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Colleen M. Cartwright

Southern Cross University

Mark Hughes

Southern Cross University

Tania Lienert

Southern Cross University

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End-of-Life Care for Gay, Lesbian, Bisexual and Transgender People: An Exploratory Study

Prof Colleen Cartwright
Assoc Prof Mark Hughes
Dr Tania Lienert

Abstract

There is little understanding in Australia of the particular issues faced by gay, lesbian, bisexual and transgender (GLBT) people in end-of-life care and advance care planning. This exploratory qualitative study aimed to achieve an initial understanding of these issues to compare with the international literature and inform the development of a larger study involving GLBT consumers. Consultations were carried out with 19 service providers and 6 GLBT community members located in the Northern Rivers and metropolitan Sydney areas of New South Wales (NSW), Australia. Participants reported barriers to health care service access due to discrimination, inappropriate care, and lack of knowledge among both consumers and health care workers of legal rights at the end of life. While advance care planning can assist with improving end-of-life care, respondents reported a number of obstacles. These included a lack of knowledge and absence of perceived need, and the additional obstacle of social isolation, leading to difficulties identifying alternative decision-makers. The study highlighted the need for community education among GLBT people and health and aged care providers on the existing legal provisions available to prevent discrimination in end-of-life care.
Introduction

Research into GLBT end-of-life care is limited, with most studies originating in North America and focusing on younger gay men's experience of HIV/AIDS (Almack, Seymour and Bellamy 2010). However, like the population generally (Seale 2004), most GLBT people's experience of end-of-life care does not relate specifically to HIV/AIDS and occurs alongside their experience of growing older and accessing health and aged care services (Almack, Seymour and Bellamy 2010). Notably, GLBT people are more susceptible to certain life-threatening conditions whose prevalence increases with age. For example, as they grow older, lesbians are at greater risk than other women of breast and endometrial cancer (Cochran et al. 2001), gay and bisexual men are more at risk of Hodgkin's disease, anal cancer and non-Hodgkin's lymphoma (Smolinski and Colón 2006), and transgender people have a greater susceptibility to diabetes, cardiovascular disease and liver abnormalities (Williams and Freeman 2007).

This paper documents an exploratory study into GLBT people’s experiences with end-of-life care as reported by service providers and members of GLBT community organisations. While some of the experiences GLBT people face at end of life are similar to those experienced by non-GLBT people, others are different. In particular, this paper highlights the ongoing challenge GLBT people face in having their gender and sexual identities appropriately recognised, as well as the need for a better understanding of their rights towards the end of life. We locate this study initially within the wider literature on end-of-life care and advance care planning, and then explore the unique issues identified in relation to the GLBT population.
Review of the Literature

End-of-life care and advance care planning

Detering et al. (2010, 1) note that “[s]ince the 1990s there has been an increasing awareness of the inadequacy of end of life care”. In part this increased awareness may be attributed to both the ageing of the population, which, in turn, means an increasing number of people dying with dementia, and concerns about the cost of end-of-life care. However, it may also be part of a generational effect, as the Baby Boomers demand better care for their parents and, in increasing numbers, for themselves. Carers of people who have died are demanding more appropriate end-of-life care, with less use of invasive technologies that merely prolong the dying process, without offering any real benefit to the patient (Cartwright 2004). Access to expert end-of-life palliative care provides some patients with a good quality death but not all patients have such access. When patients lose the capacity to make their own decisions, they risk being cared for in a way they would not have chosen (Detering et al. 2010). Advance care planning can assist patients to plan for the treatment they will or will not receive during the dying process, and to appoint a substitute decision-maker to ensure that their wishes are respected (Cartwright and Parker 2004; Detering et al. 2010).

Every competent adult in Australia has the legal right under common law to accept or refuse any health care or treatment (Cartwright 2011). In addition, in common with the UK (British Medical Association 2009) and the US (Gillick 2004), all states/territories of Australia have legislative provision for appointing a substitute decision-maker, writing an advance health care directive, or both (Cartwright 2011). However, the first common law case in Australia, which clarified the legally-binding nature of the written advance health care directive, occurred in the NSW Supreme Court as recently as 2009 (Hunter and New England Area 3...
Notably, knowledge of the law among doctors, nurses and community members is minimal (Cartwright et al. 2009; Cartwright et al. 2006). A range of barriers to effective decision-making on end-of-life care have been identified in international and Australian research. In addition to a lack of knowledge of the legal provisions available, as noted above, another major barrier is the lack of time health care practitioners have to facilitate such discussions with patients (Bloomer, Tan and Lee 2010; Seymour, Almack and Kennedy 2010). Effective communication on this issue may be blocked through a lack of rapport between practitioners and patients, as well as an assumption that people do not want to talk about such matters (Bloomer, Tan and Lee 2010). The unique and complex trajectory of specific diseases and conditions, such as chronic obstructive pulmonary disease, can also impede effective advance care planning (Heffner 2011). Similarly, psychological adjustment to declining health impacts on people's readiness to participate in decisions regarding the end of one's life (Fried et al. 2009). Clearly, the onset of dementia - which limits the period of legal competence to make decisions regarding advance care planning - is a major barrier (Stewart et al. 2011). Overall, though, one of the most common themes from prior research on barriers to advance care planning is individuals' perceived lack of need for such plans (Schickedanz et al. 2009).

**GLBT people's experiences with end-of-life care and advance care planning**

Many of the experiences of GLBT people in receiving end-of-life care are invariably similar to those of non-GLBT people (Smolinski and Colón 2006). Nonetheless, some particular challenges facing GLBT people in accessing end-of-life care have been identified in prior literature, although it is recognised that international research on this topic is in its infancy (Almack, Seymour and Bellamy 2010; Smolinski and Colón 2006), and there have been no
prior studies on GLBT end-of-life care, outside of those related to HIV/AIDS, conducted in Australia.

Key barriers faced by GLBT people in receiving end-of-life care and making end-of-life decisions include discrimination and heteronormativity, particularly in the assumption that all people are heterosexual and the failure to provide GLBT-friendly environments for care delivery. It is well documented that GLBT people are less likely than others to seek routine health care because of discomfort in disclosing sexual or gender identity to providers (Auger 2003; Smolinski and Colón 2006). Actual experience of discrimination and abuse, as well as fears of such treatment (e.g. because of past negative experiences), are major barriers for people maintaining contact with health care providers and seeking assistance in a timely manner (Blevins and Werth 2006; Hughes 2007).

The experience of bereavement may also be different for members of the GLBT community compared to the general population. The legacy of more than two decades of AIDS-related losses - despite treatment advances increasing survival times - has resulted in direct, indirect, historical and cumulative effects on GLBT people (Blevins and Werth 2006). Surviving partners of those who have died from AIDS-related illnesses may face particular challenges, including survivor guilt and negative impacts on self-esteem and identity. HIV positive gay men who are growing older may also suffer from interrupted careers, rely heavily on benefits, and have reduced social networks (Owen and Catalan 2012).

Disenfranchised grief - where the grief of a bereaved person is not acknowledged or perceived as legitimate (Doka 1989) - may be greater among the GLBT community when same-sex partners are not recognised by service providers and family members, and when
GLBT friends - sometimes including former partners - are not appreciated as significant members of a 'family of choice' (Almack, Seymour and Bellamy 2010; Smolinski and Colón 2006). This is a particular concern when one or more individuals are 'in the closet' and thus may not be visible to family, friends and service providers. All of the above problems can lead to isolation, late presentation for treatment which results in the need for crisis management, and complicate the experience of end-of-life care (Auger 2003).

Where GLBT people do not have an advance health care directive in place and where they have diminished legal competence, a major concern is that biological family members may take over decision-making at the end of life (Auger 2003). At such times, health professionals may not understand or support the role of same-sex partners and friends in end-of-life decision making (Hash 2006), especially where there is no legal recognition of same-sex marriage (Lannutti 2011). Additionally, as discussed, when relationships are not recognised, bereaved partners and friends miss out on the social support necessary for coping with grief (Blevins and Werth 2006).

Having a legally-recognised advance care plan in place can no doubt protect the rights of many GLBT people and their partners at the end of life. However, there remain key barriers to this. In a survey of 575 gay and lesbian people in the US, Stein and Bonuck (2001) found that, despite high levels of knowledge about health care proxies (72%) and advance health care directives (90%), only about half of the participants had actually completed these documents. Reasons given included: not necessary now (28%); not knowing who to appoint (25%); hard to think about (20%); don't know where/how to do it (18%); and haven't found the time (18%). These reasons are comparable to other studies in the general population (Cartwright et al. 1998; Fagerlin and Schneider 2004; Steinberg et al. 1997). However, for
GLBT people other factors may also come into play. Auger (2003) reported that closeted and rural gay and lesbian couples in her Canadian study deliberately did not engage in advance care planning in order to maintain privacy.

Advance care planning can protect some rights at the end of life but, like the rest of the population, GLBT people need to use the legal mechanisms available and service providers need to promote their use (Auger 2003; Hash and Netting 2007; Stein and Bonuck 2001).

While GLBT people experience some end of life issues in similar ways to the general population, it is likely that they also experience some particular challenges in relation to end-of-life care and decision making. However, our knowledge of how GLBT people experience end-of-life care, especially in Australia, remains limited and requires further investigation. The study reported on in this paper was a precursor to a larger quantitative study into GLBT people’s understanding of their legal rights at the end of life.

Methods

This exploratory qualitative study, involving consultations with service providers and members of GLBT community organisations, aimed to identify the relevant issues for GLBT Australians in relation to end-of-life care and advance care planning. The study also sought to identify issues that require further exploration in a larger study on this topic involving GLBT people. Specifically, the research questions were:

- What have been your experiences providing end-of-life care for GLBT people?
- From your perspective, what understanding did these people have of their rights at the end of life?
A semi-structured questionnaire was developed to guide the service provider consultations. The study was formally approved by the Human Research Ethics Committee of the authors’ University and by the Research Ethics Review Committee of ACON, the collaborating GLBT health promotion organisation. The consultations were advertised widely in the GLBT and mainstream media, via a range of health and community service email lists and newsletters and by word of mouth.

A service provider consultation forum was held in a large regional city in northern NSW, and telephone consultations took place with metropolitan service providers. The consultation forum enabled people who have provided care to GLBT people to come together to share experiences and reflect on the issues facing GLBT people in receiving end-of-life care. The format for the consultation forum included a review of the information sheet for the research and consent and confidentiality forms, and gathering of signed forms; a brief survey of participant knowledge about the topic (adapted from Cartwright et al. 2006); a presentation about Advance Care Planning and other end-of-life issues; a scan of participant experiences in GLBT end-of-life care using a list of questions; and invitations to tell particular stories. The telephone consultations also included the survey of participant knowledge, a presentation on Advance Care Planning and discussion of experiences in GLBT end-of-life care. All participants received fact sheets and templates for completing Advance Care Directives, including information on appointing proxy decision makers.

A total of 25 people participated in this research: 19 service providers and six members of GLBT community organisations. Seventeen women and eight men were involved. There were no transgender participants, although two of the service providers spoke about their
work with transgender clients. No further demographic details were collected from the respondents.

Of the 19 service providers, 12 who were regionally based attended the service provider forum. Notification of the forum occurred via newspaper advertisements, flyers and mailing lists of end-of-life care providers. Participants represented almost all the service providers in the area who had contact with GLBT people in relation to end-of-life care, as well as others with a general interest in this issue. Seven metropolitan-based service providers also gave their views via the telephone. Service providers worked across a range of fields including nursing, home and community care, residential aged care, palliative care, allied health, social work, voluntary community care and the funeral industry. Three had experiences of multiple episodes of end-of-life care dating back to the early days of the HIV epidemic. It was originally hoped that a public consultation meeting, similar to the service provider consultation, could be held, however this did not attract participants. Instead six individual interviews with GLBT community members were conducted. While not direct service providers, these people were linked to GLBT community organisations. The results of these interviews have been incorporated into the findings.

Data were collected from the service provider consultation forum, individual interviews with metropolitan providers and the GLBT community member interviews by audio recording and taking field notes. Transcripts were provided back to participants for verification and additional comments. A thematic analysis of the data from the transcripts and field notes was conducted (Grbich 2007). This involved, following the grounded theory tradition, open coding where broad themes and categories were generated from the data, as well as axial coding by which the major themes were identified (Ezzy 2002).
Results

A range of themes emerged from the analysis of the transcripts of the service provider consultation forum interviews, and the interviews with community members. These related to: a lack of recognition faced by GLBT people in receiving care and support towards the end of life; the participants' lack of understanding of legal provisions around end-of-life care; the barriers to GLBT being involved in advance care planning; and the value of GLBT people communicating their wishes to key people. While the first of these themes clearly reflects the particular experiences of GLBT people, the other themes may be reflective of the concerns relating to the wider population. Nonetheless, the qualitative data illustrate the ways in which these issues were uniquely experienced by GLBT people, as reported on in the consultation forum and by GLBT community members.

Lack of recognition of sexual or gender identity

A major theme from the service provider consultations was the lack of legitimacy of same-sex relationships and sexual and gender identity accorded by family, health professionals, and society. For gay and lesbian patients, failure by family members and health professionals to acknowledge the appropriate decision-maker at the end of life caused additional grief, loss of dignity and loss of property upon the death of same-sex partners. One service provider reported that:

One guy who was diagnosed went downhill very quickly. His parents came the day before he died. They wanted to take his body back to the country town where they were from. They didn’t want his partner or friends involved. We had a ‘deviants’
funeral separate to the family funeral – that was the compromise. The kid thought mum and dad would be okay but they weren’t. Absolutely everything was taken from the partner.

For transgender people, the lack of recognition of their chosen gender identity, or the humiliation of having to explain that they are transgender, were salient issues. One service provider told of a transgender woman who had lived all her life as a woman, but had never had sex reassignment surgery. She now had dementia and lived in an aged care facility run by a religious charity. Staff there forced her to live as a man. Other transgender people who have not had sex reassignment surgery, or who are left with incontinence after the surgery, have to explain their situation to care providers in order to get appropriate products. One service provider reflected on the very high levels of education, advocacy and training, and personal support, needed to ensure transgender clients received appropriate services, even from trans-friendly agencies.

Discrimination or anticipated discrimination was also reported as preventing access to health care. Service providers observed that, in a small town, clients who could access services locally chose not to in order to protect their privacy and identity. Some travelled to other areas but others just missed out. Further, community participants spoke about how some GLBT people chose to live on the margins of society, for example in self-sufficient rural communities, to avoid the confrontation of discrimination in the mainstream heterosexual and heterosexist world. Participants believed both decisions resulted in failures to access advance care planning and quality end-of-life care when it was needed.

*Lack of knowledge of legal rights relating to end-of-life care*
Medical and dental practitioners have a legal and professional responsibility to obtain consent before treating a patient. In Australia, if the patient is unable to consent, the practitioner should seek consent from the person legally authorised under the specific state/territory legislation to give that consent (e.g. in NSW, the designated person is called 'Person Responsible'). This is not necessarily the patient’s next-of-kin, and the order of authority differs from state to state. In NSW, the order is: a guardian appointed by the Guardianship Tribunal; an Enduring Guardian appointed by the person themselves; a spouse or partner, including a same-sex or de facto partner with whom the patient has a close and continuing relationship; an unpaid carer; or a relative or friend who has a close personal relationship with the patient.

At the service provider consultation, several participants did not know about the rights of same-sex partners to claim status as Person Responsible, and therefore to make health care decisions should their partner lack capacity. Service providers also identified that levels of awareness and use of the legal mechanisms that assist in advance care planning varied considerably among their clients. When service providers encouraged the use of legal mechanisms, they reported that awareness and use improved.

**Barriers to advance care planning**

Participants identified some likely barriers to advance care planning by GLBT people. Most commented that lack of knowledge about advance care planning prevented GLBT people for accessing this resource. Several participants identified key barriers as not having enough time to do the paperwork or people feeling that they did not need to do it now as they were currently in good health. A commonly reported barrier was not wanting to think about or plan
for the end of life. For some, this resulted from a fear or denial of death arising as a legacy of
the HIV epidemic. One GLBT community member said:

   Back in the height of the epidemic, not a day went by when someone didn’t die or you
   heard of someone close to death.

For others, this was reinforced by the perceived emphasis placed on youth and beauty in the
gay male community. One GLBT community member commented:

   This denial of death marries into what I call “the Peter Pan syndrome” among gay
   men. We might age, and we don’t want to think about this, instead of being practical
   and planning for it. People are scared of death: ‘it’s not going to happen to me’.

Some participants believed older GLBT people, particularly older gay men, can become
socially isolated and alienated from the GLBT community. Participants reported knowing of
some older gay men who lacked strong connections and relationships to the extent that they
did not know who to appoint to crucial decision-making roles. This was also a critical issue
for some participants reflecting on the nature of their own relationships and networks.
According to one GLBT community member:

   I can’t think of who to appoint or what my advance health care directive decisions
   might be. I don’t know how to figure this out. It is very personally confronting. Is it a
   new partner, or an old friend or family member? How do I tell the new partner if it’s
   not him? What impact will this have on our relationship?
HIV service providers also commented on the social isolation they had observed among some HIV-positive gay men in the study area. Some clients, they noted, had no-one to look after them when they were ill or facing discharge from hospital.

**Communication and advocacy can improve end-of-life care**

Participants stressed the importance of GLBT people communicating their end-of-life care wishes to partners, family and health professionals before they become incapacitated. If they did not, they risked their wishes and those of their close friends and partners being overridden by biological family members and health care workers. Further, they described the important role of advocates in ensuring that the wishes of the dying person were met. An advocate could be a family member who is close to the dying person and also to the rest of the family, a friend, a service provider or a volunteer carer. These people can be “buffers” between the dying person, their close friends and partners, and other people who may have an interest in the dying person. Service providers noted the importance of health professionals acting cooperatively as advocates for and supporters of GLBT people who may be isolated and die alone.

When same-sex and other important relationships are communicated to and recognised by families and health professionals, and when advance care planning is well organised and communicated to significant people, it is possible for GLBT people to experience appropriate end-of-life care and to die with dignity. For one service provider:

> If you have the paperwork done, it alleviates the chaos, and makes the roles really clear … the partner could just get on with giving care. Then everything around the death went smoothly as there were defined roles and responsibilities.
Discussion

This exploratory qualitative study highlighted issues of concern regarding end-of-life care for GLBT people. It is important to acknowledge that this was a small-scale study and that the results are not generalisable to the wider population of GLBT service providers. As noted below, though, the findings generally accord with those from the emerging international literature on end-of-life care and advance care planning in the GLBT community. Crucially, the findings of this project have directly informed the development of a larger national study, involving GLBT consumers.

As is increasingly reported in the literature on GLBT ageing (Harrison 2006), participants emphasised the failure of health and aged care providers to properly acknowledge the diverse sexual and gender identities of GLBT people. This may result in discrimination and/or inappropriate care and, significantly, impact on people's preparedness to access services in the future. And as in previous research involving GLBT people in regional and rural settings (Auger 2003; Hughes 2007), in this study it was reported that some GLBT people living in small communities choose not to access available services because of a desire to preserve privacy and/or a preference to be cared for by friends and community members, rather than local health professionals. For GLBT people, who are at heightened risk of some life-threatening illnesses, failure to access services in a timely manner can exacerbate health conditions and contribute to problems experienced in end-of-life care.

In line with international literature (Cartwright et al. 1998; Stein and Bonuck 2001; Steinberg et al. 1997), barriers to advance care planning identified by participants in this study
included: not having enough time; not feeling the need to do it now; lack of knowledge of advance care planning procedures; and not wanting to plan for death. The latter issue was reported in this project to be particularly significant for some gay men where the community and commercial focus on youthfulness may stigmatise ageing and preparation for death.

Social isolation, especially among older gay men, was also identified to be a concern. It was reported that this meant that some did not have appropriate people to appoint as substitute decision makers. The extent of older gay men's social connections has been widely debated in the GLBT ageing literature (Hughes 2009; Shippy et al. 2004), and there remains mixed findings from research as to the extent to which older gay men may be isolated. Previous researchers have identified that even though they may be more likely to live alone than heterosexual men and lesbians, some older gay men are intimately involved in self-made communities and support networks (Heaphy 2007). Arguably, for an increasing number of gay men, 'personal communities' are taking on more significance than the wider 'gay community' (Holt 2011). Nonetheless concerns about becoming isolated in later life continue to be expressed by gay men, even if these views may be coloured by stereotypical images of gay seniors (Hughes 2010). Clearly, as Almack, Seymour and Bellamy (2010) acknowledge, there is a need for further research into isolation, sexual identity and end-of-life care.

The findings of this study, like those in international research (Auger 2003; Hash and Netting 2007; Smolinski and Colón 2006; Stein and Bonuck 2001), highlight the need for GLBT people to engage in advance care planning because of the discrimination they may face in health care settings and the lack of understanding of the complexity and significance of GLBT people's 'families of choice'. When advance care planning takes place, it can mitigate discrimination. The service providers involved in the study evidenced the lack of
understanding Australian health professionals have of the laws pertaining to substitute decision-making, including the legal rights of same-sex couples. This means that GLBT people who do not know their rights in end-of-life care may be denied them. While changes in laws, community attitudes and service provider knowledge are long-term goals, the legal mechanisms to assist people with end-of-life care planning in Australia are available now.

The need for education on advance care planning with the GLBT community and relevant health and aged care service providers is clear. Relevant federal and state government departments, private hospitals and health care agencies need to provide education to health professionals about the current Australian laws on substitute decision-making. Information is particularly needed on the rights of same-sex partners to claim status as Person Responsible. Crucially, GLBT people need to be encouraged to engage in advance care planning, informed about their rights in end-of-life care and empowered to access resources available.

It is acknowledged that there were some key limitations to this research in that it was small-scale and drew upon different groups of people reporting on GLBT people’s experiences: service providers in both regional and metropolitan areas and members of GLBT community organisations. There were also two different methods of collecting the data: the consultation forum and individual interviews. Nonetheless, the research does provide an initial exploration of some of the critical issues impacting on GLBT people in receiving end-of-life care and, in particular, in relation to Advance Care Planning. The research also provided a basis for the development of a larger survey of GLBT people’s direct experiences with end-of-life care.

**Conclusion**
At the end of their lives, GLBT Australians face the possibility of discrimination and inappropriate care. Advance care planning can help mitigate discrimination, particularly in ensuring that same-sex partners and other members of 'families of choice' are involved in end-of-life care and decision making. As in the wider population, however, significant barriers to advance care planning exist. How GLBT people experience these barriers may reflect their unique experiences and community history, as well as the additional pressure of dealing with services that fail to properly acknowledge gender and sexual diversity.
References


