominent place in the treatment room (CD1).

Participants carefully went through the end of life clinical pathway using a process mapping approach, to identify any areas that could be a problem during the planned trial of the pathway. Participants used a case scenario while reviewing the pathway. The example used was:
A resident is diagnosed as dying at 10 am on your shift and is in pain. Try to think about how the pathway would work for them and how to manage their pain.

Participants carefully read the pathway, word by word, and changed sections to suit local requirements. During this process, participants discussed who was responsible for diagnosing dying. It was generally thought that dying was often not diagnosed well, as some residents in aged care may die over a long period of time, for example, a participant said a resident had been dying in the facility for 2½ years. I suggested this example was more likely to be a resident suffering acute illnesses on a chronic condition and represented the slow decline that can result from chronic diseases. Participants agreed it was important to leave the information on the stages of dying on the front page of the pathway, to alert staff to consider the stage of a resident’s dying.

Participants discussed the optimal location for the pathway and suggestions included it could be kept at the bedside, or with the resident’s medication charts. No resolution was reached, therefore, the group agreed the issue would be discussed further, closer to the trial of the pathway.

Participants also discussed who would be responsible to ‘sign off’ each shift on the pathway. Paris felt that some staff in the facility did not acknowledge or know who the senior staff were on each shift. Jackie said this issue was to be clarified when the new model of care for the facility was implemented in the near future.
Jackie said the adjusted pathway should go to the Centre Quality Improvement (CQI) meeting the following week. Jackie agreed to present the pathway (CD 1). In addition, a copy of the pathway was to be sent to the local doctors with a covering letter, to inform them of the pathway’s trial in the facility (CD 1). This method of distributing the pathway was chosen, as the next planned MDT meeting was some time away. I agreed to assist in developing a draft letter for the doctors and submit the draft to Jackie. Jackie said she would take the pathway to all facility meetings, to inform staff that it was being implemented. Participants agreed to trial the pathway with three residents and then conduct a review/audit. It was planned to survey family and staff following the pathway trial and to distribute a report on the findings.

As the meeting ran over time, it was planned for the draft pain policy to be distributed for further discussion next meeting (CD 1). Jackie volunteered to do a case review pre pathway implementation, so that end of life care results could be compared before and after the pathway trial. I gave Jackie 10 copies of the ‘Knowledge & Attitudes to Pain’ survey, for distribution to the RNs in the facility and participants were reminded that the ‘Grief and Loss’ presentation was planned for two weeks time. The group agreed to reconvene in one month and Paris volunteered to Chair that meeting.

Journal Entry, 01.10.08

The National Association for Grief and Loss (NALAG) session was held at the facility. Approximately twenty staff attended including staff from cleaning, laundry, gardening, RN, EN and personal carers. Two facilitators, one of whom was an overseas psychologist who
was completing two years of supervised practice for registration in Australia, led the discussions. Attendees participated, contributed, and openly discussed their issues resulting in a number of stories emerging.

Prior to the meeting, the Director of Nursing discussed with the NALAG facilitators and me about the 15 recent deaths over a three-month period in the facility and that she felt this was taking its toll on the staff. She said she had noticed recently that staff had been bickering behind each others’ backs and that some of the staff were particularly upset. Katherine gave the example of a young female who had come to her office crying, because when she went to the tea room, everyone had stopped talking. The girl thought the staff had been lying when they said they weren’t talking about her.

During the grief discussions, staff disclosed personal loss and grief and the impact residents’ deaths in the facility had been having on them. For example, a participant said she had been recalling the traumatic death of her mother, who had attempted to jump out of a third floor window, due to uncontrolled pain from ovarian cancer. The participant discussed how her father had remarried and had left two teenage daughters to fend for themselves, and she was one of them. This participant then spoke of her own divorce and the trauma this had caused in her life, but told the group that ‘the straw that broke the camels back’, that helped her to make her mind up to leave a Sydney aged care facility, was when a resident’s finger was broken when a staff member stole an engagement ring.

The participant also said she connected with the issue of avoiding some residents who had been dying, as her mother had been skeletal when she was dying and a resident in this facility of whom she was very fond, was also skeletal and therefore she was avoiding her to avoid the
painful reminders of her mother’s death. The participant felt her co-worker had most likely sensed her avoidance of that resident who was skeletal and that she thought her co-worker knew this was why she was reacting, but told the group they had not actually discussed how she had been feeling until now. The co-worker told the participant that she did not realise any of the issues being discussed were a problem and said she was surprised to learn how she was feeling about the resident’s death.

I wonder if ‘we’ are one of the major barriers in end of life care, our inability to recognise we are the only ones who know how we are feeling. We have the power to control what happens, that is, we can tell others of our distress. We cannot rely on others to sense our distress, so we must assert ourselves and ask for assistance.

The trauma of admitting residents into the facility was raised by a RN, who told the group that the worst part of everything, even death, was when residents were being admitted into the facility. She spoke of a resident crying all the way to their room when being wheeled into the facility for admission. It made me question: Are aged care facilities a place for the living, or a place for the dying? Do we need to stop pretending that we all know aged care is the “last stop”, and make that clear to the staff, the resident, and their family? Rather than calling aged care a place of living, perhaps acknowledging the facility as the inevitable place of death, may assist nurses to understand they have a responsibility to deliver appropriate care to residents, so that they can have a dignified, ‘pain free’ exit.

The emotional turmoil around caring for a dying resident that some staff experienced was discussed by a carer, who told the group that she had cried when she met a relative of a resident she was very fond of in the corridor of the facility. She told the group that she cried
again at the bedside and cried later at the “drop of hat”, on and off that day. All agreed the recent death of a favourite resident and a favourite volunteer had had a big impact on them.

The NALAG facilitators asked participants about strategies they used to overcome the grief they felt in a day. One participant talked about being told to open their car window and throw out all the “pain and problems” of the day on their way home. Another participant said a long drive home helped to work things out in her mind. Some participants said their partner was someone with whom they shared, while others said they either did not have a partner, or chose not to share with them. Other participants spoke of using walking or gardening to feel better.

The session ended with Katherine telling the group that the facility would hold a formal grief and loss meeting every six months, as she felt this would be good for staff. A staff member said more frequent meetings would be better, but it was decided as NALAG was accessible to staff by phone, that a six monthly meeting would be adequate. I was thinking about the person asking for more frequent meetings. I hope she takes advantage of the free counselling available through NALAG. I guess at some point nurses have to take responsibility for their own self care. I feel satisfied the offer has been made to assist them in their personal journey, or at least those participants are now aware help is out there for them.

Journal Entry, 09.10.08

Jackie and I reviewed two deaths in the facility today, to use as a pre and post pathway comparison to hopefully demonstrate the pathway is an improvement. The review took about one and half hours. I pray the pathway helps, as in both reviews the residents had untreated
pain until the last 24 hours of their death and yet all the signs of pain were there prior. Why
don’t the staff understand that waving arms, and calling out, equals pain? Are some nurses
just going through the motions, no thinking - just task orientated?

The Abbey Pain Scale had been used and scored, but not acted upon. What are the gaps
in connecting the scores to action? I think Jackie was embarrassed when we realised the lack
of action. Bowel charts were signed off until the day of death like an obsession and yet pain
was not treated and assessments were missed. Deep inside I am thinking: “This should be
better!” All these residents ask for is comfort at the end of their life; they even fill out an
Advanced Care Directive, but why bother? If staff are failing to identify dying, when the pain
medications are ordered (as demonstrated in both cases reviewed), but no one administers the
drug, why do we even pretend to allude to our ability to offer a ‘good’ death? It can’t happen
unless the nurses are willing to make it happen. Why can’t some see impending death and why
aren’t some nurses willing to make a ‘good death’ happen?

On completion of the case reviews, Katherine and Jackie gave me a tour of the facility.
Views of the ocean were magnificent from most rooms. The residents were having lunch. The
facility was very clean, tidy, music playing, but no conversations by the residents seated at the
dinner tables, just vacant looks at the passers by. Is this living, or is this dying, in aged care?

All participants attended meeting 19. Paris had volunteered to Chair the
meeting, but was running a little late, so Drew agreed to Chair. Both Drew and
Jackie thought that more PDAs would be helpful to guide end of life care. I
reinforced the idea that the distribution and comparison of pre and post surveys
was vital, before deciding to invest in more PDAs.
The recently displayed pain posters were discussed by participants. Drew felt the posters were useful as a quick reference source and Katherine had commented the Complementary and Alternative Therapies in Pain Management poster was “too busy”. Participants discussed this point and agreed, as the poster was based on the Australian Pain Society Recommendations, that no further action was required to be taken to adjust the posters.

The group said they had not followed up on the pain management academic detailing handout to the RNs. Therefore, it was unknown if the handout had been read by the remaining RNs, to whom it was distributed.

Jackie reported that no staff had accessed the pain management CD, including any new staff. Jackie said: “Things may develop from the next RNs’ meeting”.

Gloria said she had thought about the question of whose needs are being met in end of life care and said: “I got the CD player then asked” the family. She realised she prompted the situation and that they may have complied through politeness. We discussed the purpose of reviewing care was to assist each person to reflect on their end of life practices and examine why they act they way they do, and how they might act differently.

The discussion was directed toward planned actions, aimed at maximising end of life care at MDT meetings. Jackie said staff had been released to sit in on the meeting to observe. Participants reported that the meeting had been useful and said they would like to sit in on more meetings and felt they would be contributing to the discussions in the future. Jackie reported the intended
circulation of the list of residents at the beginning of the month to be presented at the meeting was not happening. She said the staff of one of the doctor’s surgeries had pulled out of the meeting that month, however, staff had insisted the meeting be held for one new resident, who had been admitted. Participants said that the issues list circulation was improving, but that there had been a mix up and it was not taken to that month’s meeting. Participants were unsure if relatives had been contacted before the meeting. Drew suggested a critique sheet would be useful for the MDT meetings and Paris would review and adjust a draft. Jackie discussed the facilitation of the MDT meeting and told the group that the current facilitator would be changing, as the RN who was facilitating had told her that the meeting was too much work for her.

Jackie reported the members of the CQI meeting had given the end of life care pathway positive feedback. Two doctors responded to the circulation of the pathway and had agreed it would be appropriate to use in the facility. Jackie reported the Division of General Practitioners palliative care RN had commented that the referencing on the pathway should be changed. However, the group agreed the referencing on the pathway was correct. Participants agreed the pathway, when used, would need to be located at the nurses’ desk on a clipboard. Jackie felt the RNs would be responsible to oversee the dying resident’s care and, therefore, would have to double sign off the pathway at the end of each shift. The carer was to sign off on care provided during a shift. Jackie reported that the pathway had not been commenced, as currently no residents were in the dying stages. The current family survey distributed after a resident’s death was reviewed and a decision was made to include other aspects of end of life symptoms, including breathlessness, pain, anxiety and agitation.
Questions would also be added that included communication with the doctor and staff. It was agreed that a draft would be organised for next meeting.

The end of life pathway policy from the health service was reviewed and minor adjustments were requested. Participants said they would like to finalise the policy at the next meeting.

Recently completed case reviews were then discussed by participants. It was planned to compare these reviews as pre end of life pathway care with post end of life pathway care. Issues identified pre pathway included untreated pain and pain scores not acted upon, despite analgesics being ordered. Participants attributed untreated pain to pain scores not being handed over shift by shift.

The inclusion of a complementary treatment section on the draft pain policy (CD 1) was discussed and a decision was made to adjust the draft and finalise the policy by the next meeting.

Jackie returned five completed ‘Knowledge and Attitudes to Pain’ surveys. She said there were six surveys yet to come.

The submission regarding the research project had not appeared in the facilities newsletter. Jackie requested the overview be sent to her by email again.

Participants reported that the feedback on the grief and loss presentation given by NALAG had been positive. Jackie said the NALAG brochures had been distributed in the facility and that she had attempted to obtain the advertised grief and loss DVD, but was unable to locate it. I said I would attempt to obtain
the DVD for the facility. The meeting ended with Paris agreeing to Chair the November meeting.

Georgia, Jackie and Paris attended meeting 20. Paris agreed to Chair the meeting and followed the prepared agenda. Paris said Drew and Lindsay had sent their apologies. No pre use personal digital assistant (PDA) surveys had been received. Jackie said she would arrange for Paris to use the PDA on medication rounds.

Jackie reported the Pain Management CD was reported by a staff member as not playing. I had recently collected and checked the CD and had found no problems with running the CD on two different computers. Jackie said she would check the staff member was up-skilled in using the CD on a computer.

Overall, participants said they felt the functioning of the MDT meetings was improving, however, the resident list circulation and contact with relatives prior to the meeting still required improvements. Participants reported there had been good follow through by the facilitator and that staff had been more confident reporting at the meeting. Lindsay had attended the meeting as an observer and said that changing the day the meeting was held was an improvement, as extra staff were available to attend or back fill those who did attend.

I presented two MDT meeting critique sheets. One sheet was to critique the actual meeting, to determine the meeting’s efficiency and function. The second sheet was to outline the process of presenting residents’ issues (CD 1). Jackie said she would review and feedback to me on the meeting critique sheet. Paris
suggested additions and deletions to the resident sheet. Participants said the agenda for the MDT meeting was a similar format to the sheet currently used.

Jackie said the end of life pathway had been used for one resident; a second resident had been commenced on the pathway, but had improved and was taken off the pathway. Participants discussed the importance of diagnosing the stages of dying appropriately. A third resident had been commenced on the pathway. An audit was planned when three pathways had been used. Jackie reported locating the pathway at the nurses’ desk was working, but there had been a few problems related to who was signing off on care and the RN double signing the care provided.

I presented the draft end of life pathway policy. Jackie said the group would review and feedback in the New Year.

Paris suggested the research group’s end of life information could be collated into an ‘End of Life or Palliative Care’ folder for staff. Laurie stated it would be used for the accreditation purposes and would that it should contain policy, brochures and the end of life pathway.

Additional questions for inclusion in the survey relatives received following a resident’s death were distributed to the group. The aim of the survey was to determine relative’s satisfaction with care. Jackie said the new additions would be discussed with the Director of Care.
Current Survey Questions:

Were the care needs of resident met?
Did you feel that the resident’s privacy was respected?
Did you feel that the resident’s dignity was respected?
Were the resident’s financial arrangements handled appropriately?
Was the staffs’ manner professional toward the resident?
Was the staffs’ manner professional toward the relatives?

Planned New Additions:

Did you feel the resident’s symptoms were adequately managed in the final stages of dying?
Did you feel the communication regarding your relative’s condition at the end of life was adequate? If not, what would have helped?
Did you receive sufficient end of life care information, both verbal and written?
Were you provided with bereavement support information?
Would you like to raise any issues?

The group agreed it was important that the end of life care case reviews were to be compared as pre end of life pathway care with post end of life pathway care, when three pathways were completed in the facility. The final version of the pain policy was distributed to participants. Changes were italicised in the document for easy identification. Participants were asked to feedback to me through Jackie on any final changes to the document.
Jackie returned one more completed ‘Knowledge and Attitudes to Pain’ survey. I told her that if we had two more completed surveys, it would allow a direct number comparison, when I presented results in the New Year.

Jackie reported that the newsletter submission regarding the research project was received, but had not appeared in the facility’s newsletter. Jackie said components of the submission had been used for accreditation with the document completed and faxed to head office. Jackie reported the submission had resulted in not as many issues with head office and it was quick and focused. We discussed the importance of celebrating staff improvements and achievements, to maintain interest and momentum within the working group.

Jackie said the ‘Grief and Loss’ DVD had been in the ‘Managing Loss in the Workplace’, Work Cover booklet. I said I would follow up on locating the DVD for staff to view.

Participants agreed, as the year was coming to an end, there would be no further meetings until the first month of the following year. Planned presentations for the New Year were discussed and these included: results and answers to the ‘Knowledge and Attitudes to Pain’ survey; the end of life care pre and post pathways audit results; and a presentation by an expert on spiritual aspects of end of life care. Participants agreed on a date to meet and that teamwork would be the next issue to address. Gloria volunteered to Chair the meeting in the New Year.
I am interested in how, compared to Facility One, the issue of sustainability of the practice changes in Facility Two has become less of an issue. What a relief! I want these changes to be sustained after I exit the facility. Participants are demonstrating a determination to improve end of life care, despite a number of hurdles, not least of all, a lack of engagement by the RNs in the facility. As the workforce is remaining stable and participants in the group are not changing, only increasing by one RN, the monthly meetings continue and the staffs’ commitment to improving end of life care is being sustained. Is that one of the keys for end of life care practice improvements? Regular, structured meetings that have permanent, committed staff attend, who know they have management support?

This section described the processes and discussions of critical reflection on action. The challenges and benefits of generating and applying an action plan to maximise nursing care practices to improve aspects of end of life care to residents dying from non malignant disease were described.

Summary

This chapter provided a description of the main aspects of each meeting taken directly from the minutes of the meetings, which were verified weekly by participants. The six main phases of the research in Facility Two were: 1) foundation building, 2) reflection on practice stories, 3) learning from the relatives 4) identifying thematic concerns, 5) action plan creation and implementation and 6) critical reflection on action outcomes.
The primary end of life care thematic concerns identified by participants and influenced by relatives’ issues of concern were pain management practices and grief and loss issues. Participants worked together to address the complex issues in the delivery of end of life care, to residents dying in the facility. Participants improved pain assessment practices at end of life, by including pain assessment in clinical auditing, standardising and improving access to pain assessment scales, and improving communication of pain assessment information between staff.

Pain medication knowledge was addressed by improving access to pain educational information for staff, residents and relatives. Nurses’ knowledge and attitudes to pain was surveyed and reassessed, to determine the impact of improvements on RNs’ knowledge and attitudes. Experts, such as a consultant pharmacist, were sourced to provide medication education, medication posters were developed, pain policies were revised, case reviews were conducted, and an end of life pathway was implemented, to improve and document end of life care.

Staff grief and loss issues were addressed, by discussing the effect of grief and loss on end of life care delivery, engaging grief and loss experts and improving staff access to counselling services. These sessions provided staff with a forum to discuss the effects residents’ deaths were having on them, and to share end of life experiences.

Participants found the action orientated meetings beneficial and planned to continue meeting to develop nursing care improvements, which would maximise the likelihood of a good death for dying residents in their care.
CHAPTER SEVEN: DISCUSSION AND CONCLUSION

This chapter discusses the thematic concerns and associated issues that emerged and the insights and implications that arose from them. Major thematic concerns in Facility One included debriefing and medications related to pain management. The major thematic concerns in Facility Two included pain management and education. The use of reflection on practice stories and group discussions assisted the nurses to identify issues of importance to them and explore the processes of improving end of life care practices. The thematic concerns identified in interviews with relatives, are also discussed to highlight the insights they provide into end of life care. The chapter offers research insights, implications and practical suggestions for improving end of life care, and concludes with a discussion of limitations of the project, suggestions for further research and a project summary.

Thematic concerns were those issues common to each participant and were prioritised to be addressed first, in the action planning phase. Themes identified in the research were categorised according to the issues that participants identified, following review of the practice stories shared in the research group meetings. The themes assisted in identifying the issues of importance to nurses and relatives in the care of the residents at end of life, the barriers to delivering optimal care, and the relationships of the nurses with relatives of the dying residents. Thematic concerns and associated issues, which emerged in both facilities are discussed in detail in this chapter. A complete list of all the issues is located in the Appendices (See Appendix I, Appendix J).
The major thematic concerns that emerged in both facilities included: debriefing, to a lesser degree in Facility Two, and pain management in both facilities. Debriefing consisted of two sub themes: (i) grief associated with caring for the dying and (ii) identifying strategies to address grief. Pain management consisted of four sub themes: (i) nurses’ medication knowledge, (ii) pain assessment, (iii) doctors’ medication prescribing practices, and (iv) relative’s expectations. The associated issues identified included communication with the relatives, nurses’ language and palliative care education.

Debriefing and Grief

This section discusses literature related to the issue of debriefing and grief, and strategies to address grief within the context of the participants’ practice stories. As part of the action research process, which explores literature related to issues, as they arise, a search was conducted of databases CINAHL, Ovid Medline, PsychINFO, EMBASE, PubMed and Proquest, using various keyword combinations, including ‘grief/death/loss/nurses/grief resolution/debrief/nursing homes/aged care facilities and residential aged care’. Three hundred and ninety three articles were identified, and of these, 28 were linked directly to the topic area. Key articles are discussed in this section in relation to the research participants’ concerns about debriefing.

Nurses are exposed to death on a regular basis in residential aged care facilities, because death is the major reason for separation of residents from permanent residential aged care. Death equates to 88% of separations from residential aged care, with 45% of those who die being cared for from one to five years in the
facility in which they die (Australian Institute of Health and Welfare [AIHW], 2008). Nurses in both facilities discussed the need to debrief following residents’ deaths and the length of time residents may be in care prior to their death. The effect of residents’ deaths on the nurses did not necessarily correlate with the length of time the resident had been living in the facility prior to their death. For example, a participant in Facility One discussed never forgetting a newly admitted resident’s death and a participant in Facility Two discussed the importance of getting to know the family and resident’s history intricately, as the length of stay was widely variable from “six weeks to six years”. Participants in Facility Two viewed their facility as the “last stop” and said “Everyone you look after passes away” and: “All the residents are going to die. The residents here are not going anywhere else”. The degree of exposure of aged care workers to death and dying supported the decision by participants in Facility One’s research group to explore the issue of debriefing. The need for debriefing is supported by Brunelli (2005), who suggests nurses should work through the grieving process following a patient’s death as a first step toward maintaining their own physical, mental and spiritual health.

Participants in both facilities experienced a sense of loss and reflected on their unmet need to debrief and grieve following the death of residents. MacFie (1996) distinguishes between responses to loss, and refers to bereavement as an “objective state following the recognition of loss”, grief as the “subjective mental state, resulting from that bereavement” and mourning as the “processes through which grieving response is attenuated and adaption occurs” (p.48). Death is not the only reason people experience grief. Elkington (2000) describes grief as a reaction to a range of relationship losses, such as death, but also includes the loss
of health, the loss of a human or animal relationship, or the decline in a relationship once shared with a person.

Participants expressed a sense of loss as bereavement, grief and mourning, reflecting their connection to the deceased resident. Individual responses to loss are variable and people grieve in their own unique way, however, professionals can feel the pain of others. Buckman describes this pain as “sympathetic pain”, or the pain a professional can feel when caring for others (as cited in Read, 2002, p. 51). In the group discussion following the role play debriefing session, a participant discussed the need to analyse and deal with emotions following a resident’s death. She said: “The emotions can burst out in an unhealthy way in our personal relationships, or our relationships in the workplace, and can affect how we function in the workplace and how we function as a team”. When a resident dies, nurses can experience both the loss of the resident and the family’s loss. In order to maintain physical, emotional and spiritual health, nurses need to acknowledge the impact of those losses on their life and identify the most helpful strategies for them to reflect on those losses.

Kellehear (2002) suggests the term grief should not be viewed as a negative concept and blames the negative terms that surround the word grief as the fault of research conducted in the field that has linked grief to loss and disengagement. This view is supported by other authors in the field, who suggest stressors in the workplace can drive practice improvements, engage workers, make work more interesting and stimulate advocacy (Anderson, 2008; Kellehear, 2002; Lugton, 2003). At various stages in the group discussions, participants expressed a strong sense of connection to the residents in their care. For some staff, those connections had developed into close relationships and they
felt part of the resident’s extended family, stating it was hard not to get attached to the resident. The grief participants expressed is reflective of the respect and close bonds they formed with residents. This became evident in the discussion time following the role play session in Facility One, when a RN was discussing the moment of death and said:

“We have protocols to follow, but this may be the moment to sit with that person and this can help our own grief process. There is nothing more satisfying than spending time at those last moments. I just couldn’t imagine dying, without someone holding my hand, just to be there. You don’t have to do anything, say anything. Just to know when you pass, you are connected to another human being”.

The impact of grief on those who care for residents, when they will witness many of those people die, has implications for nurses working in aged care facilities or, in fact, any healthcare worker in end of life care delivery. Participants in both facilities discussed issues around grief, even though they were not always able to explicate clearly the feelings they were experiencing. Grief has been likened to pain, both in the heart and the soul and is said to effect people’s emotions by numbing or suppressing their emotions (Kuhl, 2005). By raising the profile of the effects of grief on an individual and the potential impact on care delivery it is clearly desirable to address the issue. Assisting aged care workers to identify feelings, emotions and actions surrounding death and dying encourages reflection on self and practice and facilitates the development of strategies to address unresolved issues.
Grief has implications on the health of bereaved persons, including their emotional, physical and social wellbeing. There are various models that assist to understand grief, however, individual responses to grief are variable (Carrington & Bogetz, 2004). The effects of grief on people vary through a range of associated feelings and can include feelings of sadness, heightened emotions, anger, guilt, anxiety, helplessness and relief (Crisp & Taylor, 2005; Elkington, 2000; Hoff, 2001; MacFie, 1996; Worden, 1991; Wowchuk et al., 2007).

Feelings and emotions associated with grief were expressed by the majority of participants in both facilities, in relation to the dying and their feelings toward relatives. For example, a participant described a relative’s behaviour as demanding and said the relative was “always difficult” and “demanding”. The participant told the group that the relative’s demanding behaviour increased in the last 48 hours of the resident’s death and yet showed no understanding of the behaviour, in relation to the possible grief and anxiety the relative may have been experiencing at that time. Grief and anger were also emotions discussed by participants in relation to themselves, their interpretation of residents’ behaviours following admission into residential aged care, and by relatives following admitting their partner, or family member into care. An opportunity to engage their peers in debriefing sessions was a source of encouragement for participants, as the effects of grief were not thought to be unique to only those staff participating in the research group. Relatives also discussed mixed feelings, including feeling they had let their partner down, or gone back on their word following the admission, combined with relief that the physical aspect of caring was over.
Grief can manifest physiological changes, including effects on the respiratory system, demonstrated by tightness in the throat or chest and breathlessness, digestive disturbances such as loss of appetite, insomnia, fatigue, exhaustion and lack of energy, and other manifestations, such as dreams, restlessness, weakness, and loss of libido (Carrington & Bogetz, 2004; Crisp & Taylor, 2005; Elkington, 2000; Hoff, 2001; MacFie, 1996; Worden, 1991). Participants in both facilities discussed experiencing aspects of the physiological symptoms of grief. For example, in Facility One, a participant spoke of the difficulty s/he faced following the death of a resident and how this became such a problem for her/him at the time, that s/he was considering leaving the employment. S/he said the memory of the resident’s death made her/his working life so difficult at times that s/he was having to drag her/himself out of bed, just to go to work.

Participants in Facility Two discussed the physiological symptoms of grief in terms of the burden of end of life care and how this exhausted them, using terms such as needing to be “re-energized” and “feeling weighed down.” For example, the burden of care was represented by a participant in a reflective drawing depicting a person sitting in a hunched position, with their head in their hands, and a frown on their face. A lifeless body was draped across the sitting person’s shoulders (See Figure 6.6: Liz’s drawing used for reflection).

Relatives also discussed the physiological symptom of insomnia they were experiencing following the admission of their significant other into aged care. For example, a relative said:
“Even after three months or four months you still can’t sleep, because you hear them calling through the night, and you’re out of bed and into his bedroom, and there’s no one there”.

The impact of transitioning a family member into an aged care facility has been documented as a major stressor by Hebert and Schulz (2006), who identified relinquishing the role of caregiver as a risk factor for the development of clinical depression. Davies (2005) and Pearson, Nay and Taylor (2003) also identified that the experiences of admitting a relative into a nursing home can not only alter the life of the resident, but may also alter the quality of life for the relinquishing caregiver. A period of grieving is considered normal, however, professional psychological support is considered necessary for people who display prolonged grieving behaviours, or develop physical or psychological dysfunction resulting from the loss (Potter, 2006).

The social effects of grief include withdrawal from interactions with others or irritability, inability to feel or express warmth and adherence to automatic routines (Crisp & Taylor, 2005; Elkington, 2000; Hoff, 2001; MacFie, 1996; Worden, 1991). The impact of grief on the social interactions of many of the participants was evident in their discussions. For example, a participant spoke of attempting to speak about aspects of a death with their partner, but felt that “unless you go through it (death), you don’t understand it”. This participant also described feeling “alienated” and “not fitting in anywhere”. Another participant discussed loneliness as a response to death affecting all those involved in end of life care, including the resident, the staff and the family. Many nurses fail to appreciate the effect of grief on their lives and the necessity
for self care. Seeking support, such as participation in a debriefing, may stimulate self reflection and identification of strategies to maintain self care.

Anderson (2008) identifies grief as a contributing factor in burnout and an indirect influence on turnover rates of certified nursing assistants in aged care. Participants’ working lives in both facilities ranged from short term experience (seven months) to more than 15 years experience. Interestingly, the length of time people worked in aged care did not necessarily correlate with the impact a resident’s dying and death could have on them. Therefore, the research groups decided to implement a debriefing session strategy to raise the profile of, and discuss issues around, death and dying, because they felt that all staff had the potential to experience grief issues, regardless of how long they had worked in the facility. Given the likelihood of experiencing loss and grief in the course of their employment, debriefing was considered essential for all staff. This is in line with Back (2006, in Meier and Beresford, 2006), who warns that burnout in palliative care is not confined to staff who work for a long time in settings where people die, where staff have high expectations of themselves “to transform clinical situations” (p. 1046).

Past losses can influence how people respond to present losses. Worden (1991) identifies six categories that determine how individuals experience loss and grief, in relation to past losses, including who the person was, the nature of the attachment, the mode of death, historical antecedents, personality and social variables. The influence of past losses became evident in the research groups when participants in both facilities were asked to complete a reflective exercise in the first meeting. This exercise required participants to firstly think about those people who influenced their childhood. A number of participants described the
losses they had experienced in their childhood as examples of the influences. For example, Eileen in Facility One, described a need to belong, depicting herself as an insecure child, who was raised in an orphanage with an older sister until they were fostered. She recalled being hungry enough to “suck on white shoe cleaner” in the orphanage and being cared for by nuns. The participant reflected on having issues with “abandonment” and separation from her sister. Another participant in Facility One discussed how the reflective exercise had triggered her to recall people of whom she had not thought for a long time. One of those people was her father and she told the group she remembered being “very happy until Dad left”.

Weiss (2001) proposes that grief can be sustained indefinitely in those people, who experience the loss of a relationship, such as a child, parent, or partner. If the experience of past losses is viewed as a negative experience, there is potential for all losses to be viewed in this context and, therefore, previously learnt responses to loss may influence how a person responds to present losses. Participants hoped that by implementing debriefing sessions staff would be encouraged to share their experiences and responses to loss, feel supported and appreciate that those feelings of loss can be shared by others.

Caregivers have also been identified as a high risk group for prolonged psychological stress when they experience multiple losses (Strom-Gottfired & Mowbray, 2006). Kastenbaum (1969, in Worden, 1991) coined the term “bereavement overload”, to describe the experience of multiple losses, in which the volume of people who must be grieved over becomes overwhelming (p. 85). Nurses awareness of the effect of multiple deaths on them is necessary, to avoid bereavement overload (Crisp & Taylor, 2001). Participants were aware of the
number of deaths they experienced in the workplace, however, their responses in their communication and behaviour did not demonstrate they understood the complexity of the emotions they were experiencing or the connection to their place of work.

LaPorte Matzo, Witt Sherman, Lo, Egan, Grant and Rhome (2003) refer to multiple losses in the health care setting as “cumulative loss” and suggest that nurses in some settings do not have sufficient “time to resolve the grief issues before another patient dies” (p. 73). The need to resolve grief issues was discussed by a participant in Facility One, who said: “Staff need to reflect and think about what their emotions are saying after the death, a time to recover”. Therefore, nurses can feel challenged to meet the emotional needs of residents and their significant others through the dying process, if they themselves are not given time to grieve or are not comfortable with their own feelings and emotions regarding death (Hoff, 2001). The development time for drafting and planning the debriefing session provided participants in Facility One with an opportunity to further reflect on the issues around loss and grief and examine their thoughts and feelings around death and dying issues.

A dilemma for many aged care workers is deciding how involved they should become with those residents, who they know will die. Strom-Gottfried & Mowbray (2006) acknowledge that the process of developing relationships with people, who are dying and their relatives, can be challenging personally and professionally for all health care workers. Therefore, caregivers may use distancing behaviours to protect themselves from the people with whom they are caring (Lugton, 2003; Strom-Gottfried & Mowbray, 2006). Distancing behaviours are described by Lugton (2003, p. 121) as “talking to colleagues instead of to
patients or unconsciously controlling communication with patients and relatives, so that people have little opportunity to express their real fears or negative feelings, such as anger or depression”. Lugton (2003, p. 121) suggests these strategies are used by nurses to protect themselves from “over-involvement”.

A participant, Celeste, acknowledged the importance of engaging with residents, when she commented: “We rob ourselves by not allowing ourselves to fully engage with residents”. However, Celeste also expressed how past experiences and a nurse’s own fears were valid reasons for not wanting to engage with residents and said: “It can be so awful to go there” saying further: “You can open a flood of grief”.

Participants in both facilities discussed being mindful not to take on undue stress in end of life care and protecting themselves emotionally when residents are dying. Self protection was described by a participant, who told the group that when a resident is close to death she takes a “step back a bit”. The impact of nurses trying to protect themselves from death and dying can affect the relationship with the dying person and also the communication with the relative. For example, a participant described as “confronting”, bringing up the topic of end of life with relatives and described relatives as being “blind” to end of life decisions. Issues with communicating and sharing information with relatives at end of life was a theme that emerged primarily in Facility One, where some nurses expressed feeling pressured by families to share information, avoiding talking with relatives regarding end of life and being suspicious as to relatives’ motives for wanting information. A debriefing session assisted the nurses to raise the problem of communicating information and discuss ways in which practices could be improved or changed.
The majority of people experience a normal, anticipated reaction to death and this process follows an anticipated course (Crisp & Taylor, 2005; Zhang, El-Jawahri & Prigerson, 2006). Unresolved grief, pathological grief and complicated grief are a range of labels applied when the grieving process does not follow the anticipated course (Worden, 1991). Worden suggests it is not the labeling of grief that is important, but the recognition of the complexity of the grief. Sheldon (1998) identifies a number of predisposing risk factors for a poor outcome of grief, including when people have experienced a number of bereavements, when there is an element of dependency in a relationship, if the bereaved person has a history of depression or other mental illness, and/or the bereaved person suffers from a low self esteem. When grief is unrecognised or unresolved, Elkington (2000) suggests it can lead to an extension of the negative feelings associated with grief, including feeling helpless, anxious and stressed. Unresolved grief also has the potential to develop into depression (Elkington 2000; Hoff, 2001; Worden 1991).

Doka (2006, p. 6) suggests there is “a cost for caring” and workers caring for the dying have a responsibility to identify and seek assistance to manage their personal needs in grief. The literature broadly supports therapeutic interventions in high risk bereaved individuals, however, the timing of the interventions, the most appropriate interventions and the sustainability of the interventions remain an issue of debate (Schut, Stroebe, Van Den Bout and Terheggen, 2001). Organisations have a responsibility to protect their staff from developing the more complex stages of grief and are, therefore, encouraged to provide supportive environments that foster interventions, such as debriefing (Elkington, 2000). In this project, action planning to discuss issues around death
and dying in the context of a role play that ‘exploded’ the actors responses into melodramatic proportions, encouraged participants to highlight their reactions to death against “normal” reactions and discuss the appropriateness of staff behaviours and actions.

Strategies for Resolving Grief

Grief resolution depends on a number of issues and requires different types of help over periods of time (Silverman, 2002). According to Worden (1991), the need for people to resolve issues around grief drives them to seek assistance. Assistance for grieving has historically been provided by religion based services or family and friends, however, as Western societies have evolved and changed, religion is no longer the only source people seek for assistance, and the connections to family, immediate friends and other networks are no longer core components of community structure for many people to access (Worden, 1991). Instead, people turn to professional health services, such as mental health workers, psychologists, counsellors, nurses and physicians. Other forms of grief assistance include support groups and psychotherapy (Hoff, 2001).

Only one participant, who shared having had a dysfunctional upbringing, discussed receiving counselling previously. Schut and Stroebe (2005) suggest some children may be most likely to gain benefit from grief interventions, or those who experience the loss of someone significant, for example, a parent, partner, sibling or child. However, interventions such as psychotherapy or pharmacology have not been shown to benefit all people who experience bereavement, excluding those with complicated grief. Grief was not labeled as an abnormal reaction to death in the participants’ role play in Facility One,
however, the opportunity to raise the aspect of unresolved or complicated grief can be used as a teaching tool, to improve aged care workers’ awareness of the problem.

The desire to debrief emerged from the nurses’ reflections in both facilities, Facility One developed an action plan to address this issue using role play. Actioning debriefing prompted a participant to express that a debrief session would provide an opportunity to “off load” and she suggested that within the environment of trust and respect, staff would “hear you” and “not miss what you are saying”. Studies support the idea that grief can be resolved, if there is opportunity to acknowledge, feel and express the emotion (Crisp & Taylor, 2005; Hoff, 2001; Kuhl, 2005). There are various strategies to address grief, including improvements in training for death, individuals establishing supportive practices for themselves and institutions supporting workers in establishing death reviews and shared debriefing opportunities, mourning and memorial rituals (Carrington & Bogetz, 2004; Strom-Gottfried & Mowbray, 2006). The timing of interventions in grief has been shown to be of importance, because interventions initiated soon after bereavement are thought to interfere with the usual grieving process and the improvements are short lived (Schut & Stroebe, 2005; Schut, Stroebe, Van Den Bout & Terheggen, 2001; Carrington & Bogetz, 2004).

Facility One had a culture of providing opportunities for staff to debrief. These included an onsite minister, a chapel room, opportunities to attend residents’ funerals and occasional memorial services. In contrast, Facility Two had limited practices to debrief, with participants only discussing funeral attendance on one occasion, infrequent discussions on individual deaths and participants having attended their first memorial service held in the facility at the request of a
deceased resident’s family. The role play scenario Facility One participants developed and conducted was described by the group as a debriefing session, to highlight and demonstrate the difficulties staff could face in providing care to a dying resident, when a team is not functional. The role play scenarios were incorporated into usual monthly training days, to trigger staff discussion on issues of importance to them in end of life care and were conducted on two separate occasions. The necessity for debriefing in aged care facilities is paramount, especially in view of the effects of loss and grief from staff experiencing frequent residents’ deaths.

Elkington (2000) recommends workers in aged care facilities without formal qualifications such as domestic, catering, maintenance, gardeners, office staff and volunteers, should be involved in the planning and implementation of grief management programs, as the lack of formal training in grief management may place them at risk of isolation and feeling unsupported in the workplace. Participants in Facility One involved all staff employed by the facility in the debriefing sessions and discussion time. It became evident in the discussions that staff other than nurses were involved in and affected by dying and death in the facility, for example, cleaners asked a number of questions, as to how to answer relatives’ questions when a resident is dying, and they expressed their concerns over the quick turnover of residents following a death. Kellehear (2002) advocated the concept of creating a supportive community, as opposed to medicalisation of grief and an interventional approach. In my PhD project, participants’ decision to use role play to encourage discussion provided an opportunity for issues to be raised by all facility staff and the “whole team” approach was fostered.
Group sessions to discuss issues related to death and dying are options supported by the framework for managing loss and grief in the aged care industry (Elkington, 2000). In Elkington’s framework, staff needs are identified and assessed either through workshops, interviews or surveys, and action is taken to plan and address those issues raised within the constraints of the organisation. A supportive group meeting can provide many benefits to attendees, including feeling understood, sharing a common language, and being given opportunities to gain new information and learn new skills (Silverman, 2002). LaPorte Matzo, Witt Sherman, Lo, Egan, Grant and Rhome (2003) agree that strategies to assist nurses to move forward in their understanding of issues around end of life care include combinations of formal and informal support systems.

**Pain Management**

The second major theme to be discussed in this chapter is pain management, which consists of four subthemes: (i) pain assessment, (ii) nurse’s pain medication knowledge, (iii) doctors’ medication prescribing practices and (iv) relatives’ expectations of end of life pain management. This section discusses literature related to pain management within the context of the participants’ practice stories. I searched the CINAHL, Ovid Medline, EMBASE, PubMed and Proquest databases, using various keyword combinations, including non malignant/pain/nursing home/residential aged care/nurse*/palliative care and dying. One hundred and sixty eight articles were identified, and of these 41 were linked to the topic area. Key articles from those sources are described in this section.
Chronic pain resulting from a non-malignant disease is common in the older people residing in nursing homes (McClean & Higginbotham, 2002). The Australian Pain Society [APS] (2005) report on residents’ pain in residential aged care facilities, identified “between 28 and 86% of nursing home residents have pain” and that “40% of Australian nursing home residents are totally unable to report pain due to a major cognitive or communicative disability” (p.1). Up to 65% of people dying from a non malignant disease are reported to experience pain (Colvin, Forbes & Fallon, 2006).

Residents’ deaths that participants in both facilities recalled in a negative context, were deaths where end of life care management did not go well. Inadequate pain management and issues linked to pain medications emerged in a number of discussions in both facilities. Issues relating to pain management emerged as concerns for the participants and were discussed as reasons preventing the delivery of optimal end of life care to residents dying from non malignant diseases. The importance of older residents remaining pain free was discussed by participants, for example, a participant stated it was important to “never ignore pain”, stating further: “Part of being comfortable is being pain free and enjoying your final days”. The theme of pain management also emerged in relatives’ interviews, in the context of the relatives trusting the nurses to ensure their significant other was pain free at the end of their life.

Inadequate pain management is an issue of concern in many health care settings across the world. The most distressing symptoms reported by family members, RNs and healthcare aides in the last 72 hours of life, have been identified as pain and dyspnoea (Goodridge, Bond, Cameron & McKean, 2005). Brennan, Carr & Cousins (2007) attribute inadequate treatment of pain across the globe to
“cultural, attitudinal, educational, legal and system related” issues, that have focused on pain as a disease process, as opposed to a quality of life issue (p. 207). Pantilat & Steimle (2004) suggest there are still misconceptions in the health care professions that people dying from non malignant conditions, such as heart failure, do not experience pain, when in reality they may experience pain caused by a range of associated conditions, such as angina, oedema and osteoarthritis.

In both research facilities, the acceptance by participants that some people die with pain reflected a cultural perspective that pain was inevitable for some at the end of their life. Participants’ accounts of residents in pain were discussed in both facilities and participants’ language captured the witnessing of residents’ pain in the course of their daily work. For example, participants made statements such as: “(Residents) come in crying, go out crying” and they spoke of the “agony people go through”, “hearing moaning” coming from the resident’s room, and how some residents “beg you to let me (them) go (die)”. Also, when residents suffering dementia demonstrated pain related behaviour, these were misinterpreted as “acting out” by some staff. When describing her reflective drawing to the group, a participant explained the tears on a face in the drawing were tears of “sadness” and tears of “joy”, as the resident was “out of their pain”. A group response in a pain education presentation delivered in Facility Two described pain at end of life as “unrelenting”, “ongoing” and “emotional pain”. All of these responses demonstrated participants’ awareness of the degrees of pain experienced by residents at the end of their life.

Workplace cultural influences and attitudes are identified as those behaviours that people use to maintain patterns or rituals in their work (Brennan et al., 2007; Taylor, 2006). Jones et al. (2004) suggest the undervaluing of residents reporting
pain can influence a nurse’s response to pain. For example, if the culture of the organisation is to respond to pain when other work is completed, nurses can lose their perspective on the importance of addressing pain issues first. Group discussions in the project highlighted the language participants were using to describe incidents related to pain and thereby assisted participants to examine more closely the meaning of their statements, encouraging critical reflection (Taylor, 2006). The process of reflective critical thinking assisted participants to challenge previously unquestioned assumptions and analyse the meaning of the language and practices used in their workplace (Taylor, 2006). The process of examining practices assisted participants in Facility Two to identify pain management as a major theme, which was prioritised for action planning.

Pain Assessment

To improve and increase a clinician’s awareness of the importance of pain assessment and management, pain is now considered a fifth vital sign (Sherman, LaPorte, Paice, McLaughlin & Virani, 2004; Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine [ANZCA], 2005). Phillips (2007) views pain assessment as integral to the development of an optimal pain management plan. Standardised assessment tools are used to improve the identification and assessment of pain (Allcock, McGarry & Elkan, 2002). However, the failure of organisations to provide standardised pain assessment tools was identified in a study of 65 nursing homes in the United States, where it was found that 75% of those nursing homes did not use a standardised pain assessment tool (Allcock et al., 2002).
It became evident in the participants’ discussions in this project that compliance with conducting pain assessments was variable. For example, a participant spoke of a doctor requesting the “ground work is done before things (medications) are changed”, the ground work being “assessments”. Another participant discussed how doctors would listen to the nurses’ concerns regarding pain if sufficient information was provided. Other indications that pain assessment tools were not used included comments that a preferred pain assessment tool to use in end of life care was the resident’s “vital signs” and “body language”. Poor compliance with using pain assessment tools and a reliance on observation for pain have been identified as contributing factors in the under treatment of pain at end of life (Hanson et al., 2008; Kuuppelomäki, 2002). For example, Weissman, Griffie, Muchka & Matson (2001) conducted a year long study in 87 long term care, American facilities, and their findings demonstrated that pain assessment tools for the cognitively intact and cognitively impaired residents and the need for standardised facility pain scales were two of four pain information deficits that required attention.

The single most reliable method of pain assessment is self report, so this makes the assessment of older people in aged care facilities particularly complex and challenging for nurses, as many residents have difficulties communicating, and/or they misunderstand pain terminology, deny pain, or have anxiety associated with pain (Kuuppelomäki, 2002; Phillips, 2007; Registered Nurses Association of Ontario [RNAO], 2002). Limited or no ability to communicate pain at the end of life highlights the importance of nurses using reliable tools to assess for pain and other symptoms, as it is the nurses who are frequently the primary care providers in the last 48 hours of life (Hall, Schroder & Weaver, 2002).
Pain assessments assist clinicians to identify and determine the type, location, duration and intensity of pain. Assessment can also identify factors that aggravate or relieve pain and any associated symptoms, and assist in appropriate medication prescribing (ANZCA, 2005). Despite all of these advantages in assessing pain, studies have found that cognitively impaired residents, in particular, are under-assessed and under-treated for pain (ANZCA, 2005; Zwakhalen, Hamers, Peijnenburg and Berge, 2007; Hanson et al., 2008). Poor assessment practices may reflect the difficulty nurses face in assessing cognitively impaired residents, despite the availability of a number of specifically designed assessment tools, for example, the Abbey Pain Scale and Pain Assessment in Advanced Dementia (PANAID), or that nurses are choosing not to use the assessment scales available (APS, 2005; Schofield, 2008). The misconception that cognitively impaired people are unable to be assessed for pain and, therefore, impossible to treat for pain, reflects a clinical judgment that fails to recognise pain relief as a fundamental human right (Brennan et al., 2007; Phillips, 2007). Maas, Specht, Buckwalter, Gittler & Bechen (2008b) identify limited training opportunities for aged care staff in the care of the resident with dementia, as a contributing factor in poor pain assessment practices.

Participants in this project indicated they were aware that staff in their facilities had a responsibility to assess pain, however, compliance with this practice was not evident in the discussions. A possible explanation for poor pain assessment practices in residential aged care facilities may be the political constraints operating within the organisations. Taylor (2006, p. 28) suggests political constraints represent the power relationships within organisations, that can affect practice and contribute to a “pecking order” hierarchy. Participants discussed
the difficulties they had in convincing senior staff a resident was in pain. A participant said: “You approach the RN”, telling her or him that “the pain is constant, or more than it should be”. Another participant spoke of problems carers encountered when an RN made a decision that a resident was not in pain, “without seeing the resident” and, therefore, not assessing the resident for pain.

Other discussions focused on the communication of a resident’s pain as being a process of one person “passes it on to the next level”, the next level often being the RN. This process was labeled as a ‘Chinese whisper’ and was thought to be due to the RN rarely delivering the resident’s personal care, and in some instances not seeing the resident on their shift and, therefore, relying on others to alert them of a resident’s pain. The persistence of some staff in trying to communicate a resident’s pain was evident when a participant stated: “We can keep harping”. Facility Two participants labeled the structure they worked in as ‘hierarchical’ and they claimed that this system, for them, was a barrier to obtaining pain relief for residents. The resignation to a hierarchical system and the powerlessness it presented was expressed by Kara, who said the carer can go to the RN to alert them to a problem, “but (what happened) if they didn’t action it”? In the discussions those participants, who were Assistants in Nursing (AINs), indicated that RNs were not performing the day-to-day care, repositioning or transfers of residents and, therefore, did not see the resident in pain.

The contribution of poor or lack of communication between senior staff and those who deliver the direct care, has been shown to contribute to failures in pain assessment and identification (Allcock, McGarry & Elkan, 2002). A group education session in Facility Two revealed other reasons why pain was not
assessed, including the staff being too busy, or not educated and that the RN would not give pain medication and the lack of a pain medication order. Poor pain assessment practices attributed by Maas et al (2008a) include inadequate staffing and staff lack of knowledge. Brennan et al. (2007) suggest no matter what the reasons are as to why nurses fail to act responsibly, fail to listen to complaints of pain, or fail to act on those complaints, the health professional should be judged to be acting negligently.

Facility Two participants developed an action plan that attempted to address some of the deficiencies they identified in their pain assessment practices. The plan assisted participants to highlight to other staff the importance of pain assessment and the contribution pain assessments made in obtaining pain relief for residents. Participants explored a range of issues around pain assessment practices, such as: whose responsibility it was to initiate pain assessment charts; what pain assessment charts were available to staff; how pain assessment was communicated, and in what forums pain information was shared between staff. As a result of the action plan, a number of strategies were implemented, including standardising pain assessment charts and improving how staff accessed the charts. Further strategies included pain being incorporated into clinical audits, as previous admission audits had revealed the pain section of admission documents were either not completed or not followed up by the admitting doctor; second monthly pain assessments were planned for all residents regardless of not having reported pain; responsibility to commence pain assessment charts became a shared process; pain scores were communicated at handover, and staff group assessments of difficult to assess cognitively impaired residents were trialed.
In addition, a pain assessment discussion by PowerPoint, was presented to all facility staff based on the APS (2005) Pain Management Strategies, and an academic detailing process was used to specifically target RNs. Academic Detailing involved a participant approaching one RN and sharing a brief pain assessment discussion, that included a detailed pain assessment information sheet. The information sheet was considered so useful that participants decided to attach the sheet to all staff pay slips. Participants involved in delivering the academic detailing exercise discussed how they gained benefit from the intervention and spoke of enjoying the use of a “team effort” to address pain assessment issues. Following the implementation of the planned actions, participants discussed the outcome of the changes, continued to monitor pain assessment practices and re-evaluated those actions that required further refinement, in their on-going regular group meetings.

Nurses’ Pain Medication Knowledge

A major component of successful pain management relies on nurses working from a sound knowledge base. In both facilities, participants discussed the impact nurses’ lack of pain medication knowledge had on the delivery of adequate pain relief in end of life care. For example, a participant in Facility One discussed having to explain to a RN why she thought it was important to initiate pain relief before the morning routine care was given to a resident. RN pain management knowledge was variable and this became evident in a discussion following the Facility One debrief session, where a RN correctly highlighted the importance of care being matched to drug onset and said that RNs were responsible for discussing and communicating this information with their team. Other participants expressed concerns that some nurses had a preference to
administer only the minimum analgesic dose prescribed. Delivering the minimum analgesic dose was viewed as problematic by participants, who indicated this choice related to the nurses’ level of perception of how much pain a resident was in and, therefore, often resulted in the administration of the lower range medication dose. In addition, a participant, who described the timing of medication as critical, expressed concern for residents, stating the RN should administer the drug before the resident was in “dire straits”. These approaches to pain management are consistent with findings by Jones et al. (2004), who suggest a conservative approach in pain management may be the result of nurses undervaluing residents’ reports of pain.

Fear associated with pain administration and medication prescribing has been shown to influence pain management decision making (Brennan et al., 2007). Participants in Facility Two discussed their fear of administering pain medications at the end of life. For example, a participant stated: “I don’t want to give the last dose”. A participant also spoke of being accused by staff, who had said to her: “It was that injection you gave him”, referring to the earlier administration of midazolam before a resident’s death. Participants discussed RNs’ fears they had witnessed and said RNs can be: “Too scared, afraid to give them (dying residents) too much of a drug”, or that RNs were “frightened to give them too much, as allowed by the doctor”. Preference for administering a small dose of prescribed medication was discussed by participants, who said a RN would administer a prescribed analgesic, however, if the order contained a dosage range of 1-2 milligram frequently, the lower dose was administered with no further follow up of the resident, to assess the effects. When nurses are faced with a fear of hastening death, if they are able to respond from a sound knowledge base, rather than react to the ‘rules’ of the clinical problem, it is more
likely they will make far better decisions with compassion and certainty, rather than administering a lower, ‘safer’ dose, which is, in fact, less humane and effective.

Fears associated with analgesic side effects following administration were discussed in Facility One. For example, a participant related an incident where a resident’s condition had declined rapidly, shortly after the administration of morphine saying: “His (the resident’s) breathing reduced, and the resident became drowsy” and “almost died”. The participant told the group that another staff member assumed the resident’s decline related to the morphine administration and, therefore, the morphine order was ceased. The participant described the withdrawal of the morphine as “a set back to the resident”. Failure to reassess a resident’s pain, or the pain management plan following the administration of analgesics, was discussed by participants in Facility Two. Participants indicated that those nurses, who did not reassess a resident’s response following medication administration, were often the same nurses who decided to change or withhold pain relief and who also failed to use pain charts or revisit pain treatment plans.

Effective pain management practices depend on nurses updating their knowledge, and correcting misinformation to overcome the personal constraints that impede the delivery of adequate nursing care (Taylor, 2006). Fear of opioid medications is one example of a knowledge deficit in pain management at end of life. Clinicians’ fears surrounding opioids are thought to be linked to fear of drug addiction and dependence, drug abuse, drug misuse, opioid tolerance, side effects, prolongation of life, or hastening death (Brennan et al., 2007; Stannard, 2008).
Fears associated with opioid administration are often unfounded. Firstly, opioid addiction or physical dependence is rare in people with chronic pain, who have no known drug abuse behaviours (RNAO, 2002). The opioid side effect respiratory depression, commonly feared by nurses and doctors, occurs less frequently in individuals, who have the dose of the opioid titrated appropriately. Respiratory depression is more common in people, who have the dose increased quickly, receive an intravenous dose, or have renal impairment (RNAO, 2002). When opioid side effects are anticipated and monitored, adherence to treatment can be optimised, for example, tolerance to the opioid adverse effect, nausea and vomiting, often resolves within 5-10 days following commencement of opioid treatment, therefore, if regular antiemetics are administered in the initiation period, the side effect usually resolves and the need for the antiemetic administration subsides (RNAO, 2002). If nurses are not familiar with current best practice pain management guidelines, they are more likely to succumb to the fears surrounding opioids and may fail to respond adequately to a resident’s pain at the end of life.

Nurses, residents and families may fear the prospect of residents experiencing uncontrolled pain at the end of life, due to the development of a tolerance to opioids. Tolerance, or the drug losing its effectiveness when it is needed, is a baseless fear. If pain management knowledge is adequate, a nurse’s, resident’s or family’s concerns regarding tolerance can be acknowledged and reassurance can be offered, that pain can be controlled in the majority of cases (Clayton, Hancock, Butow, Tattersall & Currow, 2007). Opioids have been shown to be the preferred drug in the treatment of long term pain. Stable pain sometimes requires increasing dosages of opioids, however, morphine has no therapeutic
ceiling, therefore, increased doses can be used safely provided the drug is titrated appropriately and individualised (RNAO, 2002; Stannard, 2008; Whitecar, Jonas & Clasen, 2000). As well as the option of increasing dosage, there are a range of other options available to prevent a lack of medication effect at the end of life, including breakthrough medications, alternative routes of administration, combinations of drugs and appropriate monitoring (Leleszi & Lewandowski, 2007).

Researchers have identified that nurses’ knowledge and attitudes regarding pain management have been inadequate (Cahana, Arigoni & Roberts, 2007; Jastrzab, Fairbrother, Kerr & McInerney, 2003). A number of factors have been suggested as contributing to inadequate pain management knowledge, including the educational curriculum and textbooks. Although pain management education programs have been shown to increase the majority of nurses’ knowledge, these programs have not been shown to be successful in influencing a change in all nurses’ pain management behaviours (Jones et al., 2004). Guidelines and recommendations for pain management are available to health care providers, however, Brennan et al. (2007) suggest these guidelines “do not change behaviour” and are not enforceable in law, if they are not utilised in care (p. 215).

Jastrzab et al (2003) studied Australian nurses’ attitudes and knowledge in adult pain management and concluded that nurses’ incorrect beliefs about side effects, tolerance and addiction may result in nurses avoiding administering pain-relieving medications. The potential for less than optimal end of life care delivery is compounded, when nurses are fearful of administering opioids and have insufficient knowledge of their use. Routine end of life care situations can be difficult enough, without considering what may happen if the nurse is faced
with an acute crisis in a dying resident. Staff responses to difficult clinical situations, when driven by fear and a lack of knowledge, may cause less than optimal actions or inaction, and poor communication with the dying resident, their significant others and staff.

The repercussion of untreated or inadequately treated pain is beyond the suffering of the individual. Brennan et al. (2007, p. 206) call for global action to relieve pain, is based on the argument that “inadequately treated pain has major physiological, psychological, economic, and social ramifications for patients, their families and society”. Unrelieved pain can stimulate the stress response, altering physical function and quality of life (Crisp & Taylor, 2005; RNAO, 2002). Older people are thought to have an increased pain threshold, however, their pain tolerance is reduced. Lower pain tolerance can contribute to a reduction in mobility, sleep disturbances and suppression of the immune system, with chronic pain being linked to depression and anxiety (ANZCA, 2005; Brennan et al., 2007).

Facility Two participants’ action planning was aimed at identifying nurses’ pain management knowledge and attitudes in the first instance, and formed the basis for a plan to develop a pain education campaign. Firstly, a ‘Knowledge and Attitudes Regarding Pain’ survey tool was located and completed by the 10 RNs employed in the facility (CD 1). The ‘Knowledge and Attitudes Regarding Pain’ survey tool has been used over several years, with proven validity and reliability, to assess pain knowledge and attitudes (Ferrell & McCaffrey, 2008). On completion, the pre-intervention survey revealed the 10 RNs employed by the facility had knowledge gaps in both pain assessment and pain medication knowledge. As a result of these findings, participants implemented a pain
assessment and medication education program (Chapter Six). The medication education component of the program included: a PowerPoint presentation by a Consultant Pharmacist; an academic detailing exercise, that included an information handout, to highlight pain medication issues; the creation and display of a drug formulations; and a complementary and alternative therapies in pain management poster. These initiatives were used to increase staff awareness of pain management, highlight the importance of communicating pain information, facilitate access to opioid information and improve the facility’s pain practices. Pain policies were reviewed and improved to include evidence based recommendations and to clarify the organisation’s expectations for pain assessment and management.

Written pain policies are often overlooked in providing a foundation on which to build pain management practices. Allcock et al. (2002), in a study of pain management in older people in nursing homes, identified 75% of 69 nursing homes did not have pain policies. In this project, action planning that incorporated staff participation in contributing, implementing and evaluating practice improvements, provided participants with an opportunity to identify concerns around end of life care and encourage participation in identifying available pain management information and developing possible solutions suitable to their local setting.
Doctors’ Medication Prescribing Practices

Resident care is dependent on doctors acting ethically, working within their scope of practice and fulfilling their duty of care to the resident, particularly if residents are experiencing pain (Brennan et al., 2007). Participants identified doctors’ medication prescribing practices as a challenge for nurses, in preventing optimal end of life care delivery to dying residents. For example, when a participant viewed a resident’s sudden change in condition in the Facility One role play, she said:

“A strict criteria for standing orders may help in these situations, for example, a stat dose of morphine could be charted” … “Most doctors shut their doors at 5pm, you may be able to get one after that, but a standing order would address problems in aged care. We are the ones who feel really slack, because we had to let that person die, or be in pain, or whatever the reason, and we are spending all this time trying to get something done and then we still don’t get a response. It really is an awkward situation”.

In the same discussion, a RN commented that it was “not dignified to have pain and not have it addressed reasonably quickly”. A contributing factor for this practice may be that the Australian Pharmaceutical Advisory Council (2002) Guidelines for Medication Management in Residential Aged Care Facilities recommend “standing orders for the administration of a new medication in response to a resident’s changed clinical state should not be used in residential aged care facilities” (p.10).
A participant in Facility Two also raised the issue of medication ordering. Facility Two participants agreed unanimously, that if “medication orders” were organised well, end of life care was “controllable”. The frustration nurses faced when trying to arrange adequate medication ordering was expressed by a participant, who said: “Some doctors are reluctant to give anything”. Doctors’ reluctance to prescribe analgesics was discussed in both facilities, with a participant in Facility Two sharing with the group that she had to request pain relieving medication over a long period of time before a doctor would prescribe. She told the group she had been “pushing with that doctor for about a week and then finally gave it” (the injection).

Participants’ discussions reflected a cautious approach, or indeed a reluctance of doctors to prescribe analgesics at end of life. Some authors view failing to respond to pain, or not adequately treating pain, as representing a form of elder abuse or abandonment (Maas, et al., 2008a; Brennan, 2007). According to Taylor (2006), a political constraint in health care is about individuals and groups “competing for power, status and resources” (p. 29). Doctors’ prescribing practices may represent the power they have over nurses, who cannot prescribe, and power over residents, who are vulnerable, often voiceless, and rely on a doctor’s expertise and compassion. The use of reflective practice in this project provided participants with a voice for their concerns regarding pain management, assisted them to identify those issues they perceived as barriers to optimal end of life care, and enabled them to collectively explore solutions to their concerns.

The grief discussion role play in Facility One portrayed other challenges nurses faced when trying to obtain medication orders for residents. A challenge
depicted in the role play ‘emergency’ was when the doctor was contacted, but declined to attend the resident. During the discussion time following the role play, a RN commented that a doctor not responding to a phone call in aged care has required a huge adaption for her, and she said: “We feel we are a low priority” and that “aged care is on the bottom of the list”. She asserted that any “emergency, including pain should be addressed reasonably quickly” by a doctor, “especially if it is an end of life issue”. In other discussions, a participant said: “A doctor will say they will come and they won’t come”. Other medication challenges participants discussed were when nurses had to struggle to have previously ceased morphine orders reinstated in a timely fashion. Limited access to doctors is not unique to aged care nursing staff, because relatives of people living in aged care facilities have also reported dissatisfaction with the quality of interaction they have with their doctor (Wetle, Shield, Teno, Miller & Welch, 2005). Limited access to doctors is problematic in end of life care, as a resident’s symptoms may escalate if not managed appropriately or adequately, causing concern and distress to all those who are witness to the suffering.

The myths surrounding pain and pain management are alive today, despite numerous initiatives by leading organisations to educate and integrate evidence into practice (Brennan et al., 2007). Doctors’ reluctance to prescribe adequate pain relieving medications in older people, particularly opioids, or trial alternative analgesics, is well documented in the literature and is based on similar fears expressed by nurses when managing these drugs. A study conducted by Won, Lapane, Vallow, Schein, Morris & Lipsitz (2006) identified 35% (n=3669) of older nursing home residents with persistent non malignant pain had not had an alternative analgesia class trialed over a 6 month period and further that 40% of those residents had not received analgesics during this time.
A lack of palliative care training in medical undergraduate programs has been identified as a contributing factor to doctors not having the skills required for this specialty field of medicine (Cairns & Yates, 2003).

Doctors’ reluctance to prescribe adequate analgesia was discussed in a RN meeting in Facility Two, where it was recounted that a doctor had visited a resident who was unwell in the evening and made a decision to delay the ordering of opiates until the following day. This decision resulted in a number of contacts being made with the doctor overnight, until a pain relief order was given for the distressed resident. Fears based on the risk of addiction, side effects, falls, delirium, impairment to accurate diagnosis, legal scrutiny, poly-pharmacy and assumptions that some pain is to be expected, all contribute to poor pain management practices (ANZCA, 2005; Brennan et al., 2007; Leleszi & Lewandowski, 2007; Maltoni, 2008; Melding, 2002). Further, the reluctance to prescribe adequate pain relief has been linked to some doctors choosing to resolve all options for a curative treatment, before a palliative approach to care is initiated (Whitecar, Jonas & Clasen, 2003).

Fears associated with pain relieving medications are realistic, as older people are known to be more sensitive to opioids and more prone to side effects. However, when opioids are used appropriately they can provide effective pain relief when non-opioid analgesics have failed to relieve pain (ANZCA, 2005; APS, 2005; RNAO, 2002). Chronic non malignant pain is acknowledged as challenging to treat, resulting in an avoidance of opioids in this patient group (Graziotti & Goucke, 1997). In recent years, opioids have been endorsed in the management of non malignant pain in older people, using the metaphor ‘start low and go slow’ (APS, 2005; RNAO, 2002). Won et al. (2006) found there are few long term
risks associated with opioids in persistent non malignant pain, as compared to the increased risks when opioids are initiated. When opioids are prescribed on a p.r.n. (pro re nata) basis or administered as necessary, the order can contribute to delays in administration and, therefore, inadequate pain control.

Participants discussed p.r.n. analgesic orders creating a ‘vicious cycle’ where the drug levels peak and trough. This problem was described by participants as creating a cycle of “having to catch up with the pain” (RNAO, 2002). The timing of analgesics is considered as important as the type of medication selected (APS, 2005). The American Geriatric Society [AGS] (2002) recommend an around the clock, timed interval regimen, to achieve pain relief in the presence of continuous pain, with as needed prescribing reserved for episodic or non continuous pain. Further, Stannard (2008, p. 8) suggests “continuous pain needs continuous relief” and that the dosing intervals are crucial to achieving pain relief. Fears of opioids have some bases, however, there are numerous strategies and management plans for the safe prescribing and administration of analgesics.

Achieving optimal pain management in chronic illness is reliant on maintaining an analgesic schedule that prevents pain (RNAO, 2002). Prescribing pain relieving medications on a p.r.n., or administer as necessary basis, denies the resident with ongoing pain sustained relief, or the reassurance that the treatment will alleviate their pain, and this may contribute to unnecessary suffering. Melding (2002) suggests p.r.n. prescribing is the “least effective method to attain adequate blood levels of analgesic” (p. 5). Studies have identified p.r.n. prescribing is a problem, with McClean & Higginbotham (2002), in a study of 917 residents of rural nursing homes, identifying that even simple analgesics used for persistent musculoskeletal pain were being prescribed on a p.r.n. schedule. P.r.n.
prescribing is contrary to pain management recommendations in the treatment of
chronic or frequently occurring pain, which is to prescribe and administer
analgesics around-the-clock to provide effective treatment (Whitecar, et al., 2000).

Narcotic analgesics have never been easier for doctors in Australia to prescribe,
or to be encouraged to use in non malignant conditions, where non opioids are
not controlling pain. Restriction on narcotic prescribing was simplified in
Australia in April 2005, when the Pharmaceutical Benefits Scheme (PBS) ruled
doctors could prescribe increased quantities and repeats of narcotic drugs for
people with chronic, severe, disabling non malignant pain. The only restriction
required by the authority is that the prescribing doctor consults a second medical
officer (National Prescribing Service [NPS], 2005). Further, South Australian
legislation has provided doctors with statutory protection in end of life care,
preventing any “criminal or civil liability if they administer treatment with the
intention of relieving pain”. The Act, as expected, includes a number of
stipulations, for example, “proper professional standards in palliative care”
(Brennan et al., 2007, p. 211).

Palliative medicine has seen the development of a range of opioid preparations,
formulations and delivery systems for use, which have revolutionized the ways
medications can be utilised in end of life care (Campbell & Currow, 2002; Colvin
et al., 2006; Miller & Miller, 2003). For example, the difficult to manage,
distressing end of life symptom, breathlessness, can now be controlled using a
carefully titrated morphine regimen with combinations of pharmacological and
non pharmacological interventions, to relieve the psychological distress and
control the symptom (Kazanowski, 2006; Stannard, 2008). Conservative
therapies, such as trialing non opioid analgesics, or anticonvulsant preparations,
before prescribing opioids, represent other strategies in the range available to
doctors in the treatment of pain (Graziotti & Goucke, 1997).

Participants’ decisions to take action to improve nurses’ pain medication
knowledge and access to pain medication information were ultimately aimed at
improving nurses’ abilities to communicate with the stakeholders in pain
management, that is, doctors, other nurses, residents and their significant others.
Empowering the nurses to advocate on behalf of the resident and make informed
decisions on which to structure care, was closely linked to their understanding of
how to deliver end of life pain management care. Participants in Facility Two
planned to review ongoing audit results, repeat the ‘Knowledge and Attitudes
Regarding Pain’ survey, perform case reviews and provide feedback to staff, in
an effort to sustain nurses’ pain medication knowledge.

Historically, nursing has played a subordinate role to medicine and this
constraint may still be operating in aged care workplaces today (Taylor, 2006).
The lack of access to drug information and the limited pain management
education available in facilities is indicative that pain management is not
recognised as a key component of a ‘good death’. In this research, a
disconnection between the organisation’s responsibility to the staff and the
doctor’s responsibility to provide the resident with a comprehensive pain
management plan, suggests the nursing staff did not appreciate the need for
them to be proactive in their role as residents’ advocates. This action research
and reflection project supported these nurses in understanding that they are an
integral component in pain management planning, for residents dying from non
malignant diseases.
Relatives’ Expectations of End of Life Pain Management

Relatives may also suffer when pain at the end of life is not adequately managed for their family member (Miller & Miller, 2003). Steinhauser et al (2000) found that all groups involved in end of life care - the resident, the family and the staff - agree that effective pain management contributes to a good death. Relatives place their significant other into an aged care facility, with the intent to keep them safe, therefore, their contribution can be valuable to the care of the resident and provide information on a resident’s history. For example, a relative of a woman who had dementia was interviewed in this project. She expressed great insight into her mother’s medical history and expression of pain, when she said: “Well, she always had irritable bowel and had a lot of pain and she’s quite irritable when she’s got that. You can always tell there’s something wrong with her”. When relatives have a role in end of life care decision making and provision, it can assist in alleviating their fears and unrealistic expectations of care (Wowchuk et al., 2007). Relatives’ insights and thoughts on end of life care were shared at the group meetings, to inform participants of the views and contributions relatives could make to care.

Similar to health professionals, relatives and residents can also fear pain relieving medications, in particular, opioids. These fears have been linked to the misconception that death is imminent if opioids are prescribed (Stannard, 2008). Further, relatives and residents fear a tolerance to the opioid drug will develop before it is really needed and, therefore, it will be ineffective at the end of life (Leleszi & Lewandowski, 2007). A participant in Facility One discussed the impact on a resident’s care when unreliable information regarding opioids was shared with relatives. An incident occurred where staff members told a
resident’s family that morphine was a “dreadful drug”. This resulted in the resident not receiving adequate pain relief, and the participant described the care from that time involved “trying to catch up” with the resident’s pain. Facility One participants described some relatives as “overly defensive” to the administration of morphine and the nurse needing to convince the family of the benefits of the drug.

Working with relatives to maintain a resident’s pain medication regimen, was discussed by participants. For example, a participant told the group: “A resident may be asleep during the medication round and the relatives may not want the resident woken for the pain medication to be administered”. The education of family members in pain management can assist in developing and achieving realistic goals of pain relief for the resident and adherence to the pain plan (AGS, 2002; RNAO, 2002).

Nurses’ pain management knowledge deficits need to be addressed, before a nurse can alleviate relatives’ and residents’ fears and concerns regarding opioid administration. The action plan in Facility Two incorporated obtaining and displaying opioid information booklets and palliative care brochures for residents and their significant others, in the hope that the information would assist their understanding of the principles of pain management and, therefore, foster a collaborative approach to care. Also, advanced care directive information booklets were sourced to pre-educate residents and their significant others, prior to discussing their end of life requests with the care providers. By sharing relatives’ views on end of life care, participants came to appreciate that relatives could play a significant role in interpreting and reporting a resident’s pain and collaborating with staff to achieve pain management goals.
Misconceptions regarding pain relieving medications were not evident in the relatives’ interviews conducted in both facilities. Participants in the nurses’ groups discussed a range of misconceptions they believed relatives had regarding pain management, however, in this project, the relatives consistently expressed the importance of maintaining their significant other in a pain free state at the end of life, with this issue emerging as a major theme in analysis of those interviews. In fact, the relatives expressed a deep concern that their significant other did not experience pain at the end of their life. For example, a relative said: “Pain free, give him, whatever they need to give him, in order to keep him comfortable, and even if that hastens his death, so be it”, saying further, “Make sure they’re (the relative is) pain-free first, and then clean”.

For another relative, the most critical issue at end of life was: “To keep him pain-free”. This relative was concerned, as she felt her husband did not have a good pain tolerance, as the relative believed her husband would mask pain, rather than be sent to hospital. The relatives’ concerns in this project match previous findings in the literature. Steinhauser et al. (2000) identified that people fear dying in pain and inadequate pain relief is viewed as a contributing factor to what their subjects described as a “bad death” (p. 826).

Sharing relatives’ interviews with participants in this project assisted them to gain insight into how important relatives viewed adequate pain management in end of life care. Identifying and communicating relatives’ requests and priorities in end of life care provided them with an anonymous voice, to raise their concerns with the nurses. This process allowed participants to examine their
misconceptions on a relative’s end of life priorities and provided perspectives on issues of importance to relatives in end of life care delivery.

**Associated Issues**

This section discusses the associated issues identified in both facilities as thematic concerns that influenced end life care delivery. While these issues were not identified by the research groups as primary concerns in relation to caring for people dying of a non malignant disease in an aged care facility, they were nevertheless important in the way nurses interacted in the aged care facilities, and as such, they influenced the way they practiced their nursing care of dying residents. Key articles of literature related to the topic area, from the aforementioned databases, are discussed in this section, in the context of participants’ concerns regarding communication with the relatives, nurses’ language and palliative care education.

**Communication with the Relatives**

To some extent, the provision of appropriate end of life care depends on good communication between the key stakeholders. Discussion with the dying person and their significant others on end of life care issues is acknowledged as difficult for health professionals, with a number of reasons cited for avoiding these conversations, including fear of upsetting someone, lack of training, no time, feeling inadequate, or having no further curative treatment to offer (Clayton et al., 2007). Poor communication with relatives emerged as an issue of importance in both facilities.
Supporting significant others of dying residents, by keeping them informed and being “totally honest” with them, was viewed as important by participants in Facility One. However, in practice, communicating with relatives did not always occur. A participant shared that families were often not told that their relative was dying. She recalled a RN saying to her: “It is the doctor’s job to tell them”, and described a RN being angry at her for telling the family of an impending death. She said she had told the family as “the RN refused to tell them”. This story was in contrast with discussions that followed the role play debriefing session in Facility One, where a RN said: “I must be the only RN, who informs the family” of imminent death.

The importance of the quality of the information shared with relatives and the fear of retributions of not communicating correct information, were the primary concerns for nurses, who did not believe it was their job to inform the family. This concern was described by a participant, who said that nurses “need to be careful what they say”. A reason discussed by participants for poor communication with relatives was the potential for litigation if incorrect information was provided to them. A participant said nurses can be: “Out on a limb, by yourself, with a lack of support”. These views are in contrast to the literature, that claims that problems associated with dying residents and their significant others could be avoided if open, honest communication breaks through the denial that surrounds death (Hoff, 2001).

Limited communication with the residents and relatives by the doctors in both facilities, was also highlighted in discussions. Participants suggested this often resulted in the facility staff acting as “a go-between” in communicating information to and from the relatives. Facility Two participants indicated it was
unusual practice for a doctor to speak with a resident’s significant other, even on admission. In the relative interviews it emerged that some relatives did not discuss the resident’s care with the attending doctor. A relative, whose mother had lived in the facility for 18 months, said:

“I talk to Katherine (Director of Care) more. Dr C, (mother’s doctor), is my doctor, but I haven’t had time to discuss Mum with him, because he’s too busy with other things. But I get fairly good information from Katherine and Jackie (Deputy Director of Care)”.

When asked, another relative said:

“No, I haven’t talked to him (the doctor) yet, but I have to make an appointment to see him. I don’t think he’s a real good doctor for dying people, for terminally ill people”.

This was a surprising admission, as the resident had been in the facility for six months and was receiving regular morphine for a chronic lung condition.

Communication of end of life problems or prognosis are acknowledged as important components of care by those affected, to enable them to make informed decisions and care planning (Clayton et al., 2007). The quality of the care delivered to the dying patient has been linked to communication, as health care teams are required to firstly manage the process of dying and also meet the needs of the resident and their significant others (Christ & Blacker, 2005; Pickering & George, 2007). When teams are not functioning well, palliative care is hampered. A number of reasons can contribute to poor team function,
including conflict within the team, unclear roles, increased workloads, interpersonal conflict, inadequate communication and leadership problems (Crawford & Price, 2003).

Crawford & Price (2003) suggest that poor communication has the potential to destroy trust and openness in teams. When residents and their relatives are attempting to prepare for death and trying to cope with the situation, they are reliant on open, honest communication with the team (Clayton et al., 2007). The importance of open, honest communication was discussed with a relative, who said that she lost confidence in the staff when she was not informed of a clinical problem in her family member’s condition and found that the staff had become defensive toward her. One possible explanation in this situation may have been the staff’s fear and the relative’s fear, which may have been the driving forces triggering both groups’ reactions to the situation.

Avoiding communicating a dying resident’s condition, a resident’s deterioration, or end of life care needs with their significant others, can be more likely to occur in a culture that demands the individual burdens of the responsibility of care, rather than a team sharing the load. Further, in the presence of denial, fear, limited knowledge, or a fundamental lack of respect within a team the end of life care, needs of residents are unlikely to be met. Communication by an educated, open, honest team is fundamental to providing quality end of life care and more so following the death of the resident, when the focus of the care shifts from the resident to their relatives.
Nurses’ Language

Language is a powerful medium, which can reflect our values and beliefs, and shape the perception of ourselves and of others (Wood, 2004). At times, participants in both facilities failed to appreciate the coarseness and harshness of the language they were using, to describe some of the dying residents’ behaviours in the dying phase. The inappropriate language may have reflected a misunderstanding by participants of what was actually happening for those residents. For example, a participant said in death: “a cry can be life sustaining, an honest expression of a resident’s emotions, reflective of aspects of their life”, or residents were “not willing to give into the death experience”. Further, a participant said the dying process was responsible for residents’ responses emerging, such as being “oppositional to everyone”.

Although participants spoke of developing close relationships with residents, at times, their use of unprofessional language did not honour those relationships, such as in saying the resident was a “pig headed man”. Further, this participant spoke of having an occasional “shouting match” with the resident and said “he would always listen to me”, which demonstrated to me, how the relationships had deteriorated to a non professional level. In other discussions, a participant discussed why she preferred not to work in the dementia unit and commented she had no patience, stating: “I don’t like kids; I don’t want to work doing little activities, amusing them.” These and other examples of nurses’ coarse and harsh language were identified and discussed at an appropriate time, throughout the action research and reflection cycles in both facilities.
Stein-Parbury (2000) suggests the jargon language of nursing can become so embedded in nurses’ conversations, that they fail to realise that others do not understand the meaning of what they are saying and suggests, for this reason, jargon should be minimised or avoided. Hoff (2001) indicates people’s values, attitudes and feelings about other people are also conveyed to others through communication and, therefore, if those values and beliefs are “respectful, unprejudiced and based on true concern”, these will be conveyed to the person (p. 106). It follows, that based on this logic, the reverse also applies, in that residents and relatives will recognise nurses’ disrespectful, prejudiced and unconcerned values and beliefs acted out in their behaviours towards them.

Participants also discussed how some relatives used language that indicated they did not trust them. For example, a participant recalled a relative asking: “What have you done to him?”, questioning the nurse’s involvement in an accusatory way. Other participants said they had developed an attitude of caution when communicating with relatives, for example, a participant said: “Pressure is put on us by families to tell them what they want to know”. This pressure caused the participant to be aware of what she said to relatives. Another participant said: “They (relatives) are trying to get us to slip up” and linked this to relatives sometimes trying to make them “look incompetent”, stating further that relatives knew: “We can’t always give information” and that “relatives judged” nurses.

In contrast, in this project, distrust for the nurses was not reflected in the interviews with the relatives, who in fact expressed a deep appreciation of the care the nurses delivered to the residents. For example, a relative said:
“Every service, the cleaner, the nurses aides, the maintenance men, the nurses, the laundry lady are all important, because without one of them you haven’t got a service, and they all contribute in a great way. When they deliver P’s clothes back, they have a lovely chat with him, which is very important for him not to have things get him down. They all treat him like a person, from the cleaner to the Sisters; they treat him as a knowing adult. I’ve seen them treating people, who are practically in a coma, the same way, which I think is very important, because my mother was in a coma and when I spoke to her she would squeeze my hand, so she knew that I was speaking to her. That’s what I love about out there. They don’t speak down to anyone, they speak on the even, as if they’re fully 100 percent able”.

Relatives also expressed an understanding of the dilemma nurses faced when their workloads were high and they were caring for a dying resident. For example, a relative said:

“They (the dying residents) need that reassurance, that presence and reassurance, that someone is there, who obviously cares. Doctors can come, but they’ve got other patients and have to go. They might pat them on the shoulder and say: “It’s okay”. The nurses come and I’ve seen some of them with tears, but they’ve got to move on and that’s not the answer. They are very caring and they’re there for them, but they have other patients as well, and that caring has got to be shared, but an individual can fill that need sometimes”. 
A health professional’s empathy conveys respect and understanding to others and is of importance when issues of conflict arise, particularly around end of life care. When conflict arises in end of life care it is important to address the issue, rather than avoid the conversation. If the problem is discussed in a timely fashion, it allows the resident or their dying family member to participate in decision making and be satisfied with their care (Clayton et al., 2007).

In this project, research group participants were encouraged to examine their coarse and harsh language through a process of progressively revealing their statements to them and challenging them to examine their use of negative language, in communicating with others and how this affected end of life care delivery. Participants focused their attention on analysing the issues surrounding the context in which the language was used and the processes driving the language, for example, if it was workload pressures, disrespect for relatives, or a personal issue that caused them to speak with residents in such an unprofessional manner.

Palliative Care Education

End of life care is reliant on many factors, such as those staff delivering the care to having an understanding of the principles of medications used, physical and emotional needs of the stakeholders, and a personal commitment to meeting the needs of the resident. A number of factors have been identified as contributing to the challenges staff face in providing end of life care in residential aged care facilities, including the higher acuity of residents admitted into aged care facilities, and the complexity of the treatment needs for these residents (Wowchuk et al., 2006).
It became evident in this project, that the staff responsible for delivering end of life care did not always have an understanding of how to deliver the required care. For example, a participant discussed how few RNs had a palliative care background and it was suggested that aged care RN job positions should include palliative care experience in the selection criteria. Another participant said there was: “No training in helping one another with death”, “nobody has ever told me how to do it” and that staff have to “get used to death”. Another participant spoke of giving new staff an “initiation to death”. She questioned “new nurses’ behaviour” when seeing death and how some nurses cry when residents die. She then recalled crying herself on seeing her first death early in her career.

A number of studies have identified deficiencies in residential aged care staff education and skills to deliver palliative care (Brazil, Bedard, Krueger, Taniguchi, Kelley, McAiney & Justice, 2006; O’Connor & Pearson, 2004; Watson, Hockley & Dewar, 2006). The importance of health professionals having expert clinical skills that assist to firstly diagnose a person is dying, and then deliver the care dying people require, can be underrated and undervalued (Ellershaw & Ward, 2003). Hansford, Robinson & Scott (2007) suggest that improving nurses’ end of life care knowledge will improve nurses’ delivery of care and confidence in providing that care.

Providers of palliative care report a need for increased training, however, the best measure of training success, as suggested by Fox (2007), is to focus on the benefits to the receiver of that care. Hanson, Reynolds, Henderson & Pickard (2005) conducted a quality improvement intervention that incorporated leadership, education sessions and team result feedback, in an effort to improve
the percentage of residents receiving palliative care services. The authors found improvements in the use of pain assessments, an increase in “discussion of end-of-life treatment preferences” and the use of non pharmacological pain treatments (p. 581).

Other methods aimed at improving care at the bedside include the Liverpool Care Pathway (LCP). Implementation of the LCP has demonstrated “a small but significant decrease of the symptom burden for dying patients” and improvements in documentation of the care for the dying (Veerbeek et al., 2008, p. 149). A multifaceted approach to aspects of end of life care education used in Veerbeek et al’s project encouraged participants to control, lead and use their new knowledge. The use of action research and reflection in this PhD project encouraged participants to be involved in the planning, researching and collecting of information, to educate other staff and to benefit from participating in the palliative care learning.

A barrier identified in Facility Two to end of life care was the lack of engagement of employed RNs in ongoing education in general, including palliative care education. For example, a participant, when discussing nurses misinterpreting pain as a behavioural problem in residents with dementia, felt it was not due to a lack of access to education, rather she said: “The facility even tried paying staff to attend sessions”, but: “They won’t come”. Participants discussed the possible reasons for poor attendances at education sessions. It was thought to be due to nurses basing their knowledge on their own individual practices and beliefs, nurses having difficulty keeping up with practice changes, nurses having difficulty retaining knowledge, and a general reluctance to attend education in either work or personal time. A participant stated: “We have to catch up after”
an education session, referring to clinical care that had to be left to attend education sessions.

The finding that staff have constraints on their time for education is consistent with those identified by Maas, et al. (2008b), who also found insufficient funding of education and a limited number of qualified RNs to provide the training. In contrast, Facility One participants indicated that training programs for death and dying were not useful. These participants felt it was best to “learn on the job” and that training “does not prepare you for death”. Learning end of life care on the job is a primary method of palliative care education. Fox (2007) identified in a survey that screened 608 predominately nursing responses, that on the job training is still prevalent, despite the availability of extensive curriculums in end of life care.

Acknowledging poor attendances at formal education sessions influenced Facility Two participants’ action planning, to address end of life care education. In addition to improvements in pain management practices, participants decided to modify the Liverpool End of Life Care Pathway to meet local requirements. Participants planned for the pathway to provide those staff caring for the dying resident written access to a treatment plan, clear strategies to address symptoms, and direction on how to communicate care shift by shift. This approach was particularly aimed at some staff, who avoided education sessions, because the pathway encouraged the caregiver to plan care and document findings for each care activity provided throughout their shift. The pathway was trialed in the hope of integrating best practices in terminal care into clinical practice and indirectly educating staff on aspects of palliative care at the bedside. Further, the use of academic detailing, or one-to-one, 15 minute intense discussions of key
end of life pain management information, included those staff who chose not to attend formal education and also engaged participants, who were required to share the information. Action research and reflection provided participants with an opportunity to collectively address shortfalls in end of life care and be imaginative in their strategies to educate staff.

**Insights and Implications**

This section describes the insights and implications that emerged from this action research and reflection project. These insights were identified by participants reflecting on practice stories about care delivery incidents for dying residents, relatives’ contributions in the key statements from their interviews, and the discussions of associated issues of importance to participants, in the two rural residential aged care facilities in this project. The implications follow from the insights, by providing suggestions for the ways nurses can provide end of life care, which maximises the likelihood of a good death, and identifies barriers nurses perceive as preventing optimal end of life care for dying residents.

The initial insight gained from this project was that both facilities needed to improve various aspects of end of life care for residents dying from non malignant causes. While this action research and reflection project focused on specific issues in two participating Australian aged care facilities, the literature reviewed suggests that the need for improved end of life care in aged care facilities is not an isolated issue (Goodridge et al., 2005; Wowchuk et al., 2007), and that care deficits occur nationally (O’Connor & Pearson, 2004), and internationally (Kelly et al., 2008). This is also more likely to be identified to be the case in any aged care facility, which is committed to constantly improving
aged care, and which is willing to reflect and act on thematic concerns related to end of life care. Therefore, although this qualitative project does not claim to have predictive power, which may have been possible from a large, controlled quantitative research design, it offers the direct implications that follow from the particular insights generated by the research participants. In this way, these insights and implications can be of use to clinicians, educators and managers, with whom they resonate, and thereby, be helpful in improving end of life care in other aged care facilities, wherever they are applied and enacted.

Participants’ discussions highlighted how caring for dying residents could have a lasting emotional effect on staff and that the management of the dying experience for residents was situational and inconsistent. For nurses to provide nursing care that maximises the likelihood of a good death, their grief, loss and bereavement issues should be acknowledged and addressed. This project raises the concern that although aged care work is recognised as a practice discipline, which anticipates and supports the dying process, opportunities for staff to debrief are either not readily available, or they are not conducted as frequently as required by the staff. This is problematic when there is an expectation that nurses will contribute positively to the likelihood of a dying resident experiencing a good death.

If nurses are working from a basis of grief embedded with fear of death and dying and that fear is a stimulus that triggers a normal ‘fight’ or ‘flight’ physiological response, then it follows that some of the behaviours nurses display in end of life care may not contribute positively to a resident’s ‘good death’. For example, when a ‘fight’ response is transferred to the bedside care, the fear of death and dying that nurses experience could result in communication
that is defensive or attacking toward other staff, relatives or even toward the resident, if a resident’s behaviour is perceived by nurses as difficult to manage. The fear driven fight response may also cause the nurse to display a lack of respect toward senior staff or relatives. Further, a fight response may be demonstrated toward the organisation in a show of defiance, resulting in a resistance to participate in change processes or education.

Alternatively, by approaching end of life care from a ‘flight’ response, the bedside care may still suffer. Possible outcomes of the flight response may include the dying resident’s care being left until last, care attended too quickly, so that the nurse can leave quickly, or avoiding the dying resident’s care altogether. A flight response may also contribute to a failure of the nurse to address important issues around death and dying, by avoiding her/his fear of death, avoiding education or change processes, and failing to communicate well with residents, other nurses, doctors or relatives.

Participants identified grief, loss and bereavement as a barrier to providing optimal end of life care. If optimal end of life care is an organisational goal, action by managers, educators and staff is necessary to ensure a variety of debriefing opportunities are available, to allow staff to discuss issues following the death of residents. Debriefing discussions can be integrated into facility schedules, as opposed to adopting an ad hoc approach, for example, only providing debriefing if there is a cluster of deaths, or if there are obvious staff performance problems. Regular scheduling of a variety of debriefing opportunities would enable staff to determine their personal ‘best fit’ intervention, for example, one-to-one counselling, or group intervention. Further, regular scheduling would facilitate early detection of grief, bereavement
and loss issues and identify possible complicated grief, if sessions are facilitated by experts. Demonstrating to staff that debriefing is a priority in an organisation would assist staff to appreciate the importance of self-care when working with dying residents.

A collaborative research approach, such as action research and reflection, may contribute to the healing process for participants, because it allows participants to share their concerns collectively and for them to find voice through reflection. In this project, action research allowed participants to raise important issues they face in end of life care and provided an opportunity for them to discuss and explore their practices, to reveal their particular problems in delivering end of life care. Reflecting on themselves and their practice assisted participants to come to the realisation that they had the power to change themselves, to influence or change existing processes that did not work well, and to support more effective end of life care practices in their facility.

Reflective drawing became participants’ preferred method of reflection in both facilities as a useful medium that assisted them to express their grief. Dyer (2008) suggests creative methods to express grief, such as drawing, can facilitate the expression of deep emotions and assist people on the path to healing. Empowering the participants through the use of reflection supported them to engage in change processes, own the changes, and participate as a team. Support by the managers, educators and all grades of nurses assisted participants to make improvements to practice and move care forward, toward maximising the likelihood of a good death. The success of the action research and reflection processes in this project has implications for staff in any aged care facility, because it encourages other nurses and allied staff to apply these collaborative
approaches as research, reflection, or both, in their workplaces, to move through their own processes of identifying and expressing their grief, in relation to residents’ deaths.

Similar to the participants, the relatives who were interviewed for this project were often operating from a basis of grief embedded with fear, and it is reasonable to assume that those fears may have driven their communication with the people caring for their family member. Relatives’ fears may be based on many concerns, such as fear of relinquishing their family member’s care to the facility staff, fear of their relative blaming them for no longer delivering their care, fear of losing their relative to death, fear of getting on the “wrong side” of the nurses or doctor, and/or fear of a painful death for their family member. If these fears are driving relatives’ responses, they may contribute to relatives also adopting either a ‘fight’ or ‘flight’ response to the staff within an aged care facility. A fight response may emerge in their actions and communications with staff, for example, they may blame, accuse or be suspicious of staff’s actions. Alternatively, a ‘flight’ response may cause avoidance behaviours, such as avoiding speaking with the resident’s doctor about their expectations of end of life care, or of even visiting the resident within the facility.

The implications are many, which follow directly from the insight that relatives may be fearful, for example, managers should consider offering relatives, verbal and written information on anticipated grief and loss, as part of the admission process. Also, managers, educators and staff need to periodically reassess relatives’ needs and responses during the dying resident’s admission, and offer opportunities to discuss concerns, or refer relatives to specialised bereavement services. Consideration by managers of using specialised bereavement services
in their area, such as the not for profit National Association of Loss and Grief (NALAG), psychologists or counsellors, and referring relatives to these services, as required.

The collaborative processes of action research and reflection provided opportunities for relatives to heal some of the pain of grief, by allowing them to speak of their experiences and inform the research groups of the issues of importance to them, in the end of life care of their family member. Participants became empowered through this shared knowledge, which facilitated a desire to support relatives in their grief, acknowledge the relatives’ fears and to offer reassurance to them on aspects of end of life care. The implications of this insight are that managers, educators and nurses should consider taking a proactive approach in seeking relatives’ input into end of life care planning and to commit to accessing specialist palliative care services early, if end of life care knowledge is limited.

Another insight identified in this project was that the symptom management for dying residents could be inconsistent and variable. Pain was the primary symptom discussed by participants in both facilities and inadequate pain management practices in end of life care were highlighted. Participants’ discussions indicated that a validated evidence based approach to managing pain for the dying resident was absent or inconsistent in end of life care in the facilities in which they worked. While this insight has obvious implications for improving this aspect of care in these particular aged care facilities, literature shows that this is a common problem in other agencies (McCLean & Higginbotham, 2002; Imhof & Kaskie, 2008). Therefore, the implications for symptom management generated by the participants within their workplaces are
potentially instructive for staff working on other agencies, with whom these implications resonate.

A dying resident may experience inadequate pain assessments, delays in medication ordering, reduced doses or irregular administration of analgesics and limited pain management planning. Inadequate pain management could persist throughout the dying process, or until someone advocates on behalf of the resident.

The project highlighted how nurses’ inadequate pain management knowledge and attitudes were a barrier to providing optimal end of life care. A starting point in addressing staff knowledge and attitudes to pain in Facility Two was to conduct a pre and post intervention knowledge and attitude survey (CD 1). The results of the surveys were then integrated into training schedules, and pain management was prioritised as a key aspect of the quality of care delivered. This strategy can be adopted by other aged care facilities. Identifying knowledge deficits enables early detection of key deficiencies in staff pain management knowledge and can demonstrate to staff areas for improvement. This is particularly important, because knowledge deficits may compound staff grief and loss issues, and as discussed previously, a lack of knowledge of what to do, particularly in difficult to manage end of life situations, could possibly trigger the ‘fight’ or ‘flight’ responses described frequently by participants.

The direct implications of inadequate pain knowledge are that educators should consider assessing staff for knowledge deficits and structure education programs to address the deficits. Also, managers should consider providing resources to support initiatives to improve pain practices. If staff are unwilling to attend
education opportunities in the facility, alternative modes of educational delivery can be used, for example, PowerPoint presentations on CD with voice over, standardised assessment tools, one on one academic detailing, paid conference attendance, and so on. Palliative care education, or an intention to complete a course in end of life care, need to be prerequisites to employment in aged care. Assessment of pain management attitudes and practices need to be components of performance management. This implication is in line with Maas, et al., (2008b), who suggests that if evidence based pain practices are to be integrated into aged care facilities, staffing levels needs to increase and those staff levels need to have aged care qualifications.

Lack of knowledge related to pain management contributes to nurses fearing the dying process, using avoidance behaviours, using inappropriate or poor communication, and it may contribute to nurses’ reluctance to challenge doctors’ prescribing practices. To reduce poor pain management practices, all staff must be held accountable and responsible for prioritising the assessment and management of pain, so that a report or observation of a resident experiencing pain cannot be ignored. Management, educators, and staff need to make pain a first priority, before any resident’s behaviour is labelled something other than pain. To raise the profile of pain as a first consideration, standardised pain assessment tools for cognitively able and cognitively impaired residents need to be made available and easily accessible to staff at the point of care. Further, staff need to be encouraged to discuss pain scores at each shift handover and regular pain assessments should be integrated into routine daily care. Untreated or inadequately treated pain must be viewed by all staff as a critical incident and addressed in the same manner as a fall or other accident. Acknowledging pain
management as an important priority, as relatives have suggested, would direct care to those end of life care issues of most importance to address first.

This project highlighted how hierarchical structures can be a barrier in aged care facilities, impeding optimal end of life care. For example, hierarchical structures impeded adequate pain management, because they contributed to a lack of ownership of the problem. A process of passing information on to another level relied on that next level having the knowledge and willingness to act. Education, in combination with other strategies, such as standardised pain assessment tools to improve communication of pain issues, and management support in their use, assist staff to appreciate that everyone in the facility owns the problem of poor pain assessment and management practices, and can assist in dismantling a “passing the buck, no responsibility” culture.

Insights were given into doctors’ pain management practices, when participants reported these as barriers to delivering optimal end of life care. Poor pain management practices, such as prescribing p.r.n. or administer as necessary analgesics, fear of prescribing opioids and delays in responding to requests for pain relief, impacted on nurses’ ability to maximise the likelihood of a good death for dying residents.

If doctors’ prescribing practices are implicit in inadequate pain management, the implications lie in identifying and rectifying the problem. Scope of practice is of equal importance to all health professionals, and if people believe they are working outside of their scope of practice, it is important the clinical issue is referred to either an expert in the field, or a doctor, who is available to consult. Regulators should be held responsible, to determine doctors’ palliative care
knowledge and periodically perform random assessments of doctors’ prescribing practices in end of life care. Doctors who choose to prescribe p.r.n. analgesics need to be held accountable by facility managers, to produce evidence that an effective pain management plan is in place, and that the resident is being monitored closely.

The relationships between nurses and relatives emerged as an issue in this project, in that nurses’ insight into relatives’ expectations of end of life care did not match the relatives’ concerns. Relatives are often the primary carer, in some cases for many years, prior to a resident’s admission to an aged care facility, therefore, their contribution and insights into care should be valued and documented in care planning by staff. Establishing a collaborative approach to care facilitates and maintains communication with relatives, to keep them informed of care planning and, therefore, relatives have the opportunity to contribute to maximising the likelihood of a good death for their family member.

Consideration by managers, to ensure that a facility’s end of life care philosophy is defined and enacted. Further, the end of life philosophy information shared with relatives is provided in both a verbal and written format, to reinforce information with relatives and help them to understand the facility’s approach to end of life care. A formalised process of sharing information with relatives may assist nurses to better represent the philosophy of the organisation and encourage open and honest discussions around end of life care issues within a structured process, as opposed to having to communicate in a fragmented fashion, predominately in crisis situations. Further, the admitting doctor and nursing director of care should consider meeting formally with the resident and their relative early in the admission process, to discuss the Advanced Care
Directive (ACD) requests and expectations for end of life management plans, and to outline what the facility can offer the resident in pain management.

A further barrier to preventing optimal end of life care to dying residents revealed in this project was that the maintenance of an effective team approach to care is a commonly espoused, but often unachievable, goal. When a team approach to care fails, communication is impeded and the quality of care to dying residents and their relatives suffers. To optimise the likelihood of a good death, managers should consider resourcing a team approach to care, by releasing staff to meet and discuss end of life care issues in a timely fashion, without the staff having to worry that they will need to attend to clinical work that has been left undone during those discussions. Doctors, managers, educators and nurses should consider committing to a collaborative approach to care, by keeping each other informed of clinical care, using appropriate assessment tools, using professional language, documenting accurately, being accessible to each other, maintaining contact when new treatments are planned, or a resident’s condition is unstable, and facilitating or participating in team building educational opportunities. Attention to all of these activities requires a well organised and maintained, constant, daily approach, so that quality care becomes commonplace.

This project revealed that staff in the facilities caring for people dying from non malignant diseases did not identify with a need for the broader concept of palliative care education, but focused on pain management as a separate entity of end of life care. In other words, they attempted to treat the pain on a case-by-case basis, but they did not assume the situation to be palliative, in the sense that pain was not anticipated and prevented by regular administration of analgesics.
and sedatives. Just as the care of a dying resident should not be based on managing end of life symptoms in isolation, so too is the knowledge required to deliver effective palliative care. To facilitate optimal end of life care in aged care facilities, palliative care education must be conducted by palliative care experts, on a regular basis. In-reaching of palliative care services could contribute to establishing and extending the concept of a team based approach to end of life care. Managers and educators should consider building bridges between their facilities and palliative care services within their local area, which are in place not only for when end of life care is “going wrong”, but also for every time it has potential to help, as the means of integrating experts into their service provision. Regulators consider the possibility to provide resources to fund in-reaching of palliative care services into aged care facilities, as they are one of the primary sites of dying for older Australians, yet they are more likely to lack palliative care expertise.

**Summary**

In this project, insights were gained into barriers to optimal end of life care, including fear of death and dying and associated behaviours, such as avoidance of issues, limited access to grief and loss therapies for stakeholders, poor pain management, palliative care knowledge deficits and practices, poor interdisciplinary communication and limited understanding of change processes. The implications relate to the consideration of improvement strategies, which are required for the research facilities to continue to address practice issues, such as grief, loss and bereavement, pain management, palliative care education and communication with relatives. As mentioned previously, the literature suggests that these issues are experienced in other aged care facilities (Maas et al., 2008b;
Wowchuk et al., 2007), so insights into the nature of these issues can have broader implications, if they are accepted as relevant and helpful by staff in other aged care facilities.

Nurses are challenged by a rapidly expanding aged care system, which is requiring them to respond to organisational change, such as new models of care, a workforce that increasingly uses unregulated staff, and regulated staff with no aged care or palliative care experience. Also, nurses are frequently required to communicate and advocate on behalf of higher acuity residents with complex conditions and treatments. Residential aged care facilities are a recognised place of dying (Hall et al., 2002; Wowchuk et al., 2007) and will be more so in the future, therefore, it is important for managers and staff to acknowledge this aspect of their service delivery and determine ways in which end of life care issues can be addressed, in a proactive, rather than a reactive approach, to care.

**Practical Suggestions for Improving End of Life Care**

This action research and reflection project is unique and important, in suggesting many practical strategies for nurses and allied staff, who are intent on improving the end of life care, for residents dying from non malignant diseases. The research demonstrated that nurses can be supported to examine their practices within the context of their workplace constraints, identify barriers to care, and explore the contributions they can make to practice improvements. In this project, the research process provided the nurses delivering the bedside care with a systematic approach to exploring end of life care, and freedom to see beyond the constraints in their practice. The approach encouraged participants to identify, plan, implement and evaluate each issue that emerged from their
reflections on practice and to see a way to move their practice forward. Ultimately, action research and reflection triggered critical enquiry into practice, which resulted in the nurses adopting and sharing a knowledgeable approach to end of life care.

The project also demonstrated how the aged care nurses in these facilities listened to and incorporated relatives’ views on end of life care priorities, and identified ways in which nurses could provide care that maximised the likelihood of a good death in their facility. Barriers that prevented delivery of optimal end of life care were identified and possible solutions were explored to change and address deficits in aspects of end of life care. The action research and reflection process and the action plans it created and implemented for both facilities, are available to nurses working in other aged care facilities, to use and incorporate in any ways they find meaningful, including setting up their own action research and reflection project.

This section offers interrelated suggestions as strategies identified by the research participants and used successfully in the research facilities for coping better with dying and death, and improving pain management practices, for residents dying from non malignant diseases.

Coping better with dying and death

- Offer relatives verbal and written information on grief and loss as part of the admission process and periodically reassess their needs;
• Encourage the admitting doctor and director of nursing/care to meet with new residents and relatives early in the admission process to formalise ACD requests and document residents’ expectations for end of life care;
• Have end of life care plans in place before the final stages of dying;
• Acknowledge grief and loss are issues in aged care and facilitate opportunities for staff to debrief;
• Clarify who in the facility is responsible for informing a relative that a resident is dying;
• Educate nursing and support staff on communicating with family members of the dying resident;
• Acknowledge that relatives can provide valuable information about a resident and can contribute to end of life care planning;
• Access specialist palliative care services early;
• Request RNs or ENs complete a palliative care course, as a prerequisite to employment;
• Acknowledge a lack of palliative care knowledge may impede optimal end of life care and offer palliative care education to existing staff;
• Establish connections and facilitate in-reaching of palliative care services;
• Assess knowledge and educate staff on the use of a palliative approach to care, including symptom management such as pain;
• Raise the profile of pain assessment and management for dying residents within the facility;
• Prioritise and share the responsibility for assessing and managing end of life symptoms;
• Establish or reinforce the organisation’s philosophy for end of life care;
• Share the organisation’s end of life care philosophy with residents and relatives and provide both verbal and written information;
• Be aware of whose needs are being met in end of life care, and confirm that staff are fully informed of a resident’s wishes;
• Provide dedicated time for educational sessions to build team processes;
• Improve communication within the team through inter-professional respect and contact, use of appropriate assessment tools, professional language, accurate documenting, and being accessible in a timely manner, especially when new treatments are implemented, or a resident’s condition is unstable and deteriorating;
• Maximise doctors’ visits to the facility, by encouraging comprehensive prescribing of end of life care medications;
• Support and provide comprehensive information to doctors, to assist them in their prescribing decisions; and
• Consider adopting and adapting an end of life care pathway as a component of education, a systematic approach to end of life care, and as a means of effective documentation of palliative care delivery.

Death and dying in aged care facilities can have effects on staff and relatives of the dying resident. Issues inherent in the recognition and acknowledgement of the effects of death and dying in the workplace on staff, the care of the dying resident, and relative/staff interactions, highlight the importance of addressing the issue of grief. In this project, exploration by nurses of end of life care practices, using a reflective approach, encouraged them to identify their attitudes to, and feelings about death and dying and encouraged them to seek support and help, for their grief and bereavement issues. This research document outlines strategies and resources to use for reflective processes in groups, which are available to aged care staff, educators and managers (Chapter Four).
The action plan created and implemented in Facility One, to improve the likelihood of a good death, included the following strategies to address grief issues and engage staff in debriefing opportunities:

- Acknowledge grief and loss in aged care work and prioritise the importance of staff self care;
- Be mindful that some staff may not have witnessed death prior to working in the facility;
- Assist staff to appreciate the potential impact of unresolved grief on end of life care;
- Provide regular, scheduled opportunities for staff to debrief;
- Use a variety of formats for debriefing;
- Acknowledge debriefing opportunities may assist staff in their grief and strengthen team bonds;
- Avoid a quick turnover of residents into vacated beds following a death, as a show of respect for the deceased resident, their relatives and staff, who have cared for them;
- Acknowledge and allow time for the packing up of a resident’s belongings following death, as this can be part of the grieving process for relatives and staff;
- Encourage all facility staff to participate in memorial services if they wish to attend; and
- Conduct regular case reviews and use this as an opportunity to discuss end of life care issues, so that grief resolution and debriefing become integrated into the organisation’s training program.
The action plan created and implemented in Facility One to improve the likelihood of a good death consisted of offering staff a debriefing session using a role play format. The following strategies are important when role play is used as a debriefing method:

- Use role play as a method of lightening the topic area of death and dying, to encourage discussion in a nontargeting, informal group environment;
- Actors in the role play should plan and rehearse together, before appearing in front of an audience;
- Use props and diverse roles to mimic a real scenario, for example, include a relative and an undertaker role;
- Provide a relaxed atmosphere for the session by including refreshments for the audience;
- Advertise and offer session attendance to all facility staff and integrate it into the regular training schedule;
- Keep attendance optional, by informing staff that session attendance is not mandatory;
- Avoid videotaping sessions, but if videotaping is used, be sure to check the video batteries and ensure the person taping is experienced;
- Introduce the role play clearly, by introducing the actors and the characters they are playing;
- State the group’s ground rules prior to the discussion time, for example, not to interrupt each other;
- Be prepared for a range of issues to emerge in discussion time;
- Be prepared to ask staff to clarify issues or statements they are raising during discussions;
- Advise staff to be prepared for criticisms of care delivered;
• Invite management staff to the discussions, so they both gain insights into issues of concern to staff and contribute to possible solutions or strategies, to address issues;
• Consider inviting palliative care service providers, to add value to discussions and offer possible solutions to end of life care problems; and
• Value everyone’s opinion and contribution to the discussions following the role play.

Improving end of life care pain management practices

The action plan created and implemented in Facility Two, and partially addressed in Facility One, consisted of ways to improve end of life care pain management practices, including the use of PDA technology. These pain management strategies were used successfully by participants in this project, and may be used by other aged care nurses:

• Be prepared to manage pain related issues in end of life care before they develop;
• Promote effective pain practices as everyone’s responsibility in the organisation;
• Communicate and share pain information with all facility staff;
• Avoid working outside of the scope of practice, and utilise palliative care experts when necessary;
• Eradicate labelling residents’ “behaviours” until pain assessment is comprehensively documented, and pain, as a cause of the behaviour, is excluded;
• View untreated or inadequately treated pain as a reportable, critical incident;
• Avoid p.r.n. or administer as necessary prescribing of pain relieving medications in end of life care;
• If p.r.n. or administer as necessary analgesics are prescribed, request the doctor produces evidence that a pain management plan is in place and the resident is being monitored closely;
• Confirm that staff are aware of the requirements of the prescribed pain management plan;
• Incorporate pain assessment and management into staff performance review;
• Assess staff to identify gaps in pain management knowledge and attitudes;
• Present knowledge and attitude survey findings to staff;
• Target education at the identified pain knowledge and attitude gaps;
• Highlight with staff the impact pain knowledge and attitude deficits have in contributing to the complexity of end of life care;
• Encourage allied staff to participate in sharing educational information with nurses;
• Provide resources for educational information, using a variety of formats, for example, PowerPoint presentations, CD, handouts, one on one education, PDA, and conference attendance;
• Standardise pain assessment tools for cognitively competent and cognitively impaired residents, provide access to them at the bedside, and integrate them into routine daily care;
• Discuss pain scores and medications at orientation and handover and include pain management issues on meeting agendas;
• Discuss and share difficult to manage pain assessments as a group;
• Embed pain assessment into a regular schedule for all residents, including those not reporting pain;
• Educate staff on medication absorption times and provide access to drug information, for example, display an opioid information poster on the medication trolley;
• If a PDA is used to provide medication information, allocate a person in the facility to be responsible for encouraging staff to use the PDA, checking the PDA is charged and the medication information is current;
• Engage staff in conducting audits, that include pain relieving strategies;
• Report pain audit findings back to staff;
• Revise or develop facility pain management policies; and
• Perform regular case reviews to recognise effective pain practices and identify pain management and other symptom problems.

This section described the importance of this action research and reflection project, in suggesting practical strategies for nurses and allied staff, who are intent on improving the end of life care, for residents dying from non malignant diseases. Nurses can be supported to examine their practices within the context of their workplace constraints, identify barriers to care, and explore the contributions they can make to practice improvements. In this project, action research and reflection triggered critical enquiry into practice, which resulted in the nurses improving end of life care. The practical strategies used successfully in this project, were offered to nurses in other aged care facilities, as interrelated suggestions for coping better with dying and death, and improving pain management practices, for residents dying from non malignant diseases.
Limitations of the Project

Action research and reflection is a collaborative, participatory research approach, which that engages people to influence their practice and to facilitate change (Taylor et al., 2006). The methodology assisted participants in this project to reflect on the ways in which end of life was delivered in their workplace, to identify barriers preventing optimal end of life care, to explore relationships between nurses and relatives of the dying resident, and to ultimately improve the end of life care of residents dying from non-malignant diseases. The process enabled participants to share insights into their practice in a safe, supportive group environment. A key aspect of the collaborative, participatory methodology is for participants to feel supported and, therefore, engaged in examining their practices, participating in identifying possible solutions and as facilitators in the change processes and evaluations. Participants in the research were enthusiastic and participatory in the processes, however, organisational barriers, as identified by Owen, Stein & Chenoweth (1999), have the potential to devalue the action research process (Minichiello, Sullivan, Greenwood & Axford, 1999).

Action research can only be as effective as those people who participate in the project. A barrier encountered in both facilities was the lack of RN participation in the groups. The project outcomes could have been strengthened further by more RNs participating in the groups and sharing their views on end of life care. In particular, the apparent RN avoidance in engaging in the research groups resulted in a process of having to outreach, to determine their needs and concerns in end of life care, which delayed some actions and changes. Organising separate meetings with RNs and confirming RNs’ cooperation at
various stages of the discussions and change processes achieved outreaching. This limitation served to reinforce the hierarchical level of workers within the aged care system with the research groups and created some discontent in participants, who felt their contributions required RN endorsement prior to implementation, when in fact, it was sufficient that RN involvement was sought as part of the consultative processes, prior to change.

The use of reflection was an integral component of the action research process in the project and was used to identify practice issues in end of life care. Many of the participants had their first introduction to the use of reflection in nursing practice in this project. Taylor (2006) suggests reflection can assist nurses and other health workers to identify and manage their perceived barriers to care, and provide them with a sustainable resource, to constantly improve work practices. Reflection assisted participants to explore end of life practices, however, reflection was new to participants and there were many important care issues to address. Therefore, the addition of a new learning experience resulted in research group time being focused on attaining the fundamentals of reflection, leaving less time overall to address care deficits.

The reflective component of the research process may have been more effective if participants were more willing to engage actively in the reflective exercises, leaving adequate time for later research phases, such as identifying the thematic concerns, and creating and implementing the action plan. Given the growing use of reflective practice in the healthcare professions generally, it is likely that the introductory research phase on the use of reflection in practice will be more effective, when participants are already conversant with the fundamentals of reflective practice, prior to participation in action research and reflection projects.
The participatory nature of action research and reflection provided participants with an opportunity to engage in, and belong to, a process that facilitated the identification of contextual barriers, to examine ways in which they could improve end of life nursing care. The research groups realised that only a certain amount of improvements or changes to practice could be managed in the project time. Also, the project highlighted relatively enduring constraints to practice change, and the difficulties often faced in sustaining practice changes. During the project, the momentum of meeting, planning and implementing change, sustained the research groups and empowered participants to ‘believe’ they could make change happen.

However, in the long term, if those changes are not embedded in the culture of the organisation, for example, when research participants leave a facility, the viability of practice changes is questionable. Therefore, collaborative research approaches, such as action research and reflection, can be problematic for an organisation, because after offering and delivering so much in the research phase, when the project ends and co-researchers exit employment sometime after a successful research project, the remaining staff may feel abandoned and become disillusioned, and be less likely to sustain a collaborative research culture. Therefore, it is important to establish an ongoing commitment to collaborative research processes, by ensuring that the remaining staff, especially influential senior managers, researchers and educators, inscribe practice based research approaches into daily practices. Even so, a one off action research and reflection project has the potential to trigger a critical review of practice, which in itself can ignite change and educate co-researchers, who can share their experiences and change processes with others in any workplace, in which they become employed.
Several other limitations of the project also need to be acknowledged. Although the process was comprehensive, the study sample size was small and limited specifically to a group of nurses working in two convenient rural Australian, aged care facilities, and participants became co-researchers because they wanted to improve end of life care. In accordance with qualitative epistemological assumptions about the relative, subjective, and context-dependent nature of knowledge, this qualitative research project did not seek to generalise its findings to other aged facilities, nor did it try to find cause and effect relationships between research variables. Therefore, the project only claims to generate insights and implications, which may be taken up as practical suggestions by nurses in other aged care facilities. In support of these qualitative research limitations, however end of life literature suggests that the end of life care issues raised in this project are experienced nationally and internationally (Allen et al., 2008a; Carlson, 2007; Grbich et al., 2005; Kristjanson et al., 2005; Miller, Teno & Mor, 2004; Wowchuck, et al., 2007).

The number of relatives interviewed for the project was small, but their stories were relevant to the specific facility and beneficial for the research processes. In qualitative research, experiential accounts are valuable for their rich insights into lived experiences, and in this research, relatives’ accounts were interpreted with due consideration of the close nature of their relationship with the resident, and with respect for the feelings of loss and grief relatives were experiencing at interview. Even given these limitations in this project, relatives’ accounts were similar to other investigations into relatives’ needs in end of life care (Munn et al., 2008; Wetle et al., 2005).
In summary, there were some specific methodological and design features in this qualitative project, which may be seen as limitations, if they are judged against quantitative research assumptions and criteria. Despite these perceived limitations, the project revealed that these facilities needed to improve end of life care practices, particularly in pain management, and in providing opportunities for staff to debrief. Action research and reflection assisted participants to examine practice issues, identify barriers and facilitate changes in aspects of end of life care, in these two residential aged care facilities. As has been argued previously, literature suggests similar issues in other aged care facilities, so the insights and implications of this project are useful for other nurses, with whom these ideas resonate.

Further Research

In recent years, numerous programs for care of the dying have been developed, ranging from training programs to specific guidelines (Edith Cowan University, 2005; Henry & Fenner, 2007; Veerbeek et al., 2008). The premise on which these strategies are offered is that they are of benefit to the dying person, by delivering appropriate end of life care, with the intention being to relieve suffering, thus providing a ‘good death’. This project demonstrated there is reason to question whether the integration of known strategies to achieve a ‘good death’ are actually being used and integrated in aged care facilities. Given the experience of working with aged care nurses in this project, the project’s insights and implications suggest that more research is required.

This action research and reflection project could be expanded, by exploring and comparing strategies used in pain management across an increased number and
diverse range of aged care facilities, to identify those strategies that best meet medical and nursing end of life care delivery needs, which demonstrate the best residents’ outcomes.

The group processes used in this project facilitated participants to meet and maintain momentum in practice changes. Participants in this project reported feeling supported, encouraged, motivated and empowered to expose issues of concern in end of life care and were introduced in a progressive manner to developing leadership skills, for example, by rotating the role of meeting chairperson. This project has been successful in creating change in two facilities, suggesting other aged care facilities consider exploring processes that model facilitative leadership qualities and are inclusive of all facility staff. Future research could set up the action research methodology, to ignite change in aged care facilities elsewhere, while at the same time developing leadership skills.

This project could also be extended to explore symptoms other than pain management, when residents are dying from non malignant diseases. An observational study using an ethnographic methodology to view RN - resident interactions relating to end of life symptoms, such as dyspnoea, restlessness and so on, may enhance the decision making processes nurses require to effectively address these symptoms.

Future research could explore if end of life care guidelines are available to staff in aged care, what aspects of those guidelines are of most use to aged care staff, and whether facilities’ resources support the use of evidence based guidelines. These objectives could be achieved through quantitative research approaches, such as
surveys, observational techniques and audits, or through qualitative approaches, such as ethnographic and interview based methods.

Further research is required to examine how grief is identified and managed in aged care facilities. This research may provide insight into the contribution grief and loss has on nurses’ decision making at end of life, staff turnover rates and care delivery in general. A nation-wide mixed method research design using quantitative and qualitative approaches, incorporating surveys, questionnaires and semi-structured interviews would strengthen the generalisability of findings and be more influential nationally, in dealing with the problem of unresolved grief.

Given the complexities in enacting the values embedded in aged care, a critical ethnography project can be used to explore how an organisation’s end of life care philosophy is enacted by nurses working in residential aged care. Interviewing and participating with a political intent, with nurses working in aged care facilities, will uncover more real issues and constraints contributing to their inability to deliver appropriate end of life care, even though ideal end of life care is espoused in the organisation’s care philosophy.

A mixed method project using interviews, surveys and observation, examining the admission processes used by a wide range of aged care facilities, may be useful to explore how end of life care is addressed at the early stages of admission. This research needs to include all stakeholders, including health carers, residents and family members. This project could provide insights into the important aspects of end of life care, which should be addressed on
admission into aged care and reviewed throughout the resident’s life in the aged care facility.

The availability and use by aged care facilities of current specialist palliative care services in rural settings needs to be explored. Pilot projects that trial palliative care specialists in-reaching into aged care facilities to assess and manage end of life care may provide insights into improved methods of overseeing care and alternative ways of providing support to aged care facilities.

A quantitative study to determine aged care nurses’ attitudes and reactions to end of life care and/or aged care training requirements should be considered, to identify the relationships between personal values and attitudes to actual end of life practices. Questionnaire and survey data could also identify the number of nurses currently working in aged care with a background of, or experience in, palliative care nursing, to examine why end of life care issues continue to be problematic in aged care settings.

A qualitative project to explore issues, which doctors with visiting rights to aged care facilities identify, that impede or enhance their decision making in pain management at end of life should be considered. This project could use interviews to identify, overcome or manage perceived barriers, and provide doctors with personal insights into aspects of their care, which make a positive contribution to optimal end of life care.

In summary, there are many research opportunities available, for continuing to address issues and improve end of life care in aged care facilities. The gains achieved in this action research and reflection project can be maintained in
practice, if these aged care facilities continue to prioritise grief and loss issues, and implement a range of strategies to address pain management, such as standardised assessment tools, the use of end of life clinical pathways, and ongoing audits and case reviews. Even so, given that aged care facilities will increasingly be the site of dying and death for more older Australians (Department of Health and Ageing, 2008), improving end of life care for all residents will be an ongoing national imperative, therefore, further research is needed, including large scale, multi-sited funded projects.

Chapter Summary

A working relationship with aged care nurses with no prior knowledge of reflection or action research processes was established in this project, to successfully identify and address aspects of end of life care. This chapter discussed the thematic concerns and associated issues that emerged in Facilities One and Two. The major thematic concerns included debriefing and pain management, and the associated issues included communication with the relatives, nurses’ language and palliative care education. This chapter also offered research insights, implications and practical suggestions for improving end of life care, and concluded with a discussion of limitations of the project and suggestions for further research.

Research Summary

As the Australian population ages, the demand for residential care and optimal end of life care for frail, older people is anticipated to increase, including people with non malignant diseases (Rosenwax et al., 2005; Wowchuk et al., 2006). The
illness trajectory in non malignant diseases can be difficult to predict, and management of symptoms related to non malignant diseases presents numerous challenges to those who care for dying residents (Janssen et al., 2008). Therefore, this study aimed to examine ways in which nurses can provide nursing care that maximises the likelihood of a good death, identify the barriers preventing optimal end of life care to dying residents, and explore the relationships between nurses and relatives of the dying resident, with the intention of improving care.

Given the premise there is limited evidence to define what a ‘good death’ is, because it raises the question of: In whose perspective is a death considered good? (Clark, 2003; Ellershaw & Ward, 2003; Steinhauser et al., 2000), this project supported the notion that a good death is one in which the process of dying is controllable (Department of Health and Ageing, 2005a; Jarabek et al., 2008; Lorenz et al., 2008; Qaseem et al., 2008). This means that, in a good death in end of life care delivery, dying can be controlled and delivered in such a way that the physical, spiritual and emotional needs of dying are attended to effectively.

Following ethical clearance, 14 staff overall within both aged care facilities, were recruited to this action research and reflection project. Participants included Registered Nurses, Enrolled Nurses, Assistants in Nursing and other aged care staff personnel, all of whom were in a carer relationship with a dying resident. In addition, eight relatives of dying relatives were interviewed, using individual, face to face, semi structured interviews.

Taylor’s (2006) 13 step method for undertaking action research and reflection were incorporated into six main research phases, including foundation building, reflection on practice stories, learning from the relatives, identifying thematic
concerns, action plan creation and implementation and critical reflection. In both facilities, group meetings were held weekly for up to 20 weeks. Data were gathered using combinations of reflective drawings, practice stories, interviews and surveys. Relatives’ interview transcripts were incorporated into the nurses’ group meetings as key statements, so that end of life care issues of importance to relatives were shared, with the intention of improving end of life care for residents dying from non malignant diseases.

Thematic analysis was conducted and through group consensus, themes and subthemes emerged from the practice stories indicating aspects of end of life care needing further improvement. The major thematic concerns prioritised for action were the need for staff debriefing and better pain management. Relatives had also raised the issue of adequate pain management and the request to ensure this was a priority in the care of the dying. Through collaborative processes, action plans were created, implemented and evaluated, with participants reporting varying degrees of success in attempting to improve these aspects of care.

This project demonstrated that the delivery of end of life care to residents in these rural residential aged care facilities was inconsistent and of varying quality. Grief and loss permeated the aged care work and affected the staff and relatives of the dying resident. Some of the barriers identified in delivering effective end of life care included hierarchical structures, poor staff attitudes, doctors’ prescribing practices, a lack of communication within the team, and limited palliative care knowledge and services. Poor pain management practices at end of life were related to numerous issues, including the demands of managing
more complex conditions, a lack of implementation of evidence based recommendations, and staff knowledge deficits.

Although this project highlighted care deficits within two specified Australian aged care facilities, literature supports the contention that issues exist nationally and internationally within other aged care facilities and systems, in relation to caring for people dying from non malignant diseases (Allen et al., 2008b; Carlson, 2007; Grbich et al., 2005; Kristjanson et al., 2005; Miller, Teno & Mor, 2004; Wowchuck, et al., 2007). The failure to adequately address dying in older people is reflected in the aged care system, which is challenged to meet the increased complexity of delivering optimal end of life care to high acuity residents. The project also suggests that when end of life care guidelines are available, they are not being enacted effectively. The enormity of these problems requires sustainable practice changes, which will embed and facilitate effective palliative care within aged care institutions.

In conclusion, the thesis statement is:

This action research and reflection project generated insights into end of life care practices in two rural Australian, residential aged care facilities and provided practical strategies for staff to cope better with the dying and death of residents, and for improving the management of dying residents’ pain. The project demonstrated that it is possible to establish a working relationship with aged care nurses, with no prior knowledge of action research or reflective processes, to influence end of life care nursing practices. The practical strategies generated and used in this project can be utilised in other aged care facilities by nurses, educators, managers and other health professionals, with whom they resonate. Critical to the success of these initiatives is the support for staff, who deliver end of life care, so they have a voice and feel supported by their facilities, to constantly examine clinical practices and plan and implement strategies to improve care.
PLAIN LANGUAGE STATEMENT FOR NURSE PARTICIPANTS

_Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease_

My name is Joanne Rowley. I am currently studying towards a Doctor of Philosophy in Nursing at Southern Cross University, NSW. I am undertaking a research project which aims to explore nurses and relatives thoughts on end of life care for patients who are dying or have died from a non cancer disease in a rural nursing home. I would like to invite you to join me in this project. The research will highlight the importance of the role nurses and relatives play in providing insight into care that can make a positive difference to a person dying from a non cancer disease.

The research will involve participation in ten, weekly, 1 hour group meetings with other nurses to share experiences of end of life care. Meetings will be held at this nursing home. You will be provided with a journal for writing your stories of end of life care. You can stop writing in the journal at any time if you have no time or do not feel like journaling. However, discussion will be facilitated by sharing your practice stories, so you are expected to share your experiences, as part of the group process. Copies of the meeting minutes will be provided to you to check your contributions and allow for any changes you might like to make.

In each action research cycle the findings will be pooled and discussed and the appropriate action will be planned and taken. Progressive observation of the effects of each action will follow, before further reflection leads to further action and analysis.

If you agree to participate in the project I can meet with you to explain more about the research, answer any of your questions and explain the consent form that is attached. You are free to withdraw from the research at any time without prejudice, and if you request, your contributions will be destroyed. To protect your identity a pseudonym instead of your name will be used, and all personal information will be kept confidential. Any information from the research will be kept in a locked cupboard, and I will not discuss it with anyone apart from my supervisor at the university. After 5 years all of the information will be destroyed. All participants will be asked to maintain the confidentiality of what they say in the group meetings.

As a nurse who has experienced some suffering while caring for a dying patient the meetings may be an emotional experience and bring up unhappy memories. If you have any unsettling emotions during the meetings, you will be given the opportunity to take time out if you wish, and I will be available to talk with you. For further support, if necessary, I can provide you with the names of counsellors and the contact details of my supervisor Professor Beverley Taylor (see list attached)

I would be happy to discuss any questions you may have about the research, so feel free to contact me (02) 6656 7323 between 8 AM and 4.30 PM. The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee. The approval number is ECN-05-75. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Ethics Complaints Officer, Ms S. Kelly, (telephone (02) 6620 9139, fax (02) 6626 9145, email: skelly@scu.edu.au).

Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome. Yours Sincerely,

Joanne Rowley SCU PhD Student. School of Nursing and Health Care Practices. Phone: (02 66 57 323)
CONSENT FORM

I have read the plain language statement for participants entitled 'Dying in a Rural Nursing Home: Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease' and agree to participate in the study. I am over the age of 18 years.

I hereby consent to be a participant in the research project conducted by Joanne Rowley entitled:

Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease.

My involvement within this research has been explained to me both in writing and verbally and my questions answered.

I understand that I will be involved in participating in group meetings and/or writing a journal (nurses) or interviews (relatives) to share experiences of end of life care. I will be given the opportunity to make changes and corrections to my contributions to the meetings or interviews. If I experience uncomfortable emotions in relating my stories, at any stage, I will be offered assistance.

I acknowledge that:

The aims, methods, anticipated benefits and possible hazards of the research study have been explained to me.

My name and details that may identify me will be altered to protect my privacy and anonymity.

I voluntarily and freely consent to be a participant in this research.

I am free to withdraw my participation from the research at any time and any information obtained from me will be destroyed, if I request it.

I understand that the aggregated results of the project are only to be used for research purposes and may be reported in professional and scientific journals and/or at professional conferences.

Signed: Participant
Date
Witness
Date

I certify that the terms of the form have been verbally explained to the subject, that the subject appears to understand the terms prior to signing the form. I asked the subject if she/he needed to discuss the project with an independent person before signing and she/he declined (or has done so).

Researcher
Date
COUNSELLOR DETAILS

Supervisor:
Professor Beverley Taylor
Address: Southern Cross University, PO Box 157 Lismore 2480.
Phone contact: (02) 6620 3156.

Counsellors:
Jim Morris
Address: PO Box J39 Coffs Harbour 2540
Phone contact: (02) 6652 8616.

Michael Hope
Address: Corindi Beach
Phone contact: (02) 6649 1175.

Pamela Davidson
Psychological and Counselling Services
Address: Suite 222/51a Little Street
Coffs Harbour
Phone contact: (02) 6652 6864
Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease.

DEMOGRAPHIC DATA COLLECTION

Please complete the following questions by ticking appropriate box.

Age:
Gender: Male ☐ Female ☐

Occupation:

Years of nursing experience (if a nurse):
1 year ☐
2 – 5 years ☐
5-10 years ☐
>15 years ☐

Educational level:
School Certificate ☐
Higher School Certificate ☐
TAFE Certificate ☐
University Level ☐
Other (please specify)

Marital status:
Single ☐
Married ☐
Separated ☐
Divorced ☐
Widowed ☐

Relationship with dying person:
Wife ☐
Husband ☐
Friend ☐
Mother ☐
Father ☐
Carer ☐
Other (please specify)
Appendix B

SOUTHERN CROSS UNIVERSITY
~ MEMORANDUM ~

To: B. Taylor / J. Rowley
School of Nursing and Health Care Practices
btaylor1@scu.edu.au, jrowley@ceinternet.com.au

From: Secretary, Human Research Ethics Committee

Date: 6.7.05

Project: Dying in a rural nursing home: An action research and reflection project to improve end of life care to people with a non malignant disease.

Status: Approved subject to standard conditions and one special condition.
Approval Number ECN-05-75

HUMAN RESEARCH ETHICS COMMITTEE (HREC)

At the HREC meeting held on the 27 June, 2005, this application was considered. It has been approved subject to the usual standard conditions and the following special conditions.

Please note that you must comply to these special conditions within one month of this approval, otherwise the approval will be revoked. Please send your responses and the signed certification to the Secretary by the 1 August 2005.

Special Conditions

(a) At the HREC meeting on 27 June, the HREC elected a new Ethics Complaints Officer. Please include the following on relevant documentation to participants.

The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee. The approval number is ECN-05-75. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Ethics Complaints Officer, Ms S. Kelly, (telephone (02) 6620 9139, fax (02) 6626 9145, email: skelly@scu.edu.au).
Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Please provide a copy of any relevant documentation where this paragraph is included, to the HREC.

(b) New Ethics application forms are available on the GRC website. Please use these forms for future applications.

(c) The approval of this application is contingent upon the approval from the St Augustine Nursing Home and Legacy Nursing Home or the Area Health Service. Please provide evidence of their approval when it is available.

(d) The Committee would like further contextualisation of the rural dimension.

(e) Please provide the ‘Notice’ to be used.

(f) The Committee recommends that the title be changed to plain English.

(g) Information Sheet.

- The Committee would like the language changed to reflect that this research is exploring the thoughts of relatives.
- Please change the word ‘meetings’ to interviews.
- Will transcriptions be made available to participants? This is unclear. Please clarify and include details in the information sheet.
- Please check the grammar of the paragraph If you agree.
- Please re-format researcher details, sign-off and Ethics Complaints Officer contact details (as above at point a) for presentation and clarity.

Standard Conditions (in accordance with National Health and Medical Research Council Act 1992 and the National Statement on Ethical Conduct in Research Involving Humans):

1. That the person responsible (usually the Supervisor) provide a report every 12 months during the conduct of the research project specifically including:

   (a) The security of the records
   (b) Compliance with the approved consents procedures and documentation
   (c) Compliance with other special conditions.
   (d) Any changes of protocol to the research.

   Please note that compliance to the reporting is mandatory to the approval of this research.

2. That the person responsible and/or associates report and present to the Committee for approval any change in protocol or when the project has been completed.

3. That the person responsible and/or associates report immediately anything that might affect ethical acceptance of the research protocol.

4. That the person responsible and/or associates report immediately any adverse effects on participants.
5. That the person responsible and/or associates report immediately any unforeseen events that might affect continued ethical acceptability of the project.

6. That subjects be advised in writing that:

*The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee. The approval number is ECN-05-75. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Ethics Complaints Officer, Ms S. Kelly, (telephone (02) 6620 9139, fax (02) 6626 9145, email: skelly@scu.edu.au).*

*Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.*

Suzanne Kelly  
Secretary, HREC  
Ph: (02) 6626 9139  
skelly1@scu.edu.au

Dr Baden Offord  
Chair, HREC  
Ph: (02) 6620 3162  
rofford@scu.edu.au

**CERTIFICATION**

**ECN-05-75 – B. Taylor/J. Rowley – June HREC**

*Dying in a rural nursing home: An action research and reflection project to improve end of life care to people with a non malignant disease.*

Please return the following certification when the special conditions have been addressed. Include a copy of your changes so that the Committee can note the changes at the next HREC meeting.

---------------------------------------------------------------------------------------------

**Certification**

Conditional approval will lapse one calendar month from the date of this memorandum if the special conditions have not been fulfilled, and thereafter the University will not accept any further responsibility in regard to the research.

If special conditions have been imposed, you must complete this and return it to the Graduate Research College by the lapse date. Please notify the Secretary if timing is a problem.

I certify that the special conditions outlined above have been fully met, a copy is attached, and that the standard conditions will be met.

Signature of Researcher: _______________________________ Date: ________________
Response to HREC

To: Secretary, Human Research Ethics Committee
CC: Professor Beverley Taylor
From: Joanne Rowley
Date: 21st July 2005

Re: Dying in a rural nursing home: An action research and reflection project improve end of life care to people with a non malignant disease.

Response to the SCU Human Research Ethics Committee (HREC)
Approval Number ECN-05-75

Special Conditions

(a) At the HREC meeting on 27 June, the HREC elected a new Ethics Complaints Officer. Please include the following on relevant documentation to participants.

(b) The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee. The approval number is ECN-05-75. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Ethics Complaints Officer, Ms S. Kelly, (telephone (02) 6620 9139, fax (02) 6626 9145, email: skelly@scu.edu.au).

Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Please provide a copy of any relevant documentation where this paragraph is included, to the HREC.

Response (a)

The ethical aspects of this study. I have included these paragraphs on the Nurses Plain Language Statement and the Relative Plain Language Statement please see attachments.

(b) New Ethics application forms are available on the GRC website. Please use these forms for future applications.

Response (b)

I take note the new application forms are available on the GRC website and will use these forms for future applications.

(c) The approval of this application is contingent upon the approval from the St Augustine Nursing Home and Legacy Nursing Home or the Area Health Service. Please provide evidence of their approval when it is available.

Response (c)
The application will be submitted to the North Coast Area Health Service Research and Ethics Committee August 2005 meeting. On receipt of approval I will forward to SCU HREC.

(d) The Committee would like further contextualisation of the rural dimension.

Response (d)
The rural context has been obtained from the Australian Institute of Health and Welfare Accessed from the publication Health in Rural and Remote Australia. Authors: Strong, K., Trickett, P., Titulaer, I., and Bhatia, K. Published 1 Dec 1998.

Rural centre in this document is defined as a population of 25,000 - 99,000. The rural, remote and metropolitan (RRMA) groupings are classified according to statistical local area (SLA) based on the Australian Standard Geographical Classification version 2.1 (ABS 1995)

The Australian Bureau of Statistics estimated Coffs Harbour resident population for June 04 was 66,529.

(e) Please provide the ‘Notice’ to be used.

Response (e)
The notice to be displayed in the nursing homes to recruit patient relatives is attached. The Notice will be displayed on coloured paper.

(f) The Committee recommends that the title be changed to plainer English.

Response (f)
The research has been sponsored by community funds allocated by the Bananacoast Credit Union in the form of a scholarship and as such it is important that the title reflect the actual content of the project funding. I appreciate the title is long and probably could be more succinct however the only word that may be confusing is non malignant. I would prefer not to change the title word non malignant to non cancer as the term non cancer is used in the plain language statement and clarification will be provided to participants if necessary. The title has been given a lot of consideration in negotiation with my supervisor Professor Beverley Taylor who has requested if there is any further clarification required to please contact her on 6620 3156.

(g) Information Sheet. Please see responses beneath each dot point.

- The Committee would like the language changed to reflect that this research is ‘exploring the thoughts of relatives.

This statement is located in the Plain Language Statement for Relatives paragraph one stating: “My name is Joanne Rowley. I am currently studying towards a Doctor of Philosophy in Nursing at Southern Cross University, NSW. I am undertaking a research project which aims to explore nurses and relatives thoughts on end of life care for patients who are dying or have died from a non cancer disease in a rural nursing home”.

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I have included nurses in this statement as I think it is important relatives are informed nurses will also be participants in the research.

- Please change the word ‘meetings’ to interviews.
I have altered paragraph 2, sentence 2 on the Plain Language Statement for Relatives. See attached.

I am reluctant to change the word meetings to interviews on the Plain Language Statement for Nurses as this project is using an Action Research and Reflection methodology. This means that the meetings are the forums for discussion and reflection for the nurses. The meetings for the nurses are distinct from the interviews to be held with relatives.

I believe I need to clarify at this point that I will be having separate nursing home meetings with the nurses. One group of ten meetings with nurses from the catholic nursing home and a separate group of ten meetings with nurses from the non catholic nursing home.

The relatives from each nursing home will be interviewed individually.

- Will transcriptions be made available to participants? This is unclear. Please clarify and include details in the information sheet.
The transcriptions being made available to participants was outlined in the original Plain Language Statement for Relatives in paragraph two, sentence three. I quote “Copies of the interview recordings will be provided to you to check your contributions and allow for any changes you might like to make”.

The transcriptions being made available to participants was outlined in the original Plain Language Statement for Nurses in paragraph two, last sentence. I quote “Copies of the meeting minutes will be provided to you to check your contributions and allow for any changes you might like to make.”

- Please check the grammar of the paragraph If you agree.
I have adjusted both plain language statements accordingly.

- Please re-format researcher details, sign-off and Ethics Complaints Officer contact details (as above at point a) for presentation and clarity.
I have adjusted the researcher details, sign-off and Ethics Complaints Officer contact details please see attached plain language statements.

Thank you for reviewing this proposal, I will forward the Certification ECN-05-75 – B. Taylor/J. Rowley – June HREC signed form when I forward NCAHS Ethics and Research Committee approval when granted.

Yours Sincerely,
Joanne Rowley  SCU PhD Student
NORTH COAST AREA HEALTH SERVICE

~ MEMORANDUM ~

To: B. Taylor / J. Rowley
School of Nursing and Health Care Practices
btaylor1@scu.edu.au, jrowley@ceinternet.com.au

From: Acting / Research Ethics Officer

Date: 7th November 2005

Project: Dying in a rural nursing home: An action research and reflection project to improve end of life care to people with a non malignant disease.

Status: NCAHS HREC Approval Number 300

RESEARCH PROPOSAL

Name: Joanne Rowley

Student Number: 21253377

Phone number: 66567 323 (work) 66540 158 (home)

Unit Name: Doctor of Philosophy

Supervisor: Professor Beverley Taylor

Project Title: Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease

Date: 26th April, 2005

Name of Project: Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease

Background:
Australia’s population is ageing; similarly many other developed countries populations are ageing. Over the course of the 20th century, the proportion of people aged 65 years and over in Australia has tripled, from 4% in 1901 to 12% in 2001. It is projected that this growth will continue over the 21st century and by 2020, 18% of the population will be
aged 65 years and over (ABS, 2002a). The over 85 age group is expected to be the highest projected growth rate overall of the population, from 1% of the total population to between 7% and 11% by 2051 (ABS, 2004).

Nursing homes are increasingly becoming the place of care and site of death for an ageing population. In 2001, 73,800 people in Australia lived in a nursing home as a recipient of care (ABS, 2003). According to Teno (2003, p. 293), in both England and Australia, one in five people now die in a nursing home. Nursing homes as defined by the Australian Bureau of Statistics as “public or private establishments providing mainly nursing care for inpatients, including sanatoria, convalescent homes and hospitals with mainly nursing facilities for the aged and terminally ill, but excluding cared accommodation for the retired or aged” (ABS, 2003, p.2).

As Australia’s population ages, the consequence of a growing number of frail, older persons, dying of chronic progressive non-malignant illnesses, in nursing homes will see the need for compassionate quality end of life care grow in importance. It will be beneficial for patients, their families and the nursing profession to gain knowledge on how best to maximise the positive aspects of nursing care during the dying process.

The leading causes of death in Australia, in 2002, were malignant neoplasm, ischaemic heart diseases and cerebrovascular diseases responsible for 57% of all deaths, these diseases were also the leading multiple causes of death reported either as the underlying or associated cause in 76% of all deaths. The fourth ranked multiple causes were influenza and pneumonia, which was reported in 14% of all deaths and ranked as the seventh leading underlying cause responsible for 2.3% of deaths. Other causes of death include heart failure, chronic lower respiratory disease, renal failure, injury, poisoning and certain other consequences of external causes, diabetes mellitus and accidents (ABS, 2002b)

Death from a non malignant disease presents numerous challenges for health care workers caring for the dying. Keay, Alexander, McNally, Crusse, & Eger, (2003, p. 206) have identified the end of life care issues such as pain control, dyspnoea control, emotional care, bereavement and carer stress, spiritual and cultural care as challenges for staff caring for dying patients in aged care facilities.

Aim of Project: This project aims to explore issues as identified by nurses and relatives of patients receiving end of life care in rural nursing home settings from a non malignant disease.

Objectives: The objectives of the project are to:
1. Examine ways in which nurses can provide nursing care that maximises the likelihood of a good death;
2. Identify the barriers nurses perceive to prevent optimal end of life care to dying patients and
3. Explore the relationships between nurses and relatives of the dying patient.

**Significance:**
The significance of the project is to provide insight into the care that can make a positive difference to a person dying from a non malignant disease. The care issues will be identified by nurses and relatives of patients receiving end of life care in rural nursing homes. Nurses caring for dying patients need to be cognizant of the needs of the patient and the patient’s relatives. Nurses should determine if family members / caregivers have unanswered questions and be able to provide information that is relevant to the families needs.

**Literature Review:**
Australian nurses working in the aged care sector are challenged to provide increasingly complex care to meet patient needs. Jackson, Mannix, & Daly (2003, p. 44) identified the aged care nursing workforce is struggling to improve the image of aged care nursing, to recruit nurses and maintain an adequately skilled workforce. Retaining nurses in the aged care sector is not unique to Australia. Teno, (2003, p. 294) describes the difficulties nursing homes in the United States face where more than half the workers are being replaced every year.

In 1999 a team of researchers, Greiner, Buhr, Phelps, & Ward (2003) assessed the palliative care needs of health care institutions in the state of Wisconsin, USA. Greiner et al., (2003, p. 544) developed a survey instrument based on end of life care guidelines. The tool was used to survey hospitals, hospice agencies, long-term care facilities, home health care agencies and other health care institutions. The survey identified in every institution the most frequently identified barrier to good end of life care were a lack of knowledge among patients / families. The second most frequently identified barrier was a lack of provider knowledge of pain and symptom control. Recommendations made by the researchers included a formal structure for disseminating information on end of life care, access to expert resources, and the provision of education programs.

According to Cantor, Blustein, Carlson, & Gould (2003, p. 540) symptom control and physician responsiveness to symptoms were serious concerns identified for hospitalised patients near the end of life and their families. Cantor et al. (2003) conducted the study in five New York teaching hospitals and although the experience of patients and their families in nursing homes may be different the issue of symptom control is important. Symptoms experienced by people diagnosed with a malignant or non malignant disease can be similar: cancer patient’s symptoms may be more severe, but those of non cancer patients tend to be more prolonged. O’Brien, Welsh, & Dunn (1998, p. 286) have reported under prescribing of opioids for pain in patients with non malignant diseases is not uncommon.
**Methodology:**

An action research methodology will be used in this project. Action research was developed and used by Kurt Lewin a social psychologist in post world war America. Lewin conducted social experiments with various community groups to foster, ‘group decisions and commitment to improvement’ (Kemmis & McTaggart, 1990, p. 6).

Action research is a method of research that engages people to influence practice or facilitate change. The process requires participants to identify issues that are relevant to practice or situations and develop solutions or strategies to change practice or improve situations (Roberts & Taylor, 2002, p. 151).

Participants are integrated into the cycles of the action research process. Roberts and Taylor (2002, p. 347) describe the ongoing cycles as stages of identifying the practice issue, generating solutions and sustaining changes. The cycles lead to group decisions being made that result in an action being taken (Minichiello, Sullivan, Greenwood, & Axford, 1999, p. 265).

Kemmis and McTaggart (1990, p. 63) suggest a process of initial reflection is used to analyse a situation in relation to a thematic concern. Reflection is then followed by a process of planning, to implement an action, a change or adoption of a new practice. The implementation of the plan and the ongoing observation of how it works in practice culminate in the research participants returning to the process of reflection. Reflection encourages participants to review achievements and examine limitations of changes to practice. The analogy of a ‘spiral’ that incorporates the four steps of action research demonstrates action research is a, ‘dynamic process that can be engaged in several times before a problem is resolved’ (Minichiello et al., 1999, p. 256). A crucial element of action research is the collaboration of group members to engage in the process and form bonds of trust with group members (Minichiello et al., 1999, p. 260).

**Method**

The research will involve nurses working in two nursing homes; one Catholic, one non-Catholic and relatives of patients dying or who have died from a non malignant disease in one of those nursing homes.

Five nurses from each of the two Coffs Harbour nursing homes (n10) will be invited to volunteer to participate in the project. I will attend a regular nurses meeting at each facility, introduce myself, provide a verbal and written explanation of the project aims and processes and extend an invitation to the nurses to participate in the project. The nurses need to be interested in reflecting on their practice in order to improve it.

Following the signing of the designated Consent Form nurses firstly will be invited to share their experiences of end of life care for patients dying from a non malignant
disease. Participating nurses from each nursing home will attend weekly meetings at their facility on ten occasions of one hour duration to discuss end of life care experiences and issues. An action research process of planning, acting, observing and reflection will be used.

Patient relatives from each of the two nursing homes (n 10) will be invited to participate in the project. I plan to place a notice in each facility to draw the attention of the relatives to the study. The notice will provide an explanation of the project aims and processes and invite the relatives to participate in an interview with the researcher. The main purpose will be to have the relatives explore their own and others’ definitions of what constitutes optimal end of life care in particular, issues that are important to them in relation to their dying relative. An exploration and discussion of the relationships between nurses and relatives of the dying patient will be integrated into these interviews.

The selection criteria of participants in this project are as follows:

**Inclusion Criteria Nurses:**
A maximum of 10 Registered or Enrolled Nurses working in one of two Coffs Harbour nursing homes who have experienced providing end of life care to patients dying from a non malignant disease.
Live within a 50 km radius of the nursing home.
Be English speaking.

**Inclusion Criteria Relatives:**
A maximum of 10 adult relatives, of patients, who have died or are dying from a non malignant disease in a nursing home.
Are self identified as a relative.
Live within a 50 km radius of the nursing home.
Be English speaking.

**Data Collection**
Techniques used to collect the data will include minutes of the meetings, group process outcomes, participants’ stories, shared reflective journal writing and interviews with relatives. The nurses’ reflective journal writing will incorporate reflections of past clinical experiences with dying patients, identify positive and negative outcomes in clinical practice, social relationships to others and outcomes from the application of planned interventions. The meetings will be facilitated by the researcher and written minutes will be recorded and validated by participants at each meeting. The interviews with the relatives will be facilitated by the researcher and transcripts of digital recordings transcribed. Collaborative analysis of the issues discussed will be undertaken by the group and evaluation and reflection on appropriate actions will be planned and used.
Nurse participants will be de-identified; pseudonym will be used instead of names. Demographic questions will be asked that will include age, educational level and marital status.

Relative participants will be de-identified; pseudonym will be used instead of names. Demographic questions will be asked that will include age, educational level, marital status, and occupation.

**The Research Questions to be investigated include:**

**For the Nurses:**
1. What are the aspects of nursing care that you believe maximise the likelihood of a good death for a patient dying from a non cancer disease?
2. Are you familiar with end of life care clinical pathways?
3. Can you identify barriers that prevent you from providing optimal end of life care to patients dying from a non cancer disease?
4. What help do you need to make your nursing care more effective, when caring for patients dying from a non cancer disease?
5. How does providing end of life care to patients affect your relationship with the relatives of a dying patient?
6. How important is it for you to provide optimal end of life care to dying patients and simultaneously develop a relationship with patient’s relatives?

**For the Relatives**
1. What are the issues that are important to you in the care of your dying or deceased relative?
2. How important is it / was it for you to develop a relationship with the nurses during this difficult time?
3. What help do you need / did you need to support you during your relatives dying process?

**Treatment of the Data**
The conversations and/or notes taken during group meetings will be transferred to a computer disk copy. After reading and re-reading the transcripts from the meetings minutes they will be circulated to participants. During the planning process a manual method of thematic analysis will be used to assist the researcher to identify the primary themes that emerge from the group discussions that are not conveyed in verbally explicit ways. That is, some meanings come forward as the result of an interpretation of the full context of what was said, rather than by the discrete words used (Roberts & Taylor, 2002).
The nurses will also generate an action plan for improving end of life care. The results of the action plan activity will be discussed in team meetings and documented as a guide to further reflective practice.

The relative’s interviews will be transcribed verbatim and analysed by a manual thematic analysis process (Roberts & Taylor, 2002). Themes will be validated by relatives as reflecting their experiences.

**Dissemination of Findings**
A final report of the project will be in the form of a Ph.D. thesis for Southern Cross University. The research findings will be disseminated in professional journals and conferences as well as to relatives and other persons and organizations concerned with end of life care. All information will de-identify participants.

**Project Time Frame**
The project will be undertaken between February 2004 and February 2007.

<table>
<thead>
<tr>
<th>Task</th>
<th>Dates</th>
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<tbody>
<tr>
<td>Literature Review commenced</td>
<td>March - October 2004 and ongoing</td>
</tr>
<tr>
<td>Proposal Development complete</td>
<td>November 2004</td>
</tr>
<tr>
<td>Gain Ethics Committee Approval</td>
<td>May 2005</td>
</tr>
<tr>
<td>Relatives interviews / nurses meetings</td>
<td>July - September 2005</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>October – December 2005</td>
</tr>
<tr>
<td>Writing the thesis chapter</td>
<td>February – July 2006</td>
</tr>
<tr>
<td>First Draft</td>
<td>August - December 2006</td>
</tr>
<tr>
<td>Full draft of the complete thesis</td>
<td>January – February 2007</td>
</tr>
<tr>
<td>Submission of thesis</td>
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</tbody>
</table>

**Ethical Considerations**
A number of processes and procedures will be used to ensure the ethical standards of the projects. Research participants have the right to full disclosure. All participants will receive a detailed explanation, verbally and in writing of what the research involves, including the aims and processes of the research, and the participant’s involvement. Participants will be offered the right to refuse to participate or withdraw at any time, without penalty of any kind. Participants will have the opportunity to ask questions, make comments, and voice concerns that they may have concerning the project. A copy of the Consent Form and a Participant Information Sheet is attached. Privacy, confidentiality and anonymity will be ensured throughout the research. Strategies will include the use of pseudonyms, instead of personally identifiable information.

The research participants have the right not to be harmed by the study. Due to the personal nature of the disclosures there may be occasions in which the participants
experience some emotional discomfort related to their perceived vulnerability. Strategies to alleviate this will be to assure participants of their anonymity and privacy as mentioned previously, but also to provide open access to the research information concerning them only, and to allow participants opportunities to comment upon, and to validate, the accounts.

The processes in this research will make a strong commitment to equalizing potential power relationships between the researcher and participants. This will be achieved by encouraging openness and trust, especially in relation to participants divulging their perceptions about their problems, how they experience loss and how they cope. All data collected will be stored in a locked filing cabinet for five years and the responsibility for the safety and security of the data will reside with the researcher.

Potential Risks of the Research
Nurse participants will be sharing stories within a semi-private setting, and may find that through sharing their stories, uncomfortable feelings or memories may be experienced. I will inform each participant prior to consent being given and again at the beginning of each meeting, how I propose to deal with the situation. I will be mindful of this and be sensitive to any indication that a participant is uncomfortable by their words or behavior. Initially participants may take ‘time out’ during the meeting, by getting up and walking around, having a drink or getting some air. At the end of the session I will give individual support and time to the participant if required. Participants who require further support will be given contact details of my supervisor and encouraged to contact one of the local counselling services. The research information will be returned to each participant for checking and at this stage the participant may choose to modify or remove some of the contributions if they feel the information is too sensitive or may identify them, despite the use of pseudonyms.

Should relative participants experience emotional discomfort the researcher, a registered nurse with 20 years experience, will provide immediate and appropriate emotional support. If participants require further emotional support, they will be referred by the researcher to qualified counsellors experienced in the area.

References


Appendix C

The First Reflective Writing Task

This is summary is a copy of a chapter taken from a book on reflective practice. (Taylor, 2000). The following task gives you an opportunity to think about yourself in your own personal, social and historical context, so that you can then think about how you have come to be the person and practitioner you are now. Think on the person you were as a child. Find a time in your childhood in which you felt you had a good sense of who you were. Record your impression freely, being sure not to edit your thoughts and feelings. This is for you, so record what you like and how you like.

- **What were you like as a child?**

  **Physically**

  **Emotionally**

  **Spiritually**

- **Where did you live and what was it like?**

- **Who were the important people in your life?**

- **Why were these people important to you?**
• What other influences were important in your childhood, such as other people, places and events?

• What were some of the ‘rules of living’ you learned from these people, places and events?

Now that you have created a cameo of yourself as a child, make some connections to your adult work life as a nurse, by responding freely to these questions.

• Who were some of the important people in your life during your professional education?

• Why did you want to work in aged care?

• What is important in your practice and the way you choose to work?

• What, if any, childhood ‘rules of living’ have been transferred into your adult work life as an aged care nurse?

From these descriptions you may be able to see a little more clearly who you are as a person and a nurse, and how you think aged care should be practiced according to your personal ideals.
Appendix D

A Practice Reflection Guide


Choose an incident at work, in which you were not entirely happy about the outcomes of your involvement, that is, you felt that you did not make a difference of a positive nature to someone in your care. The situation can involve as many people as you like, but you should be central in the activity. The following steps guide you through the reflective writing processes of construction, to describe the situation as fully as possible.

In order to remember an incident, shut your eyes and take yourself back in your imagination to that time. When you have a clear image of the situation write down, audiotape, or represent creatively, a full description of the experience. Use the following questions to build up a thick description of the event.

- What was happening?
- When was it happening?
- Where was it happening?
- What was the setting like, in terms of its smells, sounds and sights?
- Why was it happening?
- Who was involved?
- How were you involved?
- What were the outcomes of the situation?
- How did you feel honestly about the situation?

Is your description or creative representation as rich and full as possible?

Does it capture the scene as faithfully as possible?

A rich and full description provides more information on which to reflect. Revisit your account and see what you can locate in terms of motives and outcomes. Identify your involvement in the scenario by looking at your part with the eyes of an interested observer standing back from the action. When you locate aspects of your contributions to the interaction, investigate your own motives and actions by musing tentatively: ‘It seems as if I act according to my belief that…’ By completing this sentence as often as you need to, you will find the stimuli in practice that ‘push your buttons,’ and make you react each time they come up in some form or another. The chances are that you will find these themes in your reflection, even though initially your practice stories appear to have little relation to one another.
Write down or audiotape any observations you make, so that you can revisit them at a later time.

To confront the issues within your reflections you need to ask questions, such as:
• Where do my ideas about practice come from historically?
• How did I come to take them on?
• Why do I continue now to use them now in my work?
• Whose interests do they serve?
• What power relations are involved?
• How do these ideas influence my relationships with the people in my care?

In being prepared to ask these questions, you are making a critical analysis of your practice world. You will begin to see that even though you are often at the centre of your world, you are certainly not the only determinant of the situation. The world in which you exist and act is influenced by historical, sociocultural, economic and political determinants, which to greater and lesser extents constrain the ways in which you are free to interpret and act in your world in any given moment. The realisation that you are ‘not alone’ in your practice can free you from bitter self-recriminations and raise the possibilities of new awareness. At some stage it may also be possible to transform the difficult conditions which cause you to act in certain ways.

The final question to be posed is:

• In the light of what I have discovered, how might I work differently?

When you have reflected on one scenario, you can go on to reflect on as many as you choose. Keep a record of all your reflections; they will be interesting to compare, because they track your reflective journey, and they will show you your main issues and how you are working through them using reflective processes.
You are invited to participate in a research project that will explore the thoughts of relatives on issues related to dying in a rural nursing home.

The thoughts of relatives on this subject are a vital component of the study.

If you would like more information
Please contact:

Joanne Rowley PhD Student
Southern Cross University School of Nursing and Health Care Practices

Work Phone: 66 567 323
Home Phone: 66 540 158
PLAIN LANGUAGE STATEMENT FOR RELATIVES

Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease

My name is Joanne Rowley. I am currently studying towards a Doctor of Philosophy in Nursing at Southern Cross University, NSW. I am undertaking a research project which aims to explore nurses and relatives thoughts on end of life care for patients who are dying or have died from a non cancer disease in a rural nursing home. I would like to invite you to join me in this project. The research will highlight the importance of the role nurses and relatives play in providing insight into care that can make a positive difference to a person dying from a non cancer disease.

The research will involve participation in an interview of approximately 1 hour with me to share experiences of end of life care in relation to your relative dying in the nursing home. Interviews will be held at a location convenient to you. You will be invited to share your experiences, as part of the process. Copies of the interview transcripts will be provided to you to check your contributions and allow for any changes you might like to make.

If you agree to participate in the project I can meet with you to explain more about the research, answer any of your questions and explain the consent form that is attached. You are free to withdraw from the research at any time without prejudice, and if you request, your contributions will be destroyed. To protect your identity a pseudonym instead of your name will be used, and all personal information will be kept confidential. Any information from the research will be kept in a locked cupboard, and I will not discuss it with anyone apart from my supervisor at the university. After 5 years all of the information will be destroyed.

As a relative who has perhaps experienced some suffering while attending a dying relative the interview may be an emotional experience and bring up unhappy memories. If you have any unsettling emotions during the meetings, you will be given the opportunity to take time out if you wish, and I will be available to talk with you. For further support, if necessary, I can provide you with the names of counsellors and the contact details of my supervisor Professor Beverley Taylor (see list attached)

I would be happy to discuss any questions you may have about the research, so feel free to contact me (02) 6656 7323 between 8 AM and 4.30 PM. The ethical aspects of this study have been approved by the Southern Cross University Human Research Ethics Committee. The approval number is ECN-05-75. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Ethics Complaints Officer, Ms S. Kelly, (telephone (02) 6620 9139, fax (02) 6626 9145, email: skelly@scu.edu.au).

Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Yours Sincerely,

Joanne Rowley SCU PhD Student. School of Nursing and Health Care Practices.
Phone: (02 66 57 323)
# PLAN FOR RELATIVE INTERVIEW STRUCTURE

## Session Topic:
Relative Interview

## Duration:
60 minutes

## Outcome:
At the end of the interview the relative will understand why I am conducting the project what will happen with their transcript. Consent will be obtained. Issues of end of life care important to the relative determined.

<table>
<thead>
<tr>
<th>Timing</th>
<th>Key Points And Methods</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 mins</td>
<td><strong>Introduction</strong></td>
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<tr>
<td></td>
<td>Brief self introduction</td>
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<td></td>
<td><strong>Check</strong> Participant Information Sheet has been received</td>
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<tr>
<td></td>
<td>Thank for participating</td>
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<td></td>
<td><strong>Determine</strong> when relative would like to sign consent form before or after transcript.</td>
<td>Copies of participant information sheet/Consent forms</td>
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<td><strong>Briefly explain</strong> the project title is Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease</td>
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<td><strong>Explain</strong> the aim of the project is to explore issues as identified by nurses and relatives of patients receiving end of life care in rural nursing homes from a non malignant disease</td>
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<td><strong>Outline</strong> the objectives of the project will be to:</td>
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<td></td>
<td>• Examine ways in which nurses can provide nursing care that maximises the likelihood of a good death.</td>
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<td></td>
<td>• Identify the barriers nurses perceive to prevent optimal end of life care to dying patients.</td>
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<td></td>
<td>• Explore the relationships between nurses and relatives of the dying patient</td>
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<td></td>
<td><strong>Discuss</strong> the relative interview will add depth to the nurses meetings and will be shared at those meetings.</td>
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<td></td>
<td><strong>Discuss</strong> method of recording interview</td>
<td>Digital Recorder</td>
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<td></td>
<td><strong>Ask</strong> relative about their and their relative/partners background/Ages/Marital status/Medical conditions of relative in facility/How long in facility/Are they still alive?</td>
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<td>50 mins</td>
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<tr>
<td><strong>Interview Questions</strong></td>
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</table>
| **Prompts:** You were saying before…
| That’s interesting, let’s come back to… |

**Can you tell me about your husband/wife/partner’s transition into the aged care facility?**
*Prompt:* How well prepared was your relative/partner for this move?
How well prepared were you for this move?

**What are the issues that are important to you in the care of your husband/wife/partner now or when they were dying?**
*Prompt:* Dignity/Distress/Comfort/Support

**Think about an instance where you were pleased with care?**
*Prompt:* Can you describe why that care you described was pleasing to you?
Who was involved in the care?

**Think about another instance where you were not pleased with care?**
*Prompt:* Is the level of care what you expected?
Is your husband/wife/partner receiving adequate care? Can you describe why that was not pleasing to you?
Who was involved in the care?

**What might be done to improve care?**
*Prompt:* Are there things you would like changed?
Was the dying process discussed on admission to the facility or since?

**How important is it for you to develop a relationship with the nurses?**
*Prompt:* Is a relationship important to you?
Do you see any benefits in developing a relationship with the nurses?
Are there others in the facility you have developed a relationship with?
Why are these relationships important to you?
Would you have felt vulnerable if you complained?

**Do you feel you have been well supported during this time?**
*Prompt:* Who provides/ed this support?
| **Is support from the nurses important to you?**
What type of support is/was important?
What other types of support would you like to receive?
What was ‘good’ support for you?
How do you think the support could be improved? |
| **Can you tell me what you think optimal end of life care is?**
*Prompt:* Can you describe what you believe is a ‘good death’?
Can you tell me what you think would maximise the likelihood of a good death?
What do you consider are barriers to a good death? |
| **5 mins**
**Conclusion**
Organise next meeting date / time to read transcript and sign consent form if not signed. |
| **Reminders**
Give the relative time to reflect
Use silence and allow time for response
You can go back and re-interview after transcribing
Don’t include umm and ahhs in transcriptions
Ask relative if they want anything in transcription changed/added/deleted
Have questions ready in case relative is quiet
Encourage relative to stay with the one story |
**RELATIVE’S COVERING LETTER**

Date

Relative
Address

_Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease_

Dear:

My name is Joanne Rowley. I interviewed you in (Date) as part of my studies towards a Doctor of Philosophy in Nursing at Southern Cross University, NSW.

If you recall the interview was an opportunity to share your experiences of end of life care in relation to your (relative) in the (Care Facility). The research is highlighting the importance of the role nurses and relatives play in providing insight into care that can make a positive difference to a person dying from a non cancer disease. I very much appreciated your contribution in this project.

I have enclosed a copy of the interview recordings for you to check your statements in the interview and allow for any changes you might like to have made to those statements.

To protect your identity your name, your husband’s name and the facility your names have been concealed. All personal information will be kept confidential. Any information from the research is kept in a locked cupboard, and after 5 years all of the information will be destroyed.

If you agree with the interview transcript could you please sign the enclosed Consent Form and return in the stamped self addressed envelope.

I would be happy to discuss any questions you may have about the research or your interview transcript at any time, so please feel free to contact me on (phone) or if you prefer return your changes to the transcript in the enclosed stamped self addressed envelope. Alternatively if you wish to make a complaint about the conduct of the research project you may contact Administrative Officer Southern Cross University, Graduate Research College, Lismore (02) 6620 3705.

Once again many thanks for your contribution to the research.

Regards Joanne
Appendix F

RELATIVE INTERVIEW 3
FACILITY ONE 5TH November 2007

RESEARCHER: Firstly, (name) died at (aged care facility name)?

RELATIVE: Yes, five weeks ago.

RESEARCHER: Only five weeks ago?

RELATIVE: Of course there was the time for the funeral and all that sort of thing and the cremation then we had to take her down to Sydney because there’s a plot down there. We came from Sydney so there was another funeral or memorial service down there and the internment, which I took at the grave site, so it went on for a fortnight after she died really, and I had to settle the children down. They’re adults but I had to settle them down.

RESEARCHER: Are they all in Sydney, the children?

RELATIVE: No, my son is a Baptist pastor here in (town).

RESEARCHER: Okay, so how many children do you have?

RELATIVE: Three.

RESEARCHER: To know a little bit more about (name), she obviously had some severe medical conditions over the years.

RELATIVE: I can tell you briefly her story fully. She was born in the Depression and lived in P in Sydney. Because of the Depression her father left the family to go looking for work and never came back. There was no social security in those days so the family virtually starved. There were two girls and a boy. The other girl and boy were older than (name) and she was the youngest. At 11 years of age she got scarlet fever which destroyed her hearing totally so she became deaf and was therefore severely disadvantaged. Her mother was over-protective because she felt that (name) needed her care all the time. There was no social interaction, school was cruel because kids are cruel when people can’t hear and she was isolated and therefore became extremely introverted. Then her brother, who was the nearest carer because the oldest girl got married, died of a heart attack at 21 years of age and that left (name) with her mother. The mother was told that hearing aids would never be any use to her and so (name) was
isolated. She went to school but was really not educated because she couldn’t hear and at that stage she couldn’t lip read either so it was very difficult.

RESEARCHER: We’re talking about the 1930s or 40s.

RELATIVE: 1940s and the war was on and everyone had to work. She was sent to a furniture factory in (town) 9 kilometers away roughly, and she had to walk to work every day and back. She made a couple of friends there and she began to learn to lip read.

RESEARCHER: How long was she there?

RELATIVE: Until she was 17 or 18. My grandmother lived in the same building, which was a two-storey house and she asked me whether I would write to (name) and whether (name) would write to me. I was a soldier and was away so we corresponded and it was pretty rough. (Name) had no confidence at all and everyone said she’d never be able to marry because she couldn’t communicate.

RESEARCHER: Which were the expectations in those days?

RELATIVE: Yes, it was the thing. Anyway, I was overseas and we were communicating and I came back and met her twice. We went to the movies on one occasion and then I went back into service. We got on fairly well and I learnt to communicate with her by putting my head on her shoulder. It looked all very romantic but it wasn’t, it was a means of communication. Then when I was in Japan after the war (I didn’t come home because I was too young) I got a letter from my mother saying to send £56. I thought what the hell for? It was all the money I had in the world, but I sent it and my mother wrote back and said it was for an engagement ring. I thought for goodness sake, why am I paying for someone’s engagement ring? She said it’s you, you’re getting engaged to Daphne. The two mothers and the grandmother decided that we were made for each other because of our backgrounds and because I’d been able to communicate with her in a way that no one else had. They thought therefore it must happen. So I came back and we went out a few times and we began to communicate and she began to trust me and I became her alternate carer, if you like. It wasn’t long before we were married, had three kids and so on. In that time I became her voice, I became her hearing, I became her confidante, and I became her world. So therefore she became very close to me.

Now, my story. I was born about the same time, 1924. My mother became pregnant outside wedlock which was a no-no in those days and you had to marry. The man already had five children and his wife had committed suicide and he was a violent, vicious alcoholic so I got beaten many times because the fourth marriage was my fault. I was only a baby and my mother got beaten unmercifully many times. I became so clouded in fear as an infant that I never learnt to speak. I was fearful of any adult. I got
many beatings then I had an accident at school and had my leg put in plaster and I was never taken back to the doctor to have the plaster taken off. It burst underneath the plaster and it became infected and they thought it was gangrene and they were going to amputate, but another doctor came along and tried to save it and he did.

RESEARCHER: This was in the 1930s?

RELATIVE: Yes. I had limited schooling because I was going backwards and forwards, but then I determined as I grew to be the very opposite that my father represented in every possible way so I’ve never drunk, never smoked, I don’t swear, although during the war I swore a bit – I was a bit angry then. I had a different sort of lifestyle. Therefore we were thrown together because of backgrounds that were unenviable I suppose. There’s a bit more to my life, but that’s not what this is all about, but that gives you a background how we came to be close together. Then finally I talked her into seeing a specialist about getting hearing aids and the specialist said my goodness, you must be profoundly deaf and she was, she had only learnt to lip read and she was so terribly hurt from time to time because people would say things about her from the other side of the room, but she could lip read. She would pronounce words the way she thought they should be pronounced and people laughed at her. It was very hard. We got her over that and we decided that once we got our children on their feet we would overcome and we travelled the world and mixed with high society, we called it that, and we changed our lives.

RESEARCHER: So did (name) work or was she a housewife?

RELATIVE: A housewife most of the time but she went to work mainly as confidence building and we began to do crossword puzzles together. So she would learn the meaning of words, the pronunciation of words and alternate meaning of words. We were doing that right at the time she died.

RESEARCHER: You were like a teacher.

RELATIVE: I was a teacher, I was everything to her, but I needed education myself because I was in hospital most of the time and I missed out on education, I had to educate myself, and we helped each other. She depended on me. When I came back from the war I was pretty badly traumatised, I was an infantry soldier, and I needed her. I never cried until 1960 I think it was because if I cried as an infant my mother would want to come and she would not be allowed to come and comfort me, so then I learnt not to cry. It’s a bit of a sad and sorry story, but that’s the way it was. So you can understand the bond that we had, that’s what I’m getting at.

RESEARCHER: Absolutely. You were inseparable really for all those years.
RELATIVE: Yeah and that’s why I feel a bit empty at the moment. Even when she went to the nursing home, because of having a need for me to be with her, I was there every day.

RESEARCHER: When she had the stroke though she was at home. So that was her first major illness?

RELATIVE: No. She had high blood pressure in the fifties and sixties and was getting treatment for it. Then she had a heart attack in the late eighties or something then had a second one a few years later, was clinically dead and they revived her. I took her on an overseas trip and they said that she was okay to travel, just to test her, and got her through it and when she came back she was quite okay. Then we came up here to visit my son (he’d only been here a year) to see what sort of a lifestyle he had. We liked the lifestyle so went back home and sold our house within 24 hours, came up and stayed in (town).

RESEARCHER: When did you arrive in (town)?

RELATIVE: 1998 and she was okay then and then in the year 2000 she had a massive stroke which paralysed her totally on the left side. She was in hospital for about four months here, not in this one but in the old one. Got her home and got her through rehab and she began to walk with aid.

RESEARCHER: But she had lots of that left side – she still had a deficit?

RELATIVE: Yes – face, everything, but she was a very determined lady and she got the use back in her speech, use of the hands and so on, but then it faded again for some reason we didn’t know. We took her in rehab as far as we could and she was able to walk but then that started to fade away and then she became wheelchair bound. I was her total carer, used to dress and shower her, do her toilet and everything else.

RESEARCHER: Did you have any home help in that time?

RELATIVE: No, we needed each other and she wouldn’t have anyone else but me. We had advice and people would come and talk to us and the doctor used to come and have a word with us now and again. She became quite cheery and everything else, she became oh well it’s just one of the things that’s happened to me, but she had a background that made her decide, like me, that nothing’s going to put us down and nothing is impossible and maybe we’ll get out of this. But she knew she was dying, that she was going to die.

RESEARCHER: So, you were the primary carer and she got to the point where she was either in the bed or in the chair.
RELATIVE: In the chair all the time, yeah. We moved her around as much as we could. I bought her a little tiny electric scooter, only a little fold-up one and she used to get around the shopping centre and that, you know with one hand and used to frighten the daylights out of everybody. But it was her independence. During her lifetime she became involved in everything confidence building. That’s a summary of my story.

RESEARCHER: That must have been a critical point for you, when you had to decide whether or not (name) was going …

RELATIVE: I got a call to say that (name) blood test on this occasion has shown she has a life-threatening disease and you better bring her into hospital straight away. So we did. She said that doesn’t mean I’ve got cancer or something does it? I said it looks like it might, we’ll go and find out. And it was, it was a [?] myloma.

RESEARCHER: So first she came to hospital.

RELATIVE: Yes, she was in hospital for quite a while and then they sent her out to (town) because they couldn’t keep her in the hospital for too long then we had to look for respite so we went to (facility name), went out to (town name) for a while, kept moving around until a vacancy became available at (facility name).

RESEARCHER: So was that the choice or was that just the first vacancy at (facility name)?

RELATIVE: We had a look at all of them and our preference was for (facility name). We had opportunities to go out to (town) and to (facility name) and we had a chance to go to (facility name). I don’t know if you’ve been there, but it’s overcrowded, conditions are poor (facility name) is registered as a hotel and in high care they get their individual room, ensuite and everything else, telephone and you know.

RESEARCHER: So a very pleasant environment.

RELATIVE: Most of the staff are pretty good. One or two might be a bit dicey, but the pressure gets to them a little bit. I got to know all of them.

RESEARCHER: In total, (name) was at (facility name) for how long?

RELATIVE: Fifteen months or so.

RESEARCHER: So you would’ve visited …
RELATIVE: Every day. I got there after all the morning routine was carried out and I sat with her say from 9:30 until 11:30. I’d come home and get the mail and phone calls, do any business I had to do and be back there by say 1:30 and I’d stay with her until 3:30 or 4:00 then settle her down then I’d go home and as soon as I’d get home I’d ring her, just keep moving within the loop.

RESEARCHER: And (name) was completely coherent with you?

RELATIVE: Oh yes, all the time. There was a little bit of confusion as a result of the stroke primarily but not much. She lost about 10% of her normal IQ and sometimes she’d get a bit confused when two or three things were happening at once and she couldn’t take it all in. One thing at a time and she was okay. We just carried on and I bought all the magazines for her. Everyone used to love her and talk to her and read the magazines and get roused on for wasting their time because they had other duties to do – get on with it.

RESEARCHER: But they did her care at (facility name), like the toileting ...

RELATIVE: Yes, it was nice there. The situation meant she needed medical attention and she was getting that there and she was in high care and her spiritual needs were amply looked after, they had a chaplain there. We are church people and I’m a licensed lay minister. So we just made sure she had all of those needs she wanted looked after. Her physical needs had to be attended to by the nursing staff but because I was there and was accustomed to looking after her they’d say would you look after this or would you rather me do it? And she’d look at me as if to say you do it. So I’d take her to the toilet and if she wanted to clean her teeth I’d take her in the chair. I would never walk her in. They might walk her in from the bed hanging onto her because she liked to walk. There was nothing she would’ve loved more than walk. I’d say well you know you can’t, but we’d walk her as much as we could. And she was always pleased to report to me that she’d walked to the dining room, with aid of course. But medical, spiritual, physical needs were met. On top of that there are emotional needs that have to be covered.

RESEARCHER: Can I just go back before we get to emotional needs? In relation to physical needs, it sounds like a shared arrangement to a degree with the staff there. And you were comfortable with that?

RELATIVE: Well they knew I was her carer, but she was their responsibility and they would always ask if (name) wanted to go to the toilet they would say I’ll take her and she’d say no, (name) will take me. Sometimes she’d say I might be here a while and there might be a bit of a mess, better get the staff, it’s their responsibility. Sometimes I’d clean her up. It didn’t happen very often but sometimes it would.
RESEARCHER: But overall you were happy.

RELATIVE: Yeah, I’d look after her. Need I remind you it’s a lifetime thing. Our responsibility for one another is there, but I find a lot of people place them there and they can’t cope and walk away. It’s lack of training and knowledge and the closeness that we had was unusual probably.

RESEARCHER: There was a tight bond there and you didn’t want to walk away, did you?

RELATIVE: No, no and I know a lot of the residents up there and some of them would say my family’s just walked away from me, I wish I had a husband like you. I’d say well you can’t have me, I’m booked!

RESEARCHER: So emotionally when you talk about that obviously you felt that the spiritual needs for (name) were met.

RELATIVE: Well, we would pray, we learnt to pray and we had faith that whatever God did to us was for the benefit of us and so that other people will learn from it. And if we had something wrong we would learn how to deal with those situations and therefore we felt that was using the God-given gifts that other people have. There was the element of fear initially. Even though (name) was a Christian and not really afraid of dying, she was afraid of family separation. She said she may never see my great grandchildren. I said that to the kids and as young as they were, only babies, they were brought up to her and sat on her lap and she had that chance.

RESEARCHER: She was more afraid of letting go of the family that they wouldn’t come to her.

RELATIVE: Well, she knew they would, but the separation was what she was afraid of, of the unknown. It was a question of saying, yes I’m a Christian, I’m going to heaven, but there’s a separation from husband, family. Is there something I haven’t said that I should’ve said? And that works two ways. Our two eldest girls are now in their fifties and I’m 84 and we needed to know that if there were things that we needed to say, if you haven’t told Mum you love her, if there’s anything you haven’t said or want to ask, ask now.

RESEARCHER: You had that time.

RELATIVE: That’s right. I think most people have the time, unless it’s a sudden death, but they don’t think about it and they don’t like to broach the question, should I ask Mum. I’ve sat in a room with two daughters, one of them living in (town), one in (town) and a dying woman in the hospital arguing about who’s going to get what, and Mum’s
conscious. And she’s just shaking her head in pain, and she’s putting up with it and one of them rang me afterwards and said, don’t you let that bitch of a sister get anything. I said it’s got nothing to do with me. If you’ve got a problem like that it’s a legal problem between you, you sort it out. I said I’m absolutely disgusted with the way you’ve behaved.

RESEARCHER: You had that loving, open relationship in your family with (name).

RELATIVE: Oh yes, we were accredited here as pastoral carers and we used to visit people in hospital all the time, (name) and I.

RESEARCHER: Oh, (name) did too?

RELATIVE: Yeah, oh yeah.

RESEARCHER: Oh, that’s wonderful.

RELATIVE: Well we’ve been through most of the difficulties and emotions and things that other people had never experienced, and we felt that was a wonderful blessing, a God-given gift as far as we were concerned. I sat with a friend of ours, a man who had a burst aneurism and was very close to death and he had two sons and his wife had only recently died and I went to him and I sat with him for five days in intensive care, just sitting in a chair with him. I’d leave to have a couple of hours sleep then come back to him. (name)

RESEARCHER: I probably know (name)? I used to work in intensive care for years.

RELATIVE: Anyway, I sat with him for days and he reckoned I saved his life.

RESEARCHER: I think it’s the greatest gift you can give anyone who’s critically ill.

RELATIVE: But one of the things I think people need is knowing that someone’s there, that someone cares. They need that reassurance, that presence and reassurance that someone is there who obviously cares. Doctors can come but they’ve got other patients and have to go. They might pat them on the shoulder and say it’s okay. The nurses come and I’ve seen some of them with tears but they’ve got to move on and that’s not the answer. They are very caring and they’re there for them, but they have other patients as well, and that caring has got to be shared but an individual can fill that need sometimes.

RESEARCHER: I know what you’re saying in that you don’t have to actually even do anything, you just have to be there. You’re not actually delivering the care.
RELATIVE: I call it reassurance.

RESEARCHER: Yeah, that’s a good word for it. It’s just even the fear of being left alone and so obviously leaving (name) …

RELATIVE: (Name) felt sometimes that she might die when I went home. I’d say oh well, ring me. She’d say I won’t be able to. I’d say well, I’ll ring you to see if you’re all right. We used to talk to each other that way. All of a sudden she would say, I think we’re going to be together for another three months, she’d feel confident all of a sudden and she’d apologise – I’m sorry I was down, I feel better now.

RESEARCHER: That was good because …

RELATIVE: Again, reassurance, you know.

RESEARCHER: And also don’t you think it’s that coming to terms with the fact that, well, this is where I am at this stage of my life too, that she probably had to reconcile a lot?

RELATIVE: The last time she saw the specialist was only a couple of weeks before she died actually and he said things had been progressing but he said we have to change the medication because it’s not working now and he put her on thalidomide. I thought it was very strange actually.

RESEARCHER: No, it’s used quite a bit.

RELATIVE: Anyhow, she said what’s the prognosis and he said how old are you? She said 82. He said have they been good years? You’re not going to get another 82. She said that means she’s not far off. You know it isn’t and I know it isn’t, but let’s not think about it, enjoy the moment, you know. So that was all right. Again, reassurance, even if you know that the prognosis is pretty grim, don’t tell them.

RESEARCHER: You don’t think tell them?

RELATIVE: Oh, talk about it, they’re aware, most of them are, but they sit there and feel isolated and alone with their thoughts and their thoughts can be quite damaging and incorrect sometimes. So that’s why I’m saying reassurance is so important.

RESEARCHER: And I guess that’s too where carers like nurses as they come in have those kind words – is anything worrying you, are important things.

RELATIVE: Well, we’d talk to the nurses too and say well, what are you doing now and they’d tell you about their love life and anybody else that’d come would sit down with
her and she was so aware. Some of the other patients weren’t but she was someone they could talk to so they would come and talk to her and that was good, that would encourage her. They’d talk about their dog, their boyfriend, sometimes their ambitions, their holidays and she’d advise them. One of them was going on an ocean cruise and she’d say you behave yourself.

RESEARCHER: Be warning them because some of them are young aren’t they?

RELATIVE: That’s right, yeah.

RESEARCHER: So, towards the end, (name), (name) was aware right towards the end or did she have a period of semi-consciousness?

RELATIVE: Yeah, she was saying I can’t breathe properly now. Her lungs were starting to fail and she was saying don’t you go. I’d say well I’ve got to go home. They called me in at one stage, I think it was 9:30 at night and said she’s pretty low, can you come in? She was aware and she’s saying oh you don’t have to stay, you go home, I’ll be all right. I’d say no, I’ll just sit here and I’d stay there all weekend, just being there. She’d fall asleep and be on oxygen and everything else. It was helpful to her I feel to open an eye and see me still sitting there. I was just sort of reading, deep in thought and prayer and that sort of thing and touch her hand every now and then to let her know I was still there. That was okay. That period was a couple of days.

RESEARCHER: So it was a gradual decline like that where she …

RELATIVE: She seemed to recover a little and I went home. I’d say I’ve got to go and get some sleep and so I went home and about a minute to midnight I think it was they rang me and said she’s pretty low now, you better come back. I said can you ring (name) (that’s our son, he’s a Baptist minister) and they got him in and the two of us just sat with her. She was struggling and breathing was very, very difficult and of course you could hear the crackle of the fluid in her lungs and they’d given her morphine and they gave her another dose then she’d settle for a little while. But she’d open an eye occasionally even though she was struggling and then she’d give my hand a squeeze and I knew she knew we were there and that was comforting for me and I think it was comforting for her to know that right to the very last we were there.

RESEARCHER: The medication, they kept on top of things?

RELATIVE: They kept the medication going and I felt on occasions that often (I don’t know if I should) there wasn’t due attention given to the medication. The medication became a routine thing and sometimes it would change and they weren’t aware of the change for a couple of days and then I’d have to raise a query as to whether she was on
the correct medication and they would say yes she was and then they’d go back and check and find no, she should’ve changed over yesterday or whatever.

RESEARCHER: So there was a bit of a delay in changing the ...

RELATIVE: I don’t think it changed anything, but you like to think that everything’s right.

RESEARCHER: It sounds to me like her breathing was probably the most distressing part about the whole end of ...

RELATIVE: It was distressing because you couldn’t communicate with her then, she was really struggling.

RESEARCHER: She wouldn’t have been able to talk to you.

RELATIVE: No, she wasn’t able to talk. That little squeeze of the hand was very comforting to us. Finally she just stopped breathing and that was it. That was one minute past one.

RESEARCHER: In a sense though (relative name) it sounds like her actual end of life was fairly rapid towards the end for you.

RELATIVE: They gave her two lots of morphine within the last few hours. That might’ve sped things up, I don’t know. I’ve got no problem with that anyway.

RESEARCHER: It’s normally just for comfort, to relieve the symptoms, it’s standard treatment.

RELATIVE: I think the struggling was just gone, just finished and she just passed away.

RESEARCHER: And that’s such an in between time, isn’t it. Did you stay with her while they were doing...?

RELATIVE: My son was there with her and he said the hardest thing was walking out of that room.

RESEARCHER: And that saying goodbye is ...

RELATIVE: I was going in all the time, but he was called in to see his mum die.

RESEARCHER: But in a way it’s probably the biggest gift you can give people, isn’t it. To be there at the end with them.
RELATIVE: That’s what I’m saying reassurance is. Holding her hand, just your presence there, they’re conscious of if, they know someone’s there. You’re not there to administer anything to them or do anything for them, you’re just there for them and I think that’s important.

RESEARCHER: That’s interesting when you said that she was worried about you not being there, and yet there you were, you were there throughout the whole thing.

RELATIVE: All her married life I’ve been there for her all the time. Except when I was going to work and she was going to work and that sort of thing, but I was always coming back, she knew where I was, coming and going all the time. To build her confidence up through the years, and mine of course for that matter, we wanted to do the things that had been denied us by our backgrounds. So we did it together. She wanted to go overseas but we’d never be able to afford it. This is one of the funny things. The first 21 years we were married we never had a holiday, not even a day off, you know away together because we were looking after kids and all that sort of thing. We weren’t very rich and then we thought we’ll have a holiday and thought we can’t afford to go far but we had to have something so I went to a travel agent at Grace Bros and said I think we need a holiday. She said by the sound of it you do. Okay, fair enough. She said where would you like to go? I said might go and stay up at Manly near the beach, but we want to try and get outside the country if we can and anyway the lass said would you like to go overseas? I said well, I’d like to travel to England and I’d like to go through the States. There’s lots of things I’d like to do but we can’t afford it. She said have you got an account with us? I said yes. She said I’ll work out an itinerary for you and I’ll put it on your account and you pay when you get back. That sounded marvellous so we never paid a cent. We went seven weeks. I said to (name) is there anything you’d like to see? And she had a cousin and they’d been writing to each other ever since she became deaf at 11 years of age. Scrawl letters, kids letters and so on. Up until the last few days she’d been communicating with Michael. She said I’d love to see Michael. So we met (name) at Waterloo Bridge and they both burst into tears.

RESEARCHER: Isn’t that amazing.

RELATIVE: It fulfilled her dreams, and we did. Of all the things that I dreamed of, I was a Rudyard Kipling fan when I was young and military mad... I suddenly realised as I was looking out the window. We were on a Japanese airline and on the wing was a circle and for me as a soldier that’s absolutely amazing. Here I am fulfilling a dream and we got down and landed and everything else but we got there on a Japanese airline, and a few years before I’d been fighting for life with these fellows.

RESEARCHER: Life’s funny like that, isn’t it?
RELATIVE: We had a lot of Japanese friends until recently.

RESEARCHER: You certainly sound like you’ve had an amazing life together. You certainly came out of tragedy at the beginning.

RELATIVE: I’ve only just touched on it but it’s been absolutely amazing, miraculous really. What I did for the kids last year – I didn’t want the children or grandchildren to remember Nan the way she was then so I did a calendar for 2007 and it had all the wonderful places we’d been and doing amazing things – London and Rome, Israel and Japan – photos of her and I travelling around the world. And she looked in her prime and she was at that time, so that’s a good souvenir now. They don’t know it but I’m doing the same thing for me, to give to them. Not a calendar, I’m giving a sort of summary, a pictorial story of our lives together.

RESEARCHER: That’s a wonderful thing to leave your family like that because I know myself as a nurse you have to look behind who that person in the bed is and realise they were a person in their twenties and thirties, growing up and living their life.

What I’m trying to do with these interviews, (relative name), when I work with the nurses is to highlight to them. I believe we tend to as nurses think of end of life care so okay we keep the patient clean and comfortable and make sure they have adequate medications and that they don’t have any pain so the focus is all down there, but what I’m hearing from the relatives is it’s more than that that’s important to the relatives.

RELATIVE: To the patient it’s timetables – the time they receive medication, the time they have meals, the time they do things and if they’re late then they think something’s gone wrong. They think oh my cup of tea should’ve been here half an hour ago but people are busy.

RESEARCHER: And they don’t understand that.

RELATIVE: No, but timetables are important. They have to be reassured, again reassurance. Cup of tea’s going to be late, but it’s coming in another five minutes. Otherwise they think something’s gone wrong with them and they begin to blame themselves – have I missed out, was I asleep, did I do something wrong. I can’t go past that word ‘reassurance’.

RESEARCHER: Which is interesting because nurses tend to think about things like people wanting their privacy, that all these things are important at the end of life.

RELATIVE: Privacy is important but knowing that people are still there. Even if they just walk past and they’ve seen them, they know they’re there. If someone pops their head in and just sees how they’re going and gives a quick pat on the leg or something
then moves on. But to not come in at all, to go past the door and know that she’s there, okay that’s fine but she doesn’t know that. So again, reassurance, all the time.

RESEARCHER: And I don’t think from what I’m hearing from relatives that I’ve interviewed before that their expectations are huge around it, they’re very accepting that people get busy.

RELATIVE: I found some of the nurses [?] sometimes.

RESEARCHER: They do. I hear these stories. The other group that I’m doing are the nurses and they do struggle with a lot of the issues around end of life in that they can’t do it all …

RELATIVE: No they can’t. I got to know a lot of them there and they feel, well, when (name) became ill they came into the room and cried with her. They shouldn’t do that, but they did because they had that attachment and there are some people you can’t become attached to. They’re grumpy old coots and they’re pretty hard to handle and no matter how you try to reassure them or do something for them they’re resenting everything. They’re resenting their situation and that’s one (name) had to face early – I never expected to be in a place like this, I never expected to be separated from you like this. She’d hoped, and most of us do I suppose, to be able to die in her sleep, to go to sleep and not wake up the next morning, that’s it, that’s the end, but it isn’t always that way.

RESEARCHER: That’s right and I think that’s the reality for us all, that our expectations and what actually happens to us …

RELATIVE: She was scared about cancer. There’s too much publicity with cancer or some aspects of cancer, and it’s become a media thing. It’s damaging to some people, there’s a great fear of it.

RESEARCHER: Is that why you were saying don’t tell them too much, because you’ll make them frightened?

RELATIVE: You can tell some people, they’re all different, but there will be a reaction to it, an anxiety about it. Anxiety is one thing, you know. If relatives are coming there’s an anxiety if they can’t come. They might not turn up on time or something like that. If they’re coming from a long way away – oh what’s happened? The plane might be late or something. Little things that don’t mean a thing to people passing by or the nursing staff, they don’t know if people are coming or if something’s happening, but they don’t know and they’re anxious. Do I go before I see them? But we try to reassure them in some way that everything’s going to be okay, that things don’t always go the way you expect them to.
RESEARCHER: The feeling I get at (facility name) though, it feels like there’s a very caring attitude there towards the residents so it feels a bit like everybody knows one another and they try to include everybody.

RELATIVE: Oh yeah, I walk in there now and they … one of the ladies used to catch me and say what are you coming in for every day? Are you a doctor? I said no I’m not a doctor.

RESEARCHER: One of the residents?

RELATIVE: Yes, one of the residents – no I’m not a doctor, I’m (name) husband. Well, what are you coming in for every day? I said oh we’re mates, we’re a pair you know, she’s mine, we’ve always spent time together, as long as the staff don’t mind. One of the RNs said to me I don’t know whether it’s good for (name) for you to be here all the time. And I said oh, she thinks it’s okay and I thought if you’ve got no objections I won’t overdo it, I’m not going to sleep here.

RESEARCHER: Even though sometimes you probably wanted to.

RELATIVE: Yeah, well there was a concern that my presence might be damaging to her in some way.

RESEARCHER: It sounds like you did the right thing. What was right for you was right for you both.

RELATIVE: A couple of days before she died I’d think about it and I’d cry, yesterday I cried …

RESEARCHER: But I mean after 60 years of marriage …

RELATIVE: She was just expressing her love for me and thanking God I was there for her.

RESEARCHER: And I think that’s the worst part about a death, isn’t it. None of us ever want to lose anybody around us.

RELATIVE: We are never ready for it.

RESEARCHER: And it’s just amazing that the human being …
RELATIVE: I’ve been living alone for a while since (name) been in a nursing home and I’ve always had to go up there. I didn’t have to go but I always had a routine going to it so me, I’m not lonely, but I’m alone which is a little bit different.

RESEARCHER: Well you haven’t been like this for a long time.

RELATIVE: No, I haven't been like this forever because before that I was in the army. I spent 30 years in the army, training in national service and so on and I was a father figure for all these 18 year old kids and I always had someone to look after. A terrible thing they did to me once they gave me 107 girls to look after.

RESEARCHER: Poor you!

RELATIVE: I was known as the disciplinarian, you see. They said Captain (name), these girls need discipline. I said okay but I didn’t realise what I was getting myself into, but they were marvellous really.

RESEARCHER: And that’s it, isn’t it, having a purpose. Your purpose it sounds to me for a long time now has been your dedication to (name), hasn’t it. I mean is it any wonder you’re feeling a little lost now.

RELATIVE: And without realising it. Sometimes we didn’t realise how close we were together.

RESEARCHER: That was just your life.

RELATIVE: That’s the way things were.

RESEARCHER: Some people never get that even in one life. You’re two people that shared a special thing. They’re the main things I need, (name). What I normally do is I transcribe the interview onto paper and I’ll ask you if you’ll read it and confirm that it’s correct. Is that all right?

RELATIVE: It’s been a bit rambling but they’re the main things I thought of – medical, physical and spiritual needs attended to. And emotional needs. They need to cry sometimes if they’re worried about something. Just hold their hand for a while if they need some reassurance. There are only two or three things you can do. Face the fear. Don’t be frightened of the end of life. Like a light switch, that’s it, the life’s gone out and you’ll wake up in some other place.

RESEARCHER: And that reassurance is key isn’t it when you see that. If there’s anything that others can do.
RELATIVE: I’ve gone round to nursing homes and lectured on care and attention and all that sort of thing. I talk about the spiritual side of things. People have said to me I’m scared of dying. I said so am I, but I’m not scared of dying, but it’s when and how.

RESEARCHER: And they’re answers that no one has, but like you say there’s people around you that care and that’s what makes the difference. I haven’t got your address, (name), but if I will transcribe the interview and then if you agree to the transcription I’ll need you to sign a consent for me. Is that all right? For me to use that data?

RELATIVE: Yes.

RESEARCHER: I’d say probably in the next couple of weeks if I could come back to you.

RELATIVE: I was one of those who joined the army under 16 years of age so I couldn’t go back home. I came out of hospital and I couldn’t walk, had to learn to re-walk and I was just a teenager at that stage. My father had to piggy-back me from the bus but he was drunk as usual and we fell through a barbed wire fence so when I go home after being away I get a hiding again, a broken nose and said I’ve got to get you out of this environment. I had two sisters who were born after me and they died in infancy because of their treatment.

RESEARCHER: Domestic violence.

RELATIVE: Dr (name) I think it is from RPA. He said my case was the worst he’s ever heard of as far as domestic violence is concerned.

RESEARCHER: It’s a wonder you survived to get out.

RELATIVE: I wouldn’t have survived unless I’d gone to hospital. Hospital got me out of the environment. And when I came back I was straight into it again.

RESEARCHER: And in those days they did put children back, they didn’t have social work and …

RELATIVE: People were afraid to intervene or even report the matter to the police because they thought they might have to become involved in the violence. If I could find an avenue any time these days I like to go and talk to people about domestic violence because the perpetrators don’t really understand what they’re doing. I’ve stopped a woman who was pulling a 10 or 11 year old girl through the shopping centre by the hair, with the girl screaming and she was just dragging her along and taking her home. She’d apparently done something she shouldn’t have.

RESEARCHER: But she still doesn’t deserve that treatment.
RELATIVE: I stopped her and I said no, you can’t do that. She said you mind your own so and so business. I said it is my business.

RESEARCHER: She walked past a lot of people before she got to you?

RELATIVE: When she got home she’d probably be even worse.

RESEARCHER: But we live in a community where everyone’s got to stand up for each other, we can’t just walk away and ignore things.

RELATIVE: Some people see tragedies like that and they laugh at it, they think it’s kind of funny. They think that stupid woman pulling her little kid, but there’s no experience there, they’ve never had to experience anything like that.

RESEARCHER: That’s right, they don’t know what that means. I always say if you’re willing to do that in public what are you doing at home?

RELATIVE: It’d be worse, yeah. I think the war probably saved my life.

RESEARCHER: It’s a wonder they took you if your leg was a bit gammy.

RELATIVE: I used to tell lies. I got my photo taken …

RESEARCHER: You were that determined.

RELATIVE: I used to rock and roll with the punches I used to get. I knew how to dodge some of them and I was lightning fast. My reactions were pretty fast when I got into the infantry and into the war, and that saved my life a couple of times. I lost friends who died alongside me.

RESEARCHER: Most of the time you were able to get out of the way.

RELATIVE: They thought I was very brave but I was just very smart I think.

RESEARCHER: All right, (relative’s name). I really appreciate you sharing (name) story with me because that’s what my hope is, by informing others …

RELATIVE: I just get wound up when I tell the story because to me our bond was so remarkable. I’ve written my autobiography and I called it Shame and Glory.

RESEARCHER: Is it in the bookstores?
RELATIVE: No, I’m re-writing (name) death so I can get it up to date. I can get you the original.

RESEARCHER: I’d appreciate that, that would be great because it gives me background then to build into how strong marriages are and all the people I’m talking to, the relationships are so close.

RELATIVE: We didn’t often think of ourselves as being closely bonded but we were just there for each other. As I said, I didn’t cry. Our fellows have often said to me (name) I wish I could cry to get the emotion out, little things you keep bottled up. I’d say for goodness sake, go down to the garage and cry.

RESEARCHER: It does make you feel better.

RELATIVE: I did, I cried half the day I think.

RESEARCHER: Yeah, there was so much there. Was it healing?

RELATIVE: Oh yeah. Another thing that we did in our life was music. Music sometimes soothes. We’d have a little tiff now and again and she’d hum a couple of tunes. One of them was You Always Hurt the One You Love.

RESEARCHER: You didn’t have to say anything then, did you.

RELATIVE: The other one was I Don’t Know Why I Love You But I Do.

RESEARCHER: She sounds a character.

RELATIVE: She was.

RELATIVE INTERVIEW 1
FACILITY TWO 24TH JANUARY 2008

Researcher arrived at the home to find (name) concerned. (Name) had received a phone call early this morning from the aged care facility to inform her that her husband was being taken to hospital by ambulance as his suprapubic catheter had fallen out overnight and needed replacing. (Name) was preparing to go to the hospital if required or if (name) was delayed at the hospital.

RESEARCHER: So we’re talking about your husband.

RELATIVE: Yes.
RESEARCHER: And you’ve been married?

RELATIVE: Thirty-one years. (Name) is twenty-five years my senior. It’s been relatively easy for me to look after him up until now. The problem was I looked after my mother for twelve years before (name), so basically I’ve been a carer for twenty-four years. Mum was crippled and blind and she was quite a big lady and I hurt my back rather badly. I’ve actually got to have neurosurgery. Hence, (name) in the nursing home. If could’ve lifted him he’d still be at home, but the doctors in the end said no, he’s not going home, you’ll end up in a wheelchair.

RESEARCHER: So (name) had dementia, it was a gradual demise over time.

RELATIVE: Following the brain tumour actually. He had a left frontal lobe meningioma about twenty-one years ago.

RESEARCHER: He’s done well then.

RELATIVE: Yes he has. He’s had one significant stroke and a lot of TIAs. He was catheterised; he had a procedure, probably five or six years ago because he was totally incontinent.

RESEARCHER: So that was sort of a gradual decline over time.

RELATIVE: Yes, continual infections, in those days, pseudomonas, which of course have added to the problem of dementia.

RESEARCHER: So it’s worse when he has an infection.

RELATIVE: Yes, very much so.

RESEARCHER: With the strokes and TIAs, you were still caring for him each time he would come out of hospital? He’d come back and you’d look after him?

RELATIVE: Yes.

RESEARCHER: Did the doctors make the decision in the end that (name) shouldn’t come home?

RELATIVE: They did, for my sake.

RESEARCHER: And you felt all right with that?
RELATIVE: I didn’t to begin with. I was quite sure that I could do it. I went to the extent of getting a hoist from AdMed, but then I found I couldn’t wheel it. It was too big and I was hurting my back anyway. He’d drop and fall in the middle of the kitchen floor because it was too big to fit anywhere else. You couldn’t get it into the hall; you certainly couldn’t get it into the bedroom. I got a hospital bed in, I got every sort of equipment that I could to try and keep him at home because I did give him an undertaking that I’d never put him into a nursing home, which in hindsight was very stupid. There comes a time when you don’t have a choice.

He reached a stage by the time he went into the nursing home where he didn’t really realise that he was at home, and that’s what I was waiting for, for him to get to the stage where he didn’t know where he was.

RESEARCHER: Did you used to try respite care?

RELATIVE: We had respite care in (aged care facility) I think twice and they said the first bed that turns up you’ve really got to think about permanent placement and the doctors backed that up and said, basically, you’re not taking him home.

RESEARCHER: When did (name) go into the nursing home?

RELATIVE: About October.

RESEARCHER: So he’s been there about twelve months?

RELATIVE: No.

RESEARCHER: Oh, October, 2007?

RELATIVE: Yes.

RESEARCHER: Okay.

RELATIVE: He went straight into high band of course. He had no respite left in (aged care facility), they’d run out, but a placement came up in the other facility at Z House and W said as soon as she had a full-time place in (aged care facility) she would let us know. I must admit that I didn’t quite believe that. I thought he’s stuck here now, that’s where he’ll stay and I was most unhappy with the nursing home. It was very clean, the food was good, but I didn’t feel the staff had their heart in it as they do in (aged care facility). It was just a job to the staff, not liking what they were doing. For instance, the first day that I went in which was the day following the day he was admitted and the morning tea lady came in and put his cup of tea and cake on his table ten feet from his bed, and he couldn’t get out of bed, so it was cold.
RESEARCHER: So that leads into the things that are important to you about the care that (name) received, they’re the things that count. Is that how you’d describe it?

RELATIVE: Very much so. Three weeks into his stay there I phoned my sister on the Sunday night and I said, look I can’t do this anymore, I’m going to bring him home. And she said I couldn’t but I can help you. That was on the Sunday, mind you they had him outside in his chair parked next to a smoker – (name) an asthmatic. They’d broken his wheelchair; they had the fan and air-conditioner going flat-out in his room all night, so he had some asthma. I think four things went wrong on the day and I can’t remember what the fourth was now, but I was very upset. As I say, the place was clean, the food was good and he seemed happy enough, but I wasn’t.

About 9 o’clock the next morning I was going to go up to the nursing home, pack his gear and bring him home. And finally it was L from the nursing home, and I burst into tears. She was ringing to say they had a bed. I asked “when can he come” and she said tomorrow after ten, so I went up and thanked them profusely for what they’d done. I was very polite about it, but very pleased.

RESEARCHER: You would’ve had some trepidation though, even going from other facility to (aged care facility) after your first experience of nursing homes.

RELATIVE: Well, (name) had been in respite in (aged care facility) for nine weeks. I was very pleased about the place. I was pleased about the care. A lot of the girls live here at the beach, I knew them and I knew they were lovely girls and they’d watch him. Even on his days when he’s a bit cranky, they’re so nice.

RESEARCHER: In the context of what’s important in the care, it’s that there is a relationship.

RELATIVE: Absolutely. Most definitely that’s probably the most important thing.

RESEARCHER: Yes. And you can get a sense of how (name) is with that in a way that you feel the vibe from him.

RELATIVE: I do. The main indication with (name) is, when he was in private hospital it was when can I go home, when can I go home? Since he’s been in (aged care facility) he’s never asked to come home. So that’s my indication that he’s settled and he’s happy. Each time I leave him I say okay buddy, I’ll be back here either tomorrow or the next day and he says it’s so lovely to see you. There’s no can I come home. So that’s given me a feeling of great contentment when you drive away thinking well he’s at home. When he arrived at (aged care facility), the ambulance guys put him into bed and were waiting and he said to the girls I’m home now.
RESEARCHER: That’s encouraging. I imagine when you first have to put your husband in a nursing home there’s a period of time where you have to adjust.

RELATIVE: Oh, it’s dreadful, you feel as though you’ve let them down, you feel as though you’ve gone back on your word, you go through all these things, but I think having cared for patients for twenty-four years you’ve got somewhat of an empty nest, you come home and think, well, what do I do now? No catheter bags to be sterilised, no beds to be changed, no washing to be done, no ironing to be done.

RESEARCHER: You were busy, busy, busy.

RELATIVE: Oh, flat-out from about five in the morning till nine at night. I would change the beds two or three times a day. If the catheter line blocked you had a major problem, if that flushing didn’t work you had to beg the ambulance to come and get him? They weren’t really keen to do that, the hospital wasn’t keen to have him. It was all a fight. I just fought his fight for so long.

RESEARCHER: You didn’t have care in the home either? Did you have support care from any services?

RELATIVE: I had a young chap from a private company come in and shower him each day, but that was all. The lifting part that was the heavy part. And he didn’t like that. He had a thing about males nursing him; he thought they were all queer.

RESEARCHER: That could be a generational thing.

RELATIVE: Yes, he’s got this absolute thing about same sex people, he just can’t handle it at all and he just assumed that they were there for that reason. So it was important to be hovering the whole time so he knew that I was there. The time before that we had a nurse that he took a dislike to she was a very nice girl, but very rough, not his scene at all, so he refused to let her shower him. We had these periods where we had no-one then someone and then we had someone else. There were even periods where we had no one.

RESEARCHER: Does he have lucid times where you really feel he was really switched on, recognising you?

RELATIVE: Yes, this week in particular he’s been quite switched on and he’s been so pleased so see me. He doesn’t talk. Apart from K saying he’s misbehaving himself sometimes yes he’s switched on enough to give a proper answer. About a month ago I went in and he was I’d say almost in a stage where he was in a coma, and we don’t know what happened. If I didn’t know the facility I’d say they’d given him an overdose.
of something, but they wouldn’t have done. But that was just what happened on the day.

RESEARCHER: It was out of the blue.

RELATIVE: I thought he’s not going to survive till tonight, but then I’d go in again and find him sitting up in his chair.

RESEARCHER: So he fluctuates.

RELATIVE: Very much so.

RESEARCHER: So you’re very much with the nursing home on that, but what about the doctor? How is your connection with the medical service?

RELATIVE: Very good. I interviewed the doctor when he first went in. It was Dr X and X had another doctor with him at the time and I sat down and he said tell me about his history so I rattled on for about 40 minutes, told him what drugs they used, what he was on, what we do if this happens or that happens and he said to me, you’re a registered nurse, aren’t you? And I said, no, I’ve just been a carer for 24 years and what hasn’t happened between my mother and (name) doesn’t happen. He said I would really like you to do nursing. But I’m 61 I would take someone else’s place and that wouldn’t be fair. So my association with the doctor was great. He’s quite happy to talk to me about whatever.

RESEARCHER: So there are no problems there.

RELATIVE: No problems whatsoever, I’m very happy with him.

RESEARCHER: I don’t want to sound negative, but (name) will die, so around that end of life care what would you say would be the most critical thing for you about (name) care in those last stages?

RELATIVE: To keep him pain-free.

RESEARCHER: Who do you see is responsible for making sure that happens?

RELATIVE: The nursing staff right from the top Y. We’ve done an end of life care plan.

RESEARCHER: That means a lot of paperwork and people don’t often like to address that.
RELATIVE: But that’s life, isn’t it? You’ve got to face it; it’s really like making a will, isn’t it?

RESEARCHER: It is, yes, it’s a necessary thing that has to be done and I think in the long-term it gives you lead-in time to really think about what is important to you.

RELATIVE: That’s right and you have the availability of changing it, but yes, that’s my priority, just to keep him out of pain. He doesn’t have a good pain management level, really quite low.

RESEARCHER: So, T’s tolerance to pain is low?

RELATIVE: Very low. Unless he’s frightened of going to hospital because he doesn’t like going to hospital.

RESEARCHER: Have all his hospital experiences been bad ones?

RELATIVE: They have, but usually they’ve been associated with infections and when he gets infections he gets extremely difficult and the nursing staff get a bit intolerant and it’s just a bit of a catch-22. I can’t blame them, but then they have to understand that that’s what happens.

RESEARCHER: Urinary tract infections are insidious in that way in that they creep up and they’re there and the behaviour changes before you know the infection’s there.

RELATIVE: Usually you know as soon as they go off the rails.

RESEARCHER: The aged care nurses would be more switched into that than hospital nurses.

RELATIVE: They are, yes. Private hospital was very good, but despite the fact that T was a veteran, they didn’t really want him there. I found that the doctors and nurse in charge of the medical ward I found a little bit insensitive and hard and she was basically telling me lies in order to get him out.

RESEARCHER: That was because she saw (name) as an aged care patient.

RELATIVE: Yes, she did. She saw him as needing too much nursing care for their level of staffing.

RESEARCHER: Because they’re looking at it from a manager’s perspective.
RELATIVE: They’re looking at it from a manager’s perspective and from a money-making thing. The reality for (private hospital) is that they made 14 billion last year, for goodness sake.

RESEARCHER: Is that right? I didn’t think they made that much money.

RELATIVE: Oh yes, a huge amount of money.

RESEARCHER: When you think about it, most people in there are veterans, aren’t they?

RELATIVE: A lot of them are. They had two rooms specifically for veterans. Veterans have a limited amount of time that they can stay. They either then go to a nursing home or the doctors do quite a lot of paperwork in order to keep them there. For an extra 43 days they don’t really like the paperwork. And I don’t think Veterans Affairs pay as much as a private medical fund, so ideally they don’t have veterans in there. In spite of people saying there’s all this help for veterans.

RESEARCHER: Do you think it’s very misleading?

RELATIVE: Very much so. I had to actually have (name) taken by ambulance to the base and the base were ringing me and asking have you got this, every half hour of the day, have you got a bed and just worried them to the point until they made a bed available.

RESEARCHER: They had to make one available.

RELATIVE: I’m not blaming the staff. They’ve come from the owner of (private hospital).

RESEARCHER: That’s right; the staff are just acting within the guidelines.

RELATIVE: Well, if they don’t work within the guidelines they don’t have a job, so I’m very sorry for them. Just the same, I’ve had to fight his fights for so long now and you have to be firm.

RESEARCHER: It sounds like you’ve been really switched onto the processes, like you probably had no idea how the systems worked.

RELATIVE: No, but I was mortified when I found out because veterans have had enough done to them.
RESEARCHER: That’s right and veterans need to feel that they’ll be OK. They need to feel that they’ll look after me no matter what. But the reality of making that happen is a whole other thing.

RELATIVE: You’ve got to remember that there are not many W2s left. Their wives are probably going to be of similar age and they’re not going to be able to fight the fight as I do.

RESEARCHER: Absolutely not. They haven’t got the energy because you have to be consistent and never let it go until you get an answer. They’re not easy battles.

RELATIVE: Yes and a lot of people can’t do that.

RESEARCHER: Sometimes you get pushed from department to department, from person to person.

RELATIVE: And you’ve got to know what steps to take. Do you can go to the local member, do you go to the federal member, do you go to the state member, but how well do elderly people know that?

RESEARCHER: And they’re not on the internet to find the answers like people do now.

RELATIVE: You can phone Veterans Affairs in Australia and it’s not an Australian number. I believe they use a call centre. The people who work for them and I believe even the Board are all Asians. It’s nearly impossible to speak to an Australian. There’s a very good veterans’ affairs section in (town) and I tend to phone them now and say this is the problem, you deal with it, ring me back within half an hour. If they don’t I ring them. At least they’re Australians.

RESEARCHER: And because they’re a rural centre they’re more likely to understand your situation.

RELATIVE: Yes.

RESEARCHER: And that’s what this project is about. I think what happens in the rural setting as opposed to somebody who’s Sydney metropolitan who could probably catch the train or the bus to Veterans’ Affairs and get this sorted out so they can get a placement for their spouse, just to get that support. I just don’t think it’s generally as available to people in the country.

RELATIVE: We are at a disadvantage take respite care, for argument’s sake. I used to ask for respite care Instead of taking an hour and a half which was what I was allowed, I would ask for four and a half hours because I can’t drive to A or B, do all the shopping
and get back in an hour and a half. In the city you can, but in the country you can’t. I really had some fights with them over that until they finally gave it to me in a block every three weeks. Then you do this massive shop so that you didn’t have to go out for another three weeks. That’s not far I shouldn’t have to fight for that.

RESEARCHER: And you had to negotiate that time.

RELATIVE: Yes.

RESEARCHER: You’re right. People don’t know these things until they’re trying to access the service.

RELATIVE: That’s right and what chance do old people have of fighting the fight?

RESEARCHER: Have you ever dealt with the ACAT team at the base?

RELATIVE: Yes, I have.

RESEARCHER: They have a lot of keys to the doors that people don’t have but again it’s are you lucky enough.

A lot of relatives have spoken to me about the relationship with the nursing staff. It seems to be a critical point as to whether or not things go well or things go bad. Is the relationship important to you?

RELATIVE: Yes, very important.

RESEARCHER: What are your expectations of a good relationship with the nurses? Is it a spoken thing or an unspoken thing?

RELATIVE: Let me say that I treat the whole of the staff, even the cleaner, the cooks, the ladies’ who deliver the washing, the nursing staff; I treat them all the same. I don’t differentiate with how I handle children. Whatever problem they might have at the time I don’t treat them differently.

RESEARCHER: So it’s not a hierarchy thing.

RELATIVE: Definitely, I don’t treat Y any different to the cleaners and I think that in order for (name) to get the best of care it’s important to have a really good relationship with everyone. It’s not just the nurses; it’s everyone in the place that makes it tick.

RESEARCHER: That’s right.
RELATIVE: I find the girls; I only had a problem with one of the girls who we used to call Sergeant Major. She was a person who would give an instruction and then end it with a ‘please’ – stand up please, sit down please, turn around please. She came in one day and I said, you know W, I really admire the way you work with the patients. You’ve got such a nice way about you, you don’t give an instruction, you just ask them very nicely. And she said, oh, well, you know it’s so important that you do treat them nicely and from that day on she changed. I thought well I’m not going to complain about her wasn’t the right way to do it, better to just use a bit of . . .

RESEARCHER: So she misinterpreted perhaps?

RELATIVE: I think she didn’t think about what she was doing and she saw from there where she was going wrong. Even the other nurse we called the Sergeant Major and in the end she changed enormously. I took an interest in her personal life, what she was doing for Christmas and all that sort of thing and she changed enormously.

RESEARCHER: Because you were seeing them on a second daily basis?

RELATIVE: Yes, second daily.

RESEARCHER: So you do get to know their family and their personal life outside.

RELATIVE: You do and if you take an interest in them I think they take more of an interest in the patient.

RESEARCHER: Yes, that’s right. I don’t think it’s intentional, I think everyone’s given the same care. From the way I see it, it seems to be that way, but if you’ve got that relationship with them then you’re more likely to get that drop by when they might have walked past the room otherwise.

As far as dignity, being sure (name) clean, are they things you’ve let go now because you feel confident?

RELATIVE: I’ve let them go to a degree, but each time I go in I always make sure that he’s perfectly clean, that he’s been showered. I can’t stand him to be dirty. A couple of times I’ve gone in and he’s had dirty pants I’ve had to tell one of the girls, I think he’s had an accident in his pants and they’ve been mortified that they haven’t noticed, but clearly they do all they can and I know that you can’t watch everything. But yes, I do feel that need to just check, and it doesn’t matter what facility he was in, whether it was privately run or government based, I think across the board there’s a shortage of caring nursing staff.
RESEARCHER: That’s what I’ve identified too. It’s not a profession that people are trying to get into, but the actual number of people that require the care is increasing so, you know, they’re trying to deal with an increased pressure to add more beds, but to staff those beds, they aren’t attracting nurses to do that care so the whole system’s facing its own dilemma around that. People are therefore dying more in aged care than they used to because they used to transfer them to the hospital, but now the hospitals are full, they can’t take them. Even if it’s imminent death, they don’t see that it’s their place for them to die in the hospital. How do you feel about that? Where will (name) die? Would you prefer he did go to the hospital?

RELATIVE: Twelve months ago I would’ve preferred that he died in private hospital, but now I prefer that he goes in the facility. He’d be much happier, and when he goes I want him to die in a place where he’s happy.

RESEARCHER: And that’s the dilemma, how that all happens because sometimes the pressure is that the hospital is not really the ideal place to go in those last days.

RELATIVE: It’s not, it’s very cold, very uncaring.

RESEARCHER: And it’s an acute facility in that they don’t think in the same way that the aged care facilities do.

RELATIVE: No, not at all.

RESEARCHER: Do you feel they’re equipped to care in the last days?

RELATIVE: I do, especially having Dr X on the premises. Obviously during surgery hours, but he does live locally as well.

RESEARCHER: So that gives you confidence?

RELATIVE: It does, yes.

RESEARCHER: So (name) always has the care.

RELATIVE: Definitely, I’m sure he will.

RESEARCHER: So that last definition is an important one. What is optimal end of life care to you? Can you give me an idea? I’m thinking from what you’ve told me that optimal end of life care is for (name) to die in the facility.

RELATIVE: Yes.
RESEARCHER: Pain-free?

RELATIVE: Pain-free, give him whatever they need to give him in order to keep him comfortable, and even if that hastens his death so be it. I can’t see any point in keeping him alive for another 24 hours just because the morphine level hasn’t been given at the right rate.

RESEARCHER: Pain seems to be the one thing that people speak to me about. As long as people don’t have pain everybody else feels that everything’s being done.

I appreciate you sharing all that with me; I know they’re difficult issues to talk about.

RELATIVE: No, it’s good for me to talk to people about it because most people don’t know where you’re coming from. It’s nice to talk to someone who does.

RESEARCHER: That’s what I’ve found with most of the relatives I’ve interviewed. They’ve actually struggled on with this whole caring issue for years and years and then they’ve suddenly got this huge gap in their lives. Some of them have been in their eighties and their lives have suddenly turned inside out and they’re sitting there on the lounge thinking, what am I doing?

RELATIVE: Well when I go into A I’m doing the shopping and then rush home, and I don’t know why I’m rushing home. I’ve got to get home. My friend says to me, why don’t you stay and we have coffee? I say, Okay.

RESEARCHER: So you’re switched on to how you were.

RELATIVE: Oh yeah.

RESEARCHER: Maybe that process of letting go that life.

RELATIVE: Yes, you’re just working like a machine the whole time, always keeping to a schedule, and you tend to still do that. It’ll probably take a while to adjust.

RESEARCHER: Definitely, and it’s also because you don’t know any different, you’ve been doing it so long you don’t know how to live any other way.

RELATIVE: That’s right. The doctor asked me the other day because I’m sleeping poorly I had to sleep very lightly in the night because I never knew when a catheter line would come out or until we got a hospital bed, he was having falls, he’d fall out of bed and I’d have to call the ambulance at 2 o’clock in the morning. You had to sleep lightly, and you couldn’t go to sleep until you knew the patient was asleep.
RESEARCHER: So you haven’t been able to have deep long sleeps because you’re still waiting for something to happen.

RELATIVE: Yes. Even this morning at 7 o’clock the phone went and I had not had a very good night at all and it woke me up and I thought, oh no, it’s the nursing home, and it was.

RESEARCHER: But in a way you’re conditioned. You can only do what you’ve learnt over the 24 years. I’m finding as I get older I don’t sleep as well.

RELATIVE: Well, (name) doesn’t, he sleeps very poorly. He said to me he gets depressed. I’m not depressed; I’m just not adjusting to not having that pressure. I will it’s just taking time.

RESEARCHER: Most people I talk to seem to say the same thing. The people who do the best are the ones who just accept that they’re awake and they get up and watch telly or read a book, but it’s the ones who tend to worry about the fact that they’re sitting up at two in the morning, or they’re tossing and turning and worrying, but they’ve forgotten they don’t have to get up early in the morning, they can actually sleep in.

RELATIVE: I haven’t had time to walk on the beach.

RESEARCHER: Not since October? That’s interesting.

RELATIVE: I’ve had visitors, I’ve had someone break up with their husband, I’ve had someone in the granny flat the whole time. It’s been the kids, I have two nuns who come down and have their holiday here each year, the kids again. G said to me, who now Mum? I said no one!

RESEARCHER: Yes, have some down-time; get your place back together again how you want it. It’s your time.

RELATIVE: It was madness there for a few months.

RESEARCHER: Is your back better now that you’re not caring?

RELATIVE: A lot better. The last report from Professor S was that I need neurosurgery on my spine, but we’ll put it off as long as we can because there’s only about a 60% chance that it’ll be successful anyway. I might go all through that and have no benefit at all.
RESEARCHER: You have to weigh it up, whether you’ll function enough to get by with what you’re doing now and whether to put yourself at risk. Neurosurgery is not an easy thing, there are no guarantees.

RELATIVE: I’m not looking forward to it at all. I’ve been on prednisone for 30 years because I’ve got Crohn’s disease. So I’m not going to heal as well as people do.

RESEARCHER: So the drugs would complicate things.

RELATIVE: And my bone density is pretty lousy anyway. It was great for a while, but it’s now become quite awful so I’ve got to be very careful. If I hurt my back again I’m in big trouble for another 18 months. So you don’t dig, you don’t lift, you don’t stretch, you don’t bend. Some of those things can’t be avoided, but I don’t do gardening anymore. I don’t lift heavy weights.

RESEARCHER: And you want to maintain your independence, I imagine.

RELATIVE: I do and this is the first time in my life I’ve had a chance to have a life in that I can just go to the shops if I want to.

RESEARCHER: Make your own choice. I know what you’re saying and that’s why we started with the men. They are totally lost; they have no idea what to do next. I think it’s harder for men.

RELATIVE: Very much harder.

RESEARCHER: Because women do find their way back.

RELATIVE: And men are not used to doing the cooking and the cleaning and the shopping, not in their old age.

RESEARCHER: Part of the caring role forces you to do it all, whether they do it as well as their wives would want them to do it I don’t know, but I think they need the purpose of doing it. I actually keep in touch with one of them because he was so lost and it’s such a shame, you just feel so sorry for them, you know what it’s like. There’d be thousands of people out there that are just the same. I must say this research has thrown in a few things that I didn’t expect. I just find it a privilege to talk to people about their lives in that way because it’s not something that people advertise. They would never tell most people what’s really going on for them.

RELATIVE: The other thing is too when you’re caring for a patient you have all these well-meaning friends who are saying (name) should be in a nursing home, so as a result of that you don’t tell anyone anything. You just keep it all to yourself.
RESEARCHER: You don’t want them telling you how to live your life.

RELATIVE: You get to a stage where you say to tell people if I want your advice I’ll ask for it. If I don’t ask for it don’t give it to me.

RESEARCHER: And then they think you’re losing it. You can’t win, and that’s where collectively the plan for this research is parts will be published over time in the hope that it influences others by these precious stories that you share with me will make others think about what the real issues are, so I’m hoping that you all feel that the stories get out there and that’s why I’m making every effort because this is an ongoing cycle. People will live and die and people will care so if it can make a difference for the next lot coming through

RELATIVE: It will be good I think people are living longer, nursing home beds are not increasing, not at the rate we need them, people are going to be at home for longer and people are going to care for them where possibly they shouldn’t.

RESEARCHER: And the support needs to be there for them as well.

RELATIVE: And they’re not.

RESEARCHER: Everyone I’ve spoken to so far saying the same, it’s a struggle to get that help you need. It sounds to the outsider that it’s all there for you waiting.

RELATIVE: Oh, people have said to me, you’re so lucky with all the help you’re getting, and I think a shower a day – that’s lucky?

RESEARCHER: Out of 24 hours it’s not much.

RELATIVE: They don’t think that you’ve got to physically lift the patient out of the bed in the morning and onto a wheelchair and when they want to go to the toilet you’ve got to do it all again. You get them back onto the toilet then back onto the chair then they want to go to bed.

RESEARCHER: And in the meantime you’re trying to have your breakfast and clean up.

RELATIVE: Sterilise catheter lines, change beds. I think I’ve changed (name) bed at least once every day; the whole bed, the mattress protector, the cotton blanket, the whole lot.

RESEARCHER: So you’re doing the job of about ten really aren’t you. It’s got to wear you down over time.
RELATIVE: It does and I think it’ll take a long time for me to pick up. I’m still very, very tired.

RESEARCHER: Yes, you don’t realise how tired you’ve gotten.

RELATIVE: My son is a sports scientist, human movement and he said, Mum, what you have is sleep debt, you’ve had this great debt; you’ve got to pay back that debt and you don’t pay it back in one night.

RESEARCHER: That’s an interesting look at it isn’t it, which could help you to adjust to the fact that you’re not sleeping as well. There’s a reason for it.

RELATIVE: I’m just over-tired I think.

RESEARCHER: One day you might get that 12 hours out of the blue.

RELATIVE: About every second night I sleep fairly well, but in between I’m lucky to get four or five and you’re really not making up that sleep debt.

RESEARCHER: But having said that, it’s not unusual, and hopefully things will pick up.

RELATIVE: People are saying to me now you should go on a holiday, but I don’t want to be too far from the nursing home and I haven’t got the energy, to pack the bag and actually do it.

RESEARCHER: You will, you’ll get there. You’re trying to get your place back again and even balance.

RELATIVE: Yes, I don’t ask for a lot out of life, I’ll enjoy just living here and being able to go down to the shops when I want to and maybe at some stage later I’ll go and visit the kids, but just at the moment I want to be within ten minutes of the nursing home call if (name) needs me.

RESEARCHER: And it’s unpredictable.

RELATIVE: It is. You really can’t plan to do anything with anyone on any given day and you’ve got the mobile phone with you the whole time in case the nursing home rings. The kids took me to (town) the other day and I was quite rattled the whole day. I thought if the nursing home rings now I’m two hours away instead of ten minutes.

RESEARCHER: That’s sort of that letting go a little bit, isn’t it? Being able to be away without worrying, but you’re not there yet. But it’s your husband, isn’t it?
RELATIVE: At the end of the day it is, and you don’t stop caring now.

RESEARCHER: No, that’s right, just because someone else is looking after him.

RELATIVE: You’ve still got to be there. When they’re not well they’re frightened and that’s when you need to be there for them. Just sit by them and hold their hand.

RESEARCHER: You sound like you’ve sort of been the rock for him.

RELATIVE: I would hope so.

RESEARCHER: And it’s a job in itself, isn’t it? Being that consistent. No matter what, you’ll be there for him.

RELATIVE: I know a lot of people criticise me for it. They’ll say he hasn’t been a great husband to you and I say but that doesn’t make it right for me not to be a good wife to him. He’s been a very selfish person. He was an only child, super spoiled but that doesn’t make it right for me to do the same thing. Would he be there for me? I don’t know. Maybe he would, maybe he wouldn’t, it’s got nothing to do with it.

RESEARCHER: But you’re being true to yourself by the sound of that. You think it’s the right thing to do, which is important.

RELATIVE: And when he dies I’ve got to know that I did it all right and made his life as happy as possible.

RESEARCHER: It’s the commitment of marriage, isn’t it?

RELATIVE: I think it is. Too many people take it lightly now.

RESEARCHER: Absolutely. I totally understand where you’re coming from because I’m the same. So long as I have a clear conscience, I know I’ve done what I had to do.

RELATIVE: You’ve got to be comfortable with what you do.

RESEARCHER: It’s a difficult time.

End of interview.
During the interview (name) rang the aged care facility to remind them (name) may not have had breakfast. As (name) had not returned (name) rang the hospital to check on (name) progress.
At the conclusion of the interview (name) was informed (name) was returning to the aged care facility.
Appendix G

AS THE ENTIRE MINUTES FOR THE TWO FACILITIES NUMBERED 100 PAGES EXAMPLES OF KEY TURNING POINTS OF THE RESEARCH ARE PROVIDED

Minutes of the Action Research and Reflection Group
Facility One
Wednesday 16th November 2005
1100 – 1145 am

Jo welcomed the group and thanked them for participating.

Celeste, Mary, Harriet and Eileen attended. Mary will be leaving employment with Facility 1 in a few weeks, Jo suggested Mary would like to continue participating in the group until that time she was most welcome. We discussed a new member will attend next week.

Participants took turns to informally introduce themselves.
Jo distributed the Participant Information Sheet to each member.
Jo presented the project background using a Laptop PowerPoint presentation.

Jo defined non malignant disease included diagnosis of dementia, kidney failure, heart failure, CAL, liver failure etc. The group discussed cancer dying has been explored in depth up to this point in time compared to non cancer dying. Participants discussed the long trajectory of non cancer dying and the crisis events in that time. The group also discussed cancer patients now die over a long period.

Jo discussed participants involvement in the group will include keeping and sharing a journal, discussion of practice stories, action research cycles and continued reflection.

In return for participants involvement in the group, Jo will share practice change experience, record group minutes, interview five relatives and share their stories with the group, assist in collating an action plan and implementing, observing and reflecting on the action plan.

Celeste asked how relatives would be recruited to the project. Jo distributed the flyer and asked it be displayed as Celeste thought appropriate. Discussion continued on a number of relatives the group thought may benefit from sharing their story. Jo stated the researcher cannot directly approach relatives however it would be helpful if relatives are made aware of the flyer.

Jo distributed the consent form, demographic form and the first reflective journal task to be discussed next week.
The first reflective writing task asked participants to:
Think about childhood influences on one’s self and work.
Jo asked participants to think about whom were the influences on my childhood?
How has this influenced my nursing practice?
One participant identified people who they had not thought about for a long time.
Participants responded spontaneously to these questions and said they will reflect on these questions for next week.

What happens next week?

We will reflect on childhood experiences and then explore a structure for reflecting on practice experiences.

Participants who did not sign consent form or complete demographic form this week to please return next week.
Prepared by Joanne Rowley 16/11/05
A participant described his/her self as an ‘over the top’ adventurous child, who was active and sporty. ‘Lived in the bush’ and was ‘very happy until Dad left’.

Two of the participants described themselves as shy children, one of those participants said she was ‘unable to speak to others’ but was adventurous, lived in the city and was always looking for excitement. Living next door to a hospital, using the grounds and exploring were his/her happy memories.

One participant described his/erself as an insecure child, who had an unhappy childhood. The participant reflected on having issues with ‘abandonment’ and separation from her sister at a young age. This reflection prompted another participant to reflect on being a foster parent and as a child holding a fete with friends to raise money (fourteen pounds) for a Children’s Home.

The next reflection question asked participants to reflect on, who were the important people in your life? One participant remembered a boy across the road who had shared life events with her, first kiss, first cigarette she then told the group he died an alcoholic.

Another participant identified older women as important in her life, referring to her grandmother who had a history of alcohol addiction. The participant then told the group many of her friends now are ‘gay people’ and recalled her grandmother often having eccentric friends. This participant then described his/her adopted mother as a ‘Matron’ and described her as big, old, ugly and always found work.

A participant shared a story of his/her father as a beautiful, caring man. “Dad left when I hit high school”. S/he told us her Dad had taught her to swim and was the swimming coach, this participant identified three men, important in her life, s/he could not think of one woman. The participant reflected on socialising with men more than women most of his/her life.

Another participant identified a primary school teacher, who had recently died of a heart attack.

When asked why were these people important to you? A participant shared the story of a happy time in his/her life and reflected on Melbourne Show day. Recalling Dad stayed sober, the family travelled from country Victoria and Mum saved up really hard.

Rules of living were discussed by the group. Participants identified the following:

- To do the right thing
- To value self
- Be honest and admit you are at fault
- You do it your way, I will just tell you
- All agreed tell the truth
• Don’t marry a man and try to change them; the participant was grateful for this advice.
• Don’t marry a Catholic

The important people participants identified in their professional life included one participant identifying the residents (of the aged care facility) and the training they received on the job from those residents.

Another participant reflected on ‘Nursing in a small bush hospital – You and Matron’ as being the best way to learn.

A participant reflected on his/her nursing training identifying Sydney Hospital as a tough environment to learn. Nurses had to go to lectures after working night shift. This statement was matched with the environment as having a ‘culture of excellence’. The participant also identified her ‘Supportive Husband’ as an important person in her professional life.

When asked why work in aged care?
One participant spoke of his/her kids growing up and leaving home and his/her needing a job and a direction. S/he spoke of going to a training centre who suggested nursing.

One participant remembered her elder sister being mortified that she was trained in aged care. She recalled her mother saying “only an aged care nurse”.

The things identified as Important in your practice and the way you choose to work? Resulted in one participant saying s/he ‘enjoying the job – adore the job’. Other aspects of practice included caring people, building a relationship with people and building good rapport with residents.

Jo distributed a journal for each participant to use for reflection stories and a copy of the ‘Practice Reflection Guide’ to begin reflecting on their practice stories.

The next meeting will be Wednesday 30/11/05.
Prepared by Joanne Rowley 25/11/05

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Minutes of the Action Research and Reflection Group
Facility One
Wednesday 14th December 2005
1100 – 1145 am
Eileen, Mary, and Agnus attended this week’s meeting. Agnus returned her signed consent form. Celeste had a prior appointment and apologised for not being able to attend today’s group.

We briefly covered Week 2 and 3 events to inform Eileen of the meeting contents. Eileen was provided with a copy of Week 2 minutes by Agnus.

Jo read out the minutes from last week – Week 4. Mary requested an alteration be made to her practice story. Jo asked the group when a participant is sharing a story if we could all give each other 10 minutes of uninterrupted time to allow each participant to share their story, maintain their train of thought and express how they feel.

Discussion then focused on the planned reflection for this week. Participants were asked to reflect on an incident at work when they felt the outcome of their involvement was positive. The group identified “family support of staff” and “understanding what is happening” as important aspects of a good death.

A participant remembered a daughter accepting her mother was dying. S/he described the scene; “her mother was in bed dying and the daughter was clearing out the cupboard”, “only the bare necessities had been left”. The group agreed this practice was not uncommon for some families to minimise belongings toward the end of a relatives life describing this time as a “waiting game”. The participant described the relative as “connected to her mother”, the daughter “knew everything that could have been done, was done”, “this made it easier”. The participant described the dying resident as being kept “comfortable” the participant believed this made the family “feel at ease”. The group described this resident’s illness trajectory as “bouncing” stating “she wasn’t going to bounce like she had before”.

When asked what the resident had died from the participant described “old age, just died, maybe a UTI”. Another participant highlighted the family were Jehovah Witness – “different religious beliefs”. S/he recalled asking the daughter if believing in resurrection made her mother’s dying any “easier to accept”. The daughter told the participant “it does, but it still doesn’t stop the grieving”. The daughter continues to visit the aged care facility where her mother died 3 months previously. When the daughter arrives the staff say “here comes the cyclone – grab hold of your chair” as the relative was known to be very organising and busy.

The participant attended the resident’s funeral, s/he recalled at the service there was mention of the now deceased resident driving her VW car. The resident had received her drivers licence when she was in her 60’s or 70’s and would drive from Hobart to Launceston to visit relatives. The participant recalled seeing a photo of the resident in the VW car.
When asked if staff attended resident’s funeral the participant stated the daughter had asked her to attend even though this was not common practice for her/im. Then recalled “I needed to go to K” (a previous resident). Another participant said “we become part of the family”. The participant was thanked by the family for her/is support at the end of the funeral. The participant felt this was related to the daughter becoming “upset at the funeral and no one was supporting her or knew what to do”. The daughter felt her mother would have been upset by her crying at the funeral when their belief was ‘resurrection’. The participant comforted the daughter and recalled “we left laughing”.

The discussion then focused on the end of funerals when the curtains close on the coffin as an upsetting time for those people attending. The group thought a pray with head down was better than seeing the curtains close or the coffin slowly descending.

The participants agreed “making residents comfortable” and “supporting the family” are important aspects of dying. Describing some families as “they turn to us and we offer them support and make them feel comfortable”.

When asked when the dying process is not peaceful a participant described “laboured breathing, gurgling, dreadful sounds” made it difficult for staff and family. The group agreed it is important to be “totally honest” with the family regarding time of death and prepare the family by saying “to be honest I think it will be….,” (time period to death) or “looks like it will be in the next few hours” or “it could be in 6 months, I could be wrong” or “it could be today, it might not be”. A participant described families are often not told their relative is dying saying “no-one will tell them” s/he recalled an RN saying “it is the doctors job to tell them” and described an RN being angry at the participant for telling the family, “the RN refused to tell them”. Participants felt it was important to prepare families as “the family have to get kids in”. A participant felt RNs are generally not challenged on their decision not to notify the family of impending death.

Challenging decision-making lead the discussion to an RN being challenged to provide pain relief to a resident. Medications prescribed prn were seen as problematic, a participant said the RN will say “we will give them a couple” and felt RNs can be “too scared, afraid to give them too much of a drug” or “be frightened to give them too much as allowed by the doctor”. One participant reflected on giving residents adequate medication and asked when a resident is in their 80’s or 90’s does it matter? “The resident has most likely had a healthy life”.

The group also spoke of residents being worried about getting addicted when starting some drugs but generally the participants felt “morphine makes death more pleasant”. A participant recalled a cancer patient being only able to complain of pain to some staff and appearing ‘strong’ to other staff, “putting on a façade”. The participant recalled telling the resident to tell staff about their pain, “You’ve got to tell them”.
Decision making was then discussed with the group stating they are in control of the residents care and go to the RN if a medication is required. One participant described having to explain to an RN why she thought it was important to initiate pain relief before the morning routine care was given to a resident, having to explain to the RN “she is in pain”.

Participants discussed it can be difficult to get a doctor to a resident at times and recalled only “at a resident’s daughters insistence” did a doctor see the resident, describing doctors as “reluctant to attend”. The participants felt doctors don’t listen or look at the resident and only see the resident as they are at that point in time describing a permanent resident who can be, “crook as” but when the doctor sees the resident he has a “smiley face”. The participants felt they knew this resident well enough and that he “grunts and groans in pain but displays a big grin”. The participants spoke of subtle changes happening you don’t think it’s extraordinary but it is important and because of regular contact the carers felt they notice the changes. One participant said s/he had “no trouble ringing a doctor” if s/he was worried or had a question about a residents care.

Who provides the care was then discussed with participants stating unless an RN gives out medications the resident will not necessarily be seen by anyone but their carer. Participants described “some residents are only seen at lunch” but reflected that usually only an RN hands over to the doctor and described the RN having to have faith in the other carers. The participants then discussed they care for a mixture of high and low care residents supported by an RN and that high care residents have a daily report written that includes events being documented such as pain when the resident is not normally in pain.

Participants then reflected on a resident who had been sent to hospital and had told staff at the hospital “I want to go home”. The participants felt proud he called the facility ‘home’ and said, “he died here, that, was the most important thing”. Calling the facility home was seen as important to the staff who reflected that not many residents were going out of the facility this Christmas. The group discussed their plans for Christmas Day at the facility and the organization of the drinks, music and decorating the hall area. The group then discussed the difficulties with residents from high and low care eating in the same dining room believing high and low care residents were more accepting of each other recently. A participant believed the low care residents were “fearful of going to high care if they get sick” describing some low care residents as saying “fancy having them here with us” and showing “absolute disgust” at sharing the dining area or at least sharing a close area with a high care resident.

The group concluded three groups had to work together the nurse, the family and the resident then it is a ‘good death’.

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Today was Mary’s last meeting with the group and she asked for the publications to be forwarded when completed. Mary provided Jo with her forwarding address. Jo thanked Mary for participating in the group.

Jo asked the group to use the ‘Practice Reflection Guide’ and journal or draw over the holidays for sharing when the meetings reconvene in January.

Jo will organise next meeting date with Celeste for January 2006.

Prepared by Joanne Rowley 16/12/05

Minutes of the Action Research and Reflection Group
Facility One
Wednesday 8th March 2006
1100 hrs

Eileen, Agnus and Keith attended the meeting. Celeste arrived a short time later.

Jo read the minutes from Week 11. Eileen requested an addition to the practice story regarding the resident who needed a cuddle to include the resident thanked her for caring. Jo will follow up with Celeste regarding why the poem ‘I have seen thee’ was chosen.

Following on from last week Jo shared the final excerpts from the relative’s interviews. Relatives expressed an important aspect of care was, ‘Keeping relatives informed’. Jo asked the group; do nurses believe it is important for relatives to be kept informed? A participant felt relatives need to be informed “sometimes” but “sometimes not too much”. The group discussed the difficulties nurses face when providing information to relatives and that the information can be “taken out of context” and “a bit of information can be used and treated as misinformation”. A participant expressed a “pressure is put on us by families to tell them what they want to know” stating I am “aware of what I say” to relatives which prompted another participant to express that s/he felt “they (relatives) are trying to get us to slip up” and linked this to sometimes relatives try to “make us look incompetent” believing relatives know “we can’t always give information” and that “relatives judged” nurses. A participant stated there is a “line you draw regarding how much you tell them, as some take it as gospel”.

Jo asked the group, whose responsibility is it to inform the relatives? This prompted a participant to say “I will always pass the buck”. The group spoke of the career structure of nursing, and the stigma that can be attached to the various grades of nurses. Generally the group felt it is appropriate for less senior nurses to refer residents and relatives to an Registered Nurse (RN) for questions to be answered but acknowledged sometimes the RNs do not know the resident as well as for example the Enrolled Nurse (EN) who is responsible to care for low care residents. This prompted a participant to comment that in the early years of nursing everything was passed onto the RN stating
“this was how you were trained”. A recently graduated nurse said “that is still taught today”.

The group also discussed the issue of “covering your back” and felt sometimes it is more appropriate to refer relatives and residents to speak to the doctor. The potential for litigation was discussed and providing incorrect information was of concern with a participant saying nurses can be “out on a limb by yourself with a lack of support”. Participants also felt relatives have an “expectation” the nurse will follow up. The group expressed it is better not to pass on information if they are not sure of the correct information.

Participants linked information sharing to “trusting the staff” and discussed new residents to the facility and their relatives asked for more information and only in exceptional circumstances this occurred with long term residents.

A participant felt providing information is part of the process of “continuity of care” and results in a “nice, restful place”.

The issues relatives were not pleased with were discussed; the first was Relatives communication with the doctor and nursing staff. Jo asked the group, why would a relative feel they were not being communicated with by health professionals? And Why would it depend on which RN was on if issues were clarified for a relative?

The group discussed the accessibility of staff with a participant stating “Assistants in Nursing (AIN) s are more accessible” to residents and relatives and that “RNs are always busy with two floors to attend to” therefore RNs were not seen as always available. This prompted a participant to discuss AINs sharing information with RNs saying “it is invaluable when AIN’s share information, even a perception, as I tuck it away and process it. I may not divulge information to a relative straight away, (pause) sometimes people may think I am reticent but that is because I am thinking about the information.”

A participant felt the ENs working in low care were the “go between” for residents and senior staff. The ENs and the consistent staff rostered in the low care area assisted staff and residents to know each other. This was viewed as beneficial and important. A participant felt the nurses “get to know these residents well” and are, “able to influence end of life decisions”.

Consistency of staff and residents in the low care and high care areas was compared by the group, a participant expressed “in high care we are behind” when referring to ‘knowing’ the residents. It was felt high care residents “are always new”, new RNs “with different ideas” and staff are less consistent or familiar to the residents in that area stating “the residents can’t keep up with the staff”.

The group discussed the differences between RNs and how some RNs “use their authority”, with a participant saying “some RN think they know better, so you just don’t bother” and said “What they say go’s” but s/he couldn’t understand why they (RN)
behaved in that manner. Commenting that s/he has seen some RNs “run around like s/he has her head cut off”.

A participant felt resident symptoms can become a “huge crisis of conflict”. S/he spoke of a resident with renal failure who had severe skin itching and spoke of the problems the itch caused for all involved saying “the doctor was unsure, the RN felt it was a renal itch but another RN treated it as scabies and another RN believed frequent showering would provide relief”. The participant then discussed RNs may use initiative and try various methods to relieve symptoms but felt “honest documentation of treatments” did not always occur.

Issues relatives were pleased with included; Going over and above what might be expected, mutual respect, respect for intellect, moving on issues straight away, and courtesy. Jo quoted one of the relative’s statements; “one assertive person can make a difference with their philosophy”. Jo then asked the group, do you as a nurse identify with mutual respect, courtesy, being assertive? This prompted the group to discuss assertive behaviour, the demeanor of assertion and how assertion translates in practice. A participant felt assertion “is in observation, action comes after”. Another participant felt “people know if you are being assertive” and that “respect and courtesy are part of the assertive behaviour”. Another participant expressed assertive behaviour “gives relatives a secure feeling” and was linked to professionalism believing those people who are assertive “take charge” have “clear boundaries”. When reflecting on how assertion affects practice s/he said “they tell you what to do and just to keep the peace you do it”. Assertive behaviour was thought to have the potential to “cause waves” but s/he felt usually the nurse had “the resident’s best interests at heart”.

Assertive behaviour was linked to ‘power’. A participant stated “power is a risky thing” s/he quoted the psychologist Adler, “the basis of our will is to have power over others”. Another participant felt some nurses “haven’t learnt their way to master their power” and may view themselves as being leaders but they may be acting as ‘bulldozers’.

The group then discussed the workplace changes and how staff now, work as proactive people “agents of change”. The working environment was viewed as constantly “evolving” and that “we are “implementing improvements in people’s lives” always thinking “how can, I do it better”, “constantly learning” and “moving forward”. This process required staff to be constantly “adapting to changes”.

A participant expressed the importance of courtesy and respect for residents and felt some people felt the low care residents were “spoilt” however s/he felt it was the least residents could expect to continue the “comforts they liked” and felt “those comforts should continue until the day the resident dies”.

At the close of the meeting a participant spoke of the difficulty s/he faced following the death of a resident and how this became such a problem for her/im at the time that s/he was considering leaving the work. S/he spoke of the emotional upheaval of the experience and how s/he had ‘worked on’ but felt the memory of the resident’s death made her/is working life so difficult at times that s/he was having to drag her/imself out
of bed just to go to work. The participant spoke of informally sharing the story with another staff member and felt comforted to know other nurses had felt the same. Jo shared the reflective practice guide with the participant and discussed the value of exploring the details of the situation in more depth through reflective journaling. The last remaining members of group discussed the importance of addressing death and finding some closure to ensure nurses develop ‘longevity’ in the profession as the participant will most likely have to deal with similar death circumstances in the future.

Following the discussion Celeste felt staff debriefing would be a useful addition to the facility. Jo said she would provide a ‘Debrief Structure’ next week.

Jo distributed copies of the practice stories as a table. Next meeting the group will discuss the themes for action. Jo asked the group if they would read over the practice stories in the table and provide a short impression of the theme they felt emerged from each story.

Celeste will attempt to follow up with another relative to be interviewed.

Prepared by Joanne Rowley 8/3/06

Minutes of the Action Research and Reflection Group
Facility One
Wednesday 22nd March 2006
1100 hrs

Keith, Eileen, Agnus and Celeste attended the meeting.

Jo read the minutes from Week 13 and distributed the 2nd table of condensing themes to issues and the resultant action plan. Jo reminded the participants that the objectives of the project are to:

4. Examine ways in which nurses can provide nursing care that maximises the likelihood of a good death;
5. Identify the barriers nurses perceive to prevent optimal end of life care to dying patients and
6. Explore the relationships between nurses and relatives of the dying patient.

The group discussed the issue of Debriefing that had emerged from the themes of the practice stories. The action plan to address Debriefing includes an introduction session that will present a case scenario to other staff in the facility. Celeste identified the staff allocated training session in May will be used for the first session. Celeste spoke of discussing the role participants will play in the scenario with Agnus. Agnus has been identified as the person who will play the resident, a nurse has been targeted to play the relative, Eileen, Celeste and Keith will play nursing roles. Celeste spoke of linking each theme from the practice stories to the script dialogue and suggested Jo would ask questions that relate to the theme being portrayed. The group then discussed the
frequency of subsequent debriefing sessions. Participants suggested sessions should be held monthly and if not required to be cancelled for that month, acknowledging frequency of the number of deaths in the facility varies. The participants felt sessions should be offered to staff to attend but should not be mandatory attendance. Participants felt mandatory attendance would defeat the purpose of encouraging expression of feelings and willingness to disclose issues. The sustainability of debriefing sessions was then discussed and Celeste suggested if the sessions are not sustainable it may be the sessions are not meeting staff needs or people are disinterested in the concept. Participants discussed the need for an evaluation sheet to be distributed at the end of the training to determine if outcomes are met and identify staff opinions related to the value of each session. Celeste said this is standard practice for training sessions in the facility.

Jo shared with the group the NSW Workcover document titled Managing Loss and Grief in the Aged Care Industry (2000) and the Department of Health and Ageing Guidelines for a Palliative Approach in Residential Aged Care (2004). Jo identified the documents suggest that members of the aged care team who had experienced many deaths still require access to support services in order to discuss their anxieties and these people had scored high levels of death anxiety when measured in studies.

Jo then discussed that more than one issue can be addressed and asked if there were any other issues that an action plan should be developed for. The issue of pain medication knowledge, pain assessment, and medication administration was then discussed. The group felt medication was generally handled well within the facility and discussed the medication chart can be problematic if a medical officer is reluctant to update the chart 3 monthly, with some doctors faxing through electronic versions and staff just having to “live with it”. The group spoke of the benefits to the organisation of a 6 monthly visit by a private Pharmacist who reviewed drug combinations and was a great resource for medication knowledge and sharing that knowledge. Participants commented that the Pharmacist will suggest medication options with medical officers (MO) and noted some MO are willing to work with the Pharmacist and some are not. Medication audits were used in the facility and the information was sent to head office. Jo spoke of a project she is involved in that provides nurses with personal digital assistants (PDA). The PDA is used as an electronic source of medication information for example the MIMS can be downloading into the PDA. The benefits of having the PDA is that drug information and drug combinations can be determined without having to leave the resident’s bedside and this hopefully demonstrates a reduction in medication incidents and improved nurses drug knowledge. Jo will investigate this option further and discuss next week.

Team and communication issues were then discussed. Celeste spoke at length of the team approach to care that is fostered and encouraged by the organisation. A participant raised the issue of what to do when a staff member makes it clear they do not want to be part of the culture of a caring team and are only there “for the money”? H/she expressed frustration and concern when working with a particular unnamed staff member. Celeste suggested taking the approach of bringing these staff alongside and using a caring model to win them over. Expressing that ultimately using teamwork and a caring team
approach will result in achieving the best interests of the resident. Jo spoke of discussing Celeste’s philosophy further with her supervisor and will relay the discussion back to the group next week.

Jo asked the group if they would continue to read over the practice stories, themes and issues in the table and provide comments next meeting.

Keith spoke of his drawing on end of life care he has developed and described a person in the fetal position surrounded by ‘claustrophobic’ type issues. The remaining participants noted Celeste’s drawing depicted pressing issues surrounding the nurse also. Keith was encouraged to bring the drawing to the group for next week.

Jo asked Eileen if her drawing/collage would be ready for next week also and if so, could it be bought to the group.

Celeste and Jo discussed with Agnus the value of her contributions to the group and asked if her representation of end of life care could be documented and shared with the group also. We spoke of the gentle, caring nature Agnus has portrayed and the deep reflections and insights she has shown through out the meetings.

Hopefully Jo will be able to provide a ‘Debrief Structure’ next week and Celeste will have followed up with another relative interview.

Prepared by Joanne Rowley 22/3/06

Minutes of the Action Research and Reflection Group
Facility One
Wednesday 12th April 2006
1100 hrs

Agnus and Celeste attended the meeting. The group focused on Celeste’s updated dialogue for the Grief Discussion Group session to be held in May.

Celeste spoke of completing the dialogue for the session that will be titled ‘Dying Well in Living Care’. Celeste spoke of participants identifying issues that the dialogue raises that will be discussed by the group on the day. Those issues identified by participants from the updated dialogue included:

Nurse behaviour: demonstrating efficiency but not being focused on the resident, striving for perfection, focusing on tasks, being supportive, connecting with relatives, inhibiting communication by using judgements, being abrupt, tactless, being directive, use of power and authority over others, conformity, admitting you don’t know, sharing information, bullying.

Nurses emotions: self doubt, anxiety, ownership of emotions, courage to speak, assertion
Residents: in denial, looking for comfort, missing home, being unable to express inner needs

Team: not sticking together, medical review of residents, not valuing all the team members' opinions, communication within the team

Relative: missing mother, being frightened, speaking about death/dying, missing the point, feeling helpless

Participants went on to speak of when a resident dies and the process of a funeral director coming to the facility and removing the deceased resident's body. Participants spoke of this process as being difficult at times for staff to witness. One participant spoke of a previous facility where she had worked many years previously and recalled a resident was dragged along the floor in a bag to the funeral directors vehicle. The participant discussed the impact on the staff and the shock and horror of witnessing the event. The participant reflected how that made staff feel who had cared for the resident. Participants discussed the quick turn over of residents following a death in the facility. Participants acknowledged the facilities are businesses but felt a quick turnover of resident's implied disrespect to the resident who had just died. Participants felt it would be useful to include this aspect of death in the grief discussion group session by having the resident die in the scenario, be removed, and then a new resident suddenly appears ready to occupy the room. The group spoke of using an opposite personality type for the new resident to highlight the difficulty for staff in moving on and having to adjust quickly to the change.

Participants expressed looking forward to and being interested in comments from other staff and what issues will be raised on the day. Celeste spoke of future training being linked to issues raised by the group following the session.

Jo showed participants a Personal Digital Assistant (PDA) and will bring a brief next meeting. Security issues were discussed. Jo suggested asking users to sign a form to verify the device will be left in a secure place following use.

Jo left the voice recorder with Celeste to give to Eileen. Jo hopes this will assist in documenting Eileen’s reflections on end of life care.

Hopefully Celeste will have followed up with another relative interview.

Jo to remember to check with Keith if he used the Practice Reflection Guide provided.

As Easter is this weekend the group will reform in two weeks.

Prepared by Joanne Rowley 14/4/06

Minutes of the Action Research and Reflection Group
Facility One
Wednesday 7th June 2006
1100 hrs
Agnus, Keith, Julie and Celeste attended the meeting. The Grief Discussion Group was held last week the 31st May 2006.

Jo commenced this meeting by asking participants questions related to the session.

Q1. Do you think that the plan of using a debrief session achieved its goal?

One participant stated “I think it did”. Other participants felt the melodrama approach ‘lightened people up’ and helped the audience to ‘open up’. A participant commented s/he felt the videotaping was distracting.

Celeste felt next time the melodrama is used it will be important the introduction of the play is clearer. Celeste felt this can be achieved by stating who the players are and provide an explanation of the characters.

A participant felt some staff spoke more than others. All participants commented how well Petal spoke during the post melodrama discussions and how her contributions and points were excellent. Jo asked what role Petal had in the organisation and was told Petal was the cleaner. The group discussed how Petal had said even though she mops the floors s/he still cares for the resident. This led a participant to comment “you can rely on the person who mops the floors” and that some residents “relate to the cleaner more than many staff”.

Petal happened to be cleaning in the wing of the building where the group were meeting and when s/he passed the door the group invited her to participate in today’s session. Petal discussed enjoying the grief discussion group and recalled some of her/is comments related to a couple s/he had spoken with before one partner had died. Petal felt “they weren’t a loving couple” but recalled saying to the partner “you are running out of time here, you may not have the opportunity tomorrow to say what you need to say”. Other participants commented the partner was “not able to express himself” and was “out of touch with his emotions”.

Q2. What came out of the discussion that you didn’t expect?

A participant commented s/he was surprised when one of the RNs said “it must only be the RN who informs the family” (of dying). A participant discussed the importance that some times, and stressed, but not all the time this is correct. Sometimes it is important the quality of the information shared with relatives is essential and that nurses “need to be careful what they say”. Keith stated that AINs are often closer to the family and that it depends on the AIN being responsible to speak appropriately. Celeste reminded the group of a previously discussed scenario where night staff had spoken with a resident regarding the dangers of morphine and this had created “a fracture” in the care of the person and between staff. Celeste felt this had “undermined the care”. Keith felt workers cannot be that “inflexible”.

Rose felt she was looking for techniques to be able to cope after some resident’s death. This was related to how she felt about the ‘quick turnover’ of residents in the rooms following a resident dying. Rose felt it was important to “get your feelings out at the time” and felt a debrief shortly after would be useful. Rose asked the group “what is the correct thing to say?” This led the participant to discuss when her sister in law (Mary) had died from cancer and how s/he had told her to go as s/he was feeling for the partner Ron who had “never opened up”. The participant recalled Ron wanted to know when Mary would die. She had told him to “hold her hand and tell
her now“ (how he felt). Rose said she had spoken with others who said “you just can’t say (she will die) in next 24 hours”.

Q3. Do you think the key issues were identified? (Team, communication, relatives, staff, resident’s needs)

The group discussed how the issue of resident’s belongings was raised on the day, due to a recent incident of a deceased resident’s room being packed up quite soon after their death. This led a participant to comment there are “inconsistencies” in the management of this issue and that the “goal posts get moved on some issues”. One participant recalled s/he knew the family of the resident and that they had told her/im how important the resident’s belongings were to them and had commented on the “haphazard way the belongings had been packed”. The group agreed the packing up of the resident’s belongings is “very much a part of grieving”. Participants agreed a “day’s grace” was reasonable but commented on the turnover of residents as “Out at 10, New at 2”. Another participant commented it is important there is no name placed on the resident’s door until the resident is settled into the room as previously family had been packing up a resident’s belongings when the next resident’s name to occupy the room had already been placed on the door. The group also discussed it can be “tricky” to talk about death processes when a resident is being admitted such as preferences for packing up belongings following death. The participants felt a time frame for how long the room will be left following a resident’s death would be useful to discuss with relatives and it should be made very clear to the family. A participant commented in one instance “we didn’t know until the last minute the family were coming”.

Q4. What do you think the constraints will be in the future sessions to achieve outcomes?
A participant commented the debriefing session will develop a “life of its own”. Another participant commented “we are pioneering new ground here, no other organisation is trying this and we have found it highly beneficial”.

The constraint of management was discussed with a participant commenting “management is prepared to listen to what people say and they see it as a benefit to staff emotionally and practically”. Participants felt the sessions will “bring people closer together as a team” and “speed up the processes for resolution of issues”.

Future session times were suggested with one participant stating it should be part of the lunch break on the training day, the atmosphere should be relaxed with staff eating and drinking and attendance should be optional. Other suggestions including holding a training day that focused on team building. A participant also suggested staff should be encouraged to attend the minister’s ceremony memorial service. The use of case conferences was also highlighted with a participant commenting they “should happen more”.

Jo needs to follow up with Eileen for collage and recorder.

Keith agreed to forward a photo of his end of life drawing to Jo via email. (Address provided)

Hopefully Celeste will have followed up with another relative interview.
Prepared by Joanne Rowley 11/06/06
Facility One: Challenge Statements

Challenging Statements can be used on cards later in the meetings to assist the nurses to examine the ‘nature’ of aged care.

Lead in phrases to ask the nurses:
“Let’s look at that (the statement), it is offensive to me what do the others think?
What causes you to act in that way?
In turn these lead in phrases assist to help the nurses express their value statements? The nurses are coached into reflection.

The cards are shuffled then each statement is shown to the group. This process assists to challenge the myths about the care nurses are providing and the restraints that nurses work under, that shape their attitudes. To identify the political, cultural, historical, financial, personal constraints.

(Week 2)
“Come in crying, go out crying” (not minuted only in my notes at end of session with nurses name beside)

(Week 3)
The group were about to commence the meeting when the Director of Care interrupted the group and said she did not want the meeting to go ahead. The reason was that the accreditors were in the facility and staff may be needed to answer questions. The group dispersed immediately without any further conversation.

(Week 4)
“Traumatic death”, “a difficult, difficult death” (describing a resident with dementia) “a battered, bruised man)
“The resident was not willing to give into the death experience”

(Week 4)
Death is a blessing
He would always listen to me; sometimes we would have a “shouting match”.

(Week 6)
“Careful what you say to relatives”
“All the residents are going to die”
“The residents here are not going anywhere else”
Staff – “Buying into the emotions to meet their own needs”
“When they are gone we say ‘thank God’”
“We deal with the pain”

Anytime I notice ‘group dynamics’
Describe the behaviour
Ask the group to name ‘it’ / label it
Why is that happening?
What can be done about that?
Appendix H

AS THE ENTIRE MINUTES FOR THE TWO FACILITIES NUMBERED 100 PAGES EXAMPLES OF KEY TURNING POINTS OF THE RESEARCH ARE PROVIDED

Minutes of the Action Research and Reflection Group
(Following the introductory meeting)
Facility Two
Wednesday 13th December 2007
1400 – 1500hrs

Jo introduced herself to the group and provided a brief, repeat outline of the project for those staff who had not attended the introductory presentation.

Jo asked and recorded each participants name and designation.

Katherine provided the name of those people who would like to attend sessions but were unable to attend today’s session. Jo provided Katherine with relative’s participant information sheets for distribution.

Jo distributed the Participant Information Sheet to the group. Consent forms were signed by participants and demographic information sheet was completed and collected.

Jo outlined the steps to ensuring the group worked well these included the importance of participants respecting the stories shared at the meetings, allowing the person telling the story time to speak and to avoid discussing the stories outside of the meeting. This will allow group participants to feel safe, sharing their stories and build mutual trust between participants.

Jo distributed the First Reflective Writing Task that provides participants with an opportunity to think about themselves in their own personal, social and historical context and how that has influenced who they are today and how that impacts on them in their workplace.

Participants were asked to firstly think of a time in their childhood when they had a good sense of who they were. The group then commenced answering the questions by writing on the sheet provided.

Periodically Jo asked the participants to share their thoughts. Initially Jo found the group quiet but very friendly and enthusiastic to ‘get on with the task at hand’. A participant reflected having had a ‘great childhood’ coming from a large family. S/he described her/is family as large, fun, into sports and having lots of company growing up.
Jackie shared her/is childhood was great up to the age of five. S/he described her/is life as ‘changing’ when her/is mum married. Jackie spoke of becoming a loner after her/is mother’s marriage. Jackie spoke with great fondness of her/is grandparents who s/he had lived with until her/is mother married. Jackie gave a special mention of her/is grandfather. Jackie shared with the group, the family lived in England and that her/is grandfather was a well respected man; a thousand people attended his funeral.

Another participant shared her/is mother died when s/he was twelve years old. There were two children in the family. This prompted another participant to share with the group her/is mother left the family and that s/he had raised her/is brothers.

Marie spoke of a happy childhood, living in the local area all her/is life. S/he recalled looking forward to Christmas holidays with her/is grandparents on their property.

Jo asked the group what were some of the ‘rules of living’ participants had learned from these important people, places and events in their life. The group discussed the importance of politeness, manners, respect for the elderly, education, and respect for others and especially for ‘yourself’, appreciate what you have. One of Liz’s ‘rules of living’ was identified as discipline.

Jo shared her/is father had been a heavy drinker during her life and that s/he had learnt drinking can be bad. This prompted some of the participants to remember that gambling had been a big part of their life. Jackie recalled s/he could read the form guide at five. Marie recalled, being the youngest of five, her/is Dad placing a bet. Liz remembered a saying ‘hedging your bets’ which prompted Jackie to say, s/he remembered being told ‘don’t put all your money on one horse’. Everyone related to this.

A participant recalled her/is father worked and that s/he ‘never saw him’. Remembering the kids were home with mum. Angelina recalled before her/is mum died her/is Dad was in the navy and could be away for up to eighteen months at a time. The participants felt the impact of losing a mother was even greater when they were not used to having a father at home.

Jo discussed having had a fond memory of hospitals as s/he had spent some time in hospital as a child and that for her/is hospitals were kind, caring places. This prompted Jackie to recall always being ‘sick’ and the link between sicknesses, caring and being a carer.

Reece recalled as student placement during her/is training. In particular s/he remembered a man in his forties who was dying at the facility. He had two daughters. The man was a solicitor, which Reece thought was ironic as he ‘argued about everything’. S/he recalled him being worried about the kids and during the student
debriefing session the experience ‘bought tears to my eyes’. Reece felt the impact of that person’s dying experience never leaves saying ‘it is always there’.

At this point Georgia became upset and left the group to collect her/is thoughts. It was explained that Georgia had experienced personal loss in recent times.

When Jo asked Marie why did you want to work in aged care? Marie said when s/he came to live in (town) that s/he had ‘tried every place in town’ to find work including the aged care facility. Marie persisted over a four year period to gain employment and eventually her/is persistence paid off as s/he enjoyed her/is work and being part of this facility.

Reece recalled her/is trigger for working in aged care. S/he told the group s/he was nineteen years of age, training to be a nanny. S/he recalled part of the course was an aged care placement. Reece recalled ‘trembling’ being ‘scared shitless’ at the prospect of being in an aged care facility. A matron in the facility took Reece under her/is wing and instead of Reece going to perform the daily personal care work s/he was taken to the activities room. Four hours later on leaving the facility Reece knew, aged care, was where s/he wanted to work. Reece still feels ‘goosebumps’ when recalling the experience. Georgia spoke of hearing ‘horror stories’ of aged care and being ‘put off’ by them.

Jackie recalled breaking into aged care as at that time in her/is life it was convenient employment for her/is. As a single parent s/he could take her/is baby to work. Aged care was foreign to Jackie as s/he had, had a critical care nursing background. The group recalled other nurses working in aged care having primarily a critical care, emergency background. Aged care was not thought to be an attractive part of the nursing profession and plagued by stereotypes. Jackie spoke of the nurses own registration board not supporting aged care nursing. Another participant felt by accident s/he went into aged care nursing, as at the time s/he ‘could do with the money’ and a friend had encouraged her/is as the facility needed nurses.

Marie said s/he had three sisters who were nurses. Marie was happy with her/is current employment as laundress and spoke of not being attracted to nursing stating, ‘I would have to wash people and put a needle in their arm’.

Jo asked the group what were the influences on their work. Reece felt since having children her/is work and how s/he works has changed.

Angelina recalled her/is mother/is being a big influence on how s/he worked. S/he recalled her/is mother preserving food and being a great organiser. Angelina felt this taught her/is early to ‘work in a team’ and to ‘get on with the other person’.
The group time ended and participants agreed as Christmas is imminent the group would reform in the New Year. It was agreed Jo will contact Katherine to organise a time.

Georgia discussed it may be a good idea to see a counsellor. Jo and Georgia agreed that would worth trying for a few sessions and Jo will organise for Georgia in the New Year. 

Prepared by J Rowley 13.12.07 (pm)

Minutes of the Action Research and Reflection Group
Facility Two
Wednesday 21st January 2008
1330 – 1430hrs

Prior to the meeting Jo and Marie were discussing the potential impact on staff other than nursing coming across a deceased resident in a room. Jo discussed a previous facility used a secret code to silently notify staff a deceased resident was in that particular room. The facility used a crocheted hanging that was hung on the doorknob as an inconspicuous message to facility staff. This saved the staff from both the surprise factor and provided privacy if the family were still in the room.

Five participants attended the second meeting. Jo introduced herself to the group and provided a brief, repeat outline of the project to the two new attendees Paris and Britney.

A participant information sheet and reflective writing task was distributed to those staff who had not attended the previous meeting. New participants signed consent forms and demographic information sheets were completed.

Jo provided a refresher on where the group had left off at the previous meeting held prior to Christmas. Jo asked participants to give one word to describe their Christmas. Two participants described their Christmas as quiet, another as relaxed. Jackie said ‘sick’ explaining s/he was unwell over the holiday.

Jo distributed and read the previous minutes requesting participants are free to ask for adjustments if necessary. No change to the minutes was required.

Jo asked the group to provide a pseudonym to de-identify participants in future minutes.

Participants were asked if they had completed a reflection during the break using the Practice Reflection Guide provided at the meeting prior to Christmas. Participants had not had an opportunity to use the guide so the group agreed to share their stories
impromptu. Jo distributed a copy of the guide and briefly refreshed participant’s memories regarding how to build a picture of the event in their minds.

This prompted Georgia to recall an end of life care event where things did not go well. Georgia recalled it was not so much the resident but the relative that contributed to her/im remembering this end of life event in a negative way. Georgia told the group “no matter how hard you tried” the care given to the resident was ‘never good enough’ for the daughter. This prompted others in the group to remember this resident and her daughter as the death in the facility was only recent. Jackie said the relative was such a hard woman and spoke in a ‘demeaning way to staff’. The participants spoke of all the extra time that had been given to the daughter. This prompted Jackie to ask other participants if they had seen the resident’s death notice in the paper. The group were surprised that the staff had been thanked publicly by the daughter for the care of her mother. The resident was 95 years old and deaf. The daughter was thought to be in her 60’s. Participants spoke of the daughter being ‘always difficult’, ‘demanding’, “Mum’s not comfortable like that..”, Georgia said this was particularly in the last 48 hours of the resident’s death. Georgia added spiritually, therapeutically everything was being attended to but the daughter was still not happy and that there was ‘always something to deal with from day one’. All staffed ‘copped it’ – ‘even the gardener’.

Participants felt the resident was more settled when the daughter was not there which prompted Britney to ask “was it the guilt factor”?

Georgia said the situation made her/im feel ‘frustrated’, ‘daughter arrived mum got agitated’. Jackie said ‘Mum was lucid’ and would repeat what the daughter had said for a couple of hours after the daughter had left.

Paris recalled the daughter ‘took off travelling for about 6 months’ with a new partner after her mother had been admitted to the facility. Jo asked the living arrangements before the mother had been admitted to the facility. Participants thought the daughter was living with the mother.

Participants discussed the “pain management was not well handled” and that the resident was having ‘all different concoctions’. Jackie reflected ‘we can only do what we can do with what we have’ but felt the resident was having enough to ‘kill an elephant’. The group further reflected the pain management was difficult and reflected “if we could have made her more comfortable”, things may have been different. Participants spoke of the daughter wanting “mum to be zoned out”.

Georgia demonstrated the positioning of the resident saying ‘you would have the pillow here and there’, saying ‘she looked uncomfortable, terrible’. The daughter had bought an electric back massager for the resident’s chair Georgia recalled “even three days before her death the daughter insisted it be on”.

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Jo asked about the communication with the daughter and senior staff. Jackie said the Director of the facility had meetings with the daughter but it was thought that there was not much contact with the doctor and the daughter.

Georgia recalled “I would sit with the daughter for an hour and that was still not enough”.

S/he described the outcome of that situation, the mother’s death, as ‘a relief’ stating “I did not have to sit for hours with the daughter”. This reminded Jackie of the final hours of the resident’s life and ‘dreading’ the daughter coming to the facility at that time but remembered having the daughter ‘get her butt down here’. Jackie spoke of checking ‘Mum was clean’, the ‘room was clean’ before the daughter arrived. When she arrived Jackie recalled the daughter having to ‘get active’, ‘pack up Mum’s things’.

Marie told the group when s/he saw the daughter after the residents death s/he had said “I’m sorry” and the daughter saying to her/im “that’s very kind of you”.

Jackie spoke of a death in the facility today. S/he shared with the group a staff member had inferred “it was that injection you gave her/im” referring to the earlier administration of midazolam. Jackie reflected “s/he’s at peace” and discussed the importance of standing palliative care orders not “this p.r.n. stuff”. Participants spoke of the fear some nurses have of administering medications in end of life care stating “I don’t want to give the last dose”. Which prompted a participant to tell Jackie “it’s good when you’re around” referring to residents receiving adequate pain relief.

Britney discussed some cleaning staff ‘blame the rooms’, saying some rooms “had mockers”. Jackie and Paris spoke of having to change a room into a respite care room for a period of time. Paris recalled two instances where low care residents suddenly deteriorated and were transferred to one particular room. Other low care residents who were their friends visited the sick residents and realised eventually both died in the same room. The other low care residents had expressed not wanting to be moved to that room.

Britney recalled cleaning staff once linking a ‘soaking bucket’ to a series of resident’s deaths. Explaining the same bucket was in those residents rooms that had died. Britney discussed the cleaners ‘got rid’ of the bucket to ‘break the cycle’.

The group spoke of the prescribing practices of doctors that attend residents in the facility. One participant reflected “some doctors are reluctant to give anything”.

The group discussed resistance from some Registered Nurses in administering pain relief drugs to residents. Prompting one participant to state these nurses say ‘s/he (the
resident) doesn’t need the drug’. Jackie said these same nurses don’t keep pain charts even though they are available.

Jo asked about the chain of command and how the RN receives information regarding a resident’s pain. The group discussed the RN is rarely delivering the patient care, and in some instances will not see the resident. The RN relies on carers or other staff e.g. cleaners or activities staff to tell them or other nursing staff who then tell the RN or some staff go straight to the RN. Britney spoke of Marie being persistent and that Marie always follows through to be sure staff are notified. Jo asked if the staff pain management knowledge level has been surveyed. Jackie responded this had not formally been established. Georgia spoke of the palliative care team attending the facility for an education session and that they were ‘excellent’.

Georgia spoke of some RN interpreting pain as a behavioural issue stating ‘they will blame the behaviour’. When Jo asked for clarification Jackie used the example of a resident with dementia may ‘act out’ rather than complain of pain and that this can be misinterpreted as a behavioural issue by nurses who lack an understanding of how pain can be exhibited by these residents. Jackie felt this was not due to a lack of education as the facility had focused on providing the education to staff in the last 12 months and had ‘even tried paying staff to attend sessions’ but stated “they won’t come”.

The group time ended and participants agreed to meet next week.

Jo provided Georgia with the counsellor’s details.
Prepared by J Rowley 21.01.08 (pm)

Minutes of the Action Research and Reflection Group
Facility Two
Wednesday 20th February 2008
1330 – 1430hrs

Marie, Lindsay, Paris, Liz, Georgia, Kara and Jackie attended the meeting.

Jo distributed and read the minutes from the previous meeting. The first adjustment was to the recount of F’s story from the 3rd meeting. The group decided to remove the ‘strong words’ from the story. Jackie explained looking at this recount her/is view was to be as ‘holistic’ as possible explaining “when the experience is outside of what is expected, you don’t know what could be causing the problem and thinking what’s troubling you?”

Marie bought along her reflection on end of life care and explained the drawing to the group and what it depicted. Marie was drawn with a smiling face and in the corner was a washing machine that symbolised Marie’s role in the facility as the laundress. Marie
explained s/he sees her/is self as “keeping the residents nice and clean as possible”. Marie explained the sun depicted in the drawing represented “happy, helpful, smiling, bright sky and clear days”. This prompted Jackie to comment “you are a ray of sunshine in the place” and the rest of the group agreed.

In the centre of Jackie’s drawing a person was laying on a bed surrounded by people who were connected by a chain. Jackie said the person in the bed represented “a resident” with the staff “circling the resident”. Jackie represented her/is self as a dominant figure at the top of the drawing with long arms outstretched to the group. As the Deputy Jackie explained her/is work was to “pull everybody in to work effectively”. In some sections of the drawing the chain was broken. Jackie said this represented when “people don’t follow instructions”, or “s/he can’t get a doctors order”.

The third drawing was from Liz. Liz explained s/he had asked a family member to do the drawing for her/im as the person was very creative. The drawing depicted a person sitting in a hunched position, with their head in their hands, a frown on their face. A lifeless body was draped across the sitting person’s shoulders. Liz said the lifeless body represented a “resident, weighing down the care giver” and that all the carers “energy was so consumed”. S/he explained “some days you can be so zapped”, “give so much of your energy to the resident”. The resident can “consume all my energy”. On the drawing Liz had written “lots of emotional support, physical support, compassion, best quality of life and sometimes I feel the residents can weigh down the caregiver”. This prompted Jackie to say “particularly when you haven’t been well” referring to the carer being unwell on occasion.

Kara’s was the final drawing shared with the group today. Kara explained the drawing represented “providing the comfort”. A resident was depicted lying in a semi upright position against a rock. Kara said “the nurse is the rock behind the person”. The resident in the drawing had long hair, a long beard, a furrowed brow and eyes closed. Kara explained the long plain covering over the body represented a “body no longer functioning”. A dominant figure of a woman with flowing hair was drawn leaning over the body, arms outstretched gently fanning currents of air that contained small crosses that looked like sparkles rising from the head of the resident. Kara said this represented the “spiritual journey”, saying s/he is “helping them (resident) resolve those issues”, adding “even despite limited time, I will cry, or laugh with them, hold their hand, share stories, let them tell you things, give guidance”. Kara explained her/is role is to “help (resident) through the process of dying” believing, “it is not the end, it is the beginning of another journey”. Kara told the group “I don’t fear death and I am not afraid to see it”, “You know there’s another journey or a new path to take”.

Jo then read from a relative’s interview and asked participants to say what value statement they thought the relative was expressing, explaining what would the relative value when making this statement? Jo read a section from a transcript where a relative
being interviewed was speaking about their life since their relative had been admitted to the facility and her/is interactions with staff. Jo was speaking to the relative regarding staff giving advice when Jo asked “you see advice as important” the relative replied “Very much so. If the staff don’t support me I don’t have any support because I don’t belong to any support groups or anything. I haven’t got a lot of friends because I’ve been caring for X for .years, so you drop off with friends. I’ve got no true friends who ring me”.

Gloria commented “that is so sad, that a relative comes to see staff and interact as much with us as see their relative”. Lindsay commented the relative’s “whole life is around care”. Gloria felt the relative’s response reflected “they are happy with the resident’s surroundings”. Paris felt the facility can be “an extension of home” stating “what happens when a resident dies is that staff, everyone goes” from that relative’s life. A participant commented they did not know they were “that important, that we are part of their life”.

Jo then read the next question to the relative “Who do you rely on to deliver the sort of care to him/her? Whose responsibility is it?” The relative stated “the nursing staff, I feel. Aged care workers are magnificent, absolutely magnificent girls…..” Participants commented the relative’s value expressed in this instance was ‘able’, ‘care’.

Further into the transcript Jo had commented “it is not just the nurses who are there for the residents, it’s all those other services”. The relative responded “every service – the cleaner, the nurses aides, the maintenance men, the nurses, the laundry lady are all important because without one of them you haven’t got a service, and they all contribute in a great way”……” they all treat him/her like a person….. “I’ve seen them treating people who are practically in a coma the same way, which I think is very important….”, That’s what I love about out there. They don’t speak down to anyone, they speak as they’re 100 percent able”. The group discussed relative’s watching their nursing care practices which prompted a participant to comment the value in this statement is ‘humanity’. Paris said this is important “despite their (resident) cognition. Respecting that they have lived their life”. Kara commented it is important to be “non judgmental as a carer even with relatives”. This prompted Jackie to remind the group of an elder abuse video scene where a nurse “chopped a resident’s hand in the cot rails, resulting in the relative moving the resident out of the facility”.

Jo then spoke to the relative about end of life care asking, “What are the important things to you”? The relative replied “S/he mustn’t suffer. I don’t want her/im to suffer. I’ve talked to her/im about it. S/he’s on morphine and they must up that dose of morphine as s/he gets sicker and s/he’s asked for that as well. When s/he gets to the end I hope s/he have a very peaceful exit with the morphine to help her/im to go quietly and peacefully. I don’t want her/im to choke or bleed because s/he’s had two bleeds already”. The comment regarding the bleeding was then discussed with Gloria asking
“if the resident does bleed, the relative would be devastated” then asking “what would her/is reaction be ‘blame’? The group felt staff had “no control over a bleed” and stated they would just have to “hope it doesn’t happen”. The group felt in this instance the value for the relative was, “trusting the nurses”.

The interview with the relative progressed to the issue of suffering with the relative commenting “Every time you look at her/im it just breaks your heart. But s/he’s human and the mo/father of my children and grand mo/father of my grandchildren. S/he’s very loved by her/is children and her/is grandchildren. S/he means so much to everyone and her/is friends”. The relative then spoke of “after three or four months you still can’t sleep because you hear them calling through the night, and you’re out of bed and into her/is bedroom, and there’s no one there”. A participant commented “it breaks your heart” this resident is “highly valued by the family” commenting further it helps to “know more about the person, the life story”. The group discussed it is interesting to know about the people they are caring for, their previous life. Jackie commented a residents “social profile is written up in the monthly newsletter” of the facility. The group spoke of the value in this instance being “acceptance and denial” and the “struggle with putting a mother or father in the facility”. A participant commented “it really is the best place to be loved and cared for”. However the group agreed part of the problem is that “people who have not worked or been in a facility” plus “the media portraying nursing homes for example only the gastro outbreaks” can influence relative’s negative reactions to having a loved one admitted into aged care.

The interview then discussed the issue of care priorities. The relative commented “make sure they’re (relative) pain-free first, and then clean. They can’t make her/im pain-free after s/he dies”....”no, you go for the pain first and then deal with everything else after”... “make death comfortable”. A participant commented “don’t clean before the Ordine”. The group agreed it is important to prioritise care.

The relative expressed an appreciation of the nurse’s workloads but asked “I know the nurses are busy and that, but I’m just hoping that at X’s time they’re going to take time, special time for X, that they will help her/im on her/is journey to a comfortable exit”....”even if you have to pay overtime for the carers and all the other things. I don’t care if they send me a bill. As long as they make X comfortable”. Participants reflected “gone are the days of, hold the hand” and wondered if the relative realises facilities are often “over budget”. Jackie commented “we do spend more time, we increase the mouth care, the turns”. A participant agreed, “we are in the room more often”, “visit the relatives in the room, chat, see if anything is needed”. Stating that some relatives “stay”.

The relative was aware the nurses would be told the requests for end of life care and stated “it might only be three or four hours in the end, but they’re there, but make it good for her/im, don’t let her/im suffer. My girlfriend’s husband screamed up here. He was dying of cancer for about five hours. They wouldn’t give him a morphine injection
either. The whole family was out and in the end they just came and gave him a morphine injection. For five hours that man screamed. Can you imagine the damage they’ve done to that family”?...“that damage, that’s all they remember, the horror of her/is death”. Participants agreed “death is traumatic enough, to witness” without the final hours being as bad as this story.

The traumatic end of life story reinforced the importance of end of life care, the relative then stated “you can’t fix something that’s broken totally, can you. We don’t bring her/im back and put her/im on ventilators, but we help them on a safe journey. That’s all you need, a safe peaceful journey to the end. Then you’ve made everyone happy. You’ve made the patient happy, you’ve made the carer, the loved ones and the children and the grandchildren, they’ve all been happy because X has gone happily, and without pain. You know without pain. You don’t need to go out struggling”. This prompted a participant to state that “unfortunately it (death) doesn’t always work like that”. Jo asked “Why not”? Jackie then stated remember “F, had all the right interventions but was restless, struggled”. Stating further her/is thoughts at the time being “accept the struggle” and believing ‘F’ was saying “no”. Jackie went on to say “we couldn’t do anything else”.

Jo then shared how much the relative valued the staff in the facility stating “they’re wonderful out there. We’re so lucky that we’ve got the X nursing home because Katherine runs it. You think s/he’s a softie, but s/he is steel. S/he is steel underneath and s/he makes sure that place runs like it should”. The group agreed it is important to “keep relatives informed, be good communicators”. The group spoke of the extra effort that is made, including, “hand massages and soft music” Jo asked “Who for? the dying resident or the relative. A participant responded “for both”. Jackie said when a resident is “terminal” Katherine and her/is self “keep going to the room” describing this as “playing tag” and making an effort to “keep the relative up to date”, “offer a cup of tea, talk” “just being there”.

Jo is to remind Katherine if s/he would bring a drawing next week and describe her interpretation to the group.  
Prepared by J Rowley 20 and 22.02.08 (pm)

Minutes of the Action Research and Reflection Group
Facility Two
Wednesday 27th February 2008
1330 – 1430hrs

Marie, Lindsay, Paris, Liz, Georgia and Kara attended the meeting.
The previous weeks meeting minutes were read to the group with no changes requested. Jo distributed a flyer for the group’s information on an aged care conference in April to be held in Wollongong. The conference will focus on healthy ageing. A problem with attending conferences was discussed and Jo suggested she could bring a scholarship list and a template of a standard scholarship supporting letter.

Challenging Statement cards were then used with the group. Each card with a Challenging Statement was shown to the group. The statements had been made by the group at previous meetings. The process was used assist the group to express their value statements, coach the group into reflection and challenge the myths about the care nurses are providing and the restraints they work under that shape their attitudes. The restraints were written on the whiteboard - Political, cultural, historical, financial, and personal.

Jo then showed the group a card and asked, “What would cause a nurse to say this or act in this way”?

Card 5 “Some rooms had mockers”
The group discussed the statement had come from a story where the room number was linked to consecutive deaths. Paris spoke of not only the cleaning staff but the residents talking about the particular room and becoming upset. Her/is concern at the time was related to perhaps having to send one of the low care resident to that room at that time. A participant commented this statement may have been the result of a personal issue with the person who raised it. The group also agreed personal superstitious beliefs could have had a part to play.

Card 6 “Some doctors are reluctant to give anything”
It was agreed this statement would have come from the frustration of “constantly trying to get something” (a medication ordered). It was thought the restraint that would have caused someone to say this may have been the politics involved. Participants spoke of a particular doctor requesting the “ground work is done before things are changed”. The ground work being; “assessments”. The group also expressed it is “easier to blame the doctor” which prompted Kara to say “they hold the power” but understood “he needs it on paper”.

Card 3 “It was that injection you gave her/im”
Marie commented the nurse would “only be doing their job” and reflected “why would they say that? It is cruel”. Paris spoke of in that particular instance the nurses had been “pushing with that doctor for about a week and then finally gave it” (the injection). The group then discussed that there were other issues around this statement and one of those was an “education gap in pain management”.

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Card 14 “battling with doctors”
Participants discussed this issue firstly “depends on the doctor” and it also “depends on what you want”. Gloria spoke of the “history the facility had with doctors over the years”. This statement reflected the personal and political restraints the nurse’s work under and that often “the doctor won’t meet staff half way”.

Paris felt the issue demonstrated a “lack of communication” and commented the MDT meetings where resident cases are presented has contributed to improvements in communication where the “doctor will listen to you”. Saying further the doctor can be “more than obliging, accepting to listen if enough information is provided”. A doctor had recently commented “s/he didn’t know about a different perspective” regarding a patient’s circumstances until it was highlighted at the meeting by staff. The group agreed MDT meetings are a “huge step forward” in care and that the meetings “break down the historical ‘stuff’ “and contribute to the “doctor being more in tune with what’s going on”.

Card 11 “that’s all I can do” saying “I have made the first step”
The group discussed this comment demonstrated the person is “limited in their role” and “couldn’t go any further” or “as far as they are allowed”. It was thought therefore to be both a personal and a cultural restraint to practice as in the facility some staff can be “listened to and others aren’t”. Kara felt the carer can go the RN to alert them to a problem, “but if they didn’t action it?” The group felt the problem in any facility can be the barrier created by a hierarchical structure.

Card 13 “A cot case for days following the resident’s death”
The group discussed this statement most likely resulted from a personal issue for the nurse as the story had been about a close relationship with the resident and the nurse.

Card 15 it is important “not to die alone”
Participants discussed this statement would come from a resident’s personal circumstances. Saying some residents “have no family or visitors”, “not having love from family or friends” can result in people dying alone. It was also discussed the financial restraints nurses work under result in these statements being made. The group thought it “would be fantastic” if residents could have someone with them 24hours per day when they are dying. Jo discussed the use of a Silent Visitors program for those people without family or friends and that as people are ageing on occasion there can be no-one alive from the person’s family left to be there when the resident is dying.

Card 9 ‘even tried paying staff to attend sessions’ but stated “they won’t come”
The group discussed this statement comes from the personal “frustration” of trying to organise staff to attend education. The group discussed staff have personal issues/lives and the demands on people’s time can result in a reluctance to attend sessions saying “days off people have other things planned”. Or if staff attend education the problem
with having to “catch up after” an education session contribute to reluctance in attending sessions.

Card 7 ‘s/he (the resident) doesn’t need the drug’
Gloria recalled in this instance it was thought by the RN that it was the residents “behaviour, not pain” that was the problem. Gloria spoke of the difficulty in an RN making this decision “without seeing the resident” and felt it was a “lack of education” (RN) and a “personality issue”. The group spoke about the importance of having knowledge of palliative care and that a one hour session was insufficient to provide this knowledge. Paris discussed few RNs had a palliative care background and that aged care job positions for RN should include palliative care experience in the selection criteria.

Card 4 “I don’t want to give the last dose”
Blame was discussed with a participant stating someone would be saying I “don’t want to be blamed” for the residents death. The restraints to practice discussed included historical, cultural and personal views. The personal view it was thought would result from the person saying this statement, their “own fear”.

Card 16 Spiritual needs are met…staff “asked if s/he wanted a Minister”
The group discussed this being a cultural issue with a participant saying “they (resident) are either Catholic or Church of England, with some going to services while they are here” (in the facility). Other residents were thought to have a ‘history’ of having gone to Church and are now “confronting things in their life” as they near their death. Jo discussed spiritual issues can be more complex than religion in the care of a dying person and suggested a person working for the Division of General Practitioners could be asked to speak at the facility. The group agreed it would be good to speak with Jackie on this point and arrange a session.

A relative’s interview was then shared with the group. Jo read from the transcript. 
Researcher: “Who do you see as your link person to inform you of where X at? Do you talk to the doctor a lot? Do you talk to Katherine now?
Relative response: “I talk to Katherine more, Dr X, his/her doctor, is my doctor, but I haven’t had time to discuss X with him/her because s/he’s too bus with other things. But I get fairly good information from Katherine and Jackie”.

The group discussed the MDT meetings and that relative’s can be invited to attend. Jo asked if on admission or at the initial resident review visit “Does the doctor speak with the relative?” The group did not think this was usual practice.

Jo then read further from the relative’s interview and asked participants to say what they thought the relative was expressing.
Relative: “Over the weekend there’s just as many staff there. Sometimes when they’re rushed off their feet they’ve got that many high care people on that side they could probably do with a few more because it’s hectic work taking care of old people like that, isn’t it?”

The group agreed relatives “see staff running around” but were not surprised as that is aged care work. The group also discussed being “watched” by relatives.

Jo read further from the relative’s interview the issues the relative prioritised in end of life care. Relative statements included: “have their quiet music going, a nice environment for them and I think they would turn them. I have seen them do that up there……”

“I think they get in touch with a minister and they come in and do the last rites. That is important, my X believed in all that. That’s what s/he would like. Some people don’t like that kind of thing, they don’t believe in it, whereas some do. My X has always been a believer so I think s/he would like that”.

“Yes, I know that they’ll give good care because I’ve seen them with other people who are dying that they’re very attentive, and that’s all you can ask for”.

“See, I’m not scared of my X dying because I wouldn’t like to be like that. S/he wouldn’t like to be like that. S/he’s a Christian so it’s a blessing for her to go and I don’t think s/he’d be frightened of dying because s/he’ll be ready for the maker. So you’ve got comfort in that kind of thing”.

The conversation in the interview changed to discussing whether or not a resident is transferred to hospital for life support. The relative replied “…I don’t see any point in just lying there like a vegetable and even with these people in the home I don’t believe in euthanasia”.

“They’ve got no life as it is. I’d hate to live like that. I’d rather take a pill and not wake up.”

“…we’re all born to die aren’t we?”

The group thought these statements were interesting in that the relative seemed to be saying euthanasia for her/is self was okay but not for the relative.

Signing and organising advanced care directives were then discussed during the relative interview with the relative replying “S/he (Director of Care) said, you can go home and discuss it with your brothers. I said, no, I don’t have to think about that one because I thought about what my father said. Definitely not. You see people who’ve been brought
back and they’re just vegetables and they’re worse. There’s one lady up there she’s had a stroke and they revived her, well she’s been a vegetable up there for over 12 months now and there’s no change in her and she still needs all the care and she just lies there. She yells out sometimes, not much, and her family have given up on coming to see her now……”.

“The family used to come to this particular lady while she was okay and once she was brought back from the hospital like that I’ve never seen anyone around her for 12 months, and I feel sorry for her…..I’d hate my X to be like that. So I said, no way”.

The group agreed the circumstances were actually different to what the relative had recounted but agreed relative’s are watching and interpreting/misinterpreting what is happening with resident’s circumstances and their care.

Jo distributed the themes table to the group and asked for participants to read and complete the section - What is this about? With one or two word answers.

Jo is to remind Katherine if s/he would bring a drawing next week and describe her interpretation to the group.

Prepared by J Rowley 28.02.08 (pm)

Minutes of the Action Research and Reflection Group
Facility Two
Wednesday 5th March 2008
1330 – 1430hrs

Marie, Lindsay, Paris, Liz and Georgia attended the meeting. Kara, Jackie and Katherine sent their apologies. Katherine sent a message her drawing and interpretation will be ready for the next meeting.

Jo distributed a list of scholarships and a brief overview of key points to include in application letter. Due to the time limitations Jo asked the group to look over the minutes from last meeting and bring any comments or changes to the next meeting.

Jo distributed spare themes story table to the group and asked if participants had a chance to read and complete the section - What is this about? With one or two word answers on previous themes story table distributed last meeting.

Theme story table was then discussed with the group reviewing each story and providing comments on what each thought each story was about. The key themes were then rated by priority or importance. See responses Themes table 2.
The group requested Story 13 be deleted as the circumstances and recount continued to be conflicting. Story 14 a participant stated this section was inaccurate as the room was not the same as recounted. Minutes to be adjusted.

Meeting planned for next week same time. 
Prepared by J Rowley 6.3.08 (pm)

Minutes of the Action Research and Reflection Group 
Facility Two 
Wednesday 12th March 2008 
1330 – 1430hrs

Marie, Britney, Katherine, Lindsay, Paris, Liz, Jackie and Georgia attended the meeting.

Katherine shared her drawing and interpretation with the group as promised. Katherine described seeing herself in end of life care was quite “simple”, but stressed to the group she had given the drawing a great deal of thought. The drawing depicted a long, straight road running through the middle of three converging circles; at the end of the road was a crucifix. Katherine described the road as “the journey of life” and said “for these residents it is the last part of the journey”. Katherine said the journey takes the resident to the facility where she sees herself, depicted as a figure beside another figure, the resident saying I stand “alongside that person to share the last bit of their journey on this earth”. Katherine described “I stand beside the resident” to “support, encourage and share my knowledge”. The converging circles at the top of the drawing near the crucifix represented at this end of the journey it becomes as Katherine described, “complicated” represented by facility staff alongside with family and friends of the resident in two of the circles. Katherine spoke of her “support for the resident and the family” and her knowledge being part of that support for both families and her staff. Katherine described her role was to provide care and support and that this “privilege is awesome to be able to come along with these people”. She stressed we have “no right to make judgements at this stage” and that being part of the “last piece of the puzzle in that persons life is a privilege”. Jo commented the circles looked to her as Katherine being pulled in different directions. Katherine then described a staff member had previously drawn a character drawing of her that depicted “me as the jester, throwing balls up all at one time in the air”. Katherine told the group this was the “greatest explanation of her role”, “always keeping all the balls in the air”.

The group then read the minutes from the previous meeting. Jo asked if there were any changes from the meeting minutes or the week before (6th), none were required.

Jo then shared with the group the completed themes table discussed at last weeks meeting and showed the group the breakdown to major themes. The major themes were
pain management, education and communication, good death, workloads, staff needs, relative’s needs. The group identified the first three were the priority issues with Katherine commenting, before having to leave, that the other issues will be addressed as a result of action in these priority areas.

The theme pain management was then discussed by the group with Jo outlining these stories are anecdotal accounts provided by the participants and asked the group what evidence is available outside of your stories that demonstrates pain management needs to be addressed in this facility? Jackie then discussed the auditing that had been completed of the three pain charts and how the admission pain section was not used or not followed up to or from the doctor. The Abby pain scale and the cognitive pain assessment had been audited and shown to have limited completion compliance. The group discussed when the palliative team had visited the facility and provided education on the use of the Abby Pain Scale the target group had not been at the education sessions. Jo asked how the results of audits were shared at the facility. Jackie spoke of displaying the results on a notice board and results being graphed. Jackie said the audits were allocated to staff and were alternated but that ‘night staff copped a lot of this work”. Jo spoke of the importance of not making audit allocations punitive. The auditing process was explained by Jackie to include “returned audits” are “double checked“ by Jackie and that the results were presented back to the auditors.

The group then started to discuss methods of communicating audit results and education to staff when time was limited. Gloria spoke of handover and said “if you could come in on report time and use just 15 minutes, to capture those who don’t usually attend education”. Jo spoke of academic detailing and how the method was used in a recent project at the hospital. Staff are trained to communicate efficiently and target staff one on one sharing of the vital pieces of concise evidence for example in this instance it would be key pain management strategies. Jackie then spoke of her concerns of taking an increased workload with this strategy. The group discussed it would be possible for each participant to target three staff each with these intensive education. Gloria commented “it would make the work more interesting”.

Jo shared with the group there is a pain survey, the knowledge and attitudes survey that can be used to assess staff knowledge and attitudes to pain management. Jackie requested to see the survey and the group decided it would be best to target no more than 5 key questions to ensure staff compliance.

The group then discussed the issue of access to specialist input and specialist management in pain management. Jo asked how did that access process work in the facility and was it easy to contact the palliative care teams? Jackie told Jo an RN had been nominated to participate in the MDT meetings and that s/he usually arranged specialist access. Jo was encouraged to make contact with the RN to determine the process. Phone numbers were given to Jo.
Use of end of life clinical pathways was then discussed by the group. Jackie said there was a pathway available but that it had a history of not being used, “no use” at the facility. Jo discussed an end of life pathway she was familiar with and used at the local hospital. The group agreed this would be worth cross checking against the current facility pathway. Jo agreed to forward the pathway to Jackie.

Jo also asked about staff access to palliative care guidelines. Jackie informed the group the Palliative Care Guideline Booklets were available one in the treatment room. Jo spoke of the use of hand held computers to provide staff with point of care access. Jo will show Jackie next visit.

Another idea generated from the discussions were the use of case scenarios to assist staff to relate real time events to outcomes and opportunities to improve practices. Jo spoke of structured case scenario outlines often used in root cause analysis investigations. Jo will obtain and share the structure with Jackie.

Meeting planned for 2 -3 weeks time. Jo is to contact Jackie. Prepared by J Rowley 12.3.08 (pm)

Minutes of the Action Research and Reflection Group
Facility Two
Wednesday 16th July 2008
1330 – 1430hrs

Marie, Britney, Paris, Jackie and Georgia attended the meeting to reflect on the action plan progress for improving pain management.

The group discussed the actions being used to improve pain management. First action was to survey Registered Nurses using the Knowledge and Attitudes to Pain survey tool. The results of the survey revealed key areas for improvement included pain assessment and pain medication knowledge. As a result a series of 3 PowerPoint presentations were created and presented to staff. The first being the Knowledge and Attitudes to Pain Survey results for the facility, the second a pain assessment presentation and the third will be a presentation by a pharmacist on medications used to control pain. Each presentation has been copied onto a CD with a voice over and the notes of the presentation printed and collated in a package with the CD for those staff who could not attend the presentations.

In combination with the pain assessment presentation an academic detailing exercise was used to improve the Registered Nurses pain assessment knowledge. Academic detailing encompasses the development of a relationship with the Registered Nurse
through seeking to understand the nurse’s practices and assess the barriers to behaviour change. The participant uses a product marketing approach where the product is pain assessment. The participant attempts to convince the nurse why pain assessment is beneficial to the RN’s practice. The participant needs to understand the topic, appreciate why the topic was chosen and deliver a small number of key messages to the RN.

The meeting commenced with the group sharing who had completed the academic detailing exercise, with five of the six participants (including Lindsay, not present) having completed the pain assessment exercise. Participants then shared their responses to the values and beliefs exercise in the academic detailing package. The values and beliefs exercise was used to raise participant’s awareness of how their behaviour impacts on others. Participants were provided with a sheet that asked them to explore their beliefs and attitudes about the Registered Nurse who is controlling the pain medication.

The first unfinished question was: Most RN are.... Marie told the group she felt most Registered Nurses are “sympathetic” toward the resident in pain and said: “Sympathy is in the make up of being a nurse”. Other participant’s said most RN are caring, need a better understanding of drug use, finding it difficult to keep up with the ongoing changes in medications. Georgia told the group most RN are accepting of being made aware of appropriate pain practices but still believe they know what to do and base their knowledge on individual practices and beliefs. The group then discussed that for those nurses who had not updated their practices that they could be using practices from their training days, for some thirty years ago.

The second unfinished question was: A good RN is..... Marie finished the question a good RN is caring and understanding of how the resident feels. Other participant’s responses included a good RN is knowledgeable about pain management and listens to other staff. This prompted Jackie to recall the previous evening when she was required to work on the floor, how she relied on the carers who were showering, turning, making the residents comfortable to tell her about a resident’s pain and said: “They have seen the transfer and the pain”.

The third unfinished question in the exercise was: Nurses other than RNs are.... This prompted Paris to state: “More knowledgeable”. The group agreed and responded with statements such as, nurses other than RNs are in tune with the pain of most residents and caring, understanding. Jackie told the group as an RN it is easier to believe the staff rather than just take a quick look as the resident may have settled following the turn. Jackie spoke of trusting the carers report as the RN is often attached to the drug trolley. Participants also discussed nurses other than RN are part of the assessment processes and should feel valued in the team.

The fourth unfinished question in the exercise was: A good doctor is.....
Jackie said a good doctor is “teachable” and compared two Doctors practices in pain management. She described how one doctor is shown all the pain charts for a resident but the reporting is not believed and the nurse “may not get what they want” in pain relief for the resident. As compared to another doctor with more experience in aged care not needing to be shown as much information and believing the nurses. Britney said a good doctor is: “controllable, just like a puppet”. Paris said a good doctor is: “Having things in place before death”. Jackie told the group of recently witnessing peer pressure between two doctors at a multidisciplinary team meeting. Following discussion of a resident’s case and review of the charts, one of the doctors suggested medication and as a result the other doctor who is often reluctant to prescribe went on to prescribe the suggested medication.

The fifth question in the exercise was: What do you think are RN values and beliefs about pain management?

Britney said some RN may be “unaware” of current practices and that they may have “no time to talk or read” about pain information. Marie said the RN she gave the pain assessment information to said: “There is nothing new” in the information and that she “knew the information”. Marie said the RN she spoke to agreed it is “good to refresh” her knowledge and more “regular palliative care” information would be helpful. Georgia told the group the RN she approached was very receptive and interested in the pain assessment information which prompted participants to discuss that some RN take their professional development more seriously than others.

The final question in the values and beliefs exercise asked how do you think the RN’s values and beliefs on pain management impact on their interactions with residents, other nurses and staff? Jackie said RN should show some concern, listen and try to understand the information that comes from other staff.

The group discussed that sharing information with senior staff such as RN can be an intense activity, and requires attention to communication skills and the interaction with the RN. Participants had been asked to reflect on what they had learnt, the good visits, the ‘energy’ from the nurse visited, and factors affecting the impact of the message or practical problems. Jackie said since the actions to improve pain management practices that there is an increased awareness of pain assessment and that she had to ring all the RN when the recent pain medication presentation was cancelled. A RN told her it was a pity as she had planned to attend the session. Jackie told the group this was a real breakthrough as the RN did not usually attend sessions. Georgia spoke of the RN she had approached as feeling threatened and targeted by the activities but felt she had seen the competency of the RN increase recently.

Jackie shared a recent event where she came onto the shift and found a resident with severe dementia being assessed for pain with the incorrect pain assessment tool. A numerical scale 0-10 was being used for a week instead of the Abbey Scale. The group
then discussed the problem that only RN can commence a pain assessment chart but that this could be rectified by writing into a policy that a broader staff group may commence a pain scale, as other staff were thought to be capable of identifying the correct tool for the resident’s condition. Georgia then spoke of the resident Jackie had discussed as being a particularly difficult resident to assess for pain, as s/he had increased anxiety and confusion and that four staff had assessed her/im. Jackie suggested at handover the group observe the resident together and decide on a pain score. This prompted Paris to say that there was a “link missing” in pain management and that medications are not discussed at handover of patient care and therefore staff other than RN did not know if a resident was receiving pain relief medication. Jackie told the group that changes were coming where pain scores would be reported at handover. Other changes included pain scoring being linked to clinical audits, pain assessments would be conducted second monthly in all residents even if no obvious problems with pain over three shifts and that these changes would be incorporated into the resident care days.

The group then discussed this exercise was a targeted approach and sold the message of pain assessment as being important. Marie said she noticed the RN she approached immediately folded her arms when she tried to share the information and was aware of not mirroring her body language. Britney said she recently noticed a resident with her head in her hands, looking at the floor and immediately thought, is she in pain? And promptly went to the nurse to ask if the resident could be assessed for pain.

All participants who completed the exercise gave the RN the handout sheet on pain assessment to take with them. Britney said she had not sat down with the RN to discuss the information but gave the RN the sheet to take with her as she was leaving after a shift. Britney said she will follow up with the RN before next meeting to determine if the RN had any questions. Georgia told the group an RN she had shared the information with told her at the session she would bring in articles linking pain and depression in the elderly.

Paris told the group she had felt fine and did not feel intimidated by the RN. She said the RN was “good” and “happy to be involved”. However at first Paris thought the RN was suspicious and asked: “What is this about”, “Why are we doing this”? Paris also said the RN immediately questioned the percentage of residents who suffer unrecognised and untreated pain. Paris said she responded to the RN by referring to the credible sources for the information that were outlined on the sheet. Britney was surprised that the RN was surprised at being approached by a cleaner regarding a resident’s care. Georgia said: “I would have liked to do other RN”. Georgia was encouraged to speak with other RN as only five of a possible ten RN would have been spoken to at this stage.
Participants discussed they enjoyed the “team effort” in doing the exercise and asked each other “who did you see” and other nurses wanted to listen and get involved in the one on one discussions.

Jackie discussed the Commonwealth Pain Kit having fact sheets and was considering attaching the sheets to all of the staff pay slips, or in the memo book however it was shown that many staff do not sign off as having read the memo book. The sheets used in the exercise where thought to have been successful so the group requested that sheet be printed on yellow paper and be distributed on pay slips.

The group agreed to meet the week after the pain medication presentation on the 30th July to discuss academic detailing pain medication information.

Prepared by Jo Rowley 18.07.08

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**Minutes of the Action Research and Reflection Group**

**Facility Two**

**Wednesday 28th January 2008**

**1330 – 1430hrs**

Jackie, Drew, Charlie (a new attendee) and Paris attended the meeting. Paris agreed to Chair the meeting as Georgia, sent her apologies as did Lindsay.

The previous weeks meeting minutes were distributed and referred to during the meeting. Drew returned 2 more pre use PDA Surveys and Paris reported she received the PDA to trial. Drew agreed to circulate PDA and continue demonstrations to other staff.

Jackie reported there were no further problems with the Pain CD and was yet to follow up with staff member regarding their computer knowledge. Jackie also said no further staff had written in the book stating they had viewed the CDs. Jackie said staff would be required to earn CE points as a process the Board had recommended for performance appraisal.

MDT meeting had been cancelled in January and Drew was being upskilled to facilitate the meeting.

Jackie reported that the MDT meeting critique sheets previously developed were all currently available in the facilities computer system and could be accessed on L: Drive/ Admin / MDT. Jackie said the sheets would go into a Quality File on completion of the meeting.
Three end of life care pathways had been used. A decision on the location of the pathway was that it was to be placed on a clipboard at the nurse’s desk or in the handover notes. Jackie reported both the carer and RN were not signing off on care. Decision made to audit pathways early in February.

Jackie reported the end of life pathway policy draft had been finalized and was to be placed in policy manual. Suggested to distribute by memo to all staff and send to doctors with a letter. An end of life procedure was also to be developed.

Jackie reported the relative’s survey was being revised, but that she had misplaced the additional questions, outlined in the minutes. A private hospital’s survey had been reviewed also.

Jackie reported the final pain policy had been distributed to all staff. That the flowchart had been laminated and placed at the nurse’s station. Jackie discussed adding a table on the back of the numerical/descriptive assessment form and adjusting to include must act on findings.

Jackie reported there would be no further Knowledge and Attitudes to Pain Surveys returned and arranged to have results presented by Jo on 17th February to staff.

Jackie reported the newsletter submission had been rejected as not suitable for the audience who would read the newsletter.

Jackie said the Grief and Loss DVD had been received but that it had not been used but would be integrated into education program.

Jackie said the Palliative Care Folder now included the pain policy and that all documents pertaining to end of life care were contained in the folder.

The end of life pathway audit pre and post implementation results would be presented on 17th February following the pain survey result presentation.

Participants were reminded AB from the Division of General Practitioners would present on spiritual aspects of end of life care on 25th February, following the group meeting.

Decision made to continue closing the gaps on unfinished pain / end of life pathway work. Gloria was nominated to Chair the February meeting.

Prepared by Nurse Researcher 7.02.09.
FACILITY TWO: MEETING SESSION PLAN  
12th March 2008

Session Topic: Theme completion / Action Plan Reflections
Duration: 60 minutes
Outcome: At the end of the session participants will have endorsed final themes and contributed to action planning and development of an implementation process.

<table>
<thead>
<tr>
<th>Timing</th>
<th>Key points and methods</th>
<th>Resources</th>
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<tbody>
<tr>
<td>10 mins</td>
<td><strong>Introduction</strong></td>
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<td>Welcome and thank for participating</td>
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<td>5 mins</td>
<td><strong>Body</strong></td>
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<td></td>
<td><strong>Briefly remind</strong> the project title is Dying in a Rural Nursing Home: An Action Research and Reflection Project to Improve End of Life Care to People with a Non Malignant Disease</td>
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<td><strong>Explain</strong> the aim of the project is to explore issues as identified by nurses and relatives of patients receiving end of life care in rural nursing homes from a non malignant disease</td>
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<td><strong>Outline</strong> the objectives of the project will be to:</td>
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<td>• Examine ways in which nurses can provide nursing care that maximises the likelihood of a good death.</td>
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<td>• Identify the barriers nurses perceive to prevent optimal end of life care to dying patients.</td>
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<td>• Explore the relationships between nurses and relatives of the dying patient</td>
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<td><strong>Discuss</strong> action research is a process of practice reflection, planning, action, observation and reflection</td>
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<td><strong>Discuss</strong> the direction of the project is to assist with collation of an action plan, implementation and observation of the process.</td>
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<td>30 mins</td>
<td><strong>Distribute and read</strong> the minutes from last meeting. Adjust with any amendments.</td>
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<td><strong>Final</strong> endorsement of themes.</td>
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<td><strong>Discuss</strong> the process of action planning. Plan / Do / Study / Act cycles.</td>
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<td><strong>Acting</strong> This is where we make a critically informed, careful and thoughtful variation to practice, by putting our plan into action. As the action may be potentially risky, we need to be flexible and</td>
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open to change in light of the real time situation. Acting may involve material, social and political struggle towards improvement and negotiation and compromise may be necessary. We may need to be content with modest gains that gradually get bigger based on previous gains (in other words, we may not always be able to ‘fix things’ the first time).

**Observing**
This is what makes action research. It involves documenting the effects of critically informed action. Use your powers of observation and stay responsive, open eyed and open minded to see how the plan of action is working. Record your observations in your journal or by whatever additional means we decide. Observe the action, the effects of the action (intended and unintended) the circumstances and constraints of the action, and any other issues that may arise.

**Reflection**
Reflection recalls action as it has been recorded in the observation, but it is active in making sense of processes, problems, issues and constraints that may manifest in the strategic action. Reflection is aided by group discussion so we can reconstruct the meaning of the social situation and revise the plan if necessary. Reflection asks us to evaluate the effects and the issues and to suggest ways of proceeding. Reflection allows reconnaissance for further action research cycles as necessary. We keep going until we know we have achieved our aims (plans) relating to the specific practice issues we raise.

| 10 mins | **Conclusion Organise** next meeting date / time. **Outline** next week action plan and process for implementation will be finalised. **Reinforce** how much I appreciate their being involved in the project and the potential benefits to residents. | Distribute Blank action plan |
## Appendix I

**Facility One: Practice Story Table Themes Stage 2**  
Action Research / Reflection Group Discussion 15th March 06

<table>
<thead>
<tr>
<th>Practice Story</th>
<th>How did the participant feel?</th>
<th>Issues / Themes</th>
<th>What is this story about?</th>
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<tbody>
<tr>
<td>Story 1 (Week 4)</td>
<td>An RN directed the participant to “make it happen” even though the participant did not feel comfortable with mobilising the resident due to concerns over her safety. The participant expressed her/is concerns repeatedly during this conversation stating “I was against it”.</td>
<td>The participant said she had “never forgotten” the events of that day, she expressed blaming herself saying “I was too weak to say no”. The participant expressed a lack of closure stating there was “no chance to say goodbye” to the resident.</td>
<td>Self Blame</td>
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<td>Courage to speak</td>
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<td>Bullying Behaviour</td>
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<td>Regret</td>
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<td>No chance to say goodbye</td>
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<td>Story 2 (Week 4 &amp; Week 10)</td>
<td>The participant reflected on last Christmas as being “special”, a week before the resident died s/he recalled even though the man was demented he sang a duet with his son. S/he spoke of being very moved witnessing this and of</td>
<td>A participant remarked death is a summation of life and that some residents are not able to accept changes in life. Residents can be “oppositional to everyone”. The dying process can bring up these responses and</td>
<td>Effect of a resident’s death on nurses</td>
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<td>Acceptance of death</td>
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<td>Speaking about death</td>
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died a “battered, bruised man” he had “Steri-strips on his eyes and arms”.

having a “strong bond with him” as they both enjoyed singing. The participant reflected on his death and said “I knew he was dying – he (name) didn’t” and the resident was “not willing to give into the death experience” stating his death was “hard death for us girls” and “I still miss him”.

a person’s views on life. Another participant felt a person’s temperament can influence their reactions even though “death is part of life for everyone”. A participant said “it is hard for staff” when referring to a resident’s denial about their death and commented some people can be helped through the process and others can’t be helped.

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<tr>
<td>Story 3 (Week 4) The group discussed aspects of a good death including a good death as being “patient’s acceptance” (of dying), “family goes with the flow”, “work as a team” (doctors and nurses).</td>
<td>A participant said death could be like a “cauldron type storm for the staff” saying you need to “know in your heart you can’t do anything”.</td>
<td>Participants spoke of family involvement saying some families say “what have you done to him/er” or at other times having to explain to the family what they can do such as “you might like to say goodbye to mum”, “you can touch Dad”.</td>
<td>Supporting relatives Communication Families Helplessness</td>
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<td>Story 4 (Week 4 &amp; Week 6) The group spoke of training for death saying there is “no training in helping one another with death”, “nobody has ever told me how to do it” and that staff have</td>
<td>A participant discussed how she assists / initiates new staff to death and spoke of showing staff “how massage can bring back a patient’s colour”. Another participant reflected</td>
<td>New staff recognizing the dying process and a nurse’s role in the dying process. Other learning points for new nurses discussed were “to be able to identify death” and that death for new</td>
<td>Training for death Education Initiation processes</td>
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to “get used to death”. “even though you know someone is dying it is still a surprise when they go”. The participant discussed not having difficulty “accepting death” and “takes it as it comes”. S/he questioned ‘new’ nurse’s behaviour and discussions among staff when some nurse’s cry when residents die then recalled crying when s/he first started nursing.

The group discussed developing, ‘detachment’ type behaviours even though they expressed “love and care” for the residents.

people “can be scary”.

The group expressed seeing death is a training process and described some staff as “buying into the emotions to meet their own needs”.

The participant stated we can “watch this person for three or four years, there’s no quality of life”; “when they are gone we say thank God”. Death was described as a “slow decline – acceptance of dying and being at peace” describing death as a “release for the person”.

importance of communication, team, and growth.

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<tr>
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| Story 5 (Week 5) The story related to a daughter accepting her mother’s death and the support nurses provide to families during and after the death of a resident. | S/he described the scene; “her mother was in bed dying and the daughter was clearing out the cupboard”, “only the bare necessities had been left”. The group agreed this practice was not uncommon for some families to minimise belongings toward the end of a relatives life describing this time as a “waiting game”. The participant was thanked by the family for her support at the end of the funeral. The participant felt this was related to the daughter becoming “upset at the funeral and no one was supporting her or knew what to do”. The daughter felt her mother would have been upset by her crying at the funeral when | Supporting relatives | Peer pressure
Communication
Team
Old and the new brigade
Admitting you don’t know
Extended role of nurse
Nurses role after death |
participant described the relative as “connected to her mother”, the daughter “knew everything that could have been done, was done”, “this made it easier”. The participant described the dying resident as being kept “comfortable” the participant believed this made the family “feel at ease”.

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<td>Story 6 (Week 5)</td>
<td>The group agreed it is important to be “totally honest” with the family regarding time of death and prepare the family by saying “to be honest I think it will be…. (time period to death) or “looks like it will be in the next few hours” or “it could be in 6 months, I could be wrong” or “it could be today, it might not be”. A participant described families are often not told their relative is dying saying “no-one will tell them” s/he recalled an RN saying “it is the doctors job to tell them” and described an RN being angry at the participant for telling the</td>
<td>Participants felt it was important to prepare families as “the family have to get kids in”. A participant felt RNs are generally not challenged on their decision not to notify the family of impending death.</td>
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<td>Role delineation / Team</td>
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<td>Admitting you don’t know</td>
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family, “the RN refused to tell them”.

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<td>Story 7 (Week 5 &amp; Week 10) The group discussed issues related to providing pain relief to residents.</td>
<td>Medications prescribed prn were seen as problematic, a participant said the RN will say “we will give them a couple” and felt RNs can be “too scared, afraid to give them too much of a drug” or “be frightened to give them too much as allowed by the doctor”. The group discussed when doctors prescribe pain relief medication as p.r.n. and the issues staff have in having p.r.n. drugs administered. A participant saying residents sometimes need the pain relief ‘now’ and said “only Registered Nurses can give Schedule 8 medication”. Another participant discussed requesting medications to be changed and was told by medical staff “it will be my decision”.</td>
<td>One participant described having to explain to an RN why she thought it was important to initiate pain relief before the morning routine care was given to a resident, having to explain to the RN “she is in pain”. Doses prescribed were viewed as problematic at times with participants stating when orders are written as 1-2mg it was variable how much was given and frequently the lower dose is given rather than the 2mg dose. This lead a participant to state pain is related to levels of perception of how much pain a resident is in and stated there are three pain assessment charts available in the facility but commented no chart provides a total assessment stating it can help when you know the person.</td>
<td>Pain Medication Knowledge Doctors prescribing habits Pain Assessment Admitting you don’t know Medication Administration</td>
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The participant suggested the chart could be put to the management committee for approval but expressed it can be difficult to have some charts approved.

The group discussed having to work with relatives to maintain a resident’s pain medication regime using the example a resident may be asleep during the medication round and the relatives may not want the resident woken for the pain medication to be administered.

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<td>Story 8 (Week 5)</td>
<td>The participant recalled only “at a resident’s daughter’s insistence” did a doctor see the resident, describing doctors as “reluctant to attend”. The participants felt doctors don’t listen or look at the resident and only see the resident as they are at that point in time</td>
<td>The participants spoke of subtle changes happening you don’t think it’s extraordinary but it is important and because of regular contact the carers felt they notice the changes.</td>
<td>Medical review of residents</td>
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<td>Who’s opinion is valued</td>
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<td>Being heard</td>
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<td>Communication</td>
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describing a permanent resident who can be, “crook as” but when the doctor sees the resident he has a “smiley face”. The participants felt they knew this resident well enough and that he “grunts and groans in pain but displays a big grin”.

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| Story 9 (Week 5 & Week 6) Who provides the care was discussed by participants. Participants stated unless an RN gives out medications the resident will not necessarily be seen by anyone but their carer. A participant discussed how RNs are separated from the low care residents. | Participants described “some residents are only seen at lunch” but reflected that usually only an RN hands over to the doctor and described the RN having to have faith in the other carers. Describing the RN when allocated other, ‘paperwork duties’ as having an opportunity to “breeze in if there is a problem” and asking “if everyone is well today?” S/he reflected on the RNs as “having so much on their plate” being unable to “responsibly cover low care residents as well as their other high care residents” and having to develop a sense of being able to “accurately gauge” the residents. The issue of gauging | The participants then discussed they care for a mixture of high and low care residents supported by an RN and that high care residents have a daily report written that includes events being documented such as pain when the resident is not normally in pain. | Documentation practices  
Medication Administration  
Pain Assessment |
when residents are experiencing pain and problems with pain medication administration was discussed and this prompted further discussion on Enrolled Nurses making use of the available pain assessment charts and assessing low care residents.

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<td>Story 10 (Week 6) A participant shared a practice story of a resident who was having morphine ordered and administered by the nursing staff; the resident’s family was told by a couple of staff members that morphine was a “dreadful drug”.</td>
<td>The participant expressed the difficulties in trying to “catch up” with the resident’s pain due to the resident’s family becoming “overly defensive” to morphine being administered. S/he expressed using techniques to convince the family morphine was a safe drug to administer including using supportive comments and convincing the family “we do know what we are doing”, “it can be difficult to source other drugs” and the patient needs are “high care”.</td>
<td>The participant reflected the importance of morphine being ordered and administered before the resident is in “dire straits”. The participant expressed the importance of all the team being “cohesive” in the information shared with relatives, the importance of using “tact, respect and wisdom” and being “careful what you say” to relatives.</td>
<td>Medication Administration Pain Medication Knowledge Team</td>
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<td>Story 11 (Week 8) A participant related a practice story involving a dying resident who she recalled being “very</td>
<td>A participant spoke of allowing or not allowing herself to become ‘attached’ to residents. She recalled called at home by the staff</td>
<td>The conversation then moved to the personal pain associated with getting involved with residents and the participant described</td>
<td>Self Reflection Debriefing</td>
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attached to the old fellow”. The resident had lost his wife. She remembered telling the dying resident to “let go” and said she often says that. If she knows they will.

who told her “Bill’s not well”. She went to the facility and sat with him until 3 am and remembered him calling out to his late wife, “Mabel, Mabel”. The participant felt some people need permission to go. She remembered giving Bill permission and telling him “there is nothing left now, Mabel’s gone, you can go”. The participant was pleased when the family asked her to be one of the pallbearers she interpreted this as being accepted into the family but remarked “Bill had heavy feet” and her place at the coffin was at his feet.

becoming “detached after that”. She recalled how she felt when she would go to Bill’s room after his death and how he used to tell her she was a ‘breath of fresh air’.

A participant commented “we rob ourselves by not allowing ourselves to fully engage with residents”. The participant acknowledged that past experiences and our own fears are valid reasons for not wanting to engage with residents and that it can be so awful to go there saying you can open a “flood of grief”.

A participant stated the staff go through many stages of grief and denial and felt when a resident is close to death some “step back a bit”.

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<td>Story 12 (Week 8)</td>
<td>A participant commented nurses “coach the family” saying we hope the family “call the shots” but nurses are influential. The group agreed most families will “hang</td>
<td>The group spoke of the role of palliative care and providing the best comfort to the resident and supportive treatment right to the end.</td>
<td>Role of Palliative Care</td>
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<td>who told her “Bill’s not well”. She went to the facility and sat with him until 3 am and remembered him calling out to his late wife, “Mabel, Mabel”. The participant felt some people need permission to go. She remembered giving Bill permission and telling him “there is nothing left now, Mabel’s gone, you can go”. The participant was pleased when the family asked her to be one of the pallbearers she interpreted this as being accepted into the family but remarked “Bill had heavy feet” and her place at the coffin was at his feet.</td>
<td>Access to Palliative Care</td>
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<td>becoming “detached after that”. She recalled how she felt when she would go to Bill’s room after his death and how he used to tell her she was a ‘breath of fresh air’.</td>
<td>Supporting Relatives</td>
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on as long as they can” to their loved one. A participant felt families can be reluctant in accepting the decline of their loved one saying families often “can’t face the thought of the changes in treatment at that stage in life” but go home and think about it then the next day agree with the change in treatment.

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<td>Story 13 (Week 8)</td>
<td>A participant expressed a story by drawing her thoughts on end of life care. In the middle of the drawing is a person standing on a surfboard. The participant describes this person as “the nurse riding the waves, despite waves coming from every direction”.</td>
<td>Waves represent all the emotions; grief, denial, fear, pain, misinformation, unrealistic expectations, sadness, acceptance, lack of understanding, starvation, dehydration, nurses lack of knowledge experienced by the family, the nurses and the resident. The participant explained the surfboard has the word love written on it representing the nurse as “standing on love to give” She said the nurse wears a badge of hope. Describing hope for family and resident.</td>
<td>The participant expressed it is important that the nurse is still standing and has ‘survived the experience’. Strategies for longevity of nurses in the profession Reflective practice Personal beliefs of death Stages of grief</td>
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A ring of yellow colour representing light surrounded the nurse and within the ring are words including, kindness, empathy, listening, acceptance, nursing skills and care. The yellow in the picture represents to her God and because of her Christian beliefs this is intentional.

One of the waves is labeled Loneliness? This represented the emotion experienced by all involved the resident, the staff and the family.

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<td>Story 14 (Week 10)</td>
<td>A previous resident’s case was discussed her husband was living in a room across the corridor. The group spoke of the families difficulties in acceptance of the resident’s cancer diagnosis and eventual death. The nurses viewed themselves as a facilitator for the husband and wife to eventually communicate more effectively before her “passing”. A participant reflected on working the day this resident died and felt</td>
<td>A participant remarked nurses frequently work with vocal, strong willed people and issues around end of life care can “come to a boiling point”. The group agreed a process of consultation and debriefing with nurses, relatives and medical staff can be helpful and occurs some of the time.</td>
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<td>Reflective Practice</td>
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<td>Nurses role after death</td>
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should be “true to yourself” and care for the patient in a way you know is expected but felt some relatives can interfere with these standards.

staff “stay positive for the sake of the resident and their family” even though the reality is the resident is dying. Stating “it is difficult for nurses to express the way we feel” for example “to cry when a resident dies”. This participant reflected when “you can open up to staff members you are closer than you thought and both feel the same feelings”. A male participant commented sometimes you need to “take it home and deal with it in another way”. This lead to a participant commenting that this can be a gender issue stating women can talk the issue through with other women.

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| Story 15 (Week 10)   | The participant felt this was unfair on residents and staff particularly when a resident “needs to go”. The participant recalled a family reacting to a resident’s imminent dying in this way and remembered the resident then went through a process of questioning her own beliefs. | The participant recalled the resident sharing and exploring her thoughts with the nurses because she felt she could not share with her family. | Disclosure by dying patients
<p>|                     |                                                                                               |                                                                                 | Nurses extended role                      |</p>
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<td>Story 16 (Week 11) Jo shared some of the relative’s interviews that detailed the reasons for placing a family member in a residential aged care facility.</td>
<td>A participant felt placing a person in care can be a good decision for both the resident and the family. Another participant commented that nine out of ten relatives need the care when placing a resident in a facility due to the stigma they attach to themselves and the guilt.</td>
<td>A participant commented asking relatives why they are placing their family member in care is not asked as a direct question but nurses ‘ask around it’ and attempt to identify the key issues of why the family have made that decision. Another participant commented it is important for the background history of the resident and assists nurses in determining how to care for the resident in the future. A participant wondered how people coped before ‘places like this’ were built.</td>
<td>Connecting with families/relatives Understanding Communication</td>
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<td>Story 17 (Week 11) Jo shared some of the relative’s interviews that detailed how the relatives felt about their family member being transferred to a hospital to die.</td>
<td>A participant stated ‘you’d rather a person’s preference to die in the facility be granted and said it would be ‘more like dying at home’. The group generally agreed a resident is happier to die at ‘home’. Another participant felt some relatives can be ‘looking for answers’ and ‘not ready to let go’</td>
<td>A participant felt it can be confronting to bring up the topic of end of life with relatives and felt at times relatives can be ‘blind to it’. She went on to say she thought ‘life issues and the relationship with the family member can be bound up in a relative’s denial’ (of the dying process).</td>
<td>Speaking about dying Knowing what people want in death Communication</td>
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therefore need their family member to go to hospital.  

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| Story 18 (Week 11)  
Jo shared some of the relative’s interviews that detailed the importance to the relative’s knowing the doctor was overseeing the care | A participant felt it is important emphasising ‘it is the most important thing’.  
Another participant felt it is a ‘generational thing’, a ‘status thing’ with elderly residents. | One participant commented that there can be an element of ‘conflict’ with the nurses not agreeing with the resident’s trust in their doctor but felt a professional approach when this occurs is important to maintain.  
The group also agreed doctors are all different and most of the doctors are willing to listen to nurses concerns. | Team |
| Story 19 (Week 11)  
Jo shared some of the relative’s interviews that detailed relatives viewed ‘Staff demonstrating they care about the resident’ as important. | Another participant discussed the ‘small things make a difference’ and commented “as you get older you see it differently, totally different”. A participant linked this to personal values and felt the ageing process changes people’s values and challenges an individual “to treat them like you want to be treated”. A participant then explained how these practices translate for her in her daily work commenting “I don’t care if a bed is not made, it is This led the group to comment on the philosophy of the organisation that drives practice in the facility, a participant commenting on the care as “subtle – we are not a regimented place”, “kindness and care are key priorities for staff, not routine”. The participant felt these were practices supported by management and viewed as important. She commented the organisation attempts to attract | Organisation’s Culture  
Recruitment processes  
Team  
Giving of oneself / caring |
important to talk to the resident” and then told a story of having to ‘catch’ a wandering resident she said “I chased him all the way over to Opal House and when I caught up with him I just gave him a cuddle” the next day he told me he “was on a downer that day and just wanted to go”. When comparing a caring culture with organisations that work from a so called “nit picking” culture i.e. a culture of incident monitoring that “create dramas” and work from a basis of “intimidation and a fear factor” were not viewed as having the residents best interests at heart. The group expressed the residents enjoy the staff that come on and felt this reflects the staff must be doing something right. and recruit staff who can demonstrate a kind, caring attitude to residents and colleagues, who have a “focus on the care we give residents” saying we want people with “a nurse’s heart”, “not just a nurse looking for a job”. She said we “discourage abruptness with residents” and the caring culture the organisation is developing more and more reflects cohesiveness amongst the staff.

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<td>Story 20 (Week 12) Relatives expressed an important aspect of care was, ‘Keeping relatives informed’. Jo asked the group; Do nurses believe it is important for relatives to be kept informed?</td>
<td>A participant felt relatives need to be informed “sometimes” but “sometimes not too much”. The group discussed the difficulties nurses face when providing information to relatives and that</td>
<td>A participant stated there is a “line you draw regarding how much you tell them, as some take it as gospel”.</td>
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<td>Supporting relatives</td>
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the information can be “taken out of context” and “a bit of information can be used and treated as misinformation” A participant expressed a “pressure is put on us by families to tell them what they want to know” stating I am “aware of what I say” to relatives which prompted another participant to express that s/he felt “they (relatives) are trying to get us to slip up” and linked this to sometimes relatives try to “make us look incompetent” believing relatives know “we can’t always give information” and that “relatives judged” nurses.

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<td>Story 21 (Week 12) Who’s responsibility is it to inform the relatives?</td>
<td>This prompted a participant to say “I will always pass the buck”. The group spoke of the career structure of nursing, and the stigma that can be attached to the various grades of nurses. Generally the group felt it is appropriate for less senior nurses to refer residents and relatives to an Registered Nurse (RN) for</td>
<td>The group also discussed the issue of “covering your back” and felt sometimes it is more appropriate to refer relatives and residents to speak to the doctor. The potential for litigation was discussed and providing incorrect information was of concern with a participant saying nurses can be “out on a limb by</td>
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questions to be answered but acknowledged sometimes the RNs do not know the resident as well as for example the Enrolled Nurse (EN) who is responsible to care for low care residents. This prompted a participant to comment that in the early years of nursing everything was passed onto the RN stating “this was how you were trained”. A recently graduated nurse said “that is still taught today”. yourself with a lack of support”. Participants also felt relatives have an “expectation” the nurse will follow up. The group expressed it is better not to pass on information if they are not sure of the correct information. Participants linked information sharing to “trusting the staff” and discussed new residents to the facility and their relatives asked for more information and only in exceptional circumstances this occurred with long term residents. A participant felt providing information is part of the process of “continuity of care” and results in a “nice, restful place”.

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<td>Story 22 (Week 12)</td>
<td>The group discussed the accessibility of staff with a participant stating “Assistants in Nursing (AIN)s are more accessible” to residents and relatives and that “RNs are always busy with two floors to attend to” therefore RNs were not seen as</td>
<td>Consistency of staff and residents in the low care and high care areas was compared by the group, a participant expressed “in high care we are behind” when referring to ‘knowing’ the residents. It was felt high care residents “are</td>
<td>Consistency of staff</td>
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<td>The issues relatives were not pleased with were discussed; the first was Relatives communication with the doctor and nursing staff. Jo asked the group, Why would a relative feel they were not being</td>
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communicated with by health professionals? And Why would it depend on which RN was on if issues were clarified for a relative?

always available. This prompted a participant to discuss AINs sharing information with RNs saying “it is invaluable when AIN’s share information, even a perception, as I tuck it away and process it. I may not divulge information to a relative straight away, (pause) sometimes people may think I am reticent but that is because I am thinking about the information.”

A participant felt the ENs working in low care were the “go between” for residents and senior staff. The ENs and the consistent staff rostered in the low care area assisted staff and residents to know each other. This was viewed as beneficial and important. A participant felt the nurses “get to know these residents well” and are, “able to influence end of life decisions”.

always new”, new RNs “with different ideas” and staff are less consistent or familiar to the residents in that area stating “the residents can’t keep up with the staff”.

The group discussed the differences between RNs and how some RNs “use their authority”, with a participant saying “some RN think they know better, so you just don’t bother” and said “What they say go’s” but s/he couldn’t understand why they (RN) behaved in that manner. Commenting that s/he has seen some RNs “run around like s/he has her head cut off”.

A participant felt resident symptoms can become a “huge crisis of conflict”. S/he spoke of a resident with renal failure who had severe skin itching and spoke of the problems the itch caused for all involved saying “the doctor was unsure, the RN felt it was a renal itch but another RN treated it as scabies and
another RN believed frequent showering would provide relief”. The participant then discussed RNs may use initiative and try various methods to relieve symptoms but felt “honest documentation of treatments” did not always occur.

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| Story 23 (Week 12) At the close of the meeting a participant spoke of the difficulty s/he faced following the death of a resident and how this became such a problem for her/im at the time that s/he was considering leaving the work. | S/he spoke of the emotional upheaval of the experience and how s/he had ‘worked on’ but felt the memory of the resident’s death made her/is working life so difficult at times that s/he was having to drag herself out of bed just to go to work. | The participant spoke of informally sharing the story with another staff member and felt comforted to know other nurses had felt the same. Jo shared the reflective practice guide with the participant and discussed the value of exploring the details of the situation in more depth through reflective journaling. The last remaining members of group discussed the importance of addressing death and finding some closure to ensure nurses develop ‘longevity’ in the profession as the participant will most likely have to deal with similar death circumstances in the future. | Debriefing  
Reflective practice  
Strategies for longevity in the nursing profession  
Perfectionism |
Facility One: Action Plan
Action Research and Reflection Discussions 15th & 22nd March 2006

Ask the group to think about what is useful and what is not useful about each theme

Planning
The plan must be flexible to allow for unforeseen effects and constraints.
The action prescribed by the plan must take account of the social risks involved and recognise the material and political constraints in the situation.
The plan allows us to go beyond our present constraints to empower us to act more effectively in the situation.
We plan by collaborating openly and honestly with one another and by analysing and improving our understanding of the situation.

Acting
This is where we make a critically informed, careful and thoughtful variation to practice, by putting our plan into action. As the action may be potentially risky, we need to be flexible and open to change in light of the real time situation.
Acting may involve material, social and political struggle towards improvement and negotiation and compromise may be necessary.
We may need to be content with modest gains that gradually get bigger based on previous gains (in other words, we may not always be able to ‘fix things’ the first time).

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<td>Introduction session – case scenario</td>
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<td>Reflective practice (Story 11, 13, 14, 23)</td>
<td>Obtain debriefing structure</td>
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<td>No chance to say good bye (Story 1)</td>
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<td><strong>Staffing</strong></td>
<td>Continuity of care (Story 21)</td>
<td></td>
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<td></td>
<td>Who’s - Responsibility (Story 6, 21)</td>
<td></td>
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<td></td>
<td>Consistency of staff (Story 22)</td>
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<td></td>
<td>Staffing ratios (Story 21)</td>
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<tr>
<td><strong>Education</strong></td>
<td>Training for death (Story 4)</td>
<td></td>
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<td></td>
<td>Fear of Litigation (Story 21)</td>
<td></td>
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<td></td>
<td>Initiation processes (Story 4)</td>
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<td></td>
<td>Peer pressure (Story 4)</td>
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<td></td>
<td>Old and the new brigade (Story 4)</td>
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<tr>
<td><strong>Documentation</strong></td>
<td>(Story 8, 9, 22)</td>
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<tr>
<td><strong>Organisation</strong></td>
<td>Organisation’s Culture (Story 19)</td>
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<td></td>
<td>Recruitment processes (Story 19)</td>
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<tr>
<td><strong>Other</strong></td>
<td>Perfectionism (Story 23)</td>
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<td></td>
<td>Judgments (Story 20)</td>
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</table>
## Appendix J

### Practice Story Table: Locating a Thematic Concern in the Practice Stories

**Facility Two: Action Research / Reflection Group Discussion 1st March 2008**

<table>
<thead>
<tr>
<th>Practice Story</th>
<th>How Did The Participant Feel?</th>
<th>Issues / Themes</th>
<th>What Is This About?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Story 1 (Week 2)</td>
<td>---- said the situation made her/im feel ‘frustrated’, ‘daughter arrived mum got agitated’.</td>
<td>----- added spiritually, therapeutically everything was being attended to but the daughter was still not happy and that there was ‘always something to deal with from day one’. All staffed ‘copped it’ – ‘even the gardener’. Participants discussed the “pain management was not well handled” and that the resident was having ‘all different concoctions’. ----- reflected ‘we can only do what we can do with what we have’ but felt the resident was having enough to ‘kill an elephant’. The group further reflected the pain management was difficult and reflected “if we could have made her more</td>
<td>1. Pain Management</td>
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<td></td>
<td></td>
<td></td>
<td>2. Communication</td>
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<td></td>
<td>Frustration</td>
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<td></td>
<td></td>
<td></td>
<td>Energy to the family</td>
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<td></td>
<td></td>
<td></td>
<td>Relatives unhappiness</td>
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<td></td>
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<td></td>
<td>Relatives coping</td>
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<td>Needs of family over the resident – taken over by the family</td>
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<td>Regrets</td>
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<td></td>
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<td>Daughter feeling guilty about mum/dad in care</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Practice Story</th>
<th>How Did The Participant Feel?</th>
<th>Issues / Themes</th>
<th>What Is This About?</th>
</tr>
</thead>
</table>
| Story 2 (Week 2) | Participants spoke of the fear some nurses have of administering medications in end of life care stating “I don’t want to give the last dose”. | Which prompted a participant to tell ------ “it’s good when you’re around” referring to residents receiving adequate pain relief. | 1. Pain Management  
2. Education  
Fear Team  
Self Doubt Individual nursing medication practices Guilt |
<table>
<thead>
<tr>
<th>Practice Story</th>
<th>How Did The Participant Feel?</th>
<th>Issues / Themes</th>
<th>What Is This About?</th>
</tr>
</thead>
</table>
| Story 5 (Week 2)  
The group discussed resistance from some Registered Nurses in administering pain relief drugs to residents. Prompting one participant to state these nurses say ‘s/he (the resident) doesn’t need the drug’.  
------- said these same nurses don’t keep pain charts even though they are available. | ----- spoke of ----- being persistent and that ----- always follows through to be sure staff are notified.  
----- spoke of the palliative care team attending the facility for an education session and that they were ‘excellent’. | 1. Pain management  
2. Education  
3. Respect  
4. Documentation  
Not following Orders  
Team  
Frustration  
Assessments  
RN needing more education on pain management in end of life | |
| Story 6 (Week 2)  
The group discussed the RN is rarely delivering the patient care, and in some instances will not see the resident. The RN relies on carers or other staff e.g. cleaners or activities staff to tell them or other nursing staff who then tell the RN or some staff go straight to the RN.  
--- asked if the staff pain management knowledge level has been surveyed? ---- responded this had not formally been established. | 1. Respect (for all staff working with RN)  
2. Teamwork  
3. Communication  
Chain of command  
Communication  
Access to Specialist input  
Assessments  
Evaluating needs  
Poor response to education | |
<table>
<thead>
<tr>
<th><strong>Practice Story</strong></th>
<th><strong>How Did The Participant Feel?</strong></th>
<th><strong>Issues / Themes</strong></th>
<th><strong>What Is This About?</strong></th>
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<tbody>
<tr>
<td><strong>Story 7 (Week 2)</strong> &lt;br&gt;----- spoke of some RN interpreting pain as a behavioural issue stating ‘they will blame the behaviour’.</td>
<td>----- used the example of a resident with dementia may ‘act out’ rather than complain of pain and that this can be misinterpreted as a behavioural issue by nurses who lack an understanding of how pain can be exhibited by these residents. ----- felt this was not due to a lack of education as the facility had focused on providing the education to staff in the last 12 months and had ‘even tried paying staff to attend sessions’ but stated “they won’t come”.</td>
<td></td>
<td><strong>1. Education</strong> &lt;br&gt;Specialist input &lt;br&gt;Staff perception between behaviours/pain</td>
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<tr>
<td><strong>Story 8 (Week 3)</strong> &lt;br&gt;A resident in pain, hearing ‘moaning’ and ----- told the group “you know when someone is in pain”…</td>
<td>Thinking “I should say something”. &lt;br&gt;Would think, “Why don’t they give something”?.</td>
<td>It was thought by some in the group that the resident’s medications could have been late. &lt;br&gt;The group agreed there could be problems behind that incident in addition to the medication being late.</td>
<td><strong>1. Pain</strong> &lt;br&gt;2. Time Management &lt;br&gt;Ability to speak Medications Always notifying someone when you have a concern</td>
</tr>
<tr>
<td>Practice Story</td>
<td>How Did The Participant Feel?</td>
<td>Issues / Themes</td>
<td>What Is This About?</td>
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<td>Story 9 (Week 3)</td>
<td>Explained as the carer “that’s all I can do” saying “I have made the first step”. One participant stated “we can keep harping”</td>
<td>------ felt this is a way s/he contributes to “making a change” for that resident. The group agreed it is a process of one person has “passed it on to the next level”, the next level often being the RN.</td>
<td>1. Pain Management</td>
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<td>------ reminded the group that the staff can speak to the Director or in charge RN.</td>
<td>2. Documentation</td>
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<td>------ suggested “documenting and re-documenting” the issue as a method of alerting other staff of the resident’s pain.</td>
<td>Assertion</td>
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<td>1. Feeling Guilt</td>
<td>Team</td>
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<td></td>
<td>2. Workloads</td>
<td>Communication</td>
</tr>
<tr>
<td>Story 10 (Week 3)</td>
<td>------ spoke of this practice not being encouraged saying it was “not allowed from training” and how this training “influences me” saying “I feel guilty”.</td>
<td>------ shared a method s/he used to prevent feeling guilty when giving a resident a “one to one” time she said “I’m better off taking the resident for a wheelchair walk”.</td>
<td>1. Feeling Guilt</td>
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<td>2. Workloads</td>
<td>2. Judging or stigma</td>
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<td>Justification of their priorities</td>
<td>Time Management</td>
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<td>One on one time with residents</td>
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<tr>
<td>Practice Story</td>
<td>How Did The Participant Feel?</td>
<td>Issues / Themes</td>
<td>What Is This About?</td>
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<tr>
<td>Story 11 (Week 3)</td>
<td>------ spoke of her/is affection for this resident and that s/he had “talked to her for a little bit” on the night she was dying. The resident had asked ------ to “be with her when she died”. ------ due to her fondness for the lady did not want to “be there at the end”. ------ spoke of being a “cot case for days” following the resident’s death due to this incident.</td>
<td>------ felt part of the problem with delivering adequate end of life care is “battling with doctors”. ------ reflected in this instance the nurses had “no issues” as compared to “like we have here p.r.n. orders”.</td>
<td>1. Palliative Medications</td>
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<td>2. Education</td>
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<tr>
<td>A lady s/he had become very fond of who was “close to 99 years old”, who “did not want to live to 100”. Describing her as “blind and bedridden”. ------ was on the night shift and the palliative medications had been “implemented”.</td>
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<td>Personal</td>
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<td></td>
<td></td>
<td>Frustration</td>
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<tr>
<td>Story 12 (Week 3)</td>
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<td>Sad to see a resident depart</td>
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<td>The group agreed if the “medication orders” are sorted end of life care is “controllable”.</td>
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<td>Story 13 (Week 3) Group decision to remove story as the circumstances and recount continued to be conflicting.</td>
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<tr>
<td>Story 14 (Week 3)</td>
<td>S/he remembered this death as “not a lot of pain”.</td>
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<td>------- described this death as “peacefully”. Why ------- remembered this as a good death was the granddaughter stayed with the resident saying staff “can’t stay</td>
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<td></td>
<td>1. Good death</td>
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<td>Love</td>
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<td>Family</td>
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<td>Humanity</td>
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<td>Laughter</td>
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<td></td>
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<td>Peaceful</td>
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</tbody>
</table>

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or talk” the same as “loved ones”.

----- remembered the grandson and granddaughter would sit and go through all the family photos. Stating the “staff would hear them laughing” and saying “remember this or that” s/he described them as “a lovely family”.

----remembered holding up a dress to the resident when s/he was trying to locate its owner when E replied “I wouldn’t be seen dead in that”, the group laughed.

### Practice Story

<table>
<thead>
<tr>
<th>Story 15 (Week 3)</th>
<th>How Did The Participant Feel?</th>
<th>Issues / Themes</th>
<th>What Is This About?</th>
</tr>
</thead>
</table>
| Another resident who had family (a daughter) with her/im at the end was remembered a participant commented J, “seemed at peace”. A participant commented on having your own relatives being present is important saying to “come this far in life” that the “only important thing left is relationships”. ----said a resident will lose their material possessions, their home and the only important thing left is their relationships commenting that there | The group spoke of it being “nice to see someone die with someone who cares beside them” and how important it is “not to die alone”. | 1.Good death  
2.Workloads  
3.Family supporting dying resident | Not Dying alone  
Comfort  
Lonliness |
is “nothing at the end of it” but those relationships. ------ recalled in Queensland that the facility used a system where they “rotate staff” so that there was “always someone with them” (dying resident)

<table>
<thead>
<tr>
<th>Practice Story</th>
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</thead>
</table>
| Story 16 (Week 3)  
------ recalled J’s death and described this resident as having had a “traumatic, hard life” and her/is “children being disgruntled”. ------ remembered this person having “beautiful friends with her, right to the end”. This resident had spoken to ------ about “issues with family and friends”. ------ expressed that “most parents give so much” and being with the parent at the end is the least children can do for the parent. | Saying, “we didn’t help them”. | 1. Alternative ways of supporting a dying resident  
Judging  
Unresolved issues  
Abandonment  
Personal choice  
Learn to forgive and move on | |
| Story 17 (Week 4)  
------- described these deaths as those people who s/he felt had “pain” | | 1. Pain Management  
2. Powerlessness  
Frustration  
Despair  
Hard to know what is right to do at the time | |
<table>
<thead>
<tr>
<th>Practice Story</th>
<th>How Did The Participant Feel?</th>
<th>Issues / Themes</th>
<th>What Is This About?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Story 18 (Week 4) ------ described it was her face in the corner crying with rocks around her</td>
<td>Depicting “me weighed down by rocks, the pressures around end of life”</td>
<td>1. Stress 2. Not Coping Powerlessness Carers energy consumed Draining to be a carer</td>
<td></td>
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</tbody>
</table>
Facility Two: Action Plan
Action Research / Reflection Group 12th March 2008

Ask: the group to think about what is useful and what is not useful about each theme.
Planning: The plan must be flexible to allow for unforeseen effects and constraints. The action prescribed by the plan must take account of the social risks involved and recognise the material and political constraints in the situation. The plan allows us to go beyond our present constraints to empower us to act more effectively in the situation. We plan by collaborating openly and honestly with one another and by analysing and improving our understanding of the situation.
Acting: This is where we make a critically informed, careful and thoughtful variation to practice, by putting our plan into action. As the action may be potentially risky, we need to be flexible and open to change in light of the real time situation. Acting may involve material, social and political struggle towards improvement and negotiation and compromise may be necessary. We may need to be content with modest gains that gradually get bigger based on previous gains (in other words, we may not always be able to ‘fix things’ the first time).

<table>
<thead>
<tr>
<th>Issue</th>
<th>Themes</th>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Management (Priority 1) (Story 1, 2, 5, 8, 9, 17)</td>
<td>Medications/ Palliative Medications (Story 8, 11, 12) Access to Specialist input/ Specialist management (Story 6, 7, 12) Assessments/charts (Story 4, 5, 9) Assessments (Story 5, 6) Evaluating needs (Story 6) Individual nursing medication practices (Story 2) Staff perception between behaviour /pain (Story 7) RN needing more education on pain management in end of life care (Story 5)</td>
<td>Staff Knowledge Survey Audit for specialist involvement/ to identify actual practices/ assessment chart completions/documentation Use Case scenarios as an education tool/ assessment of staff knowledge Determine availability of access to Palliative Care Team Trial bedside aids to knowledge e.g. Hand held computer/ booklets – need to know Dr will respond</td>
</tr>
<tr>
<td>Issue</td>
<td>Themes</td>
<td>Action Plan</td>
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<td>-------</td>
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<td>-------------</td>
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</tbody>
</table>
| **Education** *(Priority 1 & 2)*  
(Story 2, 5, 7, 11) | Documentation (Priority 2&4) (Story 5, 9)  
Fear (Priority 1x 1) (Story 2, 3)  
Planning for end of life care (Story 12)  
Self Doubt (Story 2)  
Hard to know what is right to do at the time (Story 17)  
Feeling Guilt (Story 2, 10)  
Regrets (Story 1)  
Superstition (Story 3)  
Poor response to education (Story 6)  
Room jinxed (Story 3)  
I am not responsible (Story 4) | Determine previous end of life learning,-staff knowledge survey, education program calendar  
Develop education plan to track number of end of life sessions provided to staff  
Explore End of Life Pathway  
Assessment reviews  
Explore alternative education modes e.g. packages / electronic / integrated into usual work / posters |
| **Good death** *(Priority 1)*  
(Story 14, 15) | Love (Story 14)  
Family (Story 14)  
Humanity (Story 14)  
Laughter (Story 14)  
Comfort (Story 15)  
Peaceful (Story 14)  
Not Dying alone (Story 15)  
Alternative ways of supporting a dying resident (Priority 1, Story 16)  
Abandonment (Story 16)  
Lonliness (Story 15)  
Personal choice (Story 16)  
Unresolved issues (Story 16)  
Despair (Story 17) | Structured Observational study of what is actually happening  
Explore silent visitor option  
Division of GP spiritual officer  
Discussion at MDT meeting |
<table>
<thead>
<tr>
<th>Issue</th>
<th>Themes</th>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Workloads (Priority 2)</strong> (Story 10, 15)</td>
<td>Time Management (Priority 1 x 2) (Story 8, 10) Stress (Priority 1) (Story 18) Not Coping (Story 18) One on one time with residents (Story 10)</td>
<td>Determine current staff ratios Model of Care Review – look at work practices / who delivers care</td>
</tr>
<tr>
<td><strong>Staff Needs</strong></td>
<td>Carers energy being consumed (Story 18) Draining to be a carer (Story 18) Sad to see a resident depart (Story 11)</td>
<td>Regular case debrief sessions Professional counselling opportunities</td>
</tr>
<tr>
<td><strong>Relatives Needs</strong></td>
<td>Relatives unhappiness (Story 1) Needs of family over the resident/ taken over by the family (Story 1) Energy to the family (Story 1) Daughter feeling guilty about mum/dad in care (Story 1) Relatives coping (Story 1) Family supporting dying resident (Story 15) Learning to forgive and move on (Story 16)</td>
<td>Newsletter article with a focus on ways to empower relatives e.g. action plan have you discussed end of life needs with Director of Care If you have a concern steps to take Counselling availability Explore relative support at end of life – what is offered now, is it working for relatives – exit interview?</td>
</tr>
<tr>
<td><strong>Communication (Story 1, 4, 6, 9)</strong></td>
<td>Respect (Priority 1 &amp; 3) (Story 5, 6) Frustration (Story 1, 5, 11, 17) Team / teamwork / communication x 4 (Story 5, 6, 9) Powerlessness (Story 17, 18) Judging or stigma (Story 10, 16) Doctors (Story 12) Between doctor and nurse (Story 4) Doctor having enough evidence (Story 4) Doctor not feeling it is necessary at the time (Story 4) Courage to speak (Story 4)</td>
<td>Raise findings from group at MDT meeting Logging number of requests for medication Audit number of assessment completions Documentation audit Tape conversations with Drs and use as an education tool</td>
</tr>
<tr>
<td>Ability to speak (Story 8)</td>
<td>Raise profile of respect for staff–</td>
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<tr>
<td>Assertion (Story 9)</td>
<td>Education sessions</td>
<td></td>
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<tr>
<td>Justification of their</td>
<td>Posters</td>
<td></td>
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<tr>
<td>priorities (Story 10)</td>
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<tr>
<td>Advocating (Story 4)</td>
<td>Demonstrate how the facility values</td>
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<td>Not following Orders (Story 5)</td>
<td>staff – special lunch, posters,</td>
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<tr>
<td>Chain of command (Story 6)</td>
<td>theme day e.g. massage</td>
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<td>Always notifying someone</td>
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<td>when you have a concern</td>
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<td>(Story 8)</td>
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<td>Keep pushing until resident is made calmer (Story 9)</td>
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<td>Care staff involvement (Story 9)</td>
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</tbody>
</table>
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