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Perceptions of female patients, caregivers and nurses of pain and pain management in adult patients with rheumatoid arthritis, Ratchaburi Province, Thailand

Benjawan Sriyotin
Southern Cross University

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PERCEPTIONS OF FEMALE PATIENTS, CAREGIVERS, AND NURSES OF PAIN AND PAIN MANAGEMENT IN ADULT PATIENTS WITH RHEUMATOID ARTHRITIS, RATCHABURI PROVINCE, THAILAND

Benjawan Sriyotin
RN, BNS., B.P.H. (Public Health Administration), M.N.S. (Nursing Education)

Southern Cross University
Lismore, New South Wales 2480

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

August 2005
STATEMENT OF SOURCES

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

Signed ........................................ Date..............................................
Dedication

This study is dedicated to…

patients who suffer from rheumatoid arthritis, and

for caregivers, nurses, and health care staff

who do the best for these patients.
ACKNOWLEDGEMENTS

I am very grateful to acknowledge many important people for everything they have done for me since I first started my project until now, and also in the future to come.

The greatest acknowledgement is to my supervisor, Prof. Bev Taylor, who always gives me the best she has; her love, support, encouragement, sacrifice, knowledge, and so on. Thank you very much for being my supervisor, mother, and best friend. I wish that our friendship will be stronger, and keep continuing forever.

Thank you very much to Thai Government, Ministry of Public Health, Praboromarajchanok Institute Health Workforce Development, and Boromarajonani College of Nursing, Ratchaburi for offering me a scholarship, and the chance to study in Australia.

Thank you very much to the Office of the Civil Service Commission, Office of Educational Affairs in Canberra, Australia, School of Nursing and Health Care Practice, and International Office, Southern Cross University, for the best assistance they all gave to me while I was studying in Australia. A respectful acknowledgement is for my participants, who fulfilled the objectives of my study, and who have created wonderful knowledge for caring for patients with rheumatoid arthritis.

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ABSTRACT

The care of patients with pain associated with rheumatoid arthritis is challenging and requires a systemic approach to assessment and treatment. This study aimed to explore with female patients, caregivers, and nurses, their perceptions of pain and pain management in adult patients with rheumatoid arthritis in Ratchaburi Province, Thailand. The study involved 10 female patients, 12 caregivers, and 10 nurses. Grounded theory was used as the methodology. Each participant was interviewed for at least one hour for biographical data, and experiences of pain and pain management of rheumatoid arthritis. Interviewing was audiotaped for verbatim transcription. A manual method of thematic analysis was used to find codes and categories, and to generate a grounded theory. The results showed that patients, caregivers, and nurses perceived pain and the effects of the pain of rheumatoid arthritis in terms of degeneration, and the need for intimacy and vigilance respectively. Patients expressed their negativity to pain as dejection, and they acknowledged their solicitude and receptivity towards care. Caregivers and nurses felt close understanding and connectedness respectively. Patients emphasised attribution, and nurses focused on the difficulties associated with chronicity. Pain management was in terms of physical, mental, and spiritual dimensions for all participants.
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Chapter One: Introduction

Introduction

This chapter describes the background of the study, including the significance, aim, objectives, and research questions, involved in the perception and pain management of female patients with rheumatoid arthritis, their caregivers, and attending nurses.

Background

Rheumatoid arthritis is a chronic and systematic illness, which is always classified as a type of arthritis. Since 2002, the World Health Organization (2005) claims that the burden of rheumatoid arthritis in disability-adjusted life years (DALYs) has increased. In the period between 1999 and 2002, there were increases in the population world wide of rheumatoid arthritis, with the majority being women.

In Thailand, statistics are not available for the specific disease of rheumatoid arthritis, however, the report of the number and rates of out-patients for whole country according to 21 groups of causes from Health Service Units, Ministry of Public Health per 1,000 population by region, showed that in 2003 there were 9,861,112 patients with the diseases of musculoskeletal system and connective tissue, which was 176 per 1,000 of the population. Statistics showed there were 2,222,128 patients in the central region excluding Bangkok Metropolitan, and 154,866 in-patients across the country, with diseases of the musculoskeletal system (Health Information Unit, Bureau of Health Policy and Strategy, 2003). According to the statistics of Ratchaburi Hospital, which is the regional hospital in the western region, there were between 28 and 47 in-patients with rheumatoid arthritis, who were admitted to the hospital in each year from 2001 until 2004. Of these numbers, almost all of them were women (Medical Records Department, Ratchaburi Hospital, 2004).
From the above statistics, it can be concluded that rheumatoid arthritis affects more women than men, usually in the 30s and 40s age group (Arthritis Foundation, 2003). The aetiology is still unclear, but many studies suggest that rheumatoid arthritis is a combination of environmental and genetic factors (Ignatavicius et al., 1999). Patients with rheumatoid arthritis have various symptoms, including inflammation in multiple joints, which begins in the small joints, and spreads to the larger joints as rheumatoid arthritis progresses. Joint pain, swelling, warmth, erythema, and lack of function are the main symptoms (Bautch, 2004). Boutaugh and Brady (1996) found that these symptoms affect patients’ well-being in three dimensions; physical, psychosocial, and economic.

Pain is ‘an unpleasant sensory and emotional experience associated with damage’ (The International Association for The Study of Pain, 1979 cited in Portenoy and Kanner, 1996, p. 3). Pain is a personal experience which is influenced by many factors, and the mechanisms of perception of pain are complicated (Carr and Mann, 2000; Caudill, 1995; Mitchell and Tietzl, 1999; Payne and Horn, 1997). Pain is also a major problem which threatens the patients’ physical well-being (Boutaugh and Brady, 1996). Pain is one of the most common reasons for seeking medical care (Henkelman, 1994). Medical care is focused primarily to treat the disease. It is not enough to manage pain, because psychological factors are also important, and nurses have a responsible role in dealing with illness experiences of patients and symptom relief (Ferrell, 1999). Similarly, there are some studies about perceptions in rheumatoid arthritic pain, effective ways to relieve this pain, and organisations which investigate rheumatoid arthritis (Lambert, 1991). Therefore, knowledge of rheumatoid arthritis is inadequate, and it is difficult to manage the pain of rheumatoid arthritis. The care of patients with pain associated with rheumatoid arthritis is challenging, and requires a systemic approach to assessment and treatment. It is necessary to understand pain, especially the perceptions of patients, caregivers, and nurses. Therefore, this research is timely and important.
Significance

The significance of the research lies in its potential to explore the meaning of the pain and pain management in rheumatoid arthritis, and to improve the care of people who are in the hospital or the community, to enable a good quality of life.

Aims

This interpretive research aimed to explore with female patients, caregivers, and nurses their perceptions of pain and pain management in adult patients with rheumatoid arthritis in Ratchaburi Province, Thailand.

Objectives

The objectives of this project in relation to the pain of rheumatoid arthritis were to:

1) explore with female patients, caregivers, and nurses their perceptions of pain and pain management in adult patients with rheumatoid arthritis;
2) make recommendations for health education for nurses working with adult patients;
3) influence the effective care by nurses, and other members of the health care team of adult patients with rheumatoid arthritis;
4) guide effective self care for patients with rheumatoid arthritis and effective support by caregivers; and to
5) raise the awareness of health care team to the experiences of adult patients with rheumatoid arthritis.

Research questions

The research questions related to the management of pain in rheumatoid arthritis. They were:

- How do the patients with rheumatoid arthritis perceive their pain and pain management?
- How do the caregivers and nurses perceive pain and pain management?
- In what ways can the patients’ and caregivers’ perceptions influence nurses to care more effectively?
- In what ways can the patients’ and caregivers’ perceptions influence caregivers to support more effectively?
- In what ways can the patients’ and caregivers’ perceptions influence other members of the health care team to care more effectively?
- In what ways can the health care team raise their awareness of pain management?

**Methodology**

This research relied on the accounts of the meaning of pain and pain management of adult patients with rheumatoid arthritis, nurses and caregivers of people with rheumatoid arthritis. The methodology of choice was grounded theory, because it had the potential to discover the problems that existed in participants’ everyday lives, and to describe how they were managed.

**Methods and processes**

The research involved interviewing 10 female adult patients, 12 caregivers, and 10 nurses in Ratchaburi province, Thailand at a venue convenient to the participants. Each participant was interviewed initially for approximately one hour. The interviews were audiotaped for later verbatim transcription, and a grounded theory analysis of the interviews as text was undertaken.

Participants were invited through purposive sampling selection to share their experiences of pain and pain management of rheumatoid arthritis from their respective viewpoints as patients, caregivers and nurses. The participants were invited to share their experiences purposively, because they had lived the experience, and were able to give first-hand accounts.
Summary

This chapter focused on the introduction of the research, including a description of some literature, and the project’s significance, aims, objectives, research questions, methodology, and methods and processes.

Chapter Two focuses on the literature, and research relating to rheumatoid arthritis, including the main areas of definition, incidence, causes, symptoms, diagnosis, treatment, and related studies about rheumatoid arthritis.

Chapter Three focuses on the development and methodology of grounded theory, and its application to nursing research.

Chapter Four emphasises grounded methods and processes, applied to the study from pre-data collection phase to the analysis and interpretation phase.

Chapter Five, Six, and Seven emphasise patients’, caregivers’, and nurses’ backgrounds respectively, and their experiences in pain and pain management. Three chapters are presented in the form of the emerging codes.

Chapter Eight focuses on the middle range theory, which resulted from the coding and categories. It describes the core social processes, and combines the experiences of patients.

Chapter Nine focuses on the middle range theory, which resulted from the coding and categories. It describes the core social processes, and combines the experiences of caregivers.

Chapter Ten focuses on the middle range theory, which resulted from the coding and categories. It describes the core social processes, and combines the experiences of nurses.
Chapter Eleven concludes the thesis by focusing on the discussion of the project, and its grounded theory, and the implications for the nursing profession.
Chapter Two: Literature Review

Introduction

This study aimed to explore with female patients, caregivers, and nurses, their perceptions of pain and pain management in adult patients with rheumatoid arthritis in Thailand. Therefore, this chapter describes the definition, incidence, causes, symptoms, diagnosis, treatment, nursing care, and research relating to rheumatoid arthritis.

Rheumatoid arthritis

Definition

Rheumatoid arthritis is one of the major types of arthritis (Krug, 1997), because *rheum* means ‘the stiffness, body aching, and fatigue’ (Lorig and Fries, 2000, p.7), *arth* means ‘joint’, and *itis* means ‘inflammation’ (Arthritis Foundation Australia, 2003). There are many definitions for this disease. For example, Krug (1997, p.73) explained that ‘rheumatoid arthritis is a chronic systemic inflammatory disorder resulting in destruction and proliferation of synovial membranes.’ Liang and Logigian (1992, p.1) stated that ‘rheumatoid arthritis is a chronic systemic inflammatory illness that is polyarthritic.’ LeMone and Burke (2004, p.1248) also claimed that ‘rheumatoid arthritis is a chronic systemic autoimmune disease that causes inflammation of connective tissue, primarily in the joints.’ MacDonald (2002, p.353) explained that ‘rheumatoid arthritis is a chronic, systemic autoimmune disorder whose major distinctive feature is chronic, symmetrical, and erosive inflammation of the synovial tissue of joints.’ Roberts (2005, p.1724) explained that ‘rheumatoid arthritis is a chronic, systemic disease characterised by inflammation of connective tissue in the diarthrodial (synovial) joints.’ The World Health Organization (WHO) (2005, f.1) definition is that ‘rheumatoid arthritis is a chronic systematic disease that affects the joints, connective tissues, muscle, tendons, and fibrous tissue.’
From these definitions, it can be concluded that rheumatoid arthritis is a chronic, systematic illness, which firstly causes joint inflammation, and sometimes affects other organs of the body. It causes pain and suffering, because of joint damage, and it also affects peoples’ activities of daily living.

**Incidence**

Although rheumatoid arthritis exists in all races, and in all parts of the world, there are variations in incidences of rheumatoid arthritis. The Arthritis Research Campaign, (ARC) (2003) reported that more than 350,000 people in Britain had RA, and it affected people of all ages. The third and fifth decades are most common ages for this disease, and women are more affected than men. Meanwhile, the Arthritis Foundation (2003) found that there is almost one percent of the population, or 2.1 million American people who have rheumatoid arthritis. Rheumatoid arthritis normally begins in the 30s and 40s age group, and it affects women three times more than men. The World Health Organization (WHO) (2005), and LeMone and Burke (2004) claimed that rheumatoid arthritis affects adults who are between the age of 20 and 40. The WHO (2005) showed that the incidence worldwide is between 0.3 and one percent, found more commonly in women, and mostly in developed countries. The WHO also reported that there are at least 50 percent of patients in developed countries who could not cope with full time employment 10 years after onset. In contradiction to the WHO, LeMone and Burke (2004) indicated that rheumatoid arthritis affects between one and three percent of the world population.

In Thailand, statistics are not available for the specific disease of rheumatoid arthritis, however, the report of number and rates of out-patients for the whole country according to 21 groups of disease causes from the Health Service Units, Ministry of Public Health per 1,000 population by region for 2003, showed that there were 9,861,112 patients with musculoskeletal system and connective tissue disease, which was 176 people per 1,000 of the population. Meanwhile, there were 154,866 in-patients with diseases of the musculoskeletal system, and 10,351 cases for in-patients with disorders of systemic connective tissues. According to the statistics of Ratchaburi province in the work year of
2004, there were 135,349 out-patients with diseases of musculoskeletal system and connective tissue, which were 16,222 per 100,000 of the population (Ratchaburi Provincial Public Health Office, 2004, f.1).

**Causes**

The exact cause of rheumatoid arthritis is still unknown, but it is suspected that immune system dysfunction is an important factor, related to the inflammation and damage of rheumatoid arthritis. Normally, the body’s immune system fights against bacteria, viruses, and other foreign cells. In rheumatoid arthritis, the immune system produces antibodies which are called rheumatoid factors (RFs) that attack host tissues. The Arthritis Foundation (2003) indicated that the process of inflammation in rheumatoid arthritis begins when white blood cells shift from the bloodstream to the joint tissues. The inflamed cells are contained by this fluid, and are built up in the joint. The white cells and fluid also create many substances, including enzymes, antibodies, and cytokines, which cause joint damage. In this process, there are three processes which damage the joints (LeMone and Burke, 2004, p.1249). Firstly, ‘neutrophils, T cells, and other synovial fluid cells are activated, and degrade the surface layer of the articular cartilage’. Secondly, the process involves ‘cytokines, especially interleukin-1, and tumour necrosis factor alpha, which cause the chondrocytes to attack the cartilage’. Finally, ‘the synovium digests nearby cartilage, releasing inflammatory molecules containing interleukin-1, and tumour necrosis factor alpha’. If these processes continue for years, the cartilage, joints, and other parts of the bone will be destroyed (Lorig and Fries, 2000).

The second factor causing rheumatoid arthritis is genetics. Roberts (2005, p.1725) claimed that ‘genetic predisposition appears to be important in the development of rheumatoid arthritis’. There is a belief that ‘these genes, especially HLA-DR4, create a susceptibility or tendency for an increased risk to develop rheumatoid arthritis’ (Arthritis Foundation, 2003, f.1).
Other possible factors causing rheumatoid arthritis are gender and infection. Researchers claim that women will get rheumatoid arthritis two to three times more often than men, and it will more often affect pregnant women. The theory relating to infection as a cause of rheumatoid arthritis is that infection is caused by microbes to which everyone is exposed, but to which people with RA are susceptible (Arthritis Foundation, 2003).

**Symptoms**

The symptoms of rheumatoid arthritis vary from person to person. Patients normally have inflammation in multiple joints which begin in the small joints such as hands, wrists, and feet. As rheumatoid arthritis progresses, inflammation spreads to the larger joints, including the knees, shoulders, ankles, hips, elbows, cervical spine, and temporomandibular joints. Joint pain, swelling, warmth, erythema, and lack of function are the main symptoms (Bautch, 2004). Other symptoms are fatigue, morning stiffness, weakness, reddened joints, weight loss, anaemia, and extra articular manifestations, such as pericarditis, pleuritis, rheumatoid nodules, scleritis, and Sjögren’s syndrome. Patients may feel tired, depressed, frightened, and angry while they have pain and joint swelling (Arthritis Research Campaign, 2003; Bautch, 2004; Krug, 1997).

The American Rheumatism Association (1987 cited in Lovel and Hassan, 1999, p.104) indicated the classification of rheumatoid arthritis, which involved signs and symptoms as below:

- Morning stiffness of at least one hour\(^a\)
- Arthritis in at least three joint areas\(^b\) with swelling or fluid\(^a\)
- Arthritis of hand joints (at least one area swollen in a wrist, metacarpophalangeal joint: MCP or proximal interphalangeal joint: PIP)\(^a\)
- Symmetrical joint swelling and involvement\(^a\)
- Subcutaneous nodules
- Radiographic changes typical of rheumatoid arthritis
- Positive rheumatoid factor

Note: \(^a\) specified criteria that must be present for at least six weeks.
\(^b\) right or left PIP, MCP, wrist, elbow, knee, ankle and
Liang and Logigian (1992, p.2) claim the signs and symptoms that indicate poor diagnosis are ‘uncontrolled polyarthritis for more than two years, erosive disease, high-titre rheumatoid factor, extra-articular features (e.g. nodules), positive antinuclear antibody at any point, hand-foot involvement, insidious onset, and functional loss’.

Diagnosis

Doctors can make a diagnosis from the medical history, physical examination, laboratory tests, and X-rays. Doctors record a medical history to assess the patient’s pain, signs, and symptoms. The Arthritis Foundation (2003) explains that doctors will assess patients for joint swelling, tenderness, loss of motion, and malalignment, and for signs of rheumatoid arthritis in other organs, including the skin, lungs, heart, and eyes. Patients can assess themselves using a self-report questionnaire. The most common self tests are the Health Assessment Questionnaire (HAQ), and the Arthritis Impact Measurement Scales (AIMS).

Laboratory tests are recommended by doctors, because they diagnose rheumatoid arthritis, and exclude other connective tissues disorders. The diagnostic tests include

- Rheumatoid factor (RF) which is found in 75 percent of patients who have rheumatoid arthritis.
- Erythrocyte sedimentation rate (ESR), which is used to indicate disease and inflammation.
- Synovial fluid examination, which detects inflammation.
- Complete Blood Count (CBC), which is used to indicate anaemic problems (LeMone and Burke, 2004).

In addition, C-Reactive Protein (CRP), Antinuclear Antibody (ANA) are tested to confirm a diagnosis of rheumatoid arthritis (Arthritis Research Campaign, 2003; Roberts, 2005).
Plain X-rays are common diagnostic methods to show the progression of damage in joints or bone loss. Other X-ray techniques are Magnetic Resonance Imaging (MRI), and ultrasound scanning, which are more sensitive, and confirm a diagnosis in the early stages of rheumatoid arthritis (Arthritis Research Campaign, 2003).

Treatment

LeMone and Burke (2004, p.1252) claims that the goals of treatment for rheumatoid arthritis are to ‘reduce pain and inflammation, preserve function, and prevent deformity’. There are three main ways to treat rheumatoid arthritis: taking care of joints, medication, and surgery (Arthritis Research Campaign, 2003). This section describes medications, rest and exercise, surgery, therapies, and nursing care.

Medication

Medications are used to relieve rheumatoid arthritis symptoms, and modify the disease (Arthritis Foundation, 2003). The following medication groups are used to treat rheumatoid arthritis (Arthritis Foundation, 2003; Arthritis Research Campaign, 2003; Hill and Hale, 2004; Krug, 1997; LeMone and Burke, 2004; Lorig and Fries, 2000; MacDonald in Maher et al., 2002; Roberts, 2005).

Non-steroidal Anti-Inflammatory Drugs (NSAIDs) NSAIDs are used to decrease inflammation, and relieve joint pain and swelling. The side effect is gastric irritation. Examples of these medications are aspirin, cyclooxygenase-2 (COX-2) inhibitors, Feldene, ibuprofen, Indocin, Naprosyn, and Voltaren.

Analgesic drugs These drugs are used to relieve pain only. A common side effect is constipation. Examples of these drugs are acetaminophen and propoxyphene.

Corticosteroids These drugs are also called glucocorticoids or steroids. These drugs work with cortisol hormone to relieve rheumatoid arthritis symptoms. Doctors prescribe these drugs in a low maintenance dose. Corticosteroids are administered ‘by injecting
directly into an inflamed joint, intramuscular or intravenous injections, and by mouth’ (Arthritis Research Campaign, 2003, f.11-12). Corticosteroids become dangerous if patients reduce the dose without consulting the doctors. The side effects are bruising, cataracts, glaucoma, facial oedema, and osteoporosis. The well known drugs in this group are cortisone and prednisolone.

**Disease Modifying Antirheumatic Drugs (DMARDs)** These drugs relieve symptoms and prevent joint deformity and disability. They are used with NSAIDs and/or prednisolone to slow the process of joint destruction. Examples in this group are methotrexate, gold, penicillamine, azathioprine, and sulfasalazine. A wide range of side effects can occur, for example methotrexate can cause abnormalities of liver and bone marrow function, and gold can cause blood and kidney dysfunction.

**Biologic Response Modifiers (BRMs)** These drugs inhibit cytokines, which cause inflammation. Patients who receive live vaccinations for immunisation are encouraged not to take these drugs. Examples of BRMs are Enbrel, Remicade, Kineret, and Humira.

In summary, there are four general approaches to manage medications for rheumatoid arthritis (LeMone and Burke, 2004). Firstly, aspirin, other NSAIDs, and mild analgesics are given to decrease inflammation, and control rheumatoid arthritis symptoms. Secondly, low-dose oral corticosteroids are used to relieve pain and inflammation. Thirdly, DMARDs are given to slow down the joint destruction process, and finally, intra-articular corticosteroids are used in patients for control of inflammation.

**Rest and exercise**

There are many useful exercises for patients with rheumatoid arthritis, such as range-of-motion (ROM), and isometric exercises. ROM preserves joint function, and protects against joint contraction. Isometric exercises are useful in improving muscle strength. There is no best exercise, or advice on when patients should stop exercise, or the best form of rest. The most concern in this issue is to balance rest, exercise, and physical activities. Patients should use their joints and muscles as much as possible, but avoid
hard impact exercises, violent sports, and joint overuse. Patients should stop doing any activities if their joints are warm, painful and swollen. Doctors, physical therapists, and occupational therapists can suggest appropriate programs of rest and exercise for patients (Arthritis Foundation, 2003; Arthritis Research Campaign, 2003; LeMone and Burke, 2004).

**Surgery**

Surgery is not always appropriate to treat rheumatoid arthritis. Surgery will vary in each case, and the doctors will talk to patients about the need for surgery. Examples of surgery are synovectomy and excision of synovial membranes, to relieve inflammation and pain temporarily (Arthritis Research Campaign, 2003; LeMone and Burke, 2004).

**Physical and occupational therapy**

Physical therapists and occupational therapists can advise individual patients about appropriate activities, exercise, and rest. Hot and cold compresses, and assistive devices, and splints are used. Heat and cold are used to relieve pain, and relax the muscles. While assistive devices are useful in patients who have hip or knee arthritis, splints are also beneficial in resting joints and preventive contraction (Arthritis Foundation, 2003; LeMone and Burke, 2004).

**Nutritional therapy**

Many patients with rheumatoid arthritis experience weight loss, depression, anaemia, and loss of appetite. Although there is no specific diet for patients with rheumatoid arthritis, they need to have healthy daily diets. The diets need to be rich in vitamins, protein, and iron, which are effective in building and repairing joint tissue (Bautch, 2004). Patients also need calcium to strengthen bone, and to avoid consuming alcohol if they are taking aspirin or NSAIDs, especially methotrexate. Patients should also monitor their weight, and not smoke to prevent obesity and vasoconstriction. Patients who are taking steroids require calcium supplements and multivitamins with vitamin D. Some
recently studies showed that omega-3 fatty acids can reduce joint inflammation in rheumatoid arthritis (Arthritis Foundation, 2003).

**Nursing care**

The aims of nursing care for patients with rheumatoid arthritis are to ‘promote a healthful and positive life course adaptation’ (MacDonald, 2002, p.377). LeMone and Burke (2004) suggested interventions involving managing chronic pain, fatigue, ineffective role performance, and disturbed body image. To manage chronic pain, nurses should monitor the pain level, and the duration of morning stiffness. They should advise patients about appropriate activities to prevent pain, the usefulness of medications, and possible side effects. Other nursing interventions are encouraging patients to use hot and cold compresses, and non pharmacologic therapies such as meditation and relaxation techniques. Related to fatigue management, nurses can encourage patients to have suitable periods for activities, rest, and exercise. Nurses also encourage patients and their family members to discuss the illness, how to cope with the disease, and in having positive attitudes towards care and treatment.

MacDonald (2002) suggested that nursing care should be planned to encompass physical, psychological, and social needs of patients. Nurses provide comfort by promoting physical and psychological comfort. Nurses facilitate self-care and nutrition support, and help patients to cope with their problems by giving hope, teaching, and support. Nurses also help patients and their families to have effective coping in daily life and sexuality patterns by discussing issues, and providing guidance and encouragement as appropriate.

Roberts (2005) focused nursing care in pain management, and exercise therapy to encourage joint mobility. They also provided guidance for nurses in enhancement of body image and sexual counselling, anticipatory guidance to support health care decisions, and assisting in suitable activities of daily living (ADL).
In summary, appropriate treatments and nursing care, and the successful management of rheumatoid arthritis occur, because of cooperation between patients, family members, and health care team involving doctors, nurses, physical therapists, occupational therapists, dieticians, and so on.

**Related studies about rheumatoid arthritis**

From 1982 until 2005, many research publications about rheumatoid arthritis have amassed in the database of Cumulative Index to Nursing and Allied Health Literature (CINAHL) in two main groups: nursing care and pain management.

**Nursing care in rheumatoid arthritis**

Nash (1999), and Ryan and Oliver (2002) described basic knowledge of rheumatoid arthritis, while Krug (1997) compared the differences between rheumatoid arthritis and osteoarthritis. Some articles offered psychological and social factors relating to rheumatoid arthritis (Dumas, 1992; Gio-Fitman, 1996; Ignatavicius, 1987; Lin et al., 1999; Mirabelli, 1990; Oliver, 2004; Ryan, 1998). Hill (1991) examined the use of the Stanford Health Assessment Questionnaire (HAQ), and Arthritis Impact Measurement Scale (AIMS), while Cox (1999) described the role of surgery, and Brownfield (1998) studied the effects of massage and aromatherapy.

There are many articles relating to fundamental caring and management for rheumatoid arthritis (Hill, 1985; Hosking, 1984; Moulson, 2002; Pollard and Adebajo, 2004; Ryan, 1997; Veronesi, 2003). To provide nursing care comprehensively, some researchers have used nursing theories. Orem’s theory is used by Ailinger and Dear (1997) and Stewart and Bassett (1992). Newman’s theory is used by Neill (2002). Other patterns for caring for patients with rheumatoid arthritis were evidence-based nursing care (Hill and Hale, 2004), nursing care plans (Aloy Asensi et al., 2001; Punti et al., 1995), practice framework (Oliver, 2003), and case management (Pigg, 1997). Some studies evaluated patients’ satisfaction after using special patterns (Arthur and Clifford, 2004; Hill, 1997). For example, Arthur and Clifford (2004) studied the satisfaction of patients with
rheumatoid arthritis following primary and secondary care. They found that there were significantly higher levels of satisfaction in respect to general satisfaction, provision of information, and continuity of care. They also found that there was a significant difference in relation to empathy, technical ability, and attitude to the patients.

Some authors suggested caring for specific symptoms, complications, and operations such as leg ulcers and underlying vascular condition (Armitage and Roberts, 2004), Sjögren syndrome (Bermejo and Sanchez, 2002), cervical myelopathy (Mate and Taylor, 1987; Nazaroff et al., 1989), foot care (Springett and White, 2002), intra-articular injections (Minnock, 2002), skin care (Scott, 1999), and total elbow replacement (Dale et al., 1992). Nursing care for drug monitoring and administration were described (Arthur, 1995; Capriotti, 2004; Hosie, 2002; Ryan, 1997), especially in the patients who took infliximab (Risley et al., 2004), and COX-2 (Love, 2000).

There are few studies involving patients’ and nurses’ experiences. Patients’ experiences have been described in the way they lived with rheumatoid arthritis (Redfern, 1989; Ryan, 1996), and of the experience of being admitted to hospital (Edwards et al., 2001). Nurses’ experiences were explained in caring behaviours and managing pain (Whyte, 2004; Willis, 1999), and perceptions of nurses in doctor-patient communication (Angeles et al., 2003). Some studies guided nurses in how to care for rheumatoid arthritis patients (Arthur, 1994; Long et al., 2002; Marchant, 1995; O’Donovan, 2004, Ryan, 2001; Ryan, 1996; Ryan and Seymour, 1997; Voyce, 1998). Other studies guided nurses to encourage patients towards self-determination (Loftman et al., 2003), cope with rheumatoid arthritis (Newbold, 1996), to promote self-care (Dear and Keen, 1982), and to maintain mobility and independence (Peasnell, 1984). Multidisciplinary team care was also considered (Pigg, 1995; Zimm, 1999).

**Pain management in rheumatoid arthritis**

Medication is the most common way to relieve pain. Grigor et al (2004) studied the effects of a treatment strategy of tight control for rheumatoid arthritis, and found patients in the intensive care group were prescribed higher doses of methotrexate than those in
the routine care group. They also received more intramuscular and intra-articular injections than did the routine group. Hammond and Freeman (2004) studied the long-term outcomes from a randomised controlled trial of an educational-behavioural joint protection program. They found that the joint protection group had significantly better results in joint protection adherence, early morning stiffness, and activities of daily living. Meanwhile, Massarotti (2003) discussed arthritis treatment and pain management guidelines, which were issued by the American College of Rheumatology, the American Geriatrics Society, and the American Pain Society. This article focused on the treatment in a care setting, balancing the clinical expert’s opinions with the constraints of the current health economic environment.

Researchers constantly seek better ways to manage pain. They suggest effective pain management for rheumatoid arthritis (Macklin, 1999; Morrow, 2003; Oliver and Ryan, 2004), using the Pain Management Inventory or PMI (Davis and Atwood, 1996), using stress management, emphasising cognitive-behavioural therapy to decrease pain and depression (Rhee et al., 2000), using comprehensive health promotion programs to reduce pain, depression, and disability (Oh and Seo, 2003), applying multidisciplinary approaches (Smith, 2003), managing pain by following JCAHO standards (Spanos et al., 2002), giving health education (Maycock, 1984), and interventions to encourage patients to cope with chronic pain (Mooney, 1982). Holm and Sahebzamani (2004) also supported thorough assessment and treatment of pain. Shovein (2001) claimed that nurses had an important role as advocates to give patients with rheumatoid arthritis effective treatment and medication, and in encouraging patients’ self-efficacy (Smarr et al., 1997).

Nurses can help patients to manage pain efficiently if they know the effects. Dwyer (1993) studied psychosocial factors affecting health status in rheumatoid arthritis patients and concluded that pain severity and self-efficacy were the most salient variables in the predictive model. Parker et al. (1993) reviewed cognitive-behavioural approaches to manage rheumatoid arthtritic pain, and Giorgino et al (1994) studied in rheumatoid arthritis patients in their appraisal of, and coping problems in household activities, leisure activities, and pain management. Therapies for managing pain, such as
complementary and alternative therapy (Taibi, and Bourguignon, 2003), have been researched and have been found to be of benefit.

**Pain management for patients with rheumatoid arthritis in Thailand**

Literature was reviewed from the database of Technical Information Access Center (TIAC), which collects theses from every university in Thailand, and universities databases. The studies were done by many health professionals, including nurses. In 1990, Viratyosin found there was no distinct association of C4 allotypes with rheumatoid arthritis. Ukritchon (1998) found that HLA-DRB1*0405 (04051) was associated with Thai patients with rheumatoid arthritis. Some studies focused on pathology and symptoms in rheumatoid arthritis, such as using ELISA to detect rheumatoid factor in sera (Banchuan, 1990), changing of the temporomandibular joint (Mahasantipiya, 2000), alkaline phosphatase activity (In-Thai, 2000), hand grip patterns (Sangwongthong, 2002), and the prevalence of dyslipidemia (Ekbundit, 2003). Osiri et al. (2001) evaluated patients’ ability by using a Thai version of the Health Assessment Questionnaire (HAQ), and found significance in mean HAQ scores in tender joint counts, patient global and physician global assessments, and in grip strength.

Related to pharmacotherapy, Deewattanakul (1995) studied the effects of methotrexate and Gold salt sodium thiomalate in disease modification. Two years later, Somrith (1997) compared the quality and bioavailability of methotrexate and a comparison of short-term efficacy, and safety between doxycycline and methotrexate therapy was done by Srisakul (2002). Although medications are the main treatment, complementary therapies take important roles in treating rheumatoid arthritis. Sukhonsub (1986) found positive effects of body incubation with essential oil extracted from Plai (Zingiber cassumunar Roxb) in hot water vapour to reduce joint inflammation. Thawornkul (2002) studied the effects of dietary counselling with or without fish oil supplement on nutritional and vitamin status in rheumatoid arthritis patients, and Sundrajun (2003) focused on the effects of dietary modification and omega-3 fatty acid supplement on the biochemical and clinical response.
Nurses have also researched in the area of rheumatoid arthritis. Anansawat (1987) found a statistically significant correlation between life satisfaction and illness perception. Sinthuchai (1989) claimed social support, knowledge, incomes, and education level were four significant predictors in relation to patients’ adaptation to rheumatoid arthritis. Puasiri (1990) found that there was a significantly positive relationship between self-concept, health perception and self-care in people with rheumatoid arthritis. Nurses use effective ways to manage rheumatoid arthritis and pain by using planned instruction (Raadnui, 1995), Buddhist meditation (Petmaneechote, 2000), self management in morning stiffness (Boonnun, 2001), and in encouraging patients’ empowerment (Janejob, 1999).

**Summary**

From the literature review, I concluded that rheumatoid arthritis is a complex, chronic, inflammatory disease. Many factors can affect the disease’s progress such as age, gender, culture, and genetics. Therefore, cooperation is needed among the health care team to use effective ways for helping patients to manage their illness, especially their pain. There are few studies about perceptions of patients, carers, and the health care team in rheumatoid arthritis. Nurses can provide suitable nursing care and education if they know patients’ and carers’ needs, so this is the focus of my research using grounded theory, which is discussed in Chapter Three.
Chapter Three: Methodology

Introduction

This chapter introduces the development of qualitative research and the methodology of grounded theory, describes its development as a methodology and its methods and processes, and shows how grounded theory has been used as a methodological approach in nursing research. This thesis is informed by, but does not adhere strictly to, the Strauss and Corbin approach to grounded theory.

Development of qualitative research and grounded theory

The Chicago school developed grounded theory from a collection of academics working at the Department of Sociology, University of Chicago. The most influential persons were Dewey (1894-1904), Mead (1894-1931), and Blumer (1926-1952), especially Mead who was the founder of symbolic interactionism (Harvey, 1987; Ritzer, 1996; Sharrock, 2003). Denzin and Lincoln (2000) divided the history of qualitative research in this century into five moments, each of which is described as below.

The first moment

Denzin and Lincoln (2000) named the first moment ‘the traditional period’. Between the early 1900s and World War II, field workers were admired for the stories they solicited from strangers. Their writings demonstrated validity, reliability, and interpretation. The Chicago School emphasised two points; the life story and the slice-of-life ethnography, and the centrality of interpretation in life history. Glaser’s interpretation of grounded theory was derived from Merton’s main study in 1938 (Elwell, 2003, f.1), and the quantitative methodology of Lazarsfeld (1940-1970) (Cortez, et al., 1999, f.1). Whereas, the Chicago tradition and Dewey’s (1894-1904) perspective influenced Strauss (Annells, 1997).
The second moment

Denzin and Lincoln (2000) named this moment ‘the modernist phase’, ranging from after World War II till the 1970s, when social realism, naturalism, and slice-of-life ethnographies were still valued. Many new interpretive theories occurred at this time, such as ethnomethodology, phenomenology, critical theory, and feminism. Postpositivism became important as the dominant epistemological paradigm. At this time, qualitative analysis was called on to demonstrate rigor.

The third moment

The third moment refers to ‘blurred genres’, in a time period ranging from 1970 till 1986. According to Denzin and Lincoln (2000), there were a lot of changes in this period. Firstly, qualitative researchers were validated in using their paradigms, methods, and strategies. Secondly, theories proliferated ranging from symbolic interactionism to ethnographic paradigms. Politics and ethics of qualitative research were developed, and qualitative researchers developed research strategies and reporting formats ranging from grounded theory to clinical research. The fifth change in this moment was availability of diverse data collection and analysis strategies, for example, interviewing, observation and documentary methods. Computers became more prevalent in supporting the analysis process. Furthermore, social scientists turned to the humanistic models, theories and analysis methods. Finally, the paradigms of naturalistic, postpositivist, and constructionist approaches became prevalent.

Annells (1997, p.122) claimed that grounded theory method was applied increasingly in a range of disciplines and phenomena, and that ‘further writings on the grounded theory method were contributed separately by Glaser and Strauss’. Many grounded theory research reports were published and methodological discussions such as Chenitz and Swanson’s (1986) was presented, which encouraged awareness in methods. Later, Strauss and Corbin (1990) modified the grounded theory method from the classical model. Annells (1997, p.122) also claimed ‘Glaser was the one who lamented that
Strauss and Corbin’s text failed to present the reasons for the changes to the method. On the other hand, Strauss and Corbin stated that ‘their grounded theory’s views, and the procedures they offered for consideration, arose from their own research experiences’. Benoliel (1996, p.419) claimed that researchers during this era used grounded theory method increasingly for researching 11 groups of nursing phenomena. The groups were family processes/adaptations, health-seeking practices, infertility, individual adaptations in chronic illness, family processes in chronic illness, the illness experience, processes and practices of nurses, interventions and interactional processes by nurses, contextual/environmental influences, institutional/interactional processes and practices, and passages and processes of vulnerable people.

**The fourth moment**

The fourth moment occurred in the mid of 1980s. Denzin and Lincoln (2000) named this moment ‘the crisis of representation’. Some studies occurred at this time which questioned gender, class, and race; for example, *Anthropology as Cultural Critique* by Marcus and Fisher (1986), and *Writing Culture* by Clifford and Marcus (1986). Denzin and Lincoln also referred to Rosaldo’s (1989) study that new models of truth, method and representation were needed, and classic norms in anthropology were completely eroded. They agreed with Stoller and Olkes (1987) that information can be falsified, because informants can lie and make the data worthless. Then Stoller produced ‘a memoir’, to aid in the writing of text from memory. Stoller and Olkes claimed that differences between writing and fieldwork have been debated, as methods of showing that lived experience can be captured. There is general agreement that there are no major differences between the two. Denzin and Lincoln (2000, p.17) concluded that

‘The field workers drew their text from the field experience, through intermediate and later work, and finally to the research text which was the public presentation of the ethnographic and narrative experience.’

In this moment, ‘grounded theory was displaced by a leaning of qualitative inquiry towards interpretive theories’ (Annells, 1997, p.127). Because of the realisation in importance of writing, Strauss and Corbin (1990, p.225, 229) suggested that ‘further
data collection and analysis might be necessary during the writing up phase’. Annells (1997, p.127) claimed there was a move in that direction within the presentation of their method, ‘especially in the directive to engage in extensive writings of code, theoretical and operational memos that should include the presence of one self as researcher clearly into the analytic process’. The researcher became central in the research process, indicating reflexivity within memo writing.

Annells (1997) claimed a second crisis arose in this moment, the crisis of legitimation, which arose from poststructuralist and postmodernist disclosures. This crisis questioned the notions of reliability and validity. From this crisis, Annells (1997, p.128) concluded Strauss and Corbin’s method (1990) recognised the ‘tendency of others to reconfigure validity, reliability, and credibility notions to a suitable form for qualitative research’.

**The fifth moment**

Denzin and Lincoln (2000) named the fifth moment ‘a triple crisis’, following the crises of representation and legitimation. The last crisis was praxis, coded in multiple terms, and associated with the critical, interpretive, linguistic, feminist, and rhetorical turns in social theory. Denzin and Lincoln claimed the three crises made two main assumptions. Firstly, qualitative researchers could no longer directly capture lived experience, and they had to rethink issues of validity, generalisability and reliability.

Annells (1997, p.128) referred to Strauss and Corbin’s method that varieties of postmodernism influenced researchers using grounded theory methods when focusing analytically on the conditions acting in the data. They claimed that ‘recent methodological discussions concerning grounded theory seemed to be aware of the postmodern rejection of theory, which was a major postmodernist criticism of grounded theory’.

**Grounded theory**
Grounded theory was developed by Barney Glaser and Anselm Strauss, who were sociologists collaborating on research about dying patients (Strauss and Corbin, 1998; Holloway and Wheeler, 2002). Glaser and Strauss published two books; *Awareness of Dying* (1965), and *Time for Dying* (1968) (McCann and Clark, 2003, p.8). Grounded theory is based on the perspective of symbolic interactionism developed by Mead (1934) and Blumer (1969). Symbolic interactionism emphasises interaction between human behaviour and social roles. It posits that human interaction and behaviour is based on how people relate to one another (Blumer, 1969), and ‘take account of each others’ acts’ (Holloway and Wheeler, 2002, p.153). Symbolic interactionism involves the meanings given to specific symbols in people’s lives (Speziale and Carpenter, 2003, p.110). Blumer (1969) recognised that symbolic interaction rested on three premises, that human beings act toward things on the basis of meanings that the things have for them, meaning is derived from social interaction, and that these meanings are modified through an interpretive process.

Grounded theory is a qualitative research approach which is different from other approaches. The purpose of grounded theory is to generate or modify theory from the data which are grounded in the dominant process of social life. Researchers use a constant comparison method to find ‘similarities, differences, and connections’ (Holloway and Wheeler, 2002, p.155) in the data. Researchers begin their analysis by finding codes, categories, and basic social processes (Benton, 2000; Chenitz and Swanson, 1986; Goulding, 2002; Schreiber and Stern, 2001; Speziale and Carpenter, 2003). Researchers explain the codes, categories, and basic social processes by using gerunds (Glaser, 1978; Schreiber and Stern, 2001).

Denscombe (1998, p.214-215) supported five basic premises of grounded theory. The first premise is ‘pragmatic qualitative analysis’, which allows researchers to form general principles from literature. The second premise aims to generate ‘new concepts and theories’. The third premise is that ‘theories should be grounded in empirical reality’, by using ‘constant comparative analysis’. The fourth and fifth premises are open mindedness and theoretical sampling. Glaser (1978, p.36) said that theoretical sampling refers to
‘the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his(sic) data, and decides what data to collect next, and where to find them, in order to develop his(sic) theory as it emerges’.

The sources of data are collected through ‘observations in the field, interviews of participants, diaries, and other documents like letters or even newspapers’ (Holloway and Wheeler, 2002, p.155) or from a combination and integration of these sources (Glaser, 1978). Daily journals, participant observation, formal or semi structured interviews, and informal interviews are valid means of generating data (Speziale and Carpenter, 2003, p.114). Holloway and Wheeler (2002) claimed that ‘researchers used interviews and observations more often than other data sources’. Theory which emerges from grounded theory is mid-range theory, which shows the relevance of codes, categories, and basic social processes. Hence, grounded theory is suited for any area in which there is little knowledge (Benton, 2000; Chenitz and Swanson, 1986; Goulding, 2002).

Before the researchers reach the analysis processes, there are two basic processes of theoretical sensitivity and theoretical sampling. Strauss and Corbin (1998, p.46) define theoretical sensitivity as ‘having insight into, and being able to give meaning to, the events and happenings in data’. It also means ‘being able to see beneath the obvious to discover the new’. This process happens when the researchers start to work with data. Strauss and Corbin (1998) also noted that theoretical sensitivity occurs through literature, professional and personal experience. Literature gives ‘initial ideas to be used for theoretical sampling’ while professional experience helps ‘the researchers to move into an area they were familiar more quickly’ (Strauss and Corbin, 1998, p.47). At the same time, personal experience helps researchers to ‘provide a comparative base for asking questions about the events and to define the meanings’ (Strauss and Corbin, 1998, p.48).

Another basic process of grounded theory is theoretical sampling. Glaser and Strauss (1967, p.45) define theoretical sampling as ‘the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his(sic) data and decides
what data to collect next and where to find them, in order to develop his(sic) theory as it emerges’. At the beginning, the researchers do not limit the numbers of participants, but decisions are made about participants’ characteristics and how to recruit participants. This is non-probability sampling called purposive sampling (Cutcliffe, 2000; McCann and Clark, 2003). Theoretical sampling in grounded theory ‘continues throughout the study and is not planned before the study starts’ (Holloway and Wheeler, 2002, p.157). After the data are initially collected and analysed, the researchers decide on the sample size, and continue seeking participants to saturate their concepts until no new concepts emerge.

Grounded theory uses the constant comparative method of analysis. Glaser and Strauss (1967, p.105) explained there were ‘four stages in this method; comparing incidents applicable to each category, integrating categories and their properties, delimiting the theory, and writing the theory’. The constant comparative method is used continually until the theory is completed (McCann and Clark, 2003). From this process, the researchers undertake the process of coding and categorising data. Coding in grounded theory means ‘the process by which concepts or themes are identified and named during the analysis. Data are transformed and reduced to build categories’ (Holloway and Wheeler, 2002, p.158). Open coding is the first level of coding, which starts as soon as the researchers receive the data. It is the process of breaking down the data into discrete parts, in order to conceptualise and categorise them (McCann and Clark, 2003, p.12). Categorising is the second level of coding. The researchers ‘code the data, compare them with other data, and assign the data to clusters or categories according to obvious fit’. The last level of coding is basic social process which ‘composes the title given to the central themes that emerge from the data’ (Speziale and Carpenter, 2003, p.118). Strauss and Corbin (1998) suggested that the process of coding and categorising is saturated when ‘no new properties, dimensions, conditions, actions/interactions, or consequences were seen in the data’. It also includes the need that links between categories are firmly established (Holloway and Wheeler, 2002).
Differences between classical and Strauss and Corbin’s model

Grounded theory evolved into two models; the classical approach of Glaser and Strauss and the Strauss and Corbin’s model. The philosophical differences between both models are demonstrated in Table 3.1.

<table>
<thead>
<tr>
<th></th>
<th>Classical grounded theory model (Glaser and Strauss)</th>
<th>Grounded theory model (Strauss and Corbin)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ontology</td>
<td>Critical realist.</td>
<td>Relativist.</td>
</tr>
<tr>
<td>Epistemology</td>
<td>Modified objectivist.</td>
<td>Subjectivist.</td>
</tr>
<tr>
<td>Methodology</td>
<td>A first step in a research hierarchy, which leads to experimental or survey research for verification.</td>
<td>Construction of a framework for action localised, provisional and verified.</td>
</tr>
</tbody>
</table>

Table 3.1 Philosophical differences between the models of grounded theory: adapted from Annells (1997, p.121)

Annells (1997, p.124) summarised the comparison between two models and this is shown in Table 3.2.

In relation to the sampling and source of the theoretical sensitivity, ‘sampling which was called theoretical sampling was determined to examine the phenomena where it was found to exist. It was based on the need to collect more data to examine categories and their relationships, and to assure that representativeness in the categories exists’ (Chenitz and Swanson, 1986, p.9). Annells (1997, p.125) summarised Glaser’s claim that ‘theoretical sampling was directed by emerging codes until categories were saturated. The source of theoretical sensitivity came from knowledge of coding families, conceptual ability, and literature’. Strauss and Corbin (1990) also claimed that the sampling was open, relational/variational and discriminate. The theoretical sensitivity
was from many kinds of sources such as ‘professional experience, personal experience, literature, and the analytic process’.

<table>
<thead>
<tr>
<th></th>
<th>Classical grounded theory model</th>
<th>Strauss and Corbin’s grounded theory model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focusing on</td>
<td>A substantive area.</td>
<td>A phenomenon.</td>
</tr>
<tr>
<td>Aiming to</td>
<td>Generate an inductive grounded theory.</td>
<td>Develop an inductive grounded theory.</td>
</tr>
<tr>
<td>Commencing with</td>
<td>A general area of interest.</td>
<td>A pre-identified problem or curiosity and a sensitising question.</td>
</tr>
<tr>
<td>Through use of the method</td>
<td>A grounded basic problem emerges. Grounded question/s and a grounded basic social process emerge.</td>
<td>Grounded question/s are developed. Grounded hypotheses regarding a social process are developed and tested.</td>
</tr>
<tr>
<td>Underpinned by</td>
<td>Symbolic interactionism.</td>
<td>Strauss’ s theory of continual permutations of action.</td>
</tr>
<tr>
<td>Resulting in</td>
<td>The generation of grounded hypotheses.</td>
<td>Some degree of verified grounded theory.</td>
</tr>
<tr>
<td>Leading to</td>
<td>Experimental or survey research, resulting in a verified grounded theory, or limited application as a provisional theory when there is fit to a situation.</td>
<td>An understanding with direct pragmatic application-problem management.</td>
</tr>
</tbody>
</table>

Table 3.2 Differences in two grounded theory models and their precursors: adapted from Annells (1997, p.124)

Although both models use constant comparative method as an analytic tool, there are some differences between them, as demonstrated in Table 3.3 (Annells, 1997, p.125).
<table>
<thead>
<tr>
<th>Constant comparative data analysis</th>
<th>Classical grounded theory model</th>
<th>Strauss and Corbin’s grounded theory model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coding</td>
<td>Open, theoretical and constant comparative coding.</td>
<td>Open, axial, and selective.</td>
</tr>
<tr>
<td>Coding framework</td>
<td>Choice from multiple coding families depending on best fit to data.</td>
<td>Specified coding framework, or the paradigm model.</td>
</tr>
<tr>
<td>Memos</td>
<td>Primarily for sorting to form hypotheses.</td>
<td>Code, theoretical and operational notes.</td>
</tr>
<tr>
<td>Focus on process</td>
<td>Movement over time with at least two stages-a basic social process.</td>
<td>Linking of action/ interaction sequences or non-progressive movement.</td>
</tr>
<tr>
<td>Category development</td>
<td>Relevant categories and properties emerge by comparing incident to incident and/or to concepts looking for the relevance, the fit and emergent patterns until theoretical saturation occurs.</td>
<td>In terms of properties that are dimensionalised and the categories grouped. Relationships validated against data. Gaps in categories are filled until theoretical saturation is reached.</td>
</tr>
<tr>
<td>Conditional/consequential matrix</td>
<td>Nil-micro levels of analysis only.</td>
<td>Specified-moves between micro and macro levels of analysis.</td>
</tr>
</tbody>
</table>

**Table 3.3 A comparison of analysis steps of two grounded theory models: adapted from Annells (1997, p.125)**

The other main differentiating characteristics of grounded theory are shown in Table 3.4 (McCann and Clark, 2003, p.23).
<table>
<thead>
<tr>
<th></th>
<th>Classical grounded theory model</th>
<th>Strauss and Corbin’s grounded theory model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher’s role</td>
<td>Independent.</td>
<td>Dialectic and active.</td>
</tr>
<tr>
<td>Literature review</td>
<td>Main review to support emerging theory.</td>
<td>Preliminary review to enhance theoretical sensitivity.</td>
</tr>
<tr>
<td>Research problem</td>
<td>Emerging in the study.</td>
<td>Personal experience.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Suggestion by others.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Literature.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emerges in the study.</td>
</tr>
<tr>
<td>Data collection and analysis</td>
<td>Principles and practices of qualitative research. Guided by participants and socially constructed reality.</td>
<td>Rules and procedures.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paradigm model to provide structure.</td>
</tr>
<tr>
<td>Evaluation</td>
<td>Fit, work, relevance, and modifiability.</td>
<td>Deference to canons of qualitative research outlined by other qualitative researchers.</td>
</tr>
</tbody>
</table>

Table 3.4 Other main differences between two grounded theory models: adapted from McCann and Clark (2003, p.23)

Grounded theory in nursing

Chenitz and Swanson (1986, p.14) argue that nursing is ‘a practice profession and the science of nursing must be relevant to the practice of nursing’. Nursing research becomes an important source of generating nursing knowledge and application to nursing situations. Grounded theory is a useful methodology, which nurses can use to create nursing knowledge, because grounded theory
‘offers a systematic method to collect, organise, and analyse data from the empirical world of nursing practice. Grounded theory is an approach to theory development based on the study of human conduct and the contexts, and forces that impinge on human conduct, and grounded theory holds promise for a fuller and deeper understanding of nursing knowledge, and a method to generate theory in a practice profession’ (Chenitz and Swanson, 1986, p.14).

After Strauss was recruited to work in the School of Nursing at the University of California, San Francisco, he and Glaser cooperated in studying patients who were dying in hospitals. They published their study as the book *Awareness of Dying* in 1965. They founded and introduced their new methodology in the book *The Discovery of Grounded Theory* in 1967 (Schreiber and Stern, 2001).

Since the early 1970s, Glaser and Strauss have presented grounded theory to research students, many of whom applied grounded theory in their studies. For example, Stern used grounded theory to explore stepfather families in 1978 and 1982. Benoliel, who worked with Glaser and Strauss in the study of dying, also published *The Nurse and The Dying Patient* (1967), and *Grounded Theory and Nursing Knowledge* (1996) (Schreiber and Stern, 2001).

When grounded theory became well-known in the nursing profession, it was used for creating theory, especially within nursing practice and nursing education (Backman and Helvi, 1999; Schreiber and Stern, 2001). These achievements were published in the form of books and articles in many journals of nursing. Examples of these books are *From Practice to Grounded Theory: Qualitative Research in Nursing* by Chenitz and Swanson (1986), and *Using Grounded Theory in Nursing*, which was edited by Schreiber and Stern (2001). Nursing articles relate to many nursing issues, such as development and characteristics of grounded theory (Annells, 1997; Norton, 1999; Sheldon, 1998), applying ground theory methodology into nursing (Cutcliffe, 2000; McCallin, 2003; McCann and Clark, 2003; Sandelowski, 2001), rigour and evaluation in grounded theory (Chiovitti and Piran, 2003; Lomborg and Kirkevold, 2003), grounded theory in nursing practice (Blenner, 1990; Happ and Kagan, 2001; Morgan, 2001; Woodgate, 2000),
grounded theory in nursing education (Duffy et al., 2004; Scholes et al., 2000), and grounded theory in nursing administration (Severinsson and Borgenhammar, 1997).

In Thailand, some nursing phenomena have been studied by using grounded theory. They are women’s health, medical nursing, mental health and psychiatric nursing, paediatric nursing, and care of the elderly. Regarding nursing care for women’s health, nurses studied role clarity and health perceptions in Thai women with valvular heart disease (Sindhu, 1992), experiences of wife abuse (Sripichayakan, 1999), and Thai Women’s experiences of HIV/AIDS (Klunklin, 2001). Nurses used grounded theory in medical nursing by focusing on self-care processes in adults with diabetes (Sritanyarat, 1996), family adaptation in caring for patients with HIV/AIDS (Oumtanee, 2001), self-management in patients with COPD (Duangpaeng et al., 2002), everyday life for men with paraplegia (Singhakhumfu, 2002), self-care in people with hypertension (Panpakdee et al., 2003), the struggling process in persons with HIV infection (Namjantra et al., 2003), and caregivers’ experiences in caring at home (Limpanichkulk, 2004).

In mental health and psychiatric nursing, nurses studied skill and role development in psychiatric caregiving (Tungpukom, 2000), and the recovering process in women with depression (Seeherunwong, 2002). Nurses applied grounded theory in paediatric nursing by researching children’s experiences with postoperative acute abdominal surgical pain (Fongkao, 2002), parents’ experiences in asthma attack prevention (Santati, et al., 2003), and children’s experiences in postoperative acute abdominal surgical pain (Wiroonpanich and Strickland, 2004). There are a few studies in nursing care for elderly, such as self-care (Kongin, 1998), caregivers’ process in caring elderly with stroke (Subgranon, 1999), and caring for the elderly (Choowattanapakorn, 2004). Beside this, Euswas (1991) published her study ‘The actualised caring moment: a grounded theory of caring in nursing practice’ in the conference proceedings of ‘A global agenda for caring: the Fourteenth Annual Caring Research Conference, Melbourne’ in 1992. Another study explored the experiences and health care seeking behaviours of commercial sex workers (Ratinthorn, 2000).
Summary

This chapter focused on the development of qualitative research since its inception in the early 1900’s. Grounded theory is suitable for the nursing profession in any area in which there is little knowledge. This chapter described the differences between classical and Strauss and Corbin’s models, the latter being the methodology and method for my research, because this model is more flexible for the novice qualitative researcher to apply. The next chapter describes how I applied grounded theory in my research.
Chapter Four: Methods and Processes

Introduction

This chapter continues from the previous chapter, because it explains about how to apply the methodology of grounded theory in research. It also describes the processes, step by step, from the pre-data collection phase to the data analysis and interpretation phase. In the pre-data collection phase, this chapter describes the participants and the ethical considerations. The interviewing process and participant recruitment are explained in the data collection phase. The analysis, and interpretation process and trustworthiness are described in the last phase of the chapter.

Methods and processes

McCann and Clark (2003, p.30) claimed that ‘once the research questions and aims of the study were identified, it was important to consider the methodological approach and the methods of data collection’. Methods refer to ‘the steps, procedures, and strategies of data collection and analysis which are available to researchers’ (Blaikie, 1993; Polit and Beck, 2004). I chose grounded theory for my research method, because

‘it offered a systematic method to collect, organise, and analyse data from the empirical world of nursing practice. It was an approach to theory development based on the study of human conduct and the contexts and forces that impinge on human conduct. It held promise for a fuller and deeper understanding of nursing knowledge and a method to generate theory in a practice profession’ (Chenitz and Swanson, 1986, p.14).

Speziale and Carpenter (2003, p.112) claim that ‘application of grounded theory research techniques to the investigation of phenomena important to nursing education, practice, and administration involves several processes’. Furthermore, Polit and Beck (2004, p.255) also emphasised that

‘grounded theory methods constituted an entire approach to the conduct of field
research. The fundamental features of the grounded theory approach involve data collection, data analysis, and sampling of study participants occurring simultaneously. Grounded theory methods are inherently non-linear in nature, and therefore difficult to characterise. The process is recursive. Researchers must systematically collect data, categorise them, describe the central phenomenon, and recycle earlier steps’.

Researchers using grounded theory must consider ‘which model of grounded theory they are going to use to inform their data collection and analysis’ (McCann and Clark, 2003, p.30). In my study, I decided to use Strauss and Corbin’s model of grounded theory. Firstly, the background of Strauss and Corbin’s ideas emphasise ‘change, process, variability, complexity of life and interrelationships among conditions, meaning and action’ (MacDonald, 2001, p.138), so their model focuses on the phenomenon. Secondly, a study commences with ‘a pre-identified problem or curiosity and a sensitising question’ (Annells, 1997, p.124). My study was commenced with my curiosity about how female patients, caregivers, and nurses managed pain in patients with rheumatoid arthritis. Thirdly, the research question in Strauss and Corbin’s model is a statement that defines the phenomenon to be studied. Grounded theory questions are oriented to process and action. The initial question starts broadly, and it is narrowed down and focused during the research (MacDonald, 2001, p.139). Finally, Strauss and Corbin’s model was a more structured approach to data collection than Glaser’s (McCann and Clark, 2003, p.31), making it relatively easy to apply to the research interest.

There are many qualitative data collection techniques, such as interviews, observation, document analysis (Holloway and Wheeler, 2002; McCann and Clark, 2003; Speziale and Carpenter, 2003), diaries (Holloway and Wheeler, 2002), videos, questionnaires, and organisational reports (McCann and Clark, 2003). I chose the interviews, because they allowed me to ask ‘the participants purposeful questions with the intention of investigating the research problems’ (Roberts and Taylor, 2002, p.235).
After gaining ethical clearance from Southern Cross University, I applied a grounded theory method in my research in three phases; the pre-data collection phase, the data collection phase, and data analysis, and the interpretation phase.

**Phase one: Pre-data collection**

The pre-data collection phase was the most important phase, because it was the basis of research. Research is ‘incomplete without a strong planning phase’ (Chantavanich, 2000, p.25). The main processes I applied in this phase were selecting participants and the research field, introduction to the project, preparation of equipment, and fulfilling ethical considerations.

**Theoretical sensitivity and theoretical sampling**

Before the data collection phase, I applied grounded theory by using theoretical sensitivity to access the research field and the participants. Theoretical sensitivity means that

‘researchers can differentiate between significant and less important data, and have insight into their meanings. There are a variety of sources for theoretical sensitivity. It is built up over time, from reading and experience, which guides researchers to examine the data from all sides, rather than to stay fixed on the obvious’ (Holloway and Wheeler, 2002, p.156).

My theoretical sensitivity came from my preliminary review of literature and professional experience of supervising nursing students in the hospitals. I knew my research field and participants, because my work was my research field. Although I am not working in a hospital, as a teacher, I have supervised students in orthopaedic wards. Therefore, I am familiar with rheumatoid arthritis. The patients with rheumatoid arthritis, caregivers, and nurses became my participants.

The process after theoretical sensitivity is theoretical sampling. I used purposive sampling to select my research field and participants. I chose Ratchaburi Province as my
research field, because of four reasons. Firstly, Ratchaburi Province is in the sixth health region of Thailand, and it is the public health centre of western region. Secondly, there are 27 hospitals in Ratchaburi Province. Twelve hospitals are public hospitals, which are classified according to numbers of beds for in-patients, including one 947 beds regional hospital (Ratchaburi information and technology division, f.12). Thirdly, it is my hometown, and I also worked at Boromarajonani College of Nursing, Ratchaburi. I supervised nursing students at wards in many hospitals there, therefore the context was familiar to me, and it was very comfortable for me to collaborate with the participants. Finally, Ratchaburi Province is representative of all provinces in Thailand, according to its size and the inclusion of all levels of hospitals in the Thai health care system.

I decided to interview three groups of participants, because the literature claimed that rheumatoid arthritis affects between one and three percent of the world population (LeMone and Burke, 2004), and it affects women more often than men. It also affects women between the ages of 20 and 50 (Krug, 1997). The participant groups were adult patients with rheumatoid arthritis, caregivers, and nurses. The selection criteria of participants included:

For the adult patients with rheumatoid arthritis, participants were
- female;
- aged between 20 and 59 years;
- diagnosed with rheumatoid arthritis;
- self-identified as having experienced pain not less than six months;
- being treated at Ratchaburi Hospital;
- able to speak Thai;
- living in Ratchaburi Province;
- able to consent to be a part of the research.

For the caregivers, participants were
- 20 years of age or over;
- self-identified as close relatives;
- able to speak Thai;
-caring for a relative with rheumatoid arthritis at home;
-living in Ratchaburi province;
-able to consent to be a part of the research.

For the nurses, participants were
- over 21 years of age;
- Bachelor degree of Nursing Science graduates;
- working in the orthopaedic wards;
- experienced in caring the patients with rheumatoid arthritis for at least one year;
- able to speak Thai;
- able to consent to be a part of the research.

**Reviewing the aim and objectives**

Before the interviews, I reviewed the research aim and objectives. My research aim was to explore with female patients, caregivers, and nurses their perceptions of pain and pain management in adult patients with rheumatoid arthritis in Ratchaburi Province, Thailand. Besides this, other objectives in relation to the pain of rheumatoid arthritis were to guide effective self care for patients with rheumatoid arthritis and effective support by caregivers, and also to raise the awareness of health care team to the needs of adult patients with rheumatoid arthritis.

I reviewed the questions to be asked of participants in this research to re-check the relevance of the questions to the aim and objectives. This process assisted me to focus on the phenomenon of interest. The questions used to trigger the conversation were not planned or executed rigidly, but they included prompts, such as:

For patients:
- “Thank you for agreeing to be part of this research. I am interested in your perceptions of pain you experience with rheumatoid arthritis. Tell me about it please.”
- “When you have pain, how do you manage it? Tell me about it please”.

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If the participant was hesitant in how to begin, or to maintain the flow of the stories, conversational prompts were given such as:
- “What was happening? How did that make you feel?”

To finish the conversation, the questions were:
- “If you could give advice to your caregiver or a nurse about how you would like to have care for when you suffer from pain, what would it be?”

For caregivers:
-“How do you feel when you see your loved one in pain? Tell me please.”
-“How do you support your loved one when s/he suffers from pain?”
-“What help do you need from your local health centres, in supporting you in the care of your loved one?”

For nurses:
-“How do you feel when you see patients with rheumatoid arthritis in pain? Tell me please.”
-“How do you give nursing care to people with rheumatoid arthritis, who are in pain?”
-“What help do you need to make your nursing care more effective in caring for people with pain of rheumatoid arthritis?”

**Preparation of equipment and researcher**

Before starting the interviews, I prepared both the interview equipment and myself. I prepared the interview equipment, such as audiotapes, tape-recorder, batteries, and equipment to take notes, such as pen and paper, and the participants’ addresses. I sent my car to the garage for checking, and prepared some remuneration for the participants who lost the wages when I interviewed them. Meanwhile, I also prepared myself by exercising, clearing my mind, and reviewing the researcher’s guidelines. Moreover, I arranged the schedules with my parents and their friend. My father became my driver. My mother was my personal secretary, and their friend was my navigator. I am very grateful to my parents and their friend for their help in the project.
Ethical considerations

In the course of this research, attempts were made to safeguard human rights, and a number of processes and procedures were used to ensure the ethical standards of the projects. Ethical clearance was gained from the ethics committee at Southern Cross University. Following the Protection of Human Subjects of Biomedical and Behavioural Research (1978, cited in Polit and Beck, 2004, p.143-150), three major ethical principles were applied in my research, as below.

The principle of beneficence

All participants received a detailed explanation verbally and in writing, of what the research involved, including the aim and processes of the research, and the participants’ involvement since the first time I approached them. They had the right not to be harmed by the study. Participants shared stories within a private setting, such as their homes and wards, and through sharing their stories, uncomfortable feelings or memories may have been experienced. To a degree, I informed each participant prior to consent being given and again before interviewing, how I proposed to deal with this situation. I was mindful of this, and was sensitive to any indication that a participant was uncomfortable by their words or behaviour. Initially, participants had the option to take ‘time out’ during the interviews, by getting up and walking around, having a drink or getting some air. The tape recorder was to be turned off at this stage if needed, or if the participants chose to leave the interviews. Once the interview was over, I gave individual support and time to the participant if it was still required. Although I was a nurse lecturer with counselling skills, I would not be able to act in a long term supportive capacity. Therefore, if participants required further support, they were given the contact details of my supervisor, and encouraged to contact one of the local counselling services on the list I provided. The counselling services were free of charge, as they were a part of regional health. Also the transcripts of the interviews were returned to each participant for checking, and at this stage, they could modify or remove some of their contributions if they felt the information was too sensitive, or that it might identify them, despite the use of pseudonyms. Fortunately, there was no participant who required further emotional support. They also did not check the transcripts of the interviews, because they trusted in
me that the collected data was correct. This is the Thai way; to respect and trust, without needing to crosscheck details.

*The principle of respect for human dignity*

The participants had the right to full disclosure. They were offered the right to refuse to participate or to withdraw at any time, without penalty of any kind. They had the opportunity to ask questions, make comments, and voice concerns that they had concerning the project. The processes in this research made a strong commitment to equalising potential power relationships between the researcher and participants. This was done by encouraging openness and trust, especially in relation to participants divulging their perceptions about pain and pain management.

*The principle of justice*

Privacy, confidentiality, and anonymity were ensured throughout the research. Strategies included the use of pseudonyms, instead of personally identifiable information. Audiotaped interviews with female patients, caregivers, and nurses about their perceptions of pain and pain management in adult patients with rheumatoid arthritis were protected by the use of pseudonyms and code names. Due to the personal nature of the disclosures, there might have been occasions in which the participants experienced some emotional discomfort related to their perceived vulnerability. Strategies to alleviate this were to assure participants of their anonymity and privacy as mentioned previously, but also to provide open access to the research information concerning themselves only, and to allow them opportunities to comment upon, and to validate the accounts. Moreover, all data collected in the research were stored in locked storage compartment for five years, and the responsibility for the safety and security of it resides with me.

Besides this, I also applied other principles for ethical considerations (Polit and Beck, 2004, p.150-156). There were ‘informed consent, care of vulnerable subjects and the external reviews and the protection of human rights’. 


Informed consent
Copies of the consent form and a plain language statement were given to participants. Participants were included based on the ability to give consent for themselves, to comprehend the Thai language, and to be able to understand the written and verbal explanations of the project I provided. Initially, the consent form, information sheet, and list of counselling services were provided to potential participants by myself or my contact persons at the community organisations. Once the forms were read, and if they wished to proceed, I met face to face with each participant to give further verbal information and answer any questions. An explanation of possible benefits and risks of the research was given prior to consent being given. Potential participants were free to have a relative or advocate present at any time during this process. I informed participants that they were free to withdraw at any time from the research, and any information would be destroyed if they requested it, and their contributions would be removed from the transcripts. I gave the participants the plain language statements, consent form, and local counsellors’ contact lists when I first met them. I read the documents for some participants who were uncomfortable to read. They were glad to be part of research without any doubts. They really trusted me that I needed the data from them for the value of the study and not for personal benefits, and Thai people believe that this is how they are doing merit.

Vulnerable subjects
Some of the participants were younger than 18 years old. I gave them detailed explanation, as I also gave to other participants, but I also asked parents to allow their children to be participants. I was always most concerned to treat all participants sensitively, especially children under 18 years of age, who may have been more vulnerable than adults.

The external reviews and the protection of human rights
I informed the Thai government two months before my research project started. I forwarded to them the ethics submission translated into Thai. Similarly, all plain language statements and consent forms were written in Thai for participants. The Thai
Government confirmed my research and signed the official document for ethical clearance, which was shown to each participant.

**Phase two: Data collection**

After I decided the method and data collection techniques, the next phase was data collection. There were two processes which I applied grounded theory method in this phase, including recruiting participants and the interview process.

**Recruiting participants**

I went to Ratchaburi Hospital, which is the largest public hospital in the province, and had a discussion with the staff at the Medical Records Department. They showed me that there were few patients with rheumatoid arthritis, who were admitted in the hospital. They suggested that I approached the patients and caregivers at home. After I considered the possibilities for recruiting participants, I decided I had a good chance at the largest public hospital. I returned to see the medical records staff, and they gave the contact addresses of patients with rheumatoid arthritis to me. I focused on inviting participants to share their experiences of pain and pain management of rheumatoid arthritis from their perspective viewpoints as patients, caregivers, and nurses.

I contacted the patients with rheumatoid arthritis and their caregivers by home visiting and phoning them when I found their home phone number in the yellow pages. Some nurses suggested patients to me. I asked a person to be my navigator and take me to the participants’ places, because some people lived in the remote areas. I also introduced myself to the Head of Communities, and asked for more help, who obliged, because they understood that I needed the data for research.

When I first met the patients and their caregivers, I established a relationship with them by introducing myself, informing them about my research details, which included ethical considerations, and asking them to be my participants. After talking to them, 10 female patients, who were aged between 31 and 53 years, agreed to participate. They
experienced rheumatoid arthritis between 1 and 23 years. Nine of them were married. Almost all of them graduated from school in grade four (Prathom four). Their occupations were employees, government officers, housewives, seller, and farmer. At the same time, six females and six males for the caregivers agreed to participate. They were between 14 and 60 years of age. Six of them were married. More than 50 percent were the patients’ children. There were five students, three farmers, three employees and one government officer. Their educational status was between grade four and Diploma.

Nurses were the third group of my participants. I visited them in the orthopaedic wards. I introduced myself, informed them about my research details, which including ethical considerations, and asked them to be my participants. Ten female nurses agreed to participate. Their ages were between 27 and 49 years old. Six of them were married, and they had experience in the nursing profession, and in caring for patients with rheumatoid arthritis between seven and 24 years. Four nurses had experiences in the nursing career between 11 and 20 years. They all had a Bachelor degree of Nursing Science, and five of them had training certification in orthopaedic nursing.

The interviewing process

Interviewing was used in this research. Each participant was identified by a pseudonym, and was interviewed initially for approximately one hour. I interviewed patients and their caregivers at home, and I interviewed nurses at wards when they had free time. Biographical data were collected from all of the participants. For the patients, information included age, gender, history illness with rheumatoid arthritis, and background (educational level, occupation, marital status). For the caregivers, information included age, gender, nature of relationship with patient, period of care, and background (educational level, occupation). For the nurses, information included age, gender, years of experience in work, and background (educational level, marital status).

Every interview was recorded by tape-recorder. Pseudonyms were used to protect the participants’ identities, and all data collected were stored in a locked cupboard for a period of five years. All information I received was confidential, and not disclosed to
anyone apart from my supervisor. Although I faced some problems before interviewing, such as not finding patients, and refusal to be participants, I managed to recruit the numbers of the participants I planned. No one withdrew from the research or needed further emotional support. I wrote down some contextual details I observed after I finished interviews. I reviewed the prior interview before I started the next one to confirm that I had focussed the interview questions sufficiently, to achieve the research aim and objectives.

**Phase three: Data Analysis and Interpretation**

After finishing the interviews, I commenced the last phase of data analysis and interpretation. This section describes the analysis process, the interpretation process and trustworthiness.

**The analysis process**

The audio-taped conversations were transcribed verbatim, and the notes were transferred to a computer disk copy. I did not send the transcriptions to the participants, because no one wanted them to read again, because of the Thai tradition of trust. I read, reread and also listened to the tape recordings to make sure that there were no errors. I translated them from Thai to English, and I had discussions with my editor, and also my supervisor to confirm the meaning of words and conversation. Then analysis commenced. Firstly, consideration was given to whether the transcribed data would be analysed manually or by a qualitative software program. In discussion with my supervisor, I decided to use a manual thematic analysis procedure, because the data were manageable by this means. I also needed thematic analysis method which meant ‘a method for identifying themes, essences or patterns within the text’ (Roberts and Taylor, 2002, p.426). It showed ‘the pathway through which the researchers made sense of the words and put them into some order for interpretation’ (Roberts and Taylor, 2002, p.428).

I followed the manual approaches of Roberts and Taylor (2002). I reviewed the research aim and objectives to confirm my sense of the project’s commitment, and reviewed the
main purposes of this research. This was to make sure that I kept them in my mind while I was doing the analysis. I made multiple copies both in diskettes and hard copies. Then I started to read and re-read the transcripts line by line. While I was doing that, I also went through the words and considered their meaning. I preferred the colour coding method. I read line by line, and found connected ideas by marking them with a wide range of colour pens, and jotted my ideas near the marks as shown in Figure 4.1.

Before discussion with my supervisor, I wrote my idea (code) on top of a section of transcript, and listed possible words to describe the codes. We discussed these codes and decided on possible codes. I edited some words after I and my supervisor considered those that were not related directly to my research objectives.

![Figure 4.1 Finding codes by using colouring pens](image)
After I decided on the codes, I put each one on a small card. I reviewed them and put the similar codes on a large surface, specifically on a table cloth, to develop categories (Figure 4.2).

Figure 4.2 Categories

I put this table cloth on the wall in my room. It was very helpful, because I could see all of my codes all the time. Moreover, I could think about them and move them to suitable categories, when it became apparent that they needed to be adjusted.
I re-read both codes and categories to re-check their relationship. Then I grouped the similar categories together. This process resulted in a concept as shown in Figure 4.3.

**Figure 4.3 Concepts**

For ease of discussion with my supervisor, I copied all of my codes and categories onto A4 paper, and included the concepts and the core social processes in it. I pasted many pieces of A4 paper together to make one core social process.

I re-read the concepts and reflected on the core social process (Figure 4.4). In terms of this process, I used a Thesaurus dictionary, an English-English dictionary, an English-Thai dictionary, and a Thai-English dictionary to find the words and verify their meanings. I took the opportunities to discuss, and fill out all of my analysis with other
lecturers and Ph.D. students in the seminar class. I discussed each step of the analysis with my supervisor until I summarised my findings and created the theory.

**Figure 4.4 Core social processes**

For the whole processes, I spent six months collecting the data, and transcribing, translating and editing for eight months. Furthermore, I took nearly one year for analysis, and in this time I discussed each phase with my supervisor and research colleagues. Therefore, the grounded theory that emerged from the participants’ data was systematically and carefully developed.

**Trustworthiness**

‘Qualitative research is no less rigorous than quantitative research, but it uses different words to demonstrate the ways of making explicit the overall processes and worthiness
of a project, because it is based on different epistemological assumptions’ (Roberts and Taylor, 2002, p.378). The word “trustworthiness” is used for referring to validity in qualitative research. Trustworthiness means ‘methodological soundness and adequacy’ (Holloway and Wheeler, 2002, p.254). It is ‘a process to determine the usefulness of qualitative research, including the criteria of credibility, fittingness, auditability and confirmability’ (Roberts and Taylor, 2002, p.539). In nursing research, Sandelowski (1986, cited in Roberts and Taylor, 2002, p.380) applied the ideas of Lincoln and Guba (1981) in relation to trustworthiness in four categories; ‘credibility, fittingness, auditability and confirmability’.

Credibility refers to ‘confidence in the truth of the data and interpretations of them’ (Polit and Beck, 2004, p.430). Lincoln and Guba (1985) suggested that five major techniques support credibility; including activities increasing the probability that credible findings will be produced (prolonged engagement, persistent observation and triangulation), peer debriefing, negative case analysis, referential adequacy, and member checking. One of the best ways to establish credibility is ‘through prolonged engagement with the subject matter’ (Speziale and Carpenter, 2003, p.38)

I applied credibility in my research by using prolonged engagement. I spent seven months recruiting and interviewing participants. Another technique was triangulation using data and investigator triangulation. In relation to data triangulation, I used space and person triangulation. Applying space triangulation, I collected the data in many areas of Ratchaburi Province, because the participants lived in the city, suburbs and other districts. For person triangulation, I collected the data from female patients with rheumatoid arthritis, caregivers, and nurses. They had different backgrounds (e.g. age, educational level, occupation). For investigator triangulation, my supervisor and I always discussed every process of the research from writing the proposal to analysis and interpretation.

Dependability refers to ‘the stability of data over time and over conditions’ (Polit and Beck, 2004, p.434). Lincoln and Guba (1985) suggested two techniques to establish dependability; stepwise replication and inquiry audit. Stepwise replication means ‘a
process that builds on the classic notion of replication in the conventional literature as
the means of establishing reliability’ (Lincoln and Guba, 1985, p.421). Meanwhile,
inquiry audit refers to ‘an independent scrutiny of qualitative data, and relevant
supporting documents by an external reviewer, to determine the dependability, and
by dealing with my data separately from my supervisor, and we discussed our analysis
together, and we also validated with other research colleagues the entire document.

Confirmability (Speziale and Carpenter, 2003, p.347) refers to ‘the objectivity or
neutrality of the data, that is the potential for congruence between two or more
independent people about the data’s accuracy, relevance or meaning’ (Polit and Beck,
2004, p.435). Confirmability of a project is achieved ‘when credibility, auditability and
fittingness can be demonstrated’ (Roberts and Taylor, 2002, p.380). I established
confirmability in my research by asking questions during analysis, which came from
Strauss and Glaser (1967), and Strauss and Corbin (1990). They were: (a) what is
happening in the data? (b) what does the action in the data represent? (c) is the code part
of the participants’ vocabulary? (d) in what context is the code/action used? (e) is the
code related to another code? (f) is the code compassed by a broader code?, and (g) are
there codes that reflect similar patterns? (Chiovitti and Piran, 2003, p.432). After I
developed the code, I always verified what it was. When I arrived at a category, I
considered what this experience was, what this was telling me, how it combined and
how it all related to fulfilling my research objectives. I also asked what the categories
were saying about the phenomenon of interest to me. Moreover, purposive sampling was
used in my research. Participants were recruited until the data were saturated, which was
achieved with 10 female patients with rheumatoid arthritis, 12 caregivers, and 10 nurses.

Transferability refers to ‘the probability that the study findings have meaning to
others in similar situations. Transferability has also been labeled fittingness’ (Speziale
and Carpenter, 2003, p.39) I described the biographic data of my participants, according
to age, years of experience with pain, occupation, educational level, and marital status in
female patients. I described the caregivers’ characteristics of age, years of experiences
for caring for their loved one who had rheumatoid arthritis, occupation, and educational
level. Age, education level, years of experience caring for rheumatoid arthritis patients with pain were characteristics described of nurses. Ensuring that readers had a clear understanding of the participants’ biographic information allows for the possibility that other researchers can use a similar research approach, and that participants’ experiences can resonate with readers of similar circumstances.

Summary

Ten female patients with rheumatoid arthritis, 12 caregivers, and 10 nurses in Ratchaburi Province, Thailand were involved in this research. They were interviewed for their perceptions of pain and pain management for rheumatoid arthritis. Before interviewing, the ethical issues were considered to protect the participants from any risks and harm relating to confidentiality and anonymity.

Manual thematic analysis approaches were used in this research. They included reading and re-reading line by line to find codes, categories, concepts, and core social processes. Three sub-theories combined into one grounded theory of perceptions of pain and pain management for rheumatoid arthritis patients, caregivers and nurses’ views, which will be described in the next chapter.
Chapter Five: Patients’ Backgrounds and Emerging Codes

Introduction

After interviewing the patients, I transcribed the accounts of their experiences, and translated the transcriptions from Thai to English. Following this, I analysed individual accounts. This chapter relates to patients’ backgrounds and emerging codes. The patients were identified by the pseudonyms of Wing, Doom, Da, Dara, Ta, Jai, Ead, Tim, Phit, and Boon. Ten female patients with rheumatoid arthritis were between 31 and 53 years of age. They had been living with rheumatoid arthritis and pain, for periods ranging from one to 23 years. Nine participants were married, and half of them graduated in grade four. Their occupations included employees, housewives, government officers, seller, and farmer. Three hundred and five codes emerged from these participants, involving their perceptions of pain, and how they managed their pain.

Wing’s experience

Background

Wing was first diagnosed with rheumatoid arthritis at the age of 39, when she was a housekeeper in a company. The illness originally started in her wrists and became progressively worse over time, affecting her knees and whole body. She originally went to see the doctor at the public hospital, and continued getting treatment there. Later on, she received treatment from a private hospital, which had a health insurance contract with her company. It was not a problem for her, because she could claim for full fees. She resigned from work after she noticed her knees were more swollen and inflamed. After that, she still had pain when she moved, and therefore she could not do anything well. Sometimes she had to stay in bed and could not walk. Then she continued to get treatment from the public, private hospital, and clinic. One tablet which she procured from the private hospital made her feel better. She bought it from the chemist as self medication. She showed it to the doctor at clinic, who suggested she stop taking it,
because it was very dangerous and made her bloated. She continued to take the medication until her face became swollen. She was dissolutioned with medications, because some could relieve pain, but others could not. She also noticed the pain was still there if she stopped taking all of the medications. Therefore, she sought other ways to relieve pain, such as seeing a shaman and traditional doctor, taking a bolus and decoction, and using massage.

At the time of the interview, Wing was 42 years old and had just started her new job as a chilli picker. She looked weak and pale. Her face, wrists and knees were swollen, but she had no joint deformity. She said she felt bad and suffered very much, because the pain never left her. Her self-esteem diminished when she could not do things for herself. She requested hypnotic drugs from the nearest health centre when she had pain and could not sleep. Fortunately, she felt better after she accepted rheumatoid arthritis was a chronic illness and she was resigned to the fact that she would die when her time came. She tried many alternative treatments, but she was convinced that seeing the doctor was the best solution to relieve the pain of rheumatoid arthritis. She appreciated help from family and care from health care staff, but she still needed more advice about self-care at home.

**Wing’s experience: Emerging codes**

The codes emerging from Wing’s account were: seeing the doctor; noticing taking medication continually; buying medication from the chemist; getting help for mobility from the family; needing to cook; requesting help from family for household tasks; noticing joint stiffness; noticing joint pain; noticing joint swelling; tolerating rheumatoid arthritis; getting medication from the public and private hospital; noticing decreased ability after having pain; becoming depressed, disheartened and stressed; taking hypnotic drugs; losing weight; experiencing loss of self-esteem; talking with the others who had the same symptoms; helping self at toileting; getting hot stream treatment; getting advice about exercise through walking; not getting advice about work; getting advice for food choices; doing light tasks; maintaining hygiene; doing meditation and bathing in holy water to relieve pain; using decoction; seeing a shaman; confirming the
best way to relieve pain is seeing the doctor; being unable to eat when having pain; taking a bolus; managing gastric irritation from medications; continuing hospital treatment again; being advised by husband to accept rheumatoid arthritis; using massage; seeing traditional doctor; expressing acceptance; feeling anger; believing in karma; needing sympathy from the family; appreciating visits from the daughter; recognising getting good care from the doctor; realising doctors prescribe medication; recognising good care from nurses; wanting more advice about self-care at home; taking medication for pain relief; and wanting to know more about food.

**Seeing the doctor**

*At first my wrists were stiff so I went to see the doctor. He told me that I’d got rheumatoid arthritis. After I’d had treatment for a while, I started to get pain in my knees and legs. I still worked at that time. I couldn’t stop working. I worked until my knees became swollen ... Yes (I saw the doctor immediately when my wrists were stiff).*

**Noticing taking medication continually**

*I always took medication but I still had pain. I had pain all over my body. It was still there although I’d taken the medication. Sometimes I had pain, but sometimes I felt better, but I couldn’t stop taking the medication. If I stopped or didn’t take it continually, I would get pain again. I was treated at the hospital but I didn’t get better ... I remember one kind of medication. It was a pink tablet. It was very good. I remember that I got it from the private hospital. I know it was an inflammatory drug. I remember it helped me but my doctor didn’t give me this medication much, because it made me bloated. It was very dangerous ... I was in a lot of pain and my body became swollen immediately if I stopped taking it. The medication that doctor gave me didn’t relieve my pain. I tried to make sure I got continuous treatment. Sometimes I got better, but sometimes I didn’t. I had to take medication all the time. After I resigned from the company, I only got treatment from the regional hospital. I usually took the medication, but I still had pain. I didn't know what I could do. I still suffered from pain in my joints.*
Buying medication from the chemist

I took some of it to the chemist to buy some more. Even though I took it, I still suffered from pain. When I took a lot, my face became swollen … Yes (my face became swollen from this pink tablet). I showed it to the doctor at his clinic. He told me that it was dangerous. It made me bloated. He told me that I shouldn't take too much of it. The doctor at the private hospital didn't give it to me any more either so I bought it for myself from the chemist. I couldn't stop taking it.

Getting help for mobility from the family

After I felt a bit better, I stayed home and did my household jobs again. There was a time when I couldn't walk. If I wanted to walk, I had to hold on to something. I couldn't cook food. When I had pain, my husband carried me and laid me on a bed in the kitchen. At that time, my children weren’t at home, because my daughter was married and living with her husband. My sons, one went to school, and the other one lived in Bangkok … They had to carry me when I wanted to go to the toilet … The doctor treated me well … When I was in a lot of pain, I couldn’t get out of my bed in the morning. I had to get some help from the others. They had to pull me straight up so I could walk. I couldn’t squat. I had to sit on the floor and extend my legs … I had wrist pain on the left. They held me by the right hand and my shoulder and pull me up… My legs were already extended … No (I couldn’t get up by myself), especially when I had a lot of pain. They helped me to sit so I could control my body. I got my balance before I walked. I had to sit before I walked … I couldn’t walk at all when my legs became very swollen. There was some fluid congestion in my legs. At that time, my knees were always bent and I couldn’t extend my legs. My family had to carry me when I wanted to go to anywhere, because I couldn’t walk … Yes (they carried me even though my knees were like this). When I went to the toilet, I couldn’t squat. I had to sit in that position … Yes (I felt uncomfortable), but I had to accept it.

Needing to cook

I had to cook food by myself. If I let my husband and my son cook, they were very messy … My husband always did that because he stayed with me all the time when I was admitted to the private hospital for 11 to 12 days.
Requesting help from family for household tasks

I only used to lie down during the day, and sometimes walk around my house by holding the wall. I couldn’t do things at all. I asked my sons to do things when they came back home in the evening. I did what I could and asked them to do what I couldn’t … She (my daughter) did (helped me a lot when she was here), because she didn’t go anywhere. She was always calm. She cooked food and took care of me while I ate. She did things for me without my having to ask. I was well looked after … Everyone (did the household jobs and other things around the home), I mean my husband and my sons. I asked my sons to cook rice and buy ready-cooked meals from the shop. Everyone helped me. I managed the medication by myself. If my daughter was here, she prepared food for me. I had to do it by myself after she got married. My sons weren’t interest in this. Sometimes it was difficult for me to cook during the day when everyone was at work. I had to buy some desserts and kept them in the fridge. It was good if my daughter stayed here. My sons weren’t very good. My husband was very good. He didn’t go out anywhere after he came home. He always looked after me … Now there are only my sons. They don’t help me with this. They help me to feed the pigs and wash the dishes … No one was home so I had to do it (even though I had pain) … I needed them to help me to do the household jobs when I’d finished work and had come home. I had to collect the chillies and some vegetables. I was tired because of my job. I needed my sons to help me with this. I became worse if they didn’t help me. We didn’t have much money although my husband and I both had jobs. We had to pay money for things we had on lay-buy. I felt bad if I just lay down at home all the time. At least I could support my family with buying food. I got 120 Baht per day ($A5) for watering the plants and 70 to 80 Baht per day ($A2.92 to $A 3.33) for collecting the vegetables.

Noticing joint stiffness

At the beginning, they were stiff before they became swollen and painful … My wrists were stiff more than they were swollen. They were stiff and my blood vessels were green.

Noticing joint pain

You can tell that rheumatoid arthritis patients suffer a lot of pain if they stop taking their medication … I couldn’t move my body. If I tried to, it was very painful.
Noticing joint swelling
The parts they have pain in become swollen ... My knees became very swollen.

Tolerating rheumatoid arthritis
At the beginning, I thought it would disappear after I got treatment. After I’d had treatment for a while, the doctor told me that I had to accept that. Rheumatoid arthritis is a chronic disease, and it is difficult to cure completely. I had to take the medication all the time. I didn’t know what to do but tolerate it ... I didn’t know what to do. I sometimes thought I had to accept my life like this. Pain was still there and I didn’t know how to get it out of my life. This was to be my suffering. I was like a paralysis patient. I couldn’t go anywhere. My body looked bad, because I was so thin.

Getting medication from the regional and private hospital
I went to the regional hospital first ... Many months (that I got treatment from there). They were able to cure me there as at that time I only had pain in my wrists ... I only had pain in my wrists at that time. I was not in a lot of pain. I changed to the private hospital, because I still worked as an assistant for the company. My company had a health insurance contract with this hospital so I changed hospitals ... They covered all of my expenses ... I had to get the medication every week if I was being treated in the private hospital. I went to get the medication every two weeks if I was being treated in the public hospital ... When I went to the public hospital, they checked my symptoms before they gave me the medication. If I’d got better, they gave me more of the medication to take home and then I didn’t need to go there every two weeks.

Noticing decreased ability after having pain
Before I had pain I was very strong. I could do a lot of things, such as cutting the sugar cane and digging potatoes. After I had pain I couldn’t do those things. I was glad that I still worked with the company. Later my health became worse. I was thinner and couldn’t have food ... I was an assistant. I had to clean all the offices. There were five floors. I cleaned the offices, served coffee when the guests came to the office, and took the calls when the secretary was not there. It was not heavy work. The difficult thing was cleaning the fifth floor, because there was no lift to that floor. I had to take the stairs.
My knees became inflamed when I walked up and down them. I worked there for three years. I had to get off my feet, because my knees became so swollen.

**Becoming depressed, disheartened and stressed**

Yes (my emotional state changed after I had pain). I became depressed, because I still had pain even though I always went for treatment. Pain never left me. I felt bad and suffered very much ... Yes (I felt disheartened), I felt disheartened and stressed.

**Taking hypnotic drugs**

Sometimes I couldn’t sleep, because I was so stressed. I had to take hypnotic drugs ... I bought them (hypnotic drugs) from the doctor at the hospital or the health centre. They gave me 10 tablets at a time, because I was very thin and couldn’t sleep ... I didn’t take hypnotic drugs every night. I took them if I was very stressed. I was nervous and couldn’t sleep. I couldn’t close my eyes either. I slept in the early morning. If I took them, I could sleep and I didn’t take any the next day. I worried I would become addicted, because the doctor told me it was not good to take too many. They could cause heart palpitations. He gave me 10 tablets at a time. He gave them to me when he found that I was very stressed. I thought I would get more stressed, because I couldn’t do things for myself and I was very thin ... I was very tired and I slept (when I didn’t take this medication during the day).

**Losing weight**

Yes (I felt I was thin), I was very thin. My weight went from 48 kilograms to 39. That was my latest weight after I was discharged from the hospital.

**Experiencing loss of self-esteem**

My self-esteem diminished until I almost had none, because I couldn’t do things for myself. I thought about this a lot. I couldn’t help my family. I was like someone who had lost heart and had no interest in doing anything. I used to lie down on a long bench in front of my house. I saw my neighbours going to work. I felt sad. I wanted to go to work with them. I thought about the time when I could work and then about this time that I couldn’t. I used to cry. I think I cried more than anything.
Talking with the others who had the same symptoms

I used to ask if they had the same symptoms as me. I saw one person who had knee pain and had swelling the same as me, but they still could walk by themselves. They walked lamely. I didn’t know why I couldn’t walk and they could. They might have had less pain than me ... We talked about why we’d got pain.

Helping self at toileting

I used my right hand ... Yes (I did it by myself even though it was painful for me). I had to because everyone in my family was at work ... It (my toilet) is a standard toilet that every home has. It was difficult when I went to the toilet ... I used my elbows (to hold when I was in the toilet). There was a low bowl that I could press my elbows on to support me when I went to the toilet. When I finished, I used my right elbow to support me and yelled for my family.

Getting hot stream treatment

Someone told me about them, but I never used them. There was a hot stream treatment at the hospital. They applied it to my knees, legs and wrists. They advised me to do it when I got back home. I had no equipment to do that here so I didn’t do it.

Getting advice about exercise through walking

No. They didn’t (tell me that I could improvise with some equipment at home as I didn’t have the hospital equipment) ... They told me that I had to exercise, because it would make me better ... They (both public and private hospital) told me that I had to exercise a lot ... They only told me I had to exercise. They didn’t tell me which exercises I should do and which I shouldn’t do ... They told me I had to walk ... No (they didn’t tell me the best way for to walk and how to protect my joints from the walking).

Not getting advice about work

No (they didn’t tell me what jobs I could do even though I had to work and do household jobs) ... No (they didn’t tell me whether I could work or not) ... They didn’t tell me about this (work may affect my body).
Getting advice for food choices
But they advised me about food ... They advised me to have a lot of fish and try to have something from all of the five food groups. That would make me healthier ... No (they didn’t tell me what foods were in the five food groups). They thought I knew.

Doing light tasks
I did all the household jobs except washing the clothes, because I couldn’t ... I get pain after I scrub the clothes, because I have to scrub the uniform with a brush. I can do light jobs, such as cleaning the floor. When I went to work, I couldn’t do the heavy jobs such as digging the grass or carrying big things. I could only collect the chillies or vegetables. My wrists were not good ... I couldn’t lift the full bowl when I took a bath. It was very painful for me if I did ... I put a little water in the bowl and lifted it. I had to do it by myself ... I got pain more, but I had tolerate it. I didn’t know who could help me to do it.

Maintaining hygiene
I used to do that (washed myself with cloths instead of taking a bath) when I had a lot of pain and my daughter stayed here.

Doing meditation and bathing in holy water to relieve pain
Yes (I did meditation). I used to bath in holy water for three days. They said that the pain would disappear if I did that. They prayed for me too ... My neighbours (advised me to do that). They said that my illness would be gone after I’d done it for three days. I did it for three days, but I was still in pain ... It (the place that I did) was not far from here. It was a person’s home and that person organised it. I did it for three days. I’ve been there with my husband. My children didn’t know about it.

Using decoction
I’ve never used massage, but I have used a decoction. I bought one pot. It cost 800 Baht ($A 33.33) ... I listened to the radio. There was one temple that sold the decoction. I was admitted to the hospital after I’d had it for one day and one night ... I felt hot inside after I’d taken it. It made me weak and I had diarrhoea too. I was admitted the next
morning. I paid 800 Baht ($A 33.33) for it, but I just had to leave it out in front of my house (laughed) ... No (I didn’t know the ingredients in the pot), because it came in a pack ... I just listened to the radio. They said that this decoction could treat every disease including diabetes mellitus. So I went there with my husband. I bought it, boiled it and took it. I was admitted before I knew whether it could relieve my pain or not. I wanted to try it, because I was in pain even though I took the medication from the hospital.

Seeing a shaman
Someone told me I had pain, because the Feng Shui of my home was all wrong. So I tried to see a shaman ... He was approximately 20 kilometres from here. I went there. He told me to move Pra Poom’s sacred area (San Pra Poom) to a better place. I did, but my pain was still there.

Confirming the best way to relieve pain is seeing the doctor
Finally, I stopped trying these other ways and just went to see the doctor ... I tried every way to relieve pain, but the best way was by seeing the doctor. I found that I could work within three years after the doctor had treated me.

Being unable to eat when having pain
I couldn’t have everything when I was in a lot of pain. Sometimes I had boiled rice and salty egg (Khai Khem), but other times I just couldn’t eat them. Sometimes I had rice with fish sauce or salt when I couldn’t have anything. When I saw the food, I was bored with it. I tried to have it, but I couldn’t. It was like I couldn’t swallow it. I had to have ground rice when I was in a lot of pain. I was very thin at that time. When my neighbours saw me they said they thought that I might die. I thought the doctor tried the medication on me when I was admitted to the public hospital, because I always vomited after I’d taken it and had food. I was like that for a week. I asked him for an intravenous fluid. He said no and then said something that I couldn’t understand. He gave me a new medication the next day. I still vomited even though he changed the medication. In the third week he gave me a different one that didn't make me vomit, but I couldn’t have food again. I could only have a little boiled rice. He advised me to have a bland diet too.
After that, he asked me how I was. I felt I wasn’t any better, but I told him that I was better. I thought that I would rather die at home if I had to die. I was discharged and came back home.

Taking a bolus
I felt better after I took two packs of bolus. They cost 120 Baht per pack ($A5 per pack) … I got them from a neighbour, who told me that a paralysis patient could walk after taking this bolus. I tried it and felt better. The pain would still be there if I stopped taking this bolus. Many neighbours took it. They didn’t go to see the doctor.

Managing gastric irritation from medications
I haven’t been there for a while (taking the medication from the doctor and getting it from the hospital every two weeks) … Sometimes I had stomach ache after I’d taken it, so I didn’t take it all the time … I still had pain. When I was in a lot of pain, I had to get the medication. After I’d taken it, I had stomach pain too … Yes (I told him that I had stomach ache too) and the doctor gave me other medication … He gave me antacids … I got better (after I’d taken rheumatoid arthritic medication and antacids together) … I had stomach ache again if I stopped taking the antacids.

Continuing hospital treatment again
I still go there (hospital). I have to go there even though I am getting better. The next time I’m due to go there is in two weeks.

Being advised by husband to accept rheumatoid arthritis
My husband told me to accept it. He said I had to do that, because rheumatoid arthritis is a chronic illness. He took care of me very well. My sons didn’t say anything, because they were only young. They usually looked at me, but didn’t say anything. My daughter often complained about the time it was taking to be completely cured. My husband is the best at caring for me.
Using massage

He couldn’t do a lot for me, because he had to work. He massaged me when he came home. He and my youngest son usually massaged me. My youngest son is a very good masseur, because he puts more pressure on and makes me feel better. The doctor gave me some balm to massage in. It was in a tube. He told me when I had pain I could still massage, but with only a light pressure ... I heard that some temples have oil for massaging, but I’ve never been there or tried their oils.

Seeing traditional doctor

Someone advised me to see a traditional doctor. I saw him once. My friends and I rented a car to go there. He didn’t do anything more. He only checked my pulse and told me that my joints were not good. He didn’t give me any medication.

Expressing acceptance

Sometimes I wished the pain would disappear. I didn’t have much hope, because the doctor told me that it was a chronic illness. I would have it all of my life. I only thought I would take one day at a time. I didn’t know what I could do. I didn’t know when I would die. I lived day by day. It was all right. It was fine for me ... I used to think about death, because of the pain I suffered. My daughter was married and my sons didn’t look after me much. But I thought again and knew that I should live, and I would die when my time came. I felt better after I’d thought that. I think everyone should think like this, because there is no better way to do it.

Feeling anger

Yes, because I needed to (feel anger) until I was completely cured. I suffered very much when I had pain. It was all right if I could lie down. But it was painful if I moved my body. It made me suffer, but not die. Sometimes I became angry not knowing why it wouldn’t disappear. Anyone who has the disease will understand this.

Believing in karma

Yes (I wondered why I got rheumatoid arthritis and not someone else). I thought about this a lot. Why did I get it when I wanted to work? I thought about it, but I didn’t know
what I could do. I got it, because I committed sin in the past. I’ve never killed an animal during this time. Maybe I did in the past. I felt better after I’d thought like this. I stayed in the temple for nine days. At that time I thought it might make me get better. I stayed with the nuns. I had a vegetarian diet during my stay there. I hoped I’d be able to stay there for 10 days, but I was admitted to the hospital on the ninth day.

**Needing sympathy from the family**
Sometimes I needed them to (sympathise with me when I cried) but they didn’t, because they are men. My husband often told me that I should not think too much about it and not to mind about my sons. I should take care of myself as much as I could. So everyone was all right to me. He said it was good that I could have food.

**Appreciating visits from the daughter**
Yes (she visited me after she married). She bought fruit for me every time she visited. Now she can’t visit me very often, because she lives a long way from me, she hasn’t much money and her baby is very young.

**Recognising getting good care from the doctor**
The doctors took care of me well, especially the doctors in the public hospital. They always looked after me day and night. The doctors in the private hospital often did their rounds and went. The doctors in the public hospital were better.

**Realising doctors prescribe medication**
I need them to see me a lot; as much as they can. I felt better after they’d seen me and given me some drugs. Nurses couldn’t do anything more, because they had to wait for the doctors. They didn’t give me the medication if the doctors hadn’t prescribed it.

**Recognising good care from nurses**
Yes, they did (nurses asked me again about my pain or inform the doctors after they’d given me the medication). I mean the nurses in the public hospital did. The orthopaedists and nurses in the public hospital were very good. The nurses often informed them (the doctors) how the patients were.
Wanting more advice about self-care at home

I need them to advise what I can do when I come back home, how I can relieve the pain and what food I can have. I don’t know what foods are good for me and what aren’t. I need them to advise me about how to exercise ... I thought sleeping was the best thing for me. I needed them to advise me what I could do if my legs were painful, and what I could do to improve my joints. If they advise the patients, we might do it. It would be better if my pain was completely cured.

Taking medication for pain relief

I continued to get the treatment, but I was still in pain. I was in a lot of pain if I stopped taking the medication. I had to see the doctor all the time. If I didn’t go to see the doctor, they sent me a letter to remind me. They worried that I might get pain again ... Yes (I mean the letter from the public hospital). They cared for me well there.

Wanting to know more about food

I thought I had pain from rheumatoid arthritis, because I worked very hard. The doctor told me my joints had degenerated and my synovial fluid was gone. Maybe I’ve remembered the wrong things. I would like to ask the doctor what foods I can have to build up the synovial fluid in my joint.

Doom’s experience

Background

Doom was diagnosed with rheumatoid arthritis approximately one year before the interview. She was fatigued and her whole body was in pain. Her joints were stiff and painful, especially her wrists and feet. Two or three weeks after the first signs and symptoms, she went to see the doctor, who tested her blood and gave her some medication. She went to see the doctor at a public hospital in Bangkok, because she still did not know what was wrong with her. She was admitted to hospital many times before she knew she had rheumatoid arthritis. She noticed she usually had pain when the weather became colder. She said her life had changed very much since diagnosis. Her
parents had to lift her from the bed in the morning, and she was able to do her daily activities in the late morning. She sometimes was off work for a long time. Her employer allowed her to work in the office when she had pain, and asked other colleagues to do her outdoor work.

Doom had many options to manage her pain besides getting the treatment from the doctor regularly. She took paracetamol and used hot compresses when she was in pain. She took hypnotic drugs when she was in pain and could not sleep, and supplements and herbs, which her friends suggested. She tried to exercise when the pain was absent.

At the time of the interview, Doom was 31, single, and she had already finished her Bachelor degree. She worked as documentary staff of the local government. She said she felt better than before, but she still wanted to know when her pain would disappear. Although she received advice to continue treatment, she still needed more suggestions about the diet and exercise. She often felt disheartened and cried, but her parents supported her well, especially her mother. She sometimes wondered how she would manage to if she had had no parents.

**Doom’s experience: Emerging codes**

The codes emerging from Doom’s account were: experiencing joint pain, swelling and stiffness; seeing the doctor; noticing cold weather is related to pain; worrying about the diagnosis; crying with pain; recognising life changed; receiving help from parents; helping self to move; controlling foods; taking supplement; getting help from the colleagues to adjust work practices; staying in the same place; feeling disheartened; feeling loss of self-confidence; feeling worse; lying down; waking up with pain; exercising when pain has gone; becoming thinner; describing pain; soaking in the warm water; taking hypnotic drugs; applying fomentation; using herbs; being unsure about doctor’s medications; getting advice from others about medication and supplement; attending hospital; thinking about trying a new herb; having equipment to support walking; using massage; noticing doctors order analgesics and nurses give them;
keeping warm when working; wanting to continue treatment; wanting more care from health care team; and appreciating care from family.

**Experiencing joint pain, swelling and stiffness**

*Over a year (that I had rheumatoid arthritis and pain). I’ve had rheumatoid arthritis since last year ... I was fatigued and my whole body was in pain. My joints were stiff and painful too. I was like that for two or three weeks ... My wrists (were painful). They were swollen and stiff. Sometimes I couldn’t walk, because my feet felt as if they were sprained. They were painful and contracted ... I usually had pain in my wrists and feet and sometimes all over my body ... I had it (pain) for a long time before the doctor knew what was happening to me.*

**Seeing the doctor**

*After that (I was stiff and painful), I went to see the doctor and he did a blood test ... At first he didn’t know what my disease was. He tested my blood and gave me some medication. I went to see the other doctor at the public hospital in Bangkok. I still didn’t know what was wrong with me although I’d paid more money to go there.*

**Noticing cold weather is related to pain**

*When the cold weather came (I usually had pain).*

**Worrying about the diagnosis**

*(Laughed) I thought “What a way to treat me! Why doesn’t he know ...what’s happening to me?” (after I went to see the doctor the first time and he didn’t know what my illness was) ... I was worried about what disease I had ... Yes, I did (thought about what might happen to me in the future). I thought that I didn’t want to live when the pain was bad. I was admitted five times. The fourth time I was admitted with weight loss, jaundice, and dyspnea. I had to lie down instead of sitting. I wanted to demand that they admit me instantly, because the admission process was so long. I stayed in the hospital for a week. At that time I thought I might die, because my illness was so severe.*
Crying with pain

(Laughed) I cried when the pain was bad, because I felt I couldn’t tolerate it. Sometimes I took a lot of paracetamol to relieve the pain too. I couldn’t get to sleep till the next morning. My eyes were puffy when I couldn’t sleep at night. My mum told me that I should be patient ... I cried a lot.

Recognising life changed

My life has changed very much. I couldn’t go to work. I was off work for a long time and I felt disheartened ... I had a lot of red spots and a rash on my skin, especially on the areas that aren’t covered by clothes, such as my face, neck, arms, and legs. My skin was dry too ... Yes (my joints swelled), but they’ve been better for a few months ... They were painful and stiff and I couldn’t flex them. Not all the joints were affected all the time. Sometimes only two or three fingers were affected. When they were swollen, I had to apply the ointment or balm to them till they were warmer ... They (feet) were the same as the fingers. Sometimes I couldn’t walk well and couldn’t lay my feet on the floor. I looked like someone who had sprained feet ... Yes (laughed). Normally I could get up by myself. When I had pain, my mum had to lift me from the bed.

Receiving help from parents

She (my mum) supported my neck and tried to push me forward till I could sit. After that she helped me downstairs ... In the early morning, I couldn’t walk. I did my daily activities in the late morning, because that was the time that I felt better. My mum washed my body for me if I couldn’t get up ... Normally I cooked for them. When I had pain, my mum cooked for me. My dad took me to the hospital, because my mum couldn’t ride the motorbike. If I couldn’t sit, he would rent a car to take me there ... My mum took care of me so much. When I complained, she said that I needed to accept that I had the disease ... she did things for me. She looked after me during the day when I was admitted, and held me when I went to the toilet ... I didn’t need to go very often. If I wanted to go to the toilet, my parents helped me to get there ... Yes (that some rheumatoid arthritis patients couldn’t wear clothes that are too fitted while they were in pain), especially when you want to take off your clothes or wear a bra. For me, my mum had to help me to do that.
Helping self to move

I sat and slid my body into a horizontal position. I couldn’t walk (laughed) ... I tried to move my bottom along the floor. Sometimes I yelled for mum to help me ... If I couldn’t walk, I held the bar and moved my buttocks to the next stair.

Controlling foods

I didn’t have salty food although I really love it. The doctor told me that I should have a low salt diet ... Now, I can have as much to eat as I’m able. But sometimes I can’t have a lot ... I had to have tasteless food, a low salt diet, and a low fat diet too ... I can have a little. Food’s not as tasty without them ... They told me that I should avoid a salty diet ... I want them to make suggestions about the diet that I can have, because I have to learn by myself.

Taking supplement

When I had pain, I only had the hospital’s diet and one supplement. It’s like the medication one takes for painful joints. It’s a product of a Beauty Company. But it didn’t relieve my pain ... I took Lin Chu mushrooms. They made me feel better ... My friend (suggested that) ... (it is) in a capsule. I have to have three capsules a day, but I only take two capsules a day, because they’re so expensive. I bought a small bottle. It costs 800 Baht ($A33.33). They revive me ... I’m not sure, because I’ve only been taking them for four months, and I’ve had a little pain.

Getting help from the colleagues to adjust work practices

While I worked for the local council, I often rang my colleagues when I couldn’t go to work ... At that time, I worked on a finance project ... I worked on office documents and tax matters. Sometimes I had to work outside with my colleagues ... Yes (I worked outside while I had pain). Fortunately, my employer allowed me to work in the office if I had pain. Sometimes he allowed me to stop work for a month. Sometimes I had sudden pain while I was working outside, and I couldn’t ride or control the motorbike, but I had to be patient (laughed) ... They didn’t say anything (when I stopped work for a long time), and they did my job for me too.
Staying in the same place
I always stayed in the same place, such as upstairs (laughed).

Feeling disheartened
Sometimes I felt disheartened (laughed) and didn’t want to live. My mum always told me “Dear…you should be patient. It will disappear soon”.

Feeling loss of self-confidence
It (my self-confidence) diminished until there was none left.

Feeling worse
I felt worse.

Lying down
I didn’t do anything. Sometimes I just lay down all time.

Waking up with pain
At 6 am (that the time I normally woke up) and sometimes at 5 … 2 or 3 p.m. (the time I woke up when I had pain) … When you have pain, you can’t sleep. When I was nearly asleep, I would wake up again. It was like that until I couldn’t sleep at all.

Exercising when pain has gone
Sometimes I moved my wrists, because my mum told me that it relaxed the joints. I jumped and clapped my hands above my head too … I don’t do it much. (laughed).

Becoming thinner
I was thinner … I didn’t feel strong. I was a lot thinner.

Describing pain
The pain was intolerable … I want to know when the pain will disappear.
Soaking in the warm water
I soaked my hands in warm water when I was in a lot of pain. I felt better after I did that … (I did it by ) Myself. I boiled the water, mixed in the cold water till it was warm, and then soaked the parts that were more painful. Sometimes I put the warm water in a bottle and lay it on my joints. It relieved my pain.

Taking hypnotic drugs
I took it too. I got it from the doctor … Sometimes, when I was in a lot of pain. After I took it, I slept better. I took paracetamol with it. I got both of them from the doctor. They gave me 10-15 tablets of each.

Applying fomentation
Frequently (I applied fomentation). I did it when I first had pain … I did it four days a week. I did it in the morning or in the evening after I got back home … I felt better (after I did it).

Using herbs
Sometimes. My mum cracked the root of bamboo (it looked like curcuma) till it was like a soft paste. After that she used it to foment or massaged it in, or she applied it to the painful area. It made me feel warmer … Yes (it relieved pain) … After I took the herbs, I felt better at the beginning, but not in the long term.

Being unsure about doctor’s medications
I took the medication that the doctor gave me, some herbs, and fomentation … I’m not sure which one was the best, because I felt better after I took only the medication that the doctor gave me in the first week, but I had pain again in the second week.

Getting advice from others about medication and supplement
Someone suggested that I have a treatment from a doctor that she knows. At first I felt better after he had given me an injection to relieve my fatigue. But I was worse later. The last time that I got the treatment from him I bought his medication and supplement. The supplement costs 800 Baht per can ($A33.33).
Attending hospital
Many places, but I can’t remember them all. The regional hospital in my province was the first place. I was admitted there five times ... I wasn’t admitted there continually. Sometimes I was admitted again after I had been discharged for two or three months ... I went there (private hospital) sometimes before I went to the regional hospital.

Thinking about trying a new herb
Someone told me about it before, but I never did it. Now, my colleague has suggested to me that I have black sesame seed; one spoon everyday. She said that it can cure my disease, but she forgot where she got the formula ... You roast it in a pan till it’s brown. After it’s roasted, you can have it as it is or mix it in with rice. She just suggested this to me yesterday ... I think so. She also told me that our youngest Princess got better after she took the meditation for pain relief at the seven temples in Bangkok. She said that I should try to do the same. Perhaps then I will be better.

Having equipment to support walking
Sometimes I used a stick to support me when I walked ... My home has a bar installed on the stairs. I use it to support myself when I want to stand up.

Using massage
He (my dad) massaged me when I was in a lot of pain ... At the beginning when I thought I had a sprain, my sister-in-law, who had taken a traditional massaging course, did it for me. But it made me worse. My joints became more swollen, and my hands looked stiff.

Noticing doctors order analgesics and nurses give them
The doctor gave me the medication, and the nurse gave me some paracetamol too. After they did that, they didn’t come back to see me again. Sometimes I had to be patient even though I was in so much pain ... They asked me how I was and if I was in a lot of pain. They gave me some paracetamol ... They gave me medication one day and asked me the next day ... He (the doctor) did his rounds on a certain day.
Keeping warm when working

*My room is open air, but we have an air-conditioned room upstairs. I will wear thick clothes if I have to work in that room.*

Wanting to continue treatment

*Yes (I want to continue treatment). Now I can say I am getting better, because the doctor decreased the dose after I went for a follow up visit at the hospital last month. He cut my medication to a half tablet per day ... They told me that I should continue the treatment.*

Wanting more care from health care team

*I want them to look after the patients as much as they can.*

Appreciating care from family

*It’s enough for me, because they’ve (my parents) helped me so much, especially my mum. Sometimes I think about what would have happened to me if I’d had no parents.*

Da’s experience

Background

Da was a 49 year old housewife and farmer. She graduated from school in grade six (Prathom six). She first realised that there was a problem when she sprained her neck, wrists, and fingers during Songkran Festival 2001, and she could not look to the left and right. Firstly, she took a decoction, but the pain persisted. Then she went to see the shamans, one of whom said there was nothing wrong with her, but another suggested she may have done something wrong to one of her ancestors. He suggested she see another shaman, who had a very strong record in solving black magic problems. After she had been to both shamans, she knew she was more alert, and she did not become nervous. She thought about her condition continually, so she went to see the doctor at a clinic. She did not get better after her initial visit, and had a knotted feeling in her stomach after she took the medication he prescribed. Finally, she went to see a doctor in a hospital, and
he told her she had rheumatoid arthritis. Da noticed cold weather affected her whole body. When she had pain from rheumatoid arthritis, her body and joints were swollen. She felt depressed when she could not do anything by herself. She also was very depressed that she could not have the food she liked.

She asked the doctors if the pain of rheumatoid arthritis could be completely cured. Every doctor said it was difficult, so she accepted her illness on reflecting that everyone had to die when their time came. When she had pain, she looked after herself by being careful with her diet, and getting the treatment continually. She lay down for whole day, massaged her joints with oil, and stopped working while she had pain. She sometimes exercised after the pain abated. Before finishing the interview, Da said she used to be admitted to the hospital. She received advice from the doctors and nurses about exercise and hot compresses, but she needed them to inquire how she was after they gave her medication. She did not want more help from her family, because they always supported her as much as they could. She was impressed they had never said anything to cause her hurt.

**Da’s experience: Emerging codes**

The codes emerging from Da’s account were: causing pain; noticing joint pain; noticing joint swelling; noticing joint sprain; suggesting cause of pain; getting treatment from the hospital; taking decoction and bolus; needing help from family for mobilisation and household tasks; using herbs; getting medication and injection treatment from the clinic; seeking many treatments; seeing the shaman; preferring the doctor’s treatment of only taking medication; expressing acceptance; gaining advice about food; being unable to do housework; noticing cold weather can cause pain; keeping the body warm; feeling depressed; stopping work; being unsure that Buddha’s teaching can relieve pain; lying down in bed regularly; taking medication; accepting psychological help from family; tolerating pain; appreciating visits from son; exercising in the morning; bathing in holy water and doing good deeds; appreciating care from doctors and nurses; proving independence; applying hot compresses; trying not to focus on pain; being alone when having pain; appreciating advice from patients with rheumatoid arthritis; appreciating
care from family; needing doctors and nurses to inquire about health; and feeling disheartened.

Causing sprain
I sprained my neck when I swung it from left to right. I got better after I took the medication.

Noticing joint pain
I got joint pain later. I had to hold on to a pole when I wanted to change my position from sitting to standing.

Noticing joint swelling
I’ve had swelling since last year ... My wrists, joints, and face became swollen. My eyes looked red ... I had swelling at my wrists and knuckles. They became bigger. It felt as though a force inside my body was pushing them, making them swell. Now they look better ... Now my neck has become swollen. It looks like the energy from inside my body has been forced into my neck. This symptom subsided after I took the medication.

Noticing joint sprain
I felt sprained at my neck, wrists, and fingers. My neck felt the most sprained. I couldn’t look to the left and right. When I was admitted to the hospital, I couldn’t get up because my whole body felt sprained. It felt worse if my muscles contracted.

Suggesting cause of pain
I started to get it (pain from rheumatoid arthritis) last Thai New Year. I was lucky that I could walk without using the walker or sticks. The swelling in joints went down. At that time, we organised the priesthood ceremony for my son. While I was at the ceremony, my body shook. I felt tight and couldn’t turn my neck. I asked my husband if we’d done something wrong to our ancestors and whether they’d lit the incense and informed them or not. I wondered why I was like this although he said he had. It happened quickly.
Getting treatment from the hospital

I stayed in the hospital for three days. I couldn’t get up and walk at all. I sprained my knees. I got the medication from the doctor, but it didn’t make me any better … I got better and could walk again after I was admitted … I had to get the medication from the private hospital too … I’ve been to the private hospital twice … Yes (I got treatment at both the public and private hospitals), as well as taking the decoction too. I stopped taking the decoction. I still took the medication from the private hospital.

Taking decoction and bolus

I sought other treatment and bought a decoction. It didn’t make me any better although I took three to four pots of it … My neighbours advised me (to get the decoction). They were being sold direct. Salespeople drove to my village and sold the decoctions. Someone told me they’d got better after they’d taken this particular decoction. A neighbour who lives close to me had the condition where the bone presses the tendon and ligament. This condition was completely cured after he’d taken it. I bought it when I knew about his experience. It cost 500 Baht per pot ($A 20.83). I was admitted after I took this decoction, because my body was stiff and I had a knotted feeling in my stomach … I got it (decoction) from two places; they sold it here and at that temple. I felt relaxed after I’d applied the oil. I stopped taking the decoction, because it was very difficult to take … He (the doctor) told me it made me swell up, and I should stop taking it as soon as I could. I had diarrhoea after I took the decoction, and I had a knotted feeling after I took the bolus. My joints became better after I stopped taking them. Now I’ve stopped taking both the decoction and the black bolus … I got it (decoction) in a pack, and I didn’t know how many ingredients were in it. I relied only on what they said that I would be better after I took it.

Needing help from family for mobilisation and household tasks

My children had to support me when I changed position from lying down to sitting … I didn’t do that (daily routine). I left it. I just lay down. My daughter had to brush my hair for me when I went to see the doctor, because I couldn’t. My whole body was stiff … My children did them (my jobs both in the field and at home) for me. I didn’t do things when I had pain. I didn’t care about being rich at that time. I didn’t want to have food when I
was in pain. When my son carried me to the car, I always screamed. He asked me how I was. I needed him to carry me gently, but he didn’t take any notice. He laid me very carelessly. I felt my bone might be broken ... Everyone (in my family) was good. They didn’t hate me (after they knew I had pain from rheumatoid arthritis). They bought me everything that I wanted to have. Someone told me my joints would be bruised if I had gout ... Someone told me my joints might become black. But they didn’t. They were only sprained ... Yes (I told my children when I was in pain). They only told me to go to see the doctor. My son carried me when I had to go to the examination table ... It wasn’t necessary for me to use a walker. My family helped me when I wanted to move ... There are three people in my home; my husband, my son, and myself. My daughter lives in that house (pointed to a house that was close by.) Everyone that came here always helped me to get up. I could walk by myself after I was up. When I was in pain, I asked them to massage me, because my body was stiff. I was in a lot of pain after they did ... She (my daughter) works in the field and feeds the chickens. She used to work in the cement factory. She never left me ... Although I complained they still told me that they could help me with everything that I couldn’t manage.

Using herbs
Recently I got some herb treatment from a temple. They gave me some oil to apply too.

Getting medication and injection treatment from the clinic
I’ve also been to the private clinic that’s at the junction near here. I got an injection there. I used to see a doctor at his clinic in another district. I didn’t get better after one visit there. I had a knotted feeling after I took his medication, but I got better after I’d walked a bit. Someone told me I shouldn’t take his medication, because it might damage my liver. They said it was the drug used to ventilate blood vessels or tendons. So I stopped taking it and threw it away ... The doctor told me that (it was the drug used to ventilate blood vessels or tendons) ... Someone took it and felt their liver might be damaged. They became worse after they took it. So they advised me to stop taking it.
Seeking many treatments

I went everywhere that anybody advised me to go ... First I took the decoction. Then I went to see the shaman. Then I went to see the doctor at his clinic in the other district. This is customary for people who live in the countryside. We take a decoction first when we get sick. Then I went to see the doctor at his clinic at the junction near here. Finally I went to see the doctor in the hospital. The doctor here told me I had rheumatoid arthritis ... If one of these (decoction or bathe in holy water) was any good, I would do it. I needed my pain to disappear.

Seeing the shaman

I went to see the shaman, because my neighbours had got better from their illnesses after they’d been there. I saw the first shaman and asked him if there was anything wrong with me. My home was in a small avenue. It was used a lot in the past for bullocks and carts. There were two courtyards near my home. They weren’t mine. He still said there was nothing wrong. Everything was all right. He blew on my head and said some prayer to make my illness disappear. I went to see the second shaman later. He said that I’d done something wrong to my ancestor (Khun Sai). It was all about black magic. He said I had to see the old shaman, who was very strong in solving black magic problems.

Preferring the doctor’s treatment of only taking medication

After I’d been to both shamans, I knew I was more alert. I didn’t get lost or become nervous. I thought about it over and over again, so I went to see the doctor in the hospital. I thought I couldn’t tolerate it. Everything was all right although the doctor couldn’t cure my illness ... The only thing I could do was taking the medication.

Expressing acceptance

I saw one doctor and he said I had to make up my mind to accept this illness, because it was not easy to cure. It would take a long time. I made my mind up to accept what he said. Sometimes I thought it would be all right if I died, because I was getting so many treatments from so many places.
Gaining advice about food

He advised me to restrict my food. I couldn’t have preserved food or pig bone. I had to have pork without the fat if I wanted it. I’ve been restricting my food since he advised me till now. I couldn’t straighten my body at that time. The doctor asked me if it hurt or if I had pain ... I had to be careful when I had food. I had to avoiding having poultry ... I had everything except eel, birds, and mice ... Since I was admitted to the hospital, I’ve never had pork with fat at all. I felt dizzy and nearly vomited when I got the smell from the pig’s oil. I had food that was cooked in vegetable oil. The doctor asked what food I have now. I told him I have vegetables, beans, and pork without fat. My daughter cooks them for me.

Being unable to do housework

I started to feel sprain first. It felt as if a needle was pricking my skin, and someone was hitting my body. I couldn’t lift my arms. It hurt when my muscles contracted. One day I wanted to clean my home. I wanted to be able to do anything and to exercise when I could get up. But I couldn’t do that, because it made me suffer more.

Noticing cold weather can cause pain

My whole body was stiff when the cold weather came. I couldn’t work in the field in winter, because I couldn’t get up.

Keeping the body warm

I had to keep myself warm by wearing socks, wearing two or three thick layers of clothes, and covering up with thick blankets.

Feeling depressed

I felt depressed when I couldn’t do things by myself. I felt I didn’t get what I wanted when somebody else did things for me. I was very depressed that I couldn’t have food that I liked.
Stopping work

I used to work in the field before. Now I’ve stopped doing that … I did household jobs, such as cooking rice, washing the dishes, and cleaning the house. I didn’t do them frequently. I did them once a week. I used to work in the field, and do household jobs after I came back home. Now I’ve stopped doing everything, because I get pain when my muscles contract. I used to pull the grass out in the chicken cages. I had to lie down after I’d done it for one hour.

Being unsure that Buddha’s teaching can relieve pain

I thought only my joints and body were swollen. I had to sit with my legs extended instead of sitting with my knees bent. The doctor told me I should go to the temple and follow the Buddha’s teaching. I knew someone whose tendons and ligaments in his knee had contracted. His condition disappeared after he followed the Buddha’s teaching. I was not sure I could do that, because I still killed the fish when I cooked it. I set that I had to practice Buddhism for five days or one week.

Lying down in bed regularly

I always lay down in my bed during the day from 11am until 3pm. I didn’t sleep at that time. I was aware of everything that everyone did or said … Sometimes my daughter asked her children to see if I was still alive or had died. I heard what she said, because I was keeping myself warm in the blanket … I could get up and have food. I lay down after I finished my food.

Taking medication

I took the medication when I knew I was starting to get pain. I lay down after I took it until 3pm. I got pain again after the first dose had worn off. The doctor gave me the medication for two weeks at a time … The doctor in the private hospital asked me to get the medication for a month. I resisted this and just wanted to try it for two weeks. I would get it again if it relieved my pain. The last two days he asked me again to get the medication for a month, because he knew the pain would disappear completely. I asked him to give me a stronger medication or something that could relieve the pain entirely. He said that it couldn’t be completely cured. I had to get continuous treatment … I got
better after I took the medication. I’ve never stopped taking it. The doctor told me I had to continue taking my medication. If I knew my medication was nearly finished, I would get it the next day ... I had to continue my treatment, because I couldn’t tolerate the pain and the sprain. No one can understand if they haven’t suffered like me. I kept going for my treatment as much as I could. I knew I wouldn’t die in few days. I had to be a protector for my family (Rom Pho Rom Sai) ... All my children supported me (about my medication fees), but my daughter supported me the most ... four (children I have). My youngest son stays with me. I have only one daughter ... Yes (my daughter paid most of the fees), because she has more money than the others ... He (my son who works in Chonburi) sent me money sometimes ... I took the medication that the doctor gave me, but sometimes I bought that other medication by myself ... Yes (I took paracetamol immediately when I had pain). The doctor often gave me some paracetamol and other medication. I took three tablets a week after food ... I didn’t do anything else. I only took paracetamol. When I started to get pain, I felt tense in my joints and they became swollen.

Accepting psychological help from family
My husband joked with me that I should go to hell. He was concerned about me, but he had to say that, because it is part of our beliefs that I would be better after someone said this to me. They always gave me sweets when they went to work.

Tolerating pain
I had to be patient. I never cried.

Appreciating visits from son
Sometimes (my son visited me). He rang me if he knew I was sick. When I got sick, I rang him and he sent me some money. The last two days he’s rung me and asked how I was. He said that I should not be anxious and to keep going with the treatment. He came back home at the Thai New Year Festival.
Exercising in the morning

I usually did this exercise (extended the arms sideways at the same level with the shoulders, and moved whole arms to the front.) ... I did it in the morning. I didn’t like it, because I felt tense and my muscles contracted. The doctor told me I should exercise in the morning. I did it, but it made the pain worse.

Bathing in holy water and doing good deeds

I used to go to Nakornratchasima after I took the medication. I went there, because I wanted to bathe in holy water and extend my life. I needed to do good deeds at that time, because I believed I would be fine when I died after I did them. When I went there, I had to sit most of the time. I went to do good deeds in a place that was far from my home, because I wanted to know about the differences in the life style between people here and there. I used to think that I would bathe in holy water from nine different temples too.

Appreciating care from doctors and nurses

I saw many doctors both on staff and interns. They asked me how I was and where I had pain. One massaged me too. The doctor who told me I had rheumatoid arthritis advised me that I had to exercise. I did as he advised in the morning. Nurses gave me the medication as set out in the timetable. The injection was good, but the pain came back after the effect of the injection had worn off ... I had a knotted feeling in my stomach ... They (doctors and nurses) gave me the medication (when I told them I was in pain).

Proving independence

When I could walk I went to see the other patients. I wanted to see how they were and what things I could help them with. I was discharged after the doctor saw I could walk and do things by myself. He told me I could go back home and get the medication to take home.

Applying hot compresses

The doctor told me to soak cloths in hot water, and put them on the area where I had pain. He said it would make me lose and relieve the pain. I rarely did that. I always took the medication and sometimes applied the oil. I got this oil from a temple. I stopped
applying it, because it had a strong smell ... They advised me to exercise, and apply hot
compresses when I was in pain. And they advised me to exercise in the morning. I felt I
was more tensed than before I exercised, so I didn’t do it again.

Trying not to focus on pain
They told me I shouldn’t think about things too much. I should make my mind blank.
Sometimes I couldn’t do that. I had to complain if I saw things that were not good.

Being alone when having pain
When I was in pain, I didn’t talk to anyone. I always stayed wrapped in my blanket. My
family couldn’t come too close, because I needed to be alone except for my daughter.
She always asked me if I wanted to see the doctor and how I was. If I was fine, I walked
to their home and talked with them.

Appreciating advice from patients with rheumatoid arthritis
Yes (I talked with other patients with rheumatoid arthritis when I was admitted). They
advised me about the place that I should go to get the treatment. One gave me her
telephone number too, but I didn’t ring her. I went to some place with my sister. I got
one pot of medication and some balm there. The owner was a monk ... They told me I
should go to the place they advised, because I’d just got rheumatoid arthritis.

Appreciating care from family
I don’t want anything more than this, because they always support me as much as they
can. I want them to concentrate on their jobs for their futures ... They’d never say
anything to cause me hurt. They said that not everyone has a mother. Therefore they had
to look after their mother first. I felt good after I heard that.

Needing doctors and nurses to inquire about health
I needed them to ask me again how I was after they gave me the medication. I needed
them to see me as frequently as they could.
Feeling disheartened

I felt disheartened and didn’t want anything except for the pain to disappeared ... Yes (I meant I used to get other pain, but it didn’t hurt me as much as rheumatoid arthritis pain). I didn’t want to do things when I had pain. I didn’t want anyone to come close to me. I had to tell them to please leave me alone, and I would talk with them later, after I felt better. I wanted to live alone at that time. I suffered from pain and sprain very much. I screamed when I lay down. I yelled at them when I was hungry. I didn’t do anything, because I got more pain when I did. My children often told me it was bad if after I’d worked, I had to frequently see the doctor.

Dara’s experience

Background

At the time of interview, Dara was 39, and she was 36 when she was diagnosed with rheumatoid arthritis. She was a mother of two teenagers. Her husband had just passed away before the interview. She graduated from school in grade four (Prathom four). Her first symptoms of rheumatoid arthritis were pain, swelling and joint sprain. She had swelling in her knees, elbows, and knuckles. Her knuckles were stiff, and she could not grasp anything. After she first experienced pain, she went to a clinic for treatment. The doctor told her that she had rheumatoid arthritis that it was chronic illness, and it was not easy to cure completely. Then he gave her medication. After that, she sought treatment from many different hospitals, but they did not make her feel any better. She stopped the treatment at a public hospital for over a month, and got the new treatment from a clinic in Suphanburi Province, about which she became aware from the TV. It did not make her better either. Finally, she went for treatment to a public hospital, and continued the treatment there. She said the pain changed her life, especially in the morning when it was most severe. Her legs were stiff. She could not get out of bed, and had to ask some help from her daughter to get up and stand. When she had pain, she was frightened, and thought she was different from other people. She was admitted to hospital for six days when she first had severe pain. She had x-rays of her wrists and ankles. She thought she
had bone cancer, but the doctor confirmed that it was not cancer. He showed her some pictures of patients with rheumatoid arthritis that frightened her. She explained that arthritic pain was the worst kind of pain that made her suffer, and it was the most difficult to relieve.

Dara was the same as other patients with rheumatoid arthritis, who did not want to suffer. She had many ways to relieve pain besides continuing the treatment. She used hot packs, took paracetamol, and stopped working sometimes or worked as best she could, but she did not do anything that excited her when she was in pain. She talked with herself and friends when she felt dispirited. She also tried some herbs to and massage. She received advice from a doctor about exercise, which she did after her pain gone.

At the time of the interview, Dara was feeling better than at the time of diagnosis. She had no more pain, but just a little sprain at her knees and elbow, and the bones clicked when she moved. She received a monthly medication and had her blood tested every three months. She did not go to see the masseuses and think about operations, as her neighbours advised. She said religious activities and muscle relaxation could not relieve pain, but she should continued treatment and good self-care. Although she felt disheartened, she never thought about the future. She thought that it depended on fate or karma. She hoped to recover from rheumatoid arthritis and the pain and to get well. She wanted the health care team to do all they could do to relieve her pain.

**Dara’s experience: Emerging codes**

The codes emerging from Dara’s account were: noticing joint swelling; noticing joint sprain; losing weight; noticing joint stiffness; seeing the doctor at clinic; finding treatment; getting advice to be compliant with treatment; feeling frightened; believing in karma; getting advice from the neighbours to visit masseuse; being scared about rheumatoid arthritis; getting advice about muscle strengthening exercise; wondering about poultry; feeling disheartened; asking how to get better; feeling stiff joints in the morning; needing help in the morning to mobilise; getting help for household jobs; doing light tasks; recognising severe pain in the winter; wondering about operation;
continuing the doctor’s treatment; talking to self; talking with friends; gaining mobility; recognising walking can cause pain; using hot packs; taking analgesics for severe pain; stopping work; massaging with herbs; not believing in religious activities and muscle relaxation for pain relief; describing nursing care as giving medication; wanting to recover from pain; wanting more nursing care to relieve pain; describing how joint pain affects walking; describing how arthritic pain is the worst kind; and describing self-care.

**Noticing joint swelling**

_Pain, swelling, and sprain (the symptoms when I first had rheumatoid arthritis) ... I had swelling in my knees, elbows, and knuckles. Now, my knuckles haven’t been swollen for a year, but my knees still swell._

**Noticing joint sprain**

_I still have sprain, but no pain now. When I walked I sprained myself, I could hear the bones scraping against each other ... I’m better (now). I mean I have no more pain, and just a little sprain at my knees ... My left elbow is still sprained, and the bones click when I move._

**Losing weight**

_Yes (I lose weight). I always checked my weight._

**Noticing joint stiffness**

_My knuckles are all right, but before they were stiff and I couldn’t grasp anything._

**Seeing the doctor at clinic**

_I went to the clinic for treatment. The doctor told me that I had a chronic illness, and that it wasn’t easy to cure completely. So he gave me medication ... Yes (he told me that I had rheumatoid arthritis). He tested my blood._

**Finding treatment**

_I found out what treatment was offered from many different hospitals, because I didn’t want to live with rheumatoid arthritis. I had many treatments, but they didn’t make me
any better. So I went for treatment at the regional hospital, and continued the treatment there. I was given medication every month, and had my blood tested every three months. The last time I had my blood tested on February 25, I knew the result two weeks later ... Although the doctor said that the condition was not easily cured, I wanted to find the best treatment. I stopped the treatment at the regional hospital for over a month, and get a new treatment from a clinic in Suphanburi Province. I knew about it from the TV and radio. I had to pay more, because the medication was very expensive. I paid 300 Baht ($A12.5) a month. I’ll let you guess what the result of this medication was. I didn’t get any better. So I returned to continue my treatment at regional hospital ... No (I didn’t go anywhere else), only the places that I told you.

Getting advice to be compliant with the treatment
I asked him how I’d got better. I wanted him to treat me till I recovered. He said that I had to take care of myself, and especially to continue with the right kind of treatment. If I did this, I would be better ... He only said that it’s a chronic illness.

Feeling frightened
(Laughed) I felt very frightened.

Believing in karma
No (I didn’t think about what might happen to me in the future). (laughed) ... I thought that it depended on karma. I didn’t really know what to think (laughed).

Getting advice from the neighbours to visit masseuse
Now my neighbours have advised me to find out about as many doctors (I mean masseuse. (Laughed) I’m afraid of them) as I can, who might help me with treatment. I think I will continue the cure at the regional hospital.

Being scared about rheumatoid arthritis
When I first had severe pain, I was admitted for six days. I got x-rays of my wrists and ankles. I thought I had bone cancer, but the doctor confirmed that it wasn’t cancer. I decided that I would be treated by this doctor till my pain eased, and I was discharged
(laughed). He showed me some pictures of patients with rheumatoid arthritis. They scared me (laughed).

**Getting advice about muscle strengthening exercise**

*He advised me to exercise everyday. I sit on a chair, and lift my legs 10 to 20 times. Besides this, I have to flex and extend my feet up and down. I exercise everyday, because I want to get better.*

**Wondering about poultry**

*Should patients with rheumatoid arthritis avoid having poultry? ... The doctor told me that I could have it ... I don’t have it. My neighbour said that it’s harmful for patients with gout too. The doctor didn’t prohibit me from having it, but I didn’t want to take the risk and so didn’t have it.*

**Feeling disheartened**

*Yes (there were any changes in my life), I was disheartened. I wondered if I would get better or worse. I thought about it a lot ... I always wondered when I would improved ... I thought I wasn’t like everyone else. I was different from others (laughed) ... someone told me that too (some patients with rheumatoid arthritis felt like me).*

**Asking how to get better**

*I always asked the doctor how I was and how I could get better ... he said that I had to look after myself as best as I could.*

**Feeling stiff joints in the morning**

*I felt it change especially in the morning when I had more pain. My legs were stiff. I couldn’t get out of bed.*

**Needing help in the morning to mobilise**

*My daughter had to help me to get up and to stand. She supported me when I walked or moved ... Yes (I needed someone to help me from the time I woke up), I did what I could. My daughter helped me if there was something I couldn’t do.*
Getting help for household jobs

Yes (I had many household jobs to do), I did all housework at my home. My daughter did it for me if I had pain ... Yes (she always lives at home), fortunately she’s on vacation now.

Doing light tasks

Although I had pain, I still worked as best I could. I had no other jobs. My jobs are cooking and washing the dishes. I didn’t carry the water on my shoulders or do anything that was too hard. There is a water supply system here ... although I had pain I could still help myself. I moved and did things slower than I normally would.

Recognising severe pain in the winter

I got severe pain when the winter started, but I’m fine now, because I only feel a little pain. I can sleep well. I still sprain myself when I walk. I think my walk is abnormal. I lift my feet higher, and I feel like my bones are rubbing against each other. After I got my legs x-rayed, the doctor told me that my feet were showing some effects of rheumatoid arthritis, and I had inflammation in my joints.

Wondering about an operation

He told me that I should hurry and get treatment, because I was young and maybe the doctor could operate on me. I saw many doctors, but no one told me about the operation. They said that it wasn’t necessary for me as I was only 37 years old. It’s too young for that operation. So, I wondered what a suitable age would be for me to get the operation (laughed). I talked with my neighbours about this. They told me that it’s better to have the operation while I was younger. Young folk have better immunity than older people.

Continuing the doctor’s treatment

(Laughed) I thought I should continue treatment with my doctor. I couldn’t think beyond that. I took the doctor’s advice. I felt I should trust his advice.
Talking to self
I talked with myself (when I was dispirited) (laughed).

Talking with friends
I talked with my friends. They asked what the doctor said and about how I could get better. They asked why I didn’t go to Bangkok for a cure ... I thought I’d go, but no one could take me to Bangkok ... I’d have to ask them again where I should go (If I could get treatment in Bangkok).

Gaining mobility
It’s all right now. At the beginning, I had to crawl and tip toe from my bed. Now, I can walk. I can stand up and do everything quite well by myself. I still sprain myself a little when I walk. I’d probably get well if the rheumatoid arthritis disappeared.

Recognising walking can cause pain
I rode my niece’s bike to go to a grocery shop that’s near my home. It would take too long if I walked. There was no problem when I rode there, but I had pain when I walked. While I had pain, I exercised my legs...lifted them both left and right side. I lifted them but not too high.

Using hot packs
I used hot packs. They relieved my pain.

Taking analgesics for severe pain
I took some paracetamol that I got from the doctor. I used it when I had severe pain.

Stopping work
Absolutely (I stopped working when I had pain).

Massaging with herbs
Sure. I took some herbs. The masseuse used some herbs, such as camphor. She mixed them together and steamed them till they were hot. After that she laid them on my joints
... The pain was still there. Taking the medication from the doctor is the best. I get worse when it’s hotter. I can’t tolerate it. Massaging isn’t suitable for patients with rheumatoid arthritis. It’s only effective for relaxing nerves or tendons.

**Not believing in religious activities and muscle relaxation for pain relief**

(Laughed) I don’t think so. I don’t believe that that (religious activities and muscle relaxation) can relieve pain.

**Describing nursing care as giving medication**

They (nurses) didn’t do anything other than give me the medication that the doctor had ordered for me ... They always gave me the medication and then asked about my symptoms ... No (they didn’t tell me how to relax with the pain).

**Wanting to recover from pain**

I want to recover from rheumatoid arthritis and the pain and get well soon. So I have to take the doctor’s advice.

**Wanting more nursing care to relieve pain**

But I wanted them (the nurses) to do all they could to relieve my pain.

**Describing how joint pain affects walking**

Pain is pain. I don’t know how I can explain it. Pain at the joints is one kind of pain. It made me walk slowly and feel uncomfortable.

**Describing how arthritic pain is the worst kind**

Arthritic pain is the pain that makes me suffer the most. When you have a headache, you can take paracetamol. And that makes you feel better. If you have arthritic pain like me, you can’t get well immediately after you take the medication. You have to spend more time on it.
Describing self care

I should do (control my mind and think positively), because I already have rheumatoid arthritis. I hope one day that I will be as I was before I got it. First, my fingers became swollen, and no one could touch them. They were painful. Now, they’re better. But my knees are still painful, because they have to carry my weight. Patients who have rheumatoid arthritis should take care of themselves as best as they can. If they can’t, they become worse. Their hands and feet will become stiff if they don’t take care. I exercise everyday. I don’t run, because I know I can’t do that. It’s harmful to my joints.

Ta’s experience

Background

Ta was patient with rheumatoid arthritis, who graduated from school in grade four (Prathom four). When Ta was 38, she had been diagnosed with rheumatoid arthritis in her wrists. She had pain in her fingers, then her hands and knees. The joints were tight in the mornings. She felt pain when she put her weight on her feet. After the onset of pain, she changed her job from weaving to working in the field and doing construction work. She said the new jobs gave her more free time. She went to see the doctor at a clinic, and took the medication he prescribed for a week, but it gave her flatulence and colicky pain, so she could not tolerate it. Then she went to see an orthopaedist, and told him about her treatment. He gave her a new medication, and some antacids that made her felt better. The doctor told her she had rheumatoid arthritis that she should be able to be cured, and to get treatment from a hospital, which was cheaper than a clinic. At first she looked better after she took the medication she got from the orthopaedist. One or two years later he gave her a new medication, which was not strong enough and she did not feel better, so she stopped taking the medication for a year. Then she bought a medication from a chemist, and it made her pain disappear. She continually took that medication until she went to have an operation on her uterus. When the surgeon asked her about her history of illness, she told him she had rheumatoid arthritis, and about the treatment she took.
He advised her to get the right treatment from a doctor, and to stop buying the medication herself.

Ta felt untroubled after she was told she had rheumatoid arthritis. The doctor told her to take medication for the rest of her life, and the pain would disappear. She also was not frightened, because she knew that there were differences between rheumatoid arthritis and gout. On the other hand, she felt weak and unhappy, especially in the mornings, because her whole body was stiff. Sometimes she felt she was boring, and she felt that she was losing her self-esteem when she wanted to do things that she could not. Her state of mind was worse too. Although she had rheumatoid arthritis and pain, she thought her daily life was normal. She did not tell her family how she felt when she was in pain. She always kept her feelings to herself, because she was worried that they might be unhappy, and that she might annoy them.

Ta had her own ways to manage pain in the mornings. When she woke up, she sat on the bed for a while before she started to walk slowly. Sometimes she needed some help from her husband and daughter to walk. She resigned from her job, stayed at home, and did not work too much. She usually exercised by lifting her arms and hands. She received massage long time ago, but now it made her felt stiff and sore.

Ta became a housewife after she had an operation on her uterus. She had pain in the soles of her feet, and in her heels at the time of interview. She said she had the most pain in the morning, but she had a little bit of pain and stiffness all day. She did not think about what might happen to her in the future. She made up her mind to be trouble-free and relaxed. She thought to herself that the pain would disappear if she continued the treatment, and took the medication as the health care team and her daughter, who was a nurse suggested. She thought about using decoction and herbs to relieve pain, but had not tried them yet. Information she needed from health care team was about suitable exercise, how to look after herself better, and pain relief.
Ta’s experience: Emerging codes

The codes emerging from Ta’s account were: recognising pain is related to working hard; seeing the orthopaedist; noticing pain in the morning; doing lighter work; buying medication from the chemist; accepting a rheumatoid arthritis diagnosis; feeling weak and unhappy; helping self in the morning; wondering about exercise; getting advice to take pain medication continually; hiding rheumatoid arthritis from family and acquaintances; expressing acceptance; worrying about care; losing self-esteem; realising the most important caregiver is husband; taking medication; returning to the orthopaedist’s treatment; thinking about decoction and herbs; going to the temple; exercising; using massage; appreciating care from family; needing advice on self-care and pain control from the doctors and nurses; and missing follow up treatment at the hospital.

Recognising pain is related to working hard
No one’s had rheumatoid arthritis including my parents. For the first three years that I weaved clothes, I used the general machine. I used my hands to push and pull the weaving block and change the bobbin, but it was all right. I got rheumatoid arthritis in the fourth year, because then I changed to a new machine, and it was heavier than the old one.

Seeing the orthopaedist
I had pain and weakness, so I went to see the orthopaedist at his clinic. He said that I should be able to be cured, and to get the medication from the hospital, because it was cheaper than from his clinic ... He told me that I had rheumatoid arthritis. At first I looked better after I took the medication I got from him. One or two years later he gave me a new one. In my opinion, it wasn’t strong enough, and I didn’t feel any better. It was not strong enough for me. I was still in pain.

Noticing pain in the morning
I had pain in my wrist first. I had pain in my fingers, hands, and knees later. They would be tight in the mornings ... I had pain in both my knees and ankles. At the beginning the
pain went when I put my weight on my feet, but I have pain in the soles of my feet and in my heels now. I don’t like getting up in the mornings, because I’m in pain and my body is stiff. I can’t walk well in the mornings … I’m in pain and my body is stiff, but it’s not too bad (now). I can be patient, and take the medication that the doctors have given me … Everyday (that I have these symptoms), but not too badly. I have the most pain in the morning, but I have a little bit of pain and stiffness all day. My fingers swell too. The last time the doctor checked my blood he told me that my joints were still inflamed.

Doing lighter work
I stopped it (weaving cloths) immediately after I knew (the pain started). After that, I sometimes worked in my field, and did construction work. Now, I don’t do anything anymore. Working in the field is better than weaving, because I have more free time to do other things. If I weave clothes, I have to do it all day and use my hands more to pull the heavy machine … Mixed cement. I stopped working in it some time ago, because I had a tumour in my uterus, and I just had the operation four months ago. The doctors told me to rehabilitate for a year. So I do things that are not too hard for me, such as cooking. I avoid carrying heavy things too … I didn’t work too hard. I only did laundry … I did that and cleaned my house … I had to do it if my husband was busy. I didn’t do too much. I only washed a few clothes. Now, I don’t do anything too much, and I’ve stopped my employment too … Since I had the operation I never work hard.

Buying medication from the chemist
I stopped taking the medication he (the doctor) gave me for a year, because I felt that I wasn’t getting better. I was still in pain. So I bought the medication from the chemist that was located near the hospital junction. I told them that I wanted to buy medication to relieve joint pain. My pain disappeared after I took it. I took it till I went to the hospital for the operation on my uterus. The doctor asked me the history of my illness. I told him that I had rheumatoid arthritis, and about the treatment that I got from the clinic and the hospital. So he advised me to get the right treatment from the doctor and to stop buying the medication by myself … I stopped taking the medication from this doctor almost a year before I had the operation on my uterus. During that time I bought
medication from the chemist. It was all right. I was fine after I took it. I thought that it had no effect on me ... (I decided against treatment from the doctor).

Accepting a rheumatoid arthritis diagnosis

I felt nothing. The doctor told me that I had to take medication for the rest of my life, and it would disappear. He told me that I could be pain free, but not straight away. It would take a long time. But I didn’t know how long he meant ... I knew that I had rheumatoid arthritis, and that there were some differences between rheumatoid arthritis and gout. So, I was not frightened ... Everything is as usual (in my daily life).

Feeling weak and unhappy

I always had pain and felt weak. I had no energy to do anything. My state of mind was worse too. I always thought about my pain ... I had pain, fatigue, and weakness more in the mornings. But I could still do some things ... I felt weak and unhappy, especially in the mornings. I didn’t want to wake up, because my whole body was stiff. It was all right at night. I had no pain then ... I woke up at 5.30am everyday. Even when I was in pain I didn’t get up late. After I had walked or done something, it would be better. On the other hand, if I stayed in bed the pain would stay.

Helping self in the morning

Although I had pain, I could do things by myself. When I woke up, I sat on the bed for a while, and started to walk slowly. Sometimes I needed some help from the others to walk. When I began to walk, I felt stiff. Ten minutes later, I felt better.

Wondering about exercise

How I can do that (getting the right treatment and taking care myself)? What exercise can I do in the morning?

Getting advice to take pain medication continually

They only said that I should get treatment and take medication continually ... I asked them how long I had to take the medication. They said that they weren’t able to tell me exactly when I could stop taking it.
Hiding rheumatoid arthritis from family and acquaintances

No (pain didn’t distance me from my family or anyone else), it was up to me. I didn’t want to tell them about my illness … I was worried that they would be unhappy, and that I would annoy them. I only told them that I didn’t want to wake up in the morning, because I had pain. I only told them about my pain, and said nothing about my exhaustion … No (I didn’t talk with my family about my feeling), I kept them to myself. I didn’t feel uncomfortable or frustrated about not telling them. I only told them that I had pain and tension. I worried that they would be unhappy if they knew.

Expressing acceptance

I didn’t think about it (what might happen to me in the future). I made my mind up to be trouble-free and to relax. I thought to myself that it would disappear if I continued the treatment and took the medication. The doctor told me this too.

Worrying about cure

Of course. I worried about whether I would be cured or not. I didn’t know what to say after I took the medication. Sometimes I thought I was no better, and that I still had pain. On the other hand I looked better after I took it.

Losing self-esteem

Sometimes I felt I was so boring to everyone, and I felt that I was losing my self-esteem (when I couldn’t do anything by myself). I wanted to do things, but I couldn’t. I thought that I would be able to do things better in the future.

Realising the most important caregiver is husband

My daughter (looked after me too). She’s a nurse, but she doesn’t get back home very often. There are three people in my family now; my husband, his dad, and me. His dad is very old. So my husband is the most important person, and he always looks after me … My husband always did that (took care of me) … He didn’t let me to do anything, especially in the mornings, for example he cooked for me in the mornings. I did it in the evenings, because my pain was gone. His dad couldn’t help me, because he’s over 80.
Taking medication

I didn’t do anything except take the medication that the doctor gave me. Do you know what else I can do?

Returning to the orthopaedist’s treatment

I couldn’t tolerate the pain. The doctor who performed the operation on me, the nurses and my daughter all told me again that I should stop buying the medication myself. It was dangerous. My organs such as my liver and kidneys would be damaged. I should go to see the orthopaedist. My daughter filled out a requisition for rheumatoid arthritis medication for me. But the pain was still there. Even though my daughter told me, I still didn’t believe her. I still bought the medication by myself, because it made me feel fine, and my mind was at ease. However, I did go back to get the treatment from the orthopaedist again after the nurses kept telling me.

Thinking about decoction and herbs

No one told me about holy water or herbs. I used to think about whether I should buy a decoction and herbs or not. Whether they were harmful or good for me. I thought that I might use herbs to relieve the pain, but I was still just thinking about it. I never did it.

Going to the temple

Recently, there was a ceremony at the temple to ward off bad luck. I’ve been there too. I thought it might make me better. I did it, because there was no harm in it. I’d never tried meditation or praying.

Exercising

I did things in the mornings, such as lift my arms and hands. The doctors and nurses didn’t tell me which exercises were good or how I could do them ... No (they didn’t give me exercise brochures). When I went to the hospital, the doctor asked me about my symptoms. I told him, and he gave me the medication.
Using massage

I used to massage, but a long time ago. It was no good, because I felt stiff and sore after I did it.

Appreciating care from family

Yes (my family took care of me well). It was all right. It was enough for me. My daughter had to work in the hospital and that’s far from here, so she couldn’t get back home very often … She always asked me about my illness, and she filled out a requisition for rheumatoid arthritis medication for me. She wanted me to see the doctor and get the medication, because it was better than taking the medication without seeing the doctor.

Needing advice on self-care and pain control from the doctors and nurses

I wanted them (doctors and nurses) to tell me how I could look after myself better and make my pain disappear. I didn’t ask them if they didn’t tell me. The first time that I went to see one doctor it was at his clinic in another district that’s not far from here. I went there, because someone told me that he had a lot of different kinds of good medication. I took the medication from him for a week. It was so bad. I had flatulence and colicky pain so badly that I couldn’t tolerate it. So, I went to see the orthopaedist, and told him about the treatment that I got. He wondered why that doctor had treated me like that. The medication that he gave me was inappropriate for me. It was too strong, and my stomach could have been damaged. He gave me a new medication and some antacids. I felt better. After I had the operation on my uterus, I also had joint pain. During that time I didn’t go back to see the doctor. I discussed it with my husband. He said that he didn’t know how to help me. He told me that I should buy the medication and not harm myself. I didn’t buy the medication from the chemist, and didn’t take the medication from the first doctor. I used to ask my second doctor when my pain would go. He said that it would take a long time, and he couldn’t predict how long. It depended on each person. He also asked me why I hadn’t been for follow up treatment for so long.

Missing follow up treatment at the hospital

I never got one (a letter from the hospital to have follow up treatment). Perhaps I’ve been missing my follow up for a long time.
Jai’s experience

Background

Jai was 40. She graduated from school in grade 12 (Matthayom six). She worked in the government service as a jailer, and had been suffering from rheumatoid arthritis for one year. At first she suffered a sprain, and had pain and swelling in the knuckle joints to her shoulders. She could not dress herself or lift her arms. She had fever at that time, and also had allergies when the cold weather came. When she had pain, she saw the doctor to get some medication to relieve the pain and swelling in her joints. She took chloroquine phosphate, one tablet every day. In the beginning, the doctor gave her a half of a tablet, but it did not relieve her pain. She had a full examination and a blood test, and everything was fine. She had ibuprofen to relieve the pain also, but she rarely took it, because she was worried about it affecting her stomach. She asked the doctor when he would lessen the dose, and he replied that she had to take the medication for a year.

She saw the doctor every two or three days, because of the severity of her symptoms. She was also admitted to hospital to get intravenous fluid for two days, because she was weak and dizzy at that time. She went to get treatment at a special clinic in a hospital in Bangkok, after she had had several treatments from this doctor, because she was worried that she might get more pain. She gave up going there after she noticed that the clinic doctor prescribed the same medication. However, she went to see a specialist, who gave her a general check-up, and advised her how to exercise to protect the joints.

Jai said she could get pain when she worked hard or even when she leant against things. Her pain lasted for one or two days each time, and she sometimes had pain without any cause. She noticed that she usually felt weak when she worked in the sun. Jai felt badly after the doctor told her what was wrong with her. He said everything would be fine if she looked after herself as well as she could. Someone joked with her about her illness, but she tried to keep calm, and not to think about it too much. She was not disheartened
when she had pain, because she was always aware why she was sick and had pain. She felt that the pain affected aspects of her life minimally.

Jai was very lucky that her colleagues knew about her disease, because they did not let her do too many things, such as carrying heavy things or working in the sun. Some of them worked at night for her if they were free. She got good care from her family too. Her husband usually accompanied her to see the doctor. Her three children also helped her to do things when she was in pain, although they sometimes caused her stress. Jai used a lot of options to look after herself. She tried to feel detached when she saw disturbing things, and usually smiled and laughed when somebody joked or teased her. She rested and did not move too much. She exercised minimally when having pain, and every day when the pain abated. She took some supplements such as fish oil and spirulina capsules, which she saw on a TV program. She also drank vegetable juice which she made herself, and avoided eating foods with preservative. She used some oil, which made from herbs to massage herself too.

Jai had minimal pain. She did not often take the analgesic drugs the doctor gave her, just when the pain was bad. She did not do things that might cause her a lot of pain. She started to take new herbal supplements, such as seaweed, green tea, and salmon oil. Jai needed the health care staff to advise her more about looking after by herself. She said that when she went to the hospital, she always asked them about rheumatoid arthritis, and how she could manage. She wanted to act appropriately when she was at home. She asked the doctor if he could cure her completely. He said he could not, but that she might get better as long as she always took the medication. He told he would give her a document about it when he had updated information. Besides this, she often asked the nurses about how she could handle her pain. In the near future, Jai wanted to buy books from bookstore to read about rheumatoid arthritis and pain.

**Jai’s experience: Emerging codes**

The codes emerging from Jai’s account were: describing the onset of rheumatoid arthritis; avoiding painful activities; taking medication; experiencing painful hands and
shoulders; maintaining a clean environment; accepting help from the colleagues; requesting help to do things; staying calm; feeling stressed; maintaining exercise; being admitted to hospital; expressing acceptance; taking fish oil; attending a special clinic; taking herb and a spirulina supplement; making food and beverage choices; massaging with ointment; recommending getting good care from the family; getting advice about exercise, supplements and self-care from the doctor; and not getting more advice on how to do self-care.

Describing the onset of rheumatoid arthritis
I’ve had pain for a year. At first I thought I’d sprained myself, and got some joint pain. I saw the doctor, and got some medication to relieve the pain. I had a massage too, but I didn’t feel any better. I still had pain and I had a fever. I didn’t know what was happening to me. I’d even had two blood tests at the community hospital. One doctor did a DNA test for me. She only treated me for two months, because she moved away ... I only had a little pain, because I usually took the medication. I got weak when I worked in the sun. I noticed I often got the common cold too. I had pain and swelling in the knuckle joints. I had pain from my knuckles to my shoulders. I couldn’t do things such as dressing or lifting my arms. I had fever at that time too. I also had allergies when the cold weather came. I used to see the doctor every two or three days, because of these symptoms.

Avoiding painful activities
Now I only have a little pain. I don’t take the analgesic drugs that the doctor gave me. They gave me a stomach ache. I only took them when the pain was bad. I don’t do things that might cause me a lot of pain ... All my colleagues knew about my disease. They didn’t let me do too many things, such as carrying heavy things or working in the sun. I avoided those things. If I had to do them, my colleagues would help me ... I didn’t do things when I was in pain. I didn’t use the body part that I had pain in.

Taking medication
He gave me medication to decrease the swelling in the joint. I was given chloroquine phosphate, and I took 1 tablet every day. At the beginning, he gave me a half of a tablet,
but it didn’t relieve my pain. I had a full examination and a blood test. Everything was fine. I got ibuprofen to relieve the pain. I rarely took it. I worried about it affecting my stomach. I used to ask him when he would cut the dose. He replied that I had to take it for a year. I met the doctor last month without having a blood test. I’ll see him again when my medication is nearly finished. I’ll ask him to do a blood test for me too. He always asks me how I’ve been and if I felt better after taking the medication ... I sometimes took medication to relieve it ... I still took the analgesic drugs when I had pain. I took them in tablet from when I had a lot of pain ... I used to ask the doctor if he could cure me completely. He said he couldn’t but that I’d get better as long as I always took the medication.

Experiencing painful hands and shoulders

Anytime (laughed). I could get pain when I worked hard or even when I leant against things like leaning my legs against a wall for a while. My pain lasted for one or two days each time. I sometimes had pain without any cause. I was lucky I only had hand pain. I was worried that I would get more pain in other parts of my body. I saw that that was possible from books ... It was good that I had no knee or ankle pain (and I had only hand pain). When I had hand pain, I had pain from my wrists to my shoulders, because of the inflammation.

Maintaining a clean environment

I avoid being around smokers too ... No (I didn’t feel uncomfortable in my place of work, because it is a prison). I didn’t have much contact with the prisoners. I worked in an area that was clean and well ventilated. I didn’t work in a factory, although there were many factories around there. Someone helped me to contact some of the staff there. There were too many chemical substances and too much dust.

Accepting help from the colleagues

When I was in pain, I couldn’t do things, such as cooking and picking things up. I used to get pain when I worked the night shift. My colleagues helped me to put on a jacket when I was cold, because I couldn’t manage it ... I sometimes worked at night. I had to. Some colleagues worked for me when they were free. They knew I was not strong and
should have plenty of rest. I looked pale the next day if I worked the night before. My body became yellow and green (laughed). I was weak too.

**Requesting help to do things**

I asked my children to do things for me ... I didn’t do things when I was in pain. I just left everything. I tried to use some parts of my body that had no pain, but normally there was pain at both my left and right sides. I asked my family to do things for me. They did what they could ... If I couldn’t I asked them to do them for me.

**Staying calm**

I tried not to do anything except make my mind up to stay calm ... I don’t know how I can explain it. I tried to feel nothing when I saw disturbing things. It was up to me whether I could be calm or not.

**Feeling stressing**

I always told my children off everyday. It was just the general thing that happens in every family. They sometimes stressed me out, but I never told anyone if I had pain (laughed).

**Maintaining exercise**

I only walked and got some rest. I sometimes moved my arms and legs to decrease the tension. It got bad if I didn’t move them at all. I exercised my hands and arms as the doctor advised me. He said that I should exercise a little after the pain eased. I exercised when I needed to (laughed). I ran, did aerobic dance, and sometimes exercised at home. I felt better after I’d done these things. I’ve only been doing aerobic dance for three days. The trainer advised me to do the easy version. I exercised everyday after the pain was gone. I didn’t do it when I had pain ... She (my specialist) gave me a general check-up, and saw that I had swelling or something. She advised me how to exercise when I had pain, and what I could do when I was like this. She said I should exercise a little even though I had pain. I would be stiff if I didn’t do it. She advised me to use an exercise bar to exercise up and down when I had pain. That would make me feel better ... Yes (I tried it). I had pain when I stretched out, but I had to bear it. She told me I
could do it, because I could flex, but couldn’t extend my joints. I looked like a disabled person. My bones might become deformed too. I had to exercise to prevent this problem. It wasn’t necessary to take a physical therapy course, because I’d got treatment from the beginning and always continued with it. That’s why I don’t have any more symptoms.

**Being admitted to hospital**

Yes (I’ve been admitted with pain). I was weak and dizzy. I got intravenous fluid for two days. Before I was admitted, I went to see the doctor and got some analgesic drugs from him. The doctor cured my symptoms. He didn’t want me to be admitted, because I could rest at home, and there were many diseases in the hospital. He thought I might pick up some disease there.

**Expressing acceptance**

No (I was not disheartened when I was in pain). I knew I was sick and had pain. I felt bad after the doctor told me what was wrong with me. He said everything would be fine if I looked after myself as well as I could. Someone joked with me about my illness, but I tried to make my mind calm down, and not to think about it too much … I always smiled and laughed when somebody joked or teased me. I looked after myself.

**Taking fish oil**

I take fish oil now. Someone told me it has an acid that can decrease joint swelling. I asked my doctor if I could have it. He said I could, but why I wanted to pay for the oil when I could get this acid by eating fish. I didn’t know how I could have fish everyday, so I took the fish oil.

**Attending a special clinic**

I went to get treatment at the special clinic in a hospital in Bangkok after I’d had two or three treatments from my orthopaedist. I went there, because I was worried that I might get more pain. I noticed that they gave me the same medication that I get here. It was a waste of money and time to go there. I had to arrived there at 3 or 4pm, get in a queue, pay a special fee and not get back home till 10 or 11pm. So I didn’t go there again, and I only got treatment here … It (the special clinic) was a general clinic not a rheumatoid
arthritis clinic, but it was open after hours. I paid 200 Baht ($A8.33) in out-of-hours fees, and claimed all of the medication fees from my workplace.

**Taking herb and a spirulina supplement**

Now I take some spirulina too (laughed). I tried everything to relieve the pain. I bought it after I saw it advertised on TV ... I haven’t talked to him (the doctor) yet (laughed). I’ve just bought it. It cost 450 Baht per a bottle ($A18.75) ... I bought it after I watched a TV program about women. I’m sorry I’ve forgotten its name. The compere invited the doctor to talk about it ... I don’t remember everything they said. They said that beta-carotene could help with these symptoms ... I took some supplement when I was weak. I always bought a supplement to take. I took one or two cups each time ... They were herbs. I didn’t buy anything that wasn’t herbs or plants. A nurse sold me the product from a beauty company. She said it had vitamin C in it, and that was good for me. I tried it once. I don’t know if it was good for me or not, because I was in a lot of pain at that time and very weak ... Now I take many herbal supplements, such as seaweed and green tea. I sometimes take salmon oil. It has an acid that decreases joint swelling. It’s a product of a beauty company that my colleague was a sales representative of.

**Making food and beverage choices**

I didn’t drink soft drink until now. I drink the vegetable juices that have this substance in them. I still have food as before, but I don’t have preserved food. So I think that I always look after myself as well as I can. I have food as I like. The doctor didn’t stop me from having certain foods. He said I could have anything I wanted.

**Massaging with ointment**

I used some oil to massage myself. They were made from herbs. I only applied a little, because it might have burnt my skin ... It didn’t relieve the pain, but it helped me psychologically.
Recommending getting good care from the family

Yes (they cared for me well when I was in pain). When my children knew I was sick, they did everything for me by themselves. Sometimes I got agitated; I had to get up and do the things myself.

Getting advice about exercise, supplements and self-care from the doctor

He gave me advice at the beginning. After that, he checked my symptoms and gave me medication to take home.

Not getting more advice from nurses

They (the nurses) asked me how I was. When I went for follow up treatment at the hospital, I told them what symptoms I had. They didn’t say anything. They left it to my doctor to advise me. They only told me things if I asked.

Needing more advice on how to do self-care

I need them to advise me more about looking after by myself. When I went to the hospital, I always asked them about rheumatoid arthritis, and how I could manage it. I wanted to do the right thing when I was at home. I asked the doctor once about this, he said he couldn’t give me any more details about it. He told he would give me a document about it when he had updated information. I knew I could buy books from the bookstore to read about it, but I haven’t bought any yet. I often asked the nurses I knew. They advised me how I could handle my pain.

Ead’s experience

Background

Two years prior to the interview, Ead, who was employee, did not realise that she had rheumatoid arthritis, because her period did not come for four months. She went to see the doctor at the community hospital. The first diagnosis was that she could be menopausal, and then he ordered a cancer check-up for her and gave her medication.
Fourteen days later she went back for the results; which were fine in that they ruled out menopause and cancer. During the four months of her missing period, her whole body started to swell and became painful. She was not able to walk for nearly two weeks, and she had to kneel down like a dog to move around.

On August 2001 she went to have a full check up. At that time the pain was still bad. She discussed her problem with her neighbours, and they thought that she had gout. They suggested that she got an injection from a person, who was not really qualified as a doctor. After the first injection she could work well, however she needed a second injection within one day, and the pain patterns had not changed. She went to see a nurse she knew, about her pain in the shoulders, who suggested her to see one orthopaedist at his clinic. Ead went to see him, and he examined her and gave her some medication. After a few visits to the orthopaedist she felt better, but her pain was still there. She asked him her diagnosis. He arranged a full check-up again, and told her that she only had one problem, which was rheumatoid arthritis, requiring her to take medication for the rest of her life. She said she sought many treatments, because she had no idea what was happening to her.

Ead found certain factors caused the pain. The first factor was the nature of her work. She had to sit on the ground working with her knees bent and carry deliveries to customers. Unfortunately, she could not give up this job, which she had done for more than two years with her sister. The second factor causing pain was reducing the number of doses of analgesics herself when she did not have to go to work. The other factors were not seeing the doctor every time her medication ran out, and stopping taking the medication when her symptoms improved. Ead felt detached when the orthopaedist told her had rheumatoid arthritis. She said she had no idea what to say, because she already had this disease, and there was nothing she could do about it. She just asked him if rheumatoid arthritis was dangerous. She also felt that her life was useless, and she was depressed about not being able to do the work she normally could do.

Ead was 47 at the time of the interview. Her symptoms were getting worse in her wrists, ankles, and knees. She sometimes could not grasp objects in the morning, and that was
the reason she had to stretch her body and exercise every day. She was alright if she took the medication and did not work hard. Although she kept going to see only the orthopaedist, she felt that the medication from the hospital could not cure her pain. The orthopaedist told her some particular medications were not available from the hospital, so she got them from his clinic. She thought that she should not take too much, because if the doctor moved away from the area, she could not get any more. Ead had attitudes from other people who graduated from school in grade four. She did not think that doing work that was associated with funerals could cause her pain, and she did not want to see a fortune-teller and medium either. She believed that the pain she had was a part of illness, and that there was no relation between her pain and the work that she did for charity or funerals. Before finishing the interview, she suggested that she needed the local health staff to visit her at home and enquire after her condition. She said she was not worried when she felt pain, because her sons and relatives were always willing to help her.

**Ead’s experience: Emerging codes**

The codes emerging from Ead’s account were: being advised to see the orthopaedist; reducing the number of doses of medication; noticing increased pain from hard work; being compelled to take medication; noticing medication from the hospital is ineffective; buying medication from the clinic; getting advice to decrease work; requesting help for laundry and mobilisation; appreciating help from older son; feeling life is nothing without mobility; accepting the diagnosis; gaining advice about food; helping to work; feeling depressed; doing manageable tasks; gaining advice from neighbours for treatment; using a bolus; using a powder medication; taking herbs; rejecting spiritual and mystical remedies; telling the family about pain; talking with a monk and doctors about pain; appreciating care from nurses and doctors; needing home visiting from local health staff; and getting help from her son.

**Being advised to see the orthopaedist**

*I went to see a nurse that I know, because I had pain in my shoulders. I couldn’t get my arm up right. I thought it was caused by my carrying heavy stuff. It was so painful.*
When I talked to her, she said there was an orthopaedist in front of the local council. So I went to see him, and he examined me and gave me some medication. After one week of taking the medication from this orthopaedist, I found that I felt much better. So I’ve kept going back to see only this doctor up until now ... After I’d been to see this orthopaedist a few times, although I felt better, my pain was still there. I wondered why it was like that, and I asked him what exactly my problem was. The doctor ordered me to have a full check-up again. This time the orthopaedist told me that I only had one problem, which was rheumatoid arthritis. This rheumatoid arthritis required me to take medication for the rest of my life.

Reducing the number of doses of medication
I reduced the number of doses by myself since I didn’t have to go to work. I only took one dose every two or three days. The doctor said, “You should not skip the medication even though you are not working as hard as you normally do” ... If it’s not too painful, I don’t take the medication.

Noticing increased pain from hard work
I found that the pain increased when I worked hard. For example, yesterday I sat on the ground working with my knees bent; my feet became swollen after a while ... My rheumatoid arthritis is serious in my wrists, ankles, and knees. Today the symptoms are severe, because I have been working hard for the last two days, and I was doing the laundry this morning. I realise that it’s a serious matter. The doctor gave me paracetamol, but I didn’t want to take it, because he said it could have side effects.

Being compelled to take medication
Last time, when I’d been out of medication for one week and I didn’t go to get more, the doctor reprimanded me and said that I should come to pick up the medication before it ran out ... My son will take me to see the doctor this Friday, and he’ll probably scold me for not taking the medication all the time ... Even though the doctor didn’t want me to do the laundry, I still have to do it, because my son doesn’t do it well. I have to do whatever I can do. My son told me off when he knew that the medication had run out; he didn’t understand why I didn’t tell him when we both knew that the doctor didn’t like it when
we were late in picking up the medication ... I believed that continuing to take the medication could cause my body to become immune to the beneficial effects of the medication (drug resistant), since the body gets used to it. However, I asked the doctor if it’s important for me to continuing taking the medication He said, “Yes it is!” ... I normally didn’t go to see the doctor every time my medication ran out, and he kept grumbling about my lateness in seeing him. However, I always see him for check ups, the problem is I always stop taking the medication when my symptoms improve.

Noticing medication from the hospital is ineffective
I felt that the medication from the hospital couldn’t cure my pain. And the doctor said some particular medications were not available from the hospital. If I didn’t work, taking the medication helped the pain. However, if I even did just the laundry, the medication from the hospital was not strong enough for my pain.

Buying medication from the clinic
I have to take an antacid to prevent stomach pain from this medication since it could damage my stomach. Any medication that I got from the hospital, I didn’t have to pay for, because it’s covered by health insurance, however as I said before some medication is not available from the hospital. So I had to go to buy it from the clinic.

Getting advice to decrease work
The doctor has been so kind to me; he always looks after me whatever sickness he believes I might have. He will order tests for me. The doctor scolded me, “Why do you always move around so much. You should not do too much work”. For the last two years since I started this business with my sister, I’ve had to bend my knees when I sit all the time. This is one of the reasons why the doctor didn’t like the way I was working. He even asked why I didn’t sit on a chair. Furthermore, he wanted me to stop doing all the housework in order to relax my muscles ... The last time the doctor called my son in and told him “Do not let you mum work too hard!”
Requesting help for laundry and mobilisation

Now the symptoms are getting worse, such as I can’t grasp things in the morning. I have to stretch my body and exercise every day. This morning I did the laundry, however I couldn’t wring-out the cloth, I had to ask my son to do it ... However, I still felt that some parts of my body were swollen. Any time I wanted to go anywhere or do anything, I couldn’t do it by myself. I needed my son to help me.

Appreciating help from older son

I have two sons, the older one is working, but the younger one is not working and doesn’t want to go to school. He stopped studying in Matthayom three (grade nine), and is no longer in school. With his education he can’t find any job. Every time that I have to go to see the doctor, my older son will accompany me. My older son is the only one that takes care of me, either by spending time with me or by spending money on my illness.

Feeling life is nothing without mobility

I feel that my life is nothing when I can’t do anything at all. I can’t even grasp or tighten my hair. The pain is more than I can tolerate.

Accepting the diagnosis

I felt nothing. What could I say? I already had the disease anyway. I even asked him if it was dangerous. He said, “It’s not too dangerous, but you have to take the medication all your life.” I was worried before that my symptoms might be linked to bowel cancer or diabetes mellitus.

Gaining advice about food

The doctor suggested that I drink milk or eat small fishes as this could increase my calcium.

Helping self to walk

If I really had to do it by myself, I had to crawl or use a stick to support my walking.
Feeling depressed
There is some depression about not being able to do much work, and not being able to do what I normally can do.

Doing manageable tasks
If I do too much heavy carrying, it is painful, however if I do only small household jobs, it’s not so bad. I used to be able to do some original Thai cooking by myself. I’m no longer able to do it, because it affects my joints. I make my own judgments about things I can do or cannot do. I can’t cook or handle things with my hands, if I feel pain … When the neighbours ask me to help them with some cooking for a party or funeral, I have to say no, because my health won’t allow me to do it.

Gaining advice from neighbours for treatment
At the beginning of my illness, I had a discussion with my neighbours and everyone thought that I had gout the same as them. They suggested that I go to get an injection from a doctor, who wasn’t really qualified as a doctor. Furthermore he is only on the local health staff … As I really wanted to get better, I thought I must have the injection. After the first injection I could work well, however I needed a second injection in just as short a period as a day. I felt that the injection didn’t help me much since I still felt so much pain wherever I’d had it. My neighbour who had the gout suggested that I bought the same medication as her. I asked her to buy some for me, and I took it the same as her, three times a day. I was in doubt about why my neighbour took only one tablet a day, and she felt great while on the other hand, I took three tablets a day and didn’t feel any better. I took this medication to the orthopaedist to look at. He said, “This medication is for gout patients, why are you taking it, you don’t have gout?” The doctor was upset and yelled at me, I understood what he meant, but as I said before I only wanted to feel better.

Using a bolus
Yes, I have (heard about bolus). My sister-in-law bought for me. She told me that they could cure rheumatoid arthritis and osteoporosis. I tried once by taking three tablets. The result was I couldn’t breath. I stopped taking it after that first time.
Using a powder medication

When my pain first began, I tried a powdered medication for a week; it cost 60 Baht ($A2.5) per pack. It could be taken with water or alcohol. When I took this medication, the pain completely disappeared, but I got a headache instead of it. So I stopped taking it after I finished the first pack.

Taking herbs

Someone told me about a plant that could be combined with alcohol. I only tried a small amount of this medication; it made my stomach very warm, but I was getting drunk and I had to stop it. I gave it to my nephew. That was another medication that couldn’t cure my pain. I feel dyspnea and had breathing difficulty. I did not want to take any pain tablets if the symptoms were not so extreme … There was one time that my sister went to get some plant roots. They were from another province that’s 50 kilometres from my home. She said it was an herb that I could boil and take. It was very bitter, but I was still able to take it. It cost me 100 Baht ($A 4.15) per pack. At that time I took it every day. I went to ask my orthopaedist if I was able to take this herb at the same time as his medication. He said, “It looks like piece of wood, does it?” “Yes. It does.” I replied. He asked again “After you boiled it, the water was yellow and the taste was bitter, was it?” I said “Yes” again. So he said “It’s alright to take this one, but not the bolus”. When he told me not to take things I listened to him. I know it’s dangerous.

Rejecting spiritual and mystical remedies

I have heard this before (a treatment of bathing in holy water and seeing a fortune-teller) from someone who lived near by. The person who told me had a brother-in-law, who was a medium. They said I also should be a medium. However, when I said no to this I faced the consequences of being a patient with rheumatoid arthritis. I didn’t believe this. The person had asked me to do this once before by providing the expenses for it, but I said no. This person came to see me at home and told me that I had to do it, be a medium ... About seeing a fortune-teller, I don’t believe in it, I believe in myself. However if someone comes and tells me about bad things, I will go to the temple to do some religious rituals to make myself feel better. My point of view is that although I rarely believe in this if a person, who has never known me all their life comes to see me
about something bad that’s going to happen to me, I may believe it. For example, if a monk tells me that I’ll have bad luck, I may believe it. However, if he asks for my birthday to tell my fortune, I will not believe it ... Someone told me I could extend my life by seeing a fortune-teller, but I don’t believe it. The fortune-tellers always predict when other people will die. I wondered if they ever predicted when they would die. When the time is up, everyone will die. I was not scared about the date of my dying. Seeing the fortune-teller was not just one or two Baht, it was about 10,000 Baht ($A 416.67). I believe that whatever will be, will be. What I had with rheumatoid arthritis was an illness. I had to take the medication as the doctor ordered. Rheumatoid arthritis was not bad luck or anything associated with my fortune.

Telling the family about pain
If I had extreme pain, I would tell about it. When I felt so much pain in my shoulders that I couldn’t sleep, I had to get up and sit for a while. I woke my son to call my sister, and let her know that I was in so much pain. My son said “It’s 2am. Who will come to see you or take care of you at home now? Wait until sunrise and go to see her.”

Talking with a monk and doctors about pain
I felt pain in my shoulders this time, because I helped the undertaker to carry the casket for cremation. My neighbour told me that, because I was always doing work that was associated with funerals it caused my pain or led me to have rheumatoid arthritis. I went to talk to the monk and the doctor, and they both said that what I had done was a good thing to do. But people didn’t believe what the doctor and the monk said. They said it was, because I was doing this without paying homage to the spiritual teacher. So all the bad things returned to me as side effects. But I believe that the pain I had was a part of my illness. There was no relation between my pain and the work that I did for charity or funerals. Furthermore, I also went to take care of someone in the hospital who had no one to care for them. I was always doing good things for people.

Appreciating care from nurses and doctors
They (nurses) suggested the same things as the doctor. They read my case history and advised me. I told my neighbour about what the doctor and nurses advised me to do.
Although my neighbour didn’t believe in it, I still did as they advised me ... Yes, they (doctors) were so good ... Only the doctor and the nurses at the hospital keep taking care of me. When I go to pick up the medication, the doctor asks me how I feel in order to adjust the medication until it’s suitable for my pain to respond to. The doctor said it was not too strong, but I found that when I took it, I felt better. So I kept taking it.

**Needing home visiting from local health staff**

I would like them (local health staff) to come and talk or to ask me how I am doing, but no one comes. There was only one observation about how much income that I had, not about my illness. Some doctors who want to make money from their patients order a medication that won’t cure the disease in order to keep the patients coming back to see them. As long as the patients were still sick, they still had to go back to see the doctors. Now I know that my doctor is not the kind of doctor who wants to make more money from his patients, and that’s why he told me to get any medication that’s available from the hospital in order for me to save money.

**Getting help from her son**

When I felt pain I wasn’t worried. Everyone was willing to help with such things as when I was sewing the nylon. If my oldest son saw me working, he would scold, “Why you are working? You’ll feel pain again.” My oldest son can’t bear to see me work. He didn’t want me to work at all. He always reminded me not to work, and even told me to remind him to go to pick up the medication. Any time whatsoever I wanted him to accompany me to the hospital or clinic he would never say no.

**Tim’s experience**

**Background**

Tim and her husband chose to be interviewed together. Tim was 44, a financial staff member of the public hospital, and she graduated from school in grade 12 (Matthayom six). Her husband was a 45 year old teacher. Tim said she got pain from rheumatoid
arthritis when she was 21 years old, in 1990. Firstly, her knees became swollen. The
doctor aspirated her knees to release the fluid and gave her steroid injections. She had
this treatment every one or two months after that. This went on for many years, until she
was having knee aspirations two or three times a week. Her patellae sank and the doctor
operated on her for this condition. She could not flex her knees, because of not taking a
physiotherapy course after the operation. Ten years after this operation, her hands
became deformed. The treatment she got at that time required many analgesic drugs
from the hospital dispensary, getting gold injections for six months, and seeing the
orthopaedist. He usually gave her an admission order. All this treatment was ineffective
and it affected her job, because she could not find any colleagues whom to delegate task.
So she looked elsewhere to get treatment, although her initial doctor treated her for
many years.

Her new orthopaedist treated her by giving her gold and methotrexate injections. He
advised her to avoid direct sunlight. She had two courses of injections over one year.
The pain was still there, so the orthopaedist gave her prednisolone, and continued to
treat her for over a year. He gave her many kinds of medication before he performed the
knee operation for her, and they affected her very badly. A brain x-ray and CT scan
showed that the optical nerves had degenerated, because of taking too much
chloroquine. She stopped taking every medication after she had many side effects. She
consulted the pharmacist about analgesic drugs to relieve her pain. She started to take
steroids after having the knee operation. She took one tablet per day and a half tablet
every two days, after she felt better. The doctor allowed her to decide the dose by
herself. She took tramal as well, if she had severe pain.

Somebody told her there was another good doctor. She saw him one day, and he did a
blood test and x-rayed her whole body. It showed her hip joints had become thinner. He
gave her a new medication, which debilitated her. Her friend, who had some symptoms
like her, advised her to see a doctor in Bangkok. That doctor did a full body check-up
and a blood test. The results showed nothing. He told her she had rheumatoid arthritis
after he saw her hands. He gave her medication to strengthen her bones, causing her
neck to stiffen. She felt she developed allergies after she took too much calcium, so she
stopped all medications after seeing him two or three times. She took antacids to protect her stomach from the side effect. Besides this, she visited a doctor in the private hospital in Bangkok, who said she was getting the right treatment, and he could not do anything more for her.

Tim said she felt emotionless after the doctor told her that she had rheumatoid arthritis. She thought a lot about why she had rheumatoid arthritis, but she was not sad and did not worry too much. She was very lucky that everyone around her was helpful. Her children helped her when they came home from school. Also her husband, relatives and friends always helped her as much as they could. She had plenty of opportunities to choose the best medication for herself, because she was close to the pharmacist, and used to work in a pharmacy department. She said nurse and doctors treated her well also. She did not need more from them. One thing that she still wondered was why the test results found uric acid in the synovial fluid instead of blood.

At the time of the interview, Tim knew her pain could not be completely cured, although she continued her treatment, to control the pain to a level she could tolerate. She reduced the dose a little, and always had a blood test, trusted in the doctor’s advice, and looked after herself. Although she used herbal treatments, massage, and bolus previously, she did not want to seek other treatments, because everything was the same for her. Tim said she needed to work, although she preferred not to.

Her husband had a diploma in teaching. He said there was nothing different in their lives after he knew she had rheumatoid arthritis and pain. His wife was strong-willed and patient. He never saw her disheartened. She could work and she sometimes helped him too. He had no idea which medication she should take for severe pain. He always took good care of her by serving her meals, water, and medication, and also taking her to seek alternative treatments. He said he will ring his sister who lived in the USA, and ask for the better medications. He always told her if they could become rich, they needed to be rich with happiness, not from working hard and making money.
Tim’s experience: Emerging codes

The codes emerging from Tim’s account were: describing historical information; taking analgesic drugs and getting gold injection; looking elsewhere to get treatment; taking prednisolone; stopping medication after severe side effects; consulting the pharmacist; expressing lack of trust in doctors and medications; noticing severe side effects from medications; self adjusting the dose; describing neck immobility; noticing decreased abilities; feeling anger; making mind up to be “fine”; stopping physical therapy; describing knee treatment; noticing pain with inadequate seating; using high chair to protect from pain; needing to remain ambulant; keeping up work regimes; expressing acceptance of rheumatoid arthritis; being stressed and depressed when in pain; appreciating care from family; enjoying travelling; stopping activities when in pain; gaining advice about swimming exercise from doctors and occupational therapist; using massage and compresses; seeing the shaman; being unsure about karma; taking bolus; taking an other medication someone suggested; trying everything to relieve pain; taking a garlic supplement; noticing doctor prescribes medication and nurses give them; lying down and resting in hospital; appreciating nursing care; and recommending steroids as the strongest treatment.

Describing historical information
I got pain from rheumatoid arthritis when I was 21 years old in 1990. I’ve had it more than 20 years. Firstly, my knees became swollen. They alternated in swelling first the left and then the right. The doctor punctured my knee to release the fluid and gave me steroid injections. I got better and could walk again. I had this treatment every one or two months after that. This went on for many years until I was having it two or three times a week. My patellas sank. My doctor operated on me for this condition. He took the membrane that covered my knees out. I couldn’t flex my knees because I didn’t take a physical therapy course after I had the operation.

Taking analgesics drug and getting gold injection
Ten years after this operation, my hands became deformed. The treatment I got at that time was taking every analgesic drug in the hospital dispensary, getting gold injections
for six months and seeing the orthopaedist ... I took tramal as well if I had a lot of pain ...
... If I could tolerate the pain, I’d have some food before taking the tramal in the
morning. I knew myself. I took it if I felt bad.

Looking elsewhere to get treatment
He (the orthopaedist) usually gave me an admission order. All this was no good and it
affected my job, because I couldn’t find any colleagues to run the job for me. So I looked
elsewhere to get treatment although he’d treated me for many years.

Taking prednisolone
My new orthopaedist treated me by giving me gold and methotrexate injections. I asked
him if I had cancer bone, because methotrexate is a treatment for cancer. He told me I
didn’t have it, but that this medication would make me get better. He advised me to
avoid direct sunlight, because my skin would become black. I had two courses of these
injections over one year. The pain was still there. He gave me a new medication to
relieve the pain and swelling. It was prednisolone. It’s one kind of steroid.

Stopping medication after severe side effects
This orthopaedist treated me for over a year. He gave me many kinds of medication
before he performed the knee operation for me, such as chloroquine. It affected me very
badly. I had headache, retina and optical nerve swelling. I had to have my brain x-
rayed, because my doctor suspected I had a brain tumour. The result was fine. I had to
have CT scan again. The results showed that the optical nerves had degenerated,
because of taking too much chloroquine. I stopped taking every medication after I had
the many side effects that I told you about.

Consulting the pharmacist
I consulted the pharmacist about which analgesic drugs could relieve my pain, because
the doctor had given me every kind. They not only relieved the pain, but also made me
suffer from the many side effects ... I consulted with the pharmacist again before I took
it (steroid).
Expressing lack of trust in doctors and medications

In fact, I always did as the doctor advised, but he didn’t know how the patient reacted. He couldn’t tell me what was wrong with me after he did a blood test. I didn’t get synovitis. My uric acid level was low, but my ESR level was high, because of the pain ... I noticed some diabetes mellitus patients and hypertension patients got more diseases after the doctors had given them many medications at the time. It didn’t mean I didn’t believe the doctors, but I thought they didn’t really know how the patients were after taking a lot of medications. It’s like they gained something and lost something at the same time. They controlled the diabetes mellitus, but they got heart disease, high blood pressure, and kidney disease. I wondered how the body could tolerate a lot of medications.

Noticing severe side effects from medications

Somebody told me there was a good doctor, who had just started work here. I saw him one day. He did a blood test and x-rayed my whole body. It showed my hip joints had become thinner. He gave me a new medication. I got run down after I took it. I had a headache, nausea, and dizziness. It made me unable to work. My first child, who is a senior pharmacy student, told me this medication was very strong. I would be worse than before. I felt that the doctor had tried the medication on me, because it was a new medication. I stopped taking it after almost a year ... My friend who had some symptoms like mine advised me to see a doctor in Bangkok. This doctor worked in the immune system department in the university hospital. He treated me by consulting with an orthopaedist. He did a full body check-up and a blood test. The results showed nothing. He told me I had rheumatoid arthritis after he saw my hands. He gave me medication to strengthen my bones. I felt I had a lot of calcium in my body. Giving me medication that made my calcium level higher affected my cervical spine. My neck was stiff later. I felt I got allergies after I took too much calcium. The orthopaedist there still gave me the same medication as here. So I stopped everything, provided my own dose and took only steroids and tramal.
Self adjusting the dose

I cut the dose when I’m fine. Sometimes I can survive more than a week without taking the medication. The pharmacist told me it wasn’t good if I cut the dose immediately, because my body couldn’t adapt itself. I cut the dose a little and always have a blood test.

Describing neck immobility

Regarding my neck, it was affected by calcium at the beginning but it’s stiff now ... It was stiff after I had the knee operation. I’ve had stiffness in the neck for 10 years and in my left knee for 20 years. The physical therapist advised me to use something to support my neck. It didn’t work.

Noticing decreased abilities

I could do things like driving a car and riding a motorbike, because I was very strong at that time. I haven’t been able to do those things for the last five or six years, because my body became run down, my neck was stiff, and I couldn’t make a fist with my hands. So I wasn’t game to try those things again. I wondered why the test results found uric acid in the synovial fluid instead of blood. The doctors didn’t explain this to me. The second doctor told me my body had rejected its immune system, and released the substance into the joints ... I went through some changes in a short time, but not everyday.

Feeling anger

I watched a TV program that presented a patient with rheumatoid arthritis who used steroids and her illness disappeared. It was unbelievable and it made me wonder why. My hands and feet used to be very beautiful. They became worse, and I couldn’t flex them after I had the operation. Everyone thought I was fine when they saw me at work. They wouldn’t know I was a patient with rheumatoid arthritis if they didn’t see me walking.
Making mind up to be “fine”

I made my mind up that I would be fine, and that I wouldn’t be sombre, because I’d already got it … I made my mind up to be fine. I have some good friends that love me very much. It’s not necessary to have a lot of friends.

Stopping physical therapy

I used to take a physical therapy course (PT), but I got a lot of pain so I stopped doing it. My doctor told me he would perform the operation again, and he sent me to take a physical therapy course. It made me get better. I thought I couldn’t do it, because I had to go through a lot of pain until I got better. I stopped the PT and hoped I wouldn’t get more pain.

Describing knee treatment

I was fine when I had my knee punctured at the beginning. I felt nothing when I saw the doctor doing it for me. I lay down and saw him put the needle into my patella. He got the syringe out and left the needle in. I saw the fluid coming out from where the needle was. I felt nothing at that time … The fluid was yellow like Kek huay juice. I was lucky that it was not sticky. If it was very sticky, I would get a lot of pain. I didn’t refuse this treatment, because my knees were swollen. I had to do it two or three times a week towards the end of the treatment. I didn’t have swelling when I lay down a lot and didn’t do things. My knees became smaller by themselves. But I couldn’t do that, because I had to work.

Noticing pain with inadequate seating

While I’m talking to you, I have no pain. I get pain when I sit in the wrong position or sit on an unsuitable chair with no support that I would fall into.

Using high chair to protect from pain

I had to sit on the high chair that had a strong seat, especially when I had to help my husband to clear tax matters … I felt I was very stoic, but I almost fainted when I was in a lot of pain. I felt hot and was sweating a lot. I knew I would be fine if I sat on a good chair. I changed the chair at my workplace and bought a new one by myself.
Needing to remain ambulant
I needed to work although I was like this. I felt stressed, and my health deteriorated if I didn’t walk and do things. I always lay down and didn’t have food when I didn’t do things ... My legs hurt, because I wasn’t walking.

Keeping up work regimes
I always kept up my work. I had to write the receipts and give them to every foreign worker, who’d had a health check-up here since last month. I always go to work at 7.30am. I don’t get overtime pay for this. I’ve done it for a long time, because I had no tasks to do at home in the morning. Someone asked me why I did it. I thought it was the right thing to do, because my work is a service and it’s an important job. Although my health was not good, I still did better than some others. So it became my job. OK. I thought I was doing good. My health wasn’t good, but I hoped it wouldn’t give me more pain. I accepted that I had the pain.

Expressing acceptance of rheumatoid arthritis
I felt nothing (when the doctor told I had pain from rheumatoid arthritis) ... I didn’t know what there was to be stressed about. I thought a lot about why I’d got it, but I was never sad and didn’t worry too much ... My first doctor told me there were few patients with rheumatoid arthritis and I was the youngest. I was the first one that he’d treated. I didn’t know what I should do. I saw no reason to be stressed ... I didn’t think there was anything abnormal. I could do things and I could work. I talked to the doctors and the pharmacist. The doctors told me it wouldn’t disappear. No one could cure it completely.

Being stressed and depressed when in pain
I was very stressed and depressed when I was in pain ... They (the doctors) said I would get a lot of pain if I became very stressed. So I tried not to think too much about it. I thought the patients with diabetes mellitus were worse off than I was ... I had no problems with the treatment fees, so I was not stressed about that. At least I had one good thing going for me. I might have died a long time ago if I was very stressed (laughed) ... I felt fine about the fact that I could work and live without a lot of pain. I might become stressed if I become a disabled woman. Now I can do anything, go
anywhere with my friends, my family, and my mental health is good ... I might sometimes be a little stressed from my work by being unable to finish on time or stressed by my colleagues. When I was stressed, I’d calm down for a while and then continue with my work again ... I thought what would I have if I was moody with him, because he always looked after me. I questioned why I was like that? I thought I should use my brain. Pain was pain. I had to consider that he never left me even when I was in great pain. So I didn’t have a problem with this. I was moody, but I had to pull myself up and concentrated.

Appreciating care from family

I never thought about it (what might happen to me in the future), because my family, my husband, my children, and my relatives were good. Nothing had changed in my family. They took good care of me. My mum and my sister looked after me well ... I might have been more stressed if my family was unsupportive. My husband’s relatives were good to me too. I joked with a lot of my friends at work about their booking my husband if I died (laughed), because they knew he was a very good man. It made me feel better. My husband was always there for me ... My children were very lovely. They helped me when they came home from school ... I think family is the important factor that affects patients. They will be fine if their families are caring.

Enjoying travelling

Five years ago I had two trips with a tour agency. They took me diving and to see the coral. I loved to go with them, because it was easy. They arranged the accommodation and the food for us. We felt relaxed about going and didn’t worry about anything. I couldn’t swim, but I could do every other activity they organised.

Stopping activities when in pain

Except when I got pain, I stopped doing things and rested ... We (my husband and I) go to get the money on weekends together. I always sit and help him in the car (laughed). I don’t accompany him if I am in a lot of pain ... I trusted the advice the doctors gave me. I asked them what would happen to me after they’d treated me. I stopped taking it if I felt it wasn’t helping. I didn’t do household jobs. I helped my husband with the tax matters. I
thought sleeping was the best form of rest. I only helped him and rested when I was home. I took vacation leave if I had any due to me.

Gaining advice about swimming exercise from doctors and occupational therapist
The doctor told me I could exercise by swimming, but I couldn’t do it. He said it was good for me, but it was very difficult. The occupational therapist advised me I should exercise my legs when I was not in a lot of pain. Sometimes I could do that.

Using massage and compresses
In relation to massage and compresses, I did both. I felt better after someone massaged me, but sometimes my skin hurt. My mum applied the compresses for me. The results were low to see, and I had to do it everyday. It was uncomfortable for me to do that, because I was sometimes very tired from my work.

Seeing the shaman
I tried every method to relieve the pain. I used to see the shaman after someone told me I was affected by black magic. I didn’t believe it ... A Chinese shaman (Sin Sae) asked me if my neck felt like a turtle’s neck, and whether I’d done something to a turtle. I thought about it and saw that he’d told me the truth, because I used to catch a small turtle and hit it when I was young.

Being unsure about karma
I might say that it was because of my karma if I believed in the Buddhist teachings ... I wasn’t sure it (I used to catch a small turtle and hit it when I was young ) was my karma (laughed), so I didn’t believe it.

Taking bolus
I used to take a Chinese bolus too. It cost 600 Baht per tablet ($A 25) ... It was antler paste, but I don’t think it was genuine. He called “Ya Kwan Chee Wit”. It meant I tried everything that anybody told me about.
Taking another medication someone suggested
I didn’t get better after I took it (one type of medication that someone advised). It was the same result as with the other one I tried.

Trying everything to relieve pain
I tried everything, both medication and other remedies that anyone advised me of. Now I’ve stopped everything and don’t take any more advice.

Taking a garlic supplement
I did take some product made from garlic from a Beauty Company. I think it might have harmed my kidneys.

Noticing doctor prescribes medication and nurses give them
They (nurses) didn’t do anything special. They gave me the medication that the doctor prescribed.

Lying down and resting in hospital
I was often admitted at that time. I usually lay down and got some rest there ... The thing was that the doctor ordered me to take a rest (laughed). He knew I couldn’t do that if I was home. He told the nurses not to allow me to go anywhere. After he knew I went to the cinema, he said he was very sure that I wouldn’t rest if I was home, because I even escaped from him to see a movie although I was admitted ... In my view, I was admitted so I could rest in the hospital. This was the reason the doctor admitted me.

Appreciating nursing care
I don’t know what more I need from them. If I had a wound or high blood pressure, they should attend to me as much as they can. I only had pain. I didn’t have a disease where they’d have to look after me all the time, so I don’t know what they should do for me. They didn’t apply the compresses for me, because there was no equipment in the ward. The patients were sent to take a course at the physical therapy department during the day ... The nurses often talked to me. I thought they looked after me well. I was satisfied
with it. On the other hand, I wanted to rest when I got pain. I didn’t want anyone to disturb me at that time.

**Recommending steroids as the strongest treatment**

I wouldn’t dare to use them (herbs). I’m sure steroids are the strongest treatment. They’re medication from the angels for someone who has a little pain, because their illness disappears after they’ve used them. I knew the side effects, but I had no choice. They made my face swell and my weight increase. I knew this, but I had to take them.

**Phit’s experience**

**Background**

Phit graduated from school in grade six (Prathom six). At age 27, Phit, a hairdresser, started to have pain from rheumatoid arthritis. Firstly, she developed sprains. Her hands and ankles became swollen later, then her knees and neck. She had not thought about swelling being a symptom of rheumatoid arthritis, therefore, she took a bolus. She could walk, but her face became swollen. She went to see a doctor at one of the university hospitals in Bangkok, but she did not return, because there were too many patients. She was treated in another hospital in Bangkok. She took the medication irregularly. She could not walk, because of the pain. So she went to the public hospital again, and continued the treatment there. She said the doctor did blood tests, but rheumatoid arthritis factor did not become evident. At the same time, she took many boluses and decoctions, such as Thai and Chinese medications. She bought some medication that was in a ready-to-use pack too. Some of the medications had steroids that made her oedematous. She refused a medication from the shopkeeper, because the sister of this shopkeeper got rheumatoid arthritis, and it left her sister’s body bent, and contracted like someone who had been burnt.

Phit felt unconcerned when she had pain from rheumatoid arthritis and did not think too much, because she perceived many patients suffered more than her. Although her life
changed a lot after having pain, she did not become disheartened. She tried to do things that she could. She noticed she developed pain if she had preservatives in food, cucumber, and drank coffee or soft drink. She had pain in colder weather also. She had many strategies to relieve pain, such as managing her diet, employing somebody to work, using hot compresses, and taking non-steroidal medications.

At the time of the interview, Phit’s joints were small and damaged. She said she had some other conditions with rheumatoid arthritis too, because her heart became a bit bigger, and her kidneys degenerated. She thought they were the effects of taking too many steroids. Even though she had pain, she would not stop working in the garden and selling chillies, because all her children were studying in the universities. The children and her husband made her felt good, and she employed her nephew to do some work for her, who also took care of her well. She did not want more help from the health care staff, because she felt they always did as much as they could for her too. She said she had just grown a new herb which she got from her friend. It was called heaven grass, and was supposed to cure every malady, such as heart and joint disease.

**Phit’s experience: Emerging codes**

The codes emerging from Phit’s account were: using massage; keeping the body warm; noticing joint swelling and stiffness; going to the hospital; taking Chinese and Thai medications; avoiding certain food; feeling untroubled; getting more information about rheumatoid arthritis from her children; believing in karma; buying medication from the chemist; getting a blood check up; describing joint pain; keeping work responsibilities; using palms to drive motorbike; feeling cold weather affects pain; employing others to work; stopping work when having pain; doing things in the evening; getting out of bed; persisting in helping herself to bath; buying food instead of cooking; thinking the causes of illness would be chemicals; working in spite of pain; applying hot compresses; not taking analgesic drugs to relieve pain; soaking in warm water; resting; taking bolus and steroid injection; using skin balm; connecting pain to karma; using deep breathing; hiding pain from children; receiving encouragement from doctors and nurses to not worry; getting advice about food choices; tolerating illness; taking rheumatoid arthritis
medication; appreciating care from the family; appreciating care from the doctors and nurses; recommending patients with rheumatoid arthritis should have caregivers; and planting herbs.

**Using massage**

*I had pain from rheumatoid arthritis when I was 27 or 28 years old. My whole body felt sprained, and I had to tell my children to massage me frequently.*

**Keeping the body warm**

*I was usually so cold I couldn’t tolerate it, and my joints became swollen later. Now I am 44 years old. My joints are smaller and damaged. The doctor asked me how I could still walk when I had pain and rheumatoid arthritis such a lot ... I only felt sprained, but I wasn’t in pain at that time. I usually felt cold even though the weather was hot. I covered my body with five blankets. I laid a hot water bottle on my feet, my popliteal space, my neck, and my armpits.*

**Noticing joint swelling and stiffness**

*My hands and ankles became swollen first, and my knees became swollen later ... They were swollen for 10 years before my knees. Firstly, my hands and joints were stiff. When my knees became swollen, my neck was stiff and painful too.*

**Going to the hospital**

*In 1990, my neck became swollen. I thought I had thyroid trouble at that time. I went to see the doctor in the hospital. He told me I didn’t have it, but he gave me some medication to control the symptoms. I wasn’t sure if my face and neck had become swollen, because of taking that medication ... The First time that I told the doctor that my bones harm and they felt hot, he said he’d never heard of these symptoms before. I was treated first at the university hospital in Bangkok, but I stopped going there, because there were too many patients. Then I was treated in the other university hospital in Bangkok. I was treated there, because my daughter had to get some treatment for her eyes there. It wasn’t good that I changed hospitals, because then I thought it wasn’t necessary to continue taking medication. Sometimes I took it and sometimes I didn’t ... I*
was treated at the general hospital and I continued the treatment there ... Yes (he told me at that time I had pain from rheumatoid arthritis). The doctor did a lot of blood tests, but rheumatoid arthritis factors didn’t show up. This made me think that I didn’t have rheumatoid arthritis, but my symptoms were the same as rheumatoid arthritis symptoms ... The doctor ordered me to rest immediately after I was admitted. The last time I was admitted was two months ago.

Taking Chinese and Thai medications
I took a lot of medication including Chinese and Thai medications (during those three years). I tried some medications that had steroids in them. They made me swell up, but I could walk. The doctor told me to try to stop taking them. I couldn’t walk after I stopped them. I was admitted, and felt better after I’d had treatment for a while.

Avoiding certain food
Sometimes they (my joints) went up and down; I mean bigger and smaller. I couldn’t have food with preservatives in it, such as papaya salad with preserved crab, salt, and bamboo shoot. The doctor didn’t prohibit me from having them, but I just couldn’t. I could walk if I didn’t have preservative in my diet or drink soft drink or coffee ... Now I control the type of food that I have. I don’t eat a salty diet, squid, or pork. I often eat fish ... Anytime (I usually got pain). I had pain immediately after I had cucumbers ... Last Thursday I had preserved crab with salt, and my fingers suddenly became bent.

Feeling untroubled
I’d never heard of this disease (rheumatoid arthritis) before, so I felt nothing. I thought it was not a serious disease. I only found out it is a most severe joint disease from which patients could have disabilities, and die sooner after I read the newspaper. I used to hear about rheumatism and I thought it was a very severe disease, but rheumatoid arthritis is even more so ... I felt nothing. I didn’t think too much. I did the things that I could ... I felt nothing and didn’t think about this too much, because I saw many patients who suffered more than me. So I wasn’t disheartened. When my youngest child was young, she wanted me to walk and run with her. She didn’t know I couldn’t, because I was in pain. I read in the newspaper that there were many people who suicided by...
jumping into the river or hanging themselves after they knew the doctor couldn’t treat their illness. I’ve never thought about doing that, although my mum passed away when I was 10 years old.

Getting more information about rheumatoid arthritis from her children
My children usually found information about this disease by borrowing books and documents from their friends, who were medical students ...My children want me to get well from the pain. They always ask their friends about how to care for a patient with rheumatoid arthritis. They told me after they’d asked their friends that I couldn’t have preserved food, such as bamboo shoots, shrimp paste, and preserved fish with salt. I love these kinds of food. When I want to have them I think about how I’ll be if I have them. I feel a bit frightened when I think about that (laughed).

Believing in karma
I usually thought about karma ... I think it is punishment for my karma.

Buying medication from the chemist
I had a lot of treatments to relieve the pain. I used to buy medication that cost five Baht per pack ($A .021). A shopkeeper refused to sell the medication to me, because her sister got rheumatoid arthritis, and it left her body really bent like someone who’d been burnt. She advised me to see a doctor. I bought the medication from another chemist. I bought every medication that could relieve pain and bone and joint diseases. I bought medication myself until my body couldn’t straighten and my arms were bent. My body became bent after I had food that’s bad for rheumatoid arthritis too.

Getting a blood check up
The doctor did a blood test every time I saw him. He checked my rheumatoid arthritis factor level. I didn’t want to continue treatment after I knew it had increased.

Describing joint pain
I was in a lot of pain in my joints. It felt like something was preventing my hip joints from bending and stretching. At the beginning my fingers looked like a section of
bamboo, because they became swollen and bigger. I couldn’t make a fist with my hands either. Now my wrists have been damaged for the last two years, because I grew the corn and chilli by myself.

**Keeping work responsibilities**

I needed more money for my children. They were studying in universities ... I had to do them (growing corn and chilli), because two of my children were studying in universities (Almost cried) ... I had 15 Rai (24,000 square metres) of chilli. I worked there all day and all night ... I used to have one employee, but he passed away after an accident. So I had to do it by myself ... I couldn’t stop working, because it made me more anxious. I felt better if I worked. It stopped me thinking too much about my illness. I thought I could get things for my children if I worked. If I worked, my children were fine. If I didn’t work, I was better but my children were unhappy. I would get some rest if I worked and felt tried. When I worked I could talk with others. That made me felt better than always lying down at home. I knew the pain was still there and I was not cured completely.

**Using palms to drive motorbike**

It was good that I could drive a car. I used a motorbike with a trailer before the car ... I used to (drive the car), but my nephew drives it for me now. I can’t control the steering wheel ... I didn’t use my whole hand when I rode the motorbike with the trailer. I used the palms to control it, because I couldn’t close my hands. It was different from a normal motorbike.

**Feeling cold weather affects pain**

When the cold weather came, I was in a lot of pain and I felt hot and got the sweats. Last night my daughter turned on the electric fan. I had pain late at night, because the weather became cold then. I was in such pain that I had to take a bath.
Employing others to work
I employed others to do the things that I couldn’t … Sometimes I asked my nephew to sell my chilli for me. I accompanied him, because I couldn’t stop myself doing things if I stayed home.

Stopping work when having pain
I still do most things by myself if I don’t get pain. If I had pain while I was grinding the chilli, I’d stop doing that, lie down, and lift my feet higher than my head.

Doing things in the evening
I didn’t work too much. I did things in the evening if I couldn’t do them in the morning.

Getting out of bed
It was the same for me even if I was not in pain. Before I’d get up, I’d think about which position would be the best for me, and turn my body to that position. I had to tilt to one side and get up slowly. I’d think again about how I could stand, because I only had one small mattress and I laid on the floor. I had no bed, because it was uncomfortable for me to clean the floor under it.

Persisting in helping herself to bath
I often forgot that I was in pain. I dropped the water bowl when I took a bath, because I couldn’t carry it when it had water in it. I waited for a while and tried again.

Buying food instead of cooking
I rarely cooked rice. I always had food from the market … My children have lived in Bangkok for the last four years. We usually had food from the market. We cooked when they wanted to have something special.

Thinking the causes of illness would be chemicals
I’ve had pain since my first child studied in Prathom three (Grade three), and I got a lot of pain when my youngest child was very young. I’d never thought about swelling being a symptom of rheumatoid arthritis. I just thought the air inside my body wasn’t
circulating well. My ankles became swollen too. I was a hairdresser before, and I sometimes thought I had swelling from the chemicals I used when I dressed the customers’ hair ... When I first got pain, I was a tailor and a hairdresser. I’ve dressed hair since I was 10 years old. I couldn’t roll the customers’ hair when I was in pain. I didn’t know the cause was rheumatoid arthritis.

**Working in spite of pain**

I had many employees when I had the salon. I only cut the hair and dressed the nails ... I sold desserts (laughed) ... I changed jobs a lot, because I followed my husband. I didn’t keep my equipment when I followed him, so I did any job that I could when I lived in the new place. I’d never worked in easy jobs. I used to close my salon at 11 or 12 pm, and open it at 3 or 4 am when I did brides and bridegrooms. When I cooked desserts, I prepared over 10 kilograms of dough. I prepared 10 kilograms of dough to cook Thai sweetmeat, and 10 to 20 kilograms to cook Chinese sweetmeat. It was painful when the dough was cold. I bought almost 10,000 bananas to cook each time. I didn’t really expect to sell the desserts, but I did really well at it ... I did them myself, all day, and all night. I didn’t sleep at all, but I usually drank coffee. I think coffee affected my pain. My skin was good at that time. It became worse after I got rheumatoid arthritis. My skin became purple when I was in pain. It looked like I’d burnt myself. My life changed a lot after I had pain from rheumatoid arthritis, but I didn’t get disheartened.

**Applying hot compresses**

I applied hot compresses ... My doctor (advised me to do that) ... Everyday (that I did it when I was in pain). I rarely do it now, because I’m used to the pain. It’s different from the beginning when I couldn’t tolerate it. It was unusual if a day went by and I didn’t get pain. I wanted to lie down if I wasn’t in pain. I couldn’t lie down if I was in pain, because I was in pain in every position.

**Not taking analgesics drugs to relieve pain**

The doctor gave me them (analgesics), but I didn’t take them. I usually took non-steroidal anti-inflammatory drugs (NSAIDs). I only took analgesic drugs with it if I was
in a lot of pain ... He gave me paracetamol, but it affected my kidneys and my lips became dry, so I drank a lot of water after I took it.

**Soaking in warm water**

I would soak my whole body. I used a huge tub, and set it in a place where I could hold on to something or use something to support myself when I got out of the tub.

**Resting**

I got some rest and didn’t walk when I was in a lot of pain. If I was in pain when I sold my chilli, I’d lie down in my car and not get out of it. I didn’t lie down all the time, because my body was too stiff. I’d lie down for a while, and then try to get up and start to walk. I had to walk slowly until I felt better. My doctor told me some patients couldn’t walk at all if they were at the same stage as me ... I didn’t get any rest. Firstly, I thought I would stop my job when my children graduated with bachelor degrees. I can’t rest now, because my first child has just started his master’s degree. My second child is studying for the Bar Association, and my youngest child is studying dance. My children are good and they make me feel good too (almost cried).

**Taking bolus and steroid injection**

Yes (I used to buy some medication that was in a ready-to-use pack). I used to take a bolus, but the doctor told me to stop taking it. I told him I couldn’t walk if I stopped. He still advised me to stop it. He advised me to stop it for one mealtime a day. For example, today I stopped taking it at breakfast. Two or three days later I will stop taking it at lunch. I couldn’t walk at all after I stopped it at the third mealtime. I didn’t suffer much, but I was admitted to the hospital and got some injections ... Firstly, I took a bolus that helped me to walk, but my face became swollen, so I went to see the doctor. He advised me to stop taking it. He didn’t believe that I couldn’t walk if I stopped taking it. One day I saw him and he knew that it was true; I couldn’t walk after I stopped taking it. He gave me a steroid injection. I had pain in all parts of my legs after I got that injection. A lot of the steroids were retained in my body even though I’d stopped taking them, because I’d taken them for a long time. One pack cost 1,000 to over 1,200 Baht ($A 41.67 to over $A 50). It was a Chinese medication.
Using skin balm
I got some (balm) from the doctor. I used it, but it didn’t help, because I had pain in my joints and my bones not just my skin. It was used to support us psychologically more than to relieve the pain. I felt it was too sticky when I applied it too. I didn’t use it again and I sent it to others, who wanted to use it. Balm is good if the insects bite you and you rub it on. It’s no good for me, because it doesn’t absorb into my bones.

Connecting pain to karma
Yes, I sometimes did (use religion). I thought that someone who I’d done wrong by wanted me to have pain for compensation (Jao Karma Nai Wain). So I was in pain for as long as they wanted.

Using deep breathing
Sometimes I breathed in deeply, and focused on how long I’d had pain in that day. I didn’t get disheartened.

Hiding pain from children
I always told them I was in a lot of pain, but they didn’t touch my body. I told my children that I’d tell them later when they asked how I was. I was more tired when I was in pain than I was when I was running and working, because I was in pain and tired at the same time. My children didn’t know how much pain I was in. They said I was naughty, but I was nearly dying. My body became cold when I was in pain so they thought I was dying. I still played with them even though I was in a lot of pain. I never complained about the pain. I never cried. I always smiled when I had pain. My children carried me and helped me to take a bath.

Receiving encouragement from doctors and nurses to not worry
Most of them (doctors and nurses) talked to me and encouraged me. They didn’t want me to be worried about my illness. They always talked to me about things that made me happy.
Getting advice about food choices
One person advised me. A doctor told me I could have any kind of food. Someone else prohibited me from having bamboo shoots, white radish, coffee or cucumber. When I had these foods, I couldn’t walk. My family carried me to see the doctor. The doctor said he didn’t want my money (laughed). He wanted me to do what he advised.

Tolerating illness
The axe fell on my toes, and I got a big wound and it bled badly. I didn’t tell anyone. I dressed my wound and went to the hospital. Someone asked me why I was so stoic. I knew I might make them worry a lot if I’d told them how I was.

Taking rheumatoid arthritis medication
I know the rheumatoid arthritis and pain won’t disappear, but I’ll still get ongoing treatment, because I still work ... Taking rheumatoid arthritis medication a lot has given me a kidney condition. But stopping the rheumatoid arthritis medication gives me a lot of pain. It’s all right. I’ll still get the treatment although I have many fascias on my wrists, and my bones have degenerated.

Appreciating care from the family
They do good things for me. Everything depends on me. I didn’t follow the doctor’s and my family’s advice. My family tells me about the right food to protect me from pain. Everyone around me is devoted to me, but I didn’t believe them ... They took turns to come back home. Since I employed my nephew to work with me, they’ve felt better and don’t worry too much, because he’s around more than my children were. He takes charge and cares for me a lot. He’s worried that my children will blame him if I have a lot of pain when they come back home.

Appreciating care from the doctors and nurses
They care for me well too. That’s enough for me ... I don’t think they could give me anything more besides encouragement. They noticed I felt happy when I talked about my children, and so they talked to me about them next time. You can tell if someone is happy or sad from their eyes even if they don’t express their feelings or tell you. When I was
admitted the nurses encouraged me, gave me medication, and injections when I had pain. They advised me to be careful when I walked, and to try to have someone stay with me.

**Recommending patients with rheumatoid arthritis should have caregivers**

Patients with rheumatoid arthritis should have someone to look after them. Pain is the general thing for me. If I don’t get pain, it is abnormal. Now, I still get pain but not much. I feel like some things walking inside my joints. I talked with some friends who live in the north of Thailand. They told me I’ve got silk worms (laughed). I knew I didn’t have silk worms, because there was nothing on the X-ray, and silk worms make us feel itchy on the skin. I knew I had pain in my joints.

**Planting herbs**

Recently, someone gave me an herb from Taiwan. She called it heaven grass. It can cure every disease, such as heart disease, joint disease, diabetes mellitus, and kidney disease. I haven’t tried it yet, because I only planted it 4 days ago.

**Boon’s experience**

**Background**

Boon and her husband wanted to be interviewed together. She and her husband were both 53, employed, and graduated from school in grade four (Prathom four). Boon started to have symptoms of rheumatoid arthritis when she was 41, and was cured at a private clinic in Bangkok. She stopped selling charcoal and worked home instead. Five to six years before the interview, her whole body was swollen, especially the wrists, knuckles, elbows, ankles, and knees. She was thinner and lost weight too. She went to see the doctor, and he told her she had rheumatoid arthritis. He treated her till she felt better, but the pain was still there. She could not do anything by herself, including undressing and going to the toilet, for which she had to ask for some help from her family. She consulted another orthopaedist regularly, and he did blood tests, and said
everything was fine. She had been admitted to hospital, and she said some of the nurses took care of her well, but others did not. She took a bolus preciously, but it made her stiff and contracted her body. Boon used pain relief measures, such as massaging, using a moist air tent, and hot packs, but she recommended taking medications regularly and resting.

When Boon was in pain, she cried, felt disheartened and wanted to die. She tried to commit suicide by hanging herself, taking poison, and jumping into a river, but she did not die. So she promised herself that she needed to spend time paying for all of her karma, and to nurture one of her sons who was deaf, also her young niece and nephews, as best as she could. Although she had bad luck, she had a very good husband, who always looked after every time whether she was admitted to hospital or stayed at home. She said he pitied her, but he did everything for her, such as taking her to the toilet and altering the toilet for her. He also found up-dated information about rheumatoid arthritis for her.

Before the interview finished, Boon said she did not only have pain from rheumatoid arthritis, she also had other problems with her kidneys, gall bladder, and heart. She had diabetes mellitus and hypertension also. She explained that the pain of rheumatoid arthritis was the worst kind ‘the mother of all pain’. She wanted nurses to be patient while they supported, listened to, and gave encouragement to patients when they were in pain. She suggested that doctors give patients good medications to relieve pain also.

**Boon’s experience: Emerging codes**

The codes emerging from Boon’s account were: noticing stepping can cause pain; getting help for toileting; losing weight; noticing restriction from pain; recommending medication to stop pain; buying take-away food instead of cooking; getting help from husband; using herbs; lying down; using hot compresses; noticing massage can cause pain; noticing rheumatoid arthritis can cause flu or chills; recognising body effects from the weather; feeling grinding joints; hoping to get better medication; attempting suicide; believing in karma; being visited in hospital by husband; needing more information from
nurses for self and husband; gaining advice about food choices; learning about harmful food; getting help from neighbours for food preparation; being dissatisfied with some nurses and doctors; getting general medication from local health staff; taking paracetamol to relieve pain; needing more advice about food; expressing acceptance; noticing joint swelling; becoming thinner; describing history illness; feeling untroubled; noticing loss of appetite; worrying about family’s problems; controlling emotional state; helping self in cooking and toileting; stopping working when having pain; using the tent treatment; using fomentation; using decoction; suspecting traditional treatment can’t cure rheumatoid arthritis; getting rheumatoid arthritis from working hard; restricting food; getting some advice about body movement; getting advice about soaking in warm water; advising relative to care; using bell to summon nurses; getting help from the children; being satisfied with family’s care; needing more support from nurses in listening and pain control; and appreciating advice about bed rest.

Noticing stepping can cause pain
At the beginning, he (my husband) couldn’t go anywhere. If he went out, my son would call him to come back home, because I couldn’t do anything by myself. At that time, my house had only one floor and wasn’t high from the ground. It was easy to step up from the ground, but I couldn’t even do that. It was painful if I did. No one could touch my body. It looked as though I was pretending, and needed someone to look after me all the time. I didn’t know why I was like that.

Getting help for toileting
My husband tied a rope on the toilet’s ceiling to support me when I stood up, but it wasn’t successful ... I couldn’t do anything by myself and needed some help when I went to the toilet.

Losing weight
When I had rheumatoid arthritis, I lost weight. I couldn’t eat much, and my body became smaller ... I lost weight ... from 60 kilograms to 50. Sometimes my weight was 47 kilograms if I was in severe pain.
**Noticing restriction from pain**

I don’t know how to explain it. When I was in pain I wanted to die and be born again, but I couldn’t. The pain was still there. I was in so much pain that I couldn’t even pick the medication up. I couldn’t do anything by myself, and it was painful when my husband held me too … Sometimes when I didn’t take the medication I couldn’t do things, such as taking my clothes off.

**Recommending medications to stop pain**

I had to take the medication before I saw the doctor, and I told him that I could only come to see him because of the medication. When he did a blood test, he said it was fine, and he decreased the dose of the medication. He never asked me about my pain, although I was still in pain while I was seeing him. I would say I survived, because I took the medication.

**Buying take-away food instead of cooking**

Sometimes I bought take-away meals. If my husband didn’t come back home in the morning, my nephews bought a pack of fried rice. I’d have a couple of spoons, and they’d have the rest of the pack.

**Getting help from husband**

He (my husband) did everything for me even when I gave birth. Love is not the basis for us. He pitied me, because he knew that I’d faced many terrible situations since I was young … But my husband always told me to do what I could. If I couldn’t do it, I should let him do it … He’s looked after me every time I’ve been in the hospital since I gave birth for the first time till the last time I was admitted. My children only visited me few times. Although our relatives wanted to look after me when he was busy, he didn’t allow them to. He didn’t trust them, because I didn’t get along with my family. My parents didn’t love me. They hated me … He did tell me when he knew some up-to-date information … My husband did a lot for me. It’s enough for me … I could sit like this, on the chair with my legs down. I couldn’t sit on the floor. I sat on the chair and the bed that my husband made especially for me … He made a new chair for me for when I
cooked. If I sat on the floor or on the little stool, I couldn’t stand up again and walk. I had to shout and ask for some help.

**Using herbs**

I used herbs to take a special treatment. I set up materials like a tent, put the boiled herbs inside then I came in and breathed in the steam. It was like when we take a sauna. It didn’t relieve the pain. After I did it, I was still in pain and very stiff. The pain made me cry too … When I was young, I lived with him (my grandpa). He was a traditional doctor. I saw him when he made medication from herbs, and I practiced to make it by myself. When my daughter-in-law or my neighbours had problems with their lochia, I could help them to manage them. The herb treatments that I made were different from others. They smelt good.

**Lying down**

I had to lie down and not move my body.

**Using hot compresses**

I put hot water in the bottle, and put it on top of the area that was painful.

**Noticing massage can cause pain**

No one could massage me. If they did, I had a lot of pain the next day.

**Noticing rheumatoid arthritis can cause flu or chills**

Rheumatoid arthritis made me have the flu or a chill all the time. When I had the flu or a chill, I had to curl my body up, and then couldn’t extend it again.

**Recognising body effects from the weather**

For example, the weather today is good. I’m fine. But it was bad yesterday. My body was bent in the morning, but I could stand up in the late afternoon.
Feeling grinding joints
When I tried to stand, I felt something was wrong with my knee joints. They seemed to grind against each other.

Hoping to get better medication
I hope that someone who is studying to be a doctor or some other health professional can find a good medication for patients with rheumatoid arthritis ... I wonder why there is good medication in the hospitals in Bangkok, but the hospital here doesn’t give it to patients with rheumatoid arthritis ... I wanted to tell him (the doctor) that he should find a better medication than this one to treat rheumatoid arthritis. I didn’t dare, because I didn’t have much money ... If I had more money, I would go to get better treatment in Bangkok. I know from one patient with rheumatoid arthritis who was cured there that the medication from the hospital in Bangkok is good. She had no pain after she took it. Her health was good too. She said that I needed to spend a lot of money. It cost almost two to 30,000 Baht ($A833.33 to $A1,250) ... I am concerned about the medication. I want them to give the medication that makes patients get better, so that they can do things for themselves.

Attempting suicide
I know that when I was in pain it was so severe that I didn’t want to live. I suffered everyday when I had it. I tried to commit suicide by hanging myself, taking poison, and jumping into the river, but I didn’t die.

Believing in karma
So I still get pain from rheumatoid arthritis now. I need to spend time paying for all of my sins. This means that I have to keep for my word when I say things. I don’t know how long I’ll have to do this. Regarding my niece and nephews, their parents let them be with me. Maybe I am in their debt from the past. So I will nurture them as best I can ... They should make up their minds to accept their illness. They can think that having rheumatoid arthritis is because of their karma, but why did they have rheumatoid arthritis when there are many diseases in the world. It’s lucky that they don’t have cancer. The doctor joked with me that I was not a real patient. If I were a real patient, I
would have cancer. I told him that he shouldn’t challenge me, because I’ve still had any more diseases.

**Being visited in hospital by husband**

*He (my husband) visited me at the hospital most of the time.*

**Needing more information from nurses for self and husband**

*They (nurses) only told me that I had to get some rest, and not to wash the clothes by myself. They didn’t tell me anything else, and suggest that they should talk with my husband too. Some husbands didn’t know what was happening to their wives. They would pretend to know.*

**Gaining advice about food choices**

*They didn’t tell me what vegetables I shouldn’t have. A nursing student told me that I shouldn’t have bamboo shoot.*

**Learning about harmful food**

*I asked the doctor about it after I’d learned about it by myself. One day when I was discharged from the hospital, and I really wanted to have the tops of the lead tree. I got severe pain after I’d had it. So I only have the tops of that vegetable again in very small amounts if I really want it. I didn’t have the core of the cucumber either.*

**Getting help from neighbours for food preparation**

*One person (my neighbour) cooked rice for me, and asked about buying me the food that I wanted … If there was a funeral or wedding in this area, I would prepare everything for these events. Most of them used my home. Now I still do that, but I assign somebody else to do the things that I can’t.*

**Being dissatisfied with some nurses and doctors**

*I wasn’t satisfied with the nurses when my blood vessels broke when they gave me injections. Some doctor manipulated my ankles with too much pressure. They should know that I had rheumatoid arthritis, and it put me in a lot of pain. Someone asked me*
about when I could walk. I wanted to walk as soon as I could. I tried to walk around the bed, but I couldn’t do that much if they were always twisting my ankles.

**Getting general medication from local health staff**

When they (local health staff) visited our home, they gave us general medication, such as paracetamol. I thought I suffered like this, because of the health system. First I had the health insurance card. It cost 300 Baht ($A 12.5). When I got sick, I had to go to the local centre first, and show them the health insurance card. They referred me to the hospital if they couldn’t cure my illness. I thought if I only took the medication they’d given me, I’d get worse. Therefore I went to get treatment at a private clinic. It was faster than the local health centre, because I could get treatment without having the referral form.

**Taking paracetamol to relieve pain**

I took paracetamol when I was in pain ... They (nurses) only gave me paracetamol. It could only relieve pain for a while, because it’s not the specific medication for treating rheumatoid arthritis ... I could control my pain by taking paracetamol.

**Needing more advice about food**

I think they (nurses) should make suggestions that are specific for the disease, and not just give us the same general information. I want them to advise us about the food that I can have and about care for a patient with rheumatoid arthritis. It’s not necessary to give much advice in some diseases. They should advise the relatives too, because there are some differences in each patient ... Yes, they should explain this to me (diet information).

**Expressing acceptance**

I’ve never worried about death. I’ve always hoped that I will be able to do things for myself, but there would be no meaning to life if I had to live with a disability that meant I couldn’t do anything ... I accepted my illness, and thought that I was being punished for the sins I used to do to everyone. You see...This is the scar from after I had the operation on my gall bladder. The stones gave me pain at the xiphoid.
Noticing joint swelling
Five to six years ago (I saw my joints were swollen) when a general practitioner here cured me. At the beginning, my whole body was swollen.

Becoming thinner
I was thin and I’d lost weight too.

Describing history illness
Maybe ... because I also had some problems with my kidneys. I used to do dialysis, but no longer. On the other hand, because of I took the medication for gout, my pain was still there and I had to change doctors ... I had diabetes mellitus and hypertension too ...
Yes (I had kidney problems before I had rheumatoid arthritis). I had gall bladder problems after I’d had rheumatoid arthritis for two years. After that I had diabetes mellitus and hypertension too. Now my blood pressure level and migraine are better. I still have a small problem with my trachea.

Feeling untroubled
I felt nothing (when the doctor told me that I had rheumatoid arthritis) because I already had it. I couldn’t get rid of it. At that time I had gallstones too.

Noticing loss of appetite
I could only have a couple of spoons per meal. Sometimes I didn’t want to have even that; I bought mineral salt, put it in hot water, and drank it ... Sometimes I did (vomited) but I took some medication to prevent it. I thought it was caused by the rheumatoid arthritis. If I let myself vomit, I would have to be admitted to the hospital ... I was weak and couldn’t eat food. The doctor gave me some vitamins, but I stopped taking them when I could eat again. If I had vitamins and food together, my weight increased and my knees would suffer ... I didn’t have anything much (when I was in pain).
Worrying about family’s problems

There were many problems at home. I never worried about myself, but I worried that there was no one to look after my grandchildren and especially my youngest niece. I had no money to employ a babysitter.

Controlling emotional state

I could manage it (my emotional state), but sometimes it was bad when I worked as a babysitter. At that time, I didn’t get pain like this.

Helping self in cooking and toileting

I cooked the food by myself, and sometimes bought take-away meals from the market. If I couldn’t, I stayed in bed with my niece … I did some things by myself if I could, such as going to the toilet. If I couldn’t go to the toilet, I used the bedpan and my husband emptied it in the toilet the next morning.

Stopping working when having pain

I didn’t work if I had severe pain. My nephews bought the food for us. I tried to protect my legs by only walking a little. When I had pain, I couldn’t do anything and wanted to lie down. It didn’t mean I didn’t want to do things, but I was in too much pain. If I had more money, I wouldn’t feel sad and suffer like this … I left things (when I had pain). I didn’t care if someone told me off about letting the home get dirty.

Using the tent treatment

I did the special treatment by myself that I told you about. It was better than fomentation … I called it “the tent treatment”. My steps for the tent treatment were:

1. put the circle of sticks into the ground.
2. tie the big plastic bags that we used for fertiliser to the sticks. With this step, you had the tent.
3. put hot charcoal in a traditional oven and put it in the tent. Put a pot of water on it.
4. put the herbs in the pot. I used Thai onion, camphor leaves, which is only10 Baht a bunch ($A0.42), lemon grass (crushed), basil (leaves and roots),
curcuma, tamarind leaves, cassumunar, Paederia Linearis, and Acacia Concinna.

5. leave the water to boil, get into the tent, and lift the lid a little bit to let the steam out slowly. Take your clothes off before you come in too.
6. You breathe the aroma and steam in. It goes into your body, and you should feel better.

As long as you could tolerate it (staying in the tent). After you came out, you got some rest for a while, because you’d sweated a lot. This meant you were weak and might faint. So you rested till you felt good (approximately 10 minutes), then put the rest of water into your bath water ... I felt my tendons and ligaments relax. It didn’t relieve the pain. Rheumatoid arthritis made my body curved and bent. It made me have the flu and a chill too. My joints were stiff and bent. Sometimes in winter, I didn’t feel any better although I kept my body warm with many blankets. I suffered so much.

Using fomentation
I used the herbs (for fomentation) that were left from doing the tent treatment ... I couldn’t do when I had a lot of pain, because it made me suffer more. I did it after I felt better.

Using decoction
I tried it once (decoction). It made me more bent and stiff ... I got it from my dad. He saw someone get better after they’d taken it. But I felt I should get into the pot instead of it after I’d taken it. It gave me diarrhoea, but my ligaments were relaxed. It didn’t make me better.

Suspecting traditional treatment can’t cure rheumatoid arthritis
I think rheumatoid arthritis is not cured by traditional medication.

Getting rheumatoid arthritis from working hard
I’ve never seen anyone in my family with it. I thought I was unlucky that I got it, because I’d worked hard since I was young. At that time, I helped my parents sell charcoal. I knelt on the floor, put a lot of charcoal in the basket, and put the basket on my
shoulders. Sometimes I used a harrow to scoop up the charcoal, and carry it to the storage place. When I had pain, I had to use my forearms instead of my hands to hold the glass when I wanted to drink water. This wasn’t so good, because the glass would fall to the floor. My nephews helped me too. I forgot about my hands. I couldn’t use them to hold anything when I was in pain.

**Restricting food**

I didn’t like them (salty foods). I didn’t put any sauces on my food. I didn’t have chicken. The doctor suggested that I could have it but not much, especially not the wings.

**Getting some advice about body movement**

They said that I should change positions while I was in pain and stay in bed, but avoid staying in the same position for a long time. They didn’t tell me how I could change positions. I didn’t want to do that when I was in pain, because I had pain all over my whole body. I had pain at my ribs too, but not much pain in the lower part of my body … They (nurses) told me that I should sit on the bed, let my feet touch the floor, and try to walk … After they’d taken the IV fluid line off. They told me to practice walking by holding the rail of the bed. I tried to walk. If I didn’t, they would check up on me and manipulate my ankles.

**Getting advice about soaking in warm water**

The doctor told me to soak my feet in warm water for 10 minutes when I was in pain. But it didn’t help me when the pain came. I needed to take the medication only.

**Advising relative to care**

They (nurses) told my husband to bathe me in my bed.

**Using bell to summon nurses**

The last time that I was admitted, the head of ward gave me a bell, and told me that I could ring the bell if I wanted some help from the nurses.
Getting help from the children
When they (my children) were still studying, they helped me when I took a bath, and helped my husband wash the clothes. Now they’re grown up and can’t do these things, because they have to work. If they visited me frequently, they would lose their jobs. So I let them do what they want, because they have their own families too ... It’s all right. My children could help at that time, but not now because they don’t have much time.

Being satisfied with family’s care
Yes (I satisfied). Some patients aren’t as lucky as me. Why do I need more than this? ... Sometimes they picked me up to see the doctor. I didn’t think about it too much. I wanted to live for my grandchildren.

Needing more support from nurses in listening and pain control
This disease will make you suffer pain till you feel that this is the mother of all pain. Some patients can’t accept it and get depressed. I would like the nurses to be patient while they support the patients. I thought most of the doctors were all right. Nurses were more important than them. Patients wanted nurses to listen to them, and give them encouragement when they were in pain and say things such as “Please stay in the hospital for few days till you get better.”

Appreciating advice about bed rest
I’ll give you one example. A patient who has a knee operation should not walk immediately. They should have relatives to take care of them. They should stay in bed and ask for help. It’s only two days. When I had this operation and there were more patients at that time. They forgot to advise me, but the head of the ward was very good. She advised me to stay in bed, and gave me a bell to ring when I wanted some help. One patient voided in bed. It made things worse for him. In fact, he didn’t want to do that, but he couldn’t go to the toilet by himself.
Summary

This chapter introduced the patients’ experiences, in relation to their backgrounds and emerging codes. The patients described living with rheumatoid arthritis, and how they managed the pain. The individual codes that emerged were collated into categories, which are presented in Chapter Eight of this thesis.
Chapter Six: Caregivers’ Backgrounds and Emerging Codes

Introduction

After interviewing the caregivers, I transcribed the accounts of their experiences, and translated the transcriptions from Thai to English. Following this, I analysed individual accounts. This chapter relates to caregivers’ backgrounds and emerging codes. The caregivers were identified by the pseudonyms of Dee, A and B, Dao, Aim, Man, Whan, Poon, Nhung and Song, Yon, and Ping. Twelve caregivers were between 14 and 60 years of age. They were six men and six women. Half of them were married, and seven of them were patients’ children. They graduated from school in grade four, grade six, and one of them achieved a certificate in teaching. Their occupations included students, farmers, employees, and government officer. Two hundred and eight codes emerged from these participants, relating to their perceptions of pain, and how they supported relatives with rheumatoid arthritis to manage pain.

Dee’s experience

Background

Dee was Dara’s daughter. She was 14 years old, and a grade eight student (Matthayom two) at the time of the interview. Dee was shy, but she was very glad to be interviewed. Dee noticed that her mother had symptoms of rheumatoid arthritis when she was 36. She found Dara had pain almost every day at that time, and also joint swelling and muscle tightness. She felt sympathy towards her mother when she saw her in pain, but she did not know how to explain her feelings. Even though her mother had pain and complained about it, her mother’s emotion state did not change. She thought everything was normal, so she did not support Dara’s emotions or say anything to encourage her.
Dee became Dara’s main carer, because her father had just passed away. She had an older brother, but he did not help her much. She said he was always relaxing with his friends. Dee explained the care for her mother was doing as much as possible, such as looking after medications, helping to do housework, giving massage, assisting in the hospital, and helping to nurture her mother’s niece, who was studying in kindergarten school. Dee did not worry about her cows, because Dara had already employed a neighbour to raise them.

Dee wanted to buy a car after she observed Dara’s pain associated with stepping onto the bus. She appreciated the effects of Dara’s medication, because she found her mother looked better after taking it. She noticed doctors’ and nurses’ activities when she looked after Dara at the hospital. She said they checked how her mother was and gave the medication continually, but she wanted them to try harder to get rid of Dara’s pain. She still hoped that her mother would be completely cured and pain free.

**Dee’s experience: Emerging codes**

The codes emerging from Dee’s account were: noticing the pain duration; noticing joint swelling; noticing muscle tightness; complaining of pain; feeling sympathy when seeing her in pain; looking after medications; helping to do housework; employing a neighbour to help; assessing her ability to do things; noticing her emotions did not change; giving massage; not supporting her emotions; assisting in the hospital; noticing doctors and nurses’ activities; noticing pain associated with steps; appreciating the effects of medication; hoping in treatment; wanting more support for pain relief from health care team; and doing as much as possible.

**Noticing the pain duration**

*A long time (that my mum had rheumatoid arthritis and pain) ... She had pain ...
Frequently (I noticed she had pain) ... She had pain almost everyday.*
Noticing joint swelling

Her legs were swollen ... Her knees (were swollen). Especially in her right leg ... Her knees were the parts that I saw clearly ... Her thighs were smaller, but her knees were bigger ... I’m not sure (that her hands were also swollen.). I didn’t see this condition. She had swelling when I was young.

Noticing muscle tightness

Sometimes she felt that her muscles were tight more than in pain ... If she sat, it was all right. They were tight when she walked. She felt that her bones scraped against each other when she walked.

Complaining of pain

Oh yes (my mum complained when she had pain), but not too much ... No (she never cried), because it was more sprain than pain.

Feeling sympathy when seeing her in pain

I sympathised with her ... I don’t know how to explain it (the sympathy feeling).

Looking after medications

I looked after her when she took the medication.

Helping to do housework

I did all the housework for her (when my mum had pain) ... Washing the dishes, cleaning the house, and cooking food ... He (my brother) only put the water into the bottles ... he only helped me a little bit.

Employing a neighbour to help

We employed a neighbour to look after the cows. He took them to the field in the mornings, and brought them back to my home in the evenings.
Assessing her ability to do things

She could do some household jobs, such as cooking food and washing the dishes ... She did them well when she didn’t have pain. When she had pain, she could only do a little bit. She walked lamely ... Yes (it was difficult for her to go anywhere when she was in pain), but she could walk to the neighbour’s house. They live close to my house. She could ride the bike too. She said that she had no pain when she rode it.

Noticing her emotions did not change

I thought everything was as normal. She was the same as when she had no pain. If someone touched her painful parts she told them off (laughed). Sometimes by accident I touched her legs, she told me off, and said immediately that she was in pain (laughed) ... No (she didn’t look depressed). Everything was as usual ... She is so kind and cool all the time.

Giving massage

I massaged the parts that she had pain in, and put balm or ointment on them ... She told me off if I massaged or touched the parts that she had pain in (laughed) ... Yes, she did (she felt better after I massaged her). She told me that her muscles were tight when she had pain. Massaging them made her feel better. Her muscles, tendons, and ligaments were fine after I massaged her ... I only massaged her ... He (my brother) helped to massage her ... After I massaged her, she got better.

Not supporting her emotions

I didn’t do that (support her when she complained) ... He (my brother) didn’t say anything to encourage her (laughed).

Assisting in the hospital

Yes. I looked after her while she was there (in the hospital).
Noticing doctors’ and nurses’ activities
They checked her legs, asked about her pain level, and how she was. She told them that she had sprained herself ... They gave her medication routinely ... I don’t think so (that nurses talked to her or advised her).

Noticing pain associated with steps
I want my own car. I don’t want her to catch the bus, because it’s painful for her when she steps onto the bus.

Appreciating the effects of medication
It’s really good, because she looks better after taking it (medication). She should get treatment like this continually.

Hoping in treatment
I hope she will be completely cured, and that her pain disappears.

Wanting more support for pain relief from health care team
They should test her blood. I wish her pain would disappear. I don’t know how to tell them (laughed), but I want them to do their best to get rid of her pain.

Doing as much as possible
(Laughed) I think that I take care of her as well as I can. I don’t know how I can do more than this.

A’s and B’s experience

Background

A and B were the first and second children of Jai. A was 18. She had just graduated from high school, and was waiting for the University’s result. B was a 17 years old, grade 11 student (Matthayom five). They decided to be participants, because it was the school
break, and their father was at work. They perceived Jai’s illness as possession, because she had swelling, her body colour changed to green, and there seem to be no cause. They said Jai thought that someone who practiced black magic had sent evil spirit to possess her body (Lom Pae Lom Pad). They noticed many factors could cause pain. For example, their five years old sister often touched their mother, causing her pain and stress also.

They pitied Jai when she was in pain, but they did not know how they could help her. They observed that Jai usually went to see traditional and modern doctors, and got medication from both of them, but she still had pain. They recognised the inadequacy of traditional medicines, so their family did everything to be helpful. Their father always took her to see the doctors. Their youngest sister looked after Jai when she was admitted to hospital. They gave her a massage appropriately, prepared food, and attempted to provide cheer. They encouraged her to exercise by buying exercise equipment, but it became unused and a place to hang things. They bought a sand sack for her too, but she had pain all over her body after she used it two or three times. Although they had their own duties and they were well aware of what they had to do, they sometimes caused Jai stressed. Then they let her complain and left her alone. B said she did a thankless job, but she did not tell anyone how she felt. She prayed “Chin Na Ban Chon” for Jai every day almost a month while Jai was in pain. She asked A to pray with her, but A did not. They realised that rheumatoid arthritis was a rare disease. The doctors and nurses could do nothing more. The family was the most important factor in easing Jai’s tension. A and B also worried that increased driving might be stressful for Jai when her workplace moved to a new location.

A’s and B’s experience: Emerging codes

The codes emerging from A’s and B’s accounts were: perceiving pain as possession; recognising the insufficiency of traditional medicine; causing her pain from touching; recognising pain is related to stress; noticing her body colour changed to green; feeling pity; praying for her every day; attempting to provide cheer; doing everything to be helpful; taking her to see the doctor; acknowledging the children cause annoyance;
worrying that increased driving may be stressed; becoming stressed from inadequate help; preparing food; using massage appropriately; encouraging exercise; letting her complain and leaving her alone; and feeling the health care team are doing all they can.

**Perceiving pain as possession**

At first, I thought that she was possessed (laughed), because she had swelling and there seem to be no cause. She thought that someone who practiced black magic had sent an evil spirit to possess her body (Lom Pae Lom Pad) (laughed).

**Recognising the insufficiency of traditional medicines**

So she went to see both traditional and modern doctors, and got medication from both of them. She tried to see every doctor that anybody recommended. After she took medication, it was still bad. So she went to see the specialist doctors. The decoction that she took cost 500 Baht ($A 20.83) per pot. I’m not sure how many ingredients were in the pot. It looked like grass or straw … My mum bought the whole pot. I saw the singed candle on the pot, and holy thread was tied around it. Although she finished this pot, she was still in pain.

**Causing her pain from touching**

When I touched her hands, I knew immediately that she had swelling in them. When I massaged her, she also knew that she had swelling and pain. Sometimes she complained of her illness too.

**Recognising pain is related to stress**

She had pain every day at that time. When she was more stressed, she had more pain too … My mum kept complaining. She was stressed from her complaint … When she had pain, her stress increased too. Her face looked very strained, even worse than that … Yes, she was stressed from the pain, and her illness became worse from the stress too, didn’t it mum? (Laughed). She told that if she had pain and stress at the same time, she would feel bad.
Noticing her body colour changed to green

Her hands became green. I thought that her blood circulation was obstructed, and that her blood wasn’t circulating. Maybe you’ll find what I’ve told you unbelievable, but I’ve told you my opinion. Everyone who saw her said that she might pass away, because her body was green and she couldn’t move.

Feeling pity

I pitied her, but I didn’t know how I could help her.

Praying for her every day

I never spoke to her about it. I was praying for her, but if she didn’t hear me, she didn’t know. It was my secret that I would never speak about it, and I didn’t want to speak about it (laughed). I didn’t dare to say anything and I was ashamed too (laughed). She may have thought that I didn’t care about her. But when I did this, she didn’t know. I loved to say the “Chin Na Ban Chon” prayer. It’s the most popular prayer in Buddhism. I prayed every day while she was in pain. I prayed for her and wished her to be healthy. You know ... I said this prayer for almost a month till she had no pain. During that time, I didn’t know what I could do for her. So I chose the magic explanation (laughed). I wouldn’t assume that she looks better now, because of my prayers (laughed). I tried to persuade my older sister to pray with me, but she didn’t. She was so lazy (laughed). You see ... I did a thankless job (Pid Thong Lhang Pra), but didn’t tell anyone ... So, I prayed for her.

Attempting to provide cheer

I tried to talk about funny things with her, but she thought I was just annoying her ... I did that to try and cheer her up and to ease her stress, but she wouldn’t play along with me ... When she had pain, I tried to cheer her up. I loved her so much when she had pain and didn’t complain about it. After she felt better, she started to complain again. Sometimes I thought it was good that she got sick, because then she didn’t complain too much.
Doing everything to be helpful
I did everything that I could to avoid causing her more stress ... Yes, I knew about rheumatoid arthritis from those books. So I thought about it, and promised myself that I would be a good girl, not naughty. I wouldn’t do anything that would make her sad and suffer more pain. But it’s not easy to do that. We’re not conscious of this when we see her still looking well. We’re well aware of it when she gets sick and looks worse (laughed). She would be worse if she lived in Bangkok. Fortunately her new workplace is good and has plenty of fresh air. I’m concerned that she’ll become more stressed and in pain when she works the night shift, because she can’t sleep properly. I think that will affect her pain.

Taking her to see the doctor
He (my dad) took her on the motorbike to see the traditional doctors ... He did that, because we didn’t know what was happening to her at the beginning. So he took her to buy the decoction from them ... He didn’t know what else he could do, except take her to see the doctors. Now she’s better, so he doesn’t do anything for her anymore ... When she was admitted, my youngest sister looked after her and took care of her. She did what my mum asked, such as picking things up ... He helped her by taking her to see the doctors when she was in a lot of pain and couldn’t drive the car.

Acknowledging the children cause annoyance
Although she (my youngest sister) always looked after her (in the hospital), she was still the main one who caused mum’s stress. If mum didn’t have stress, everything was all right. I thought that we had caused her stress, because she usually complained about everything at home and when we annoyed her ... We didn’t want to annoy her. We tried to do everything that would protect her from further pain.

Worrying that increased driving may be stressful
I’m not sure whether she’ll be under more stress in the future, because her workplace is moving to another district that’s far from home. She drives the car there and sometimes works night shift too. Every morning, she drives the car, drops us at our schools, and goes to her workplace. She picks us up in the evening too.
Becoming stressed from inadequate help

Normally, we have our own duties, and we are well aware of what we have to do. When she had pain, she became the helper and complained about things such as cleanliness. She didn’t do anything, except complain about things that we did. When we did household jobs, she couldn’t sit calmly. She followed us around and complained. It made her get even more stressed and increased her pain.

Preparing food

She took her medication by herself, because there were plenty of medications. We called her to come and eat after we finished cooking. She only ate a little bit, because she wanted to lose her weight (laughed). She didn’t want to have a lot.

Using massage appropriately

Massage. We didn’t do it when she was in a lot of pain, because her pain would increase … Later, we massage her some of the time. We used to do foot massage for her too.

Encouraging exercise

And we also took her to do aerobic exercise, because we wanted her to exercise continually. We bought exercise equipment for her, but it’s become a place to hang things on already (laughed). She just exercised for a few days, because she wasn’t used to it. We bought a sand sack for her to exercise with. She only used it two or three times, because she had pain all over her body after she used it (laughed).

Letting her complain and leaving her alone

She complained when she had pain and told us when she couldn’t tolerate it. She usually had pain when we quarrelled with her (laughed). But she’s a strong woman. She’s a working woman. She doesn’t want anyone to care for her too much. She can take care of herself. So we let her and left her alone (laughed) … The best thing to do was to leave her alone, and not disturb or annoy her when she was in pain. That would make her more stressed. We needed to get on with our own lives. If we annoyed her, it caused her more tension. You know, it’s typical of people when they’re sick. They want to be left alone. They feel worse if you annoy them or make a fuss over them … We can’t do that.
with her. She doesn’t like it, because we love to annoy her (laughed). We loved to play around with her, but she didn’t like it. She would be solemn.

Feeling the health care team are doing all they can

I think rheumatoid arthritis is a rare disease. There are few patients with rheumatoid arthritis. I noticed that mum had pain from the stress. When she saw the doctors, they gave her home medication. I think our family is the most important factor in easing her tension. The doctors and nurses can’t do anything more than what they do now. We have to help her as much as we can ... I don’t think so (that the local health staff was concerned about this and visited her at home).

Dao’s experience

Background

Dao was Da’s middle child. She was a 28 years old mother of two children. She graduated from school in grade six (Prathom six). She worked in the fields and raised chickens at home. Her home was closed to Da’s home, so it was convenient for her to look after Da. Dao said her mother showed a lot of symptoms, such as neck pain and sprain in all of her joints one year ago during the Songkran Festival (Thai New Year). Everyone in the family did not like to hear Da complain of pain, because they felt bad. Dao said her heart had a sinking feeling. She was nervous, because she could not help her mother, and she did not know what she could do.

Dao thought the best thing for Da was to leave her to rest until she felt better and to take her to the hospital. Dao had other ways to manage her mother’s pain also. She took care of her mother by looking after her herbs and medication, and she helped Da to remain mobile and encouraged her to do less work. She and her family took Da to see the doctor, accompanied her to get the treatment, and paid for the doctors’ services. Dao left her mother alone to rest, let her complain, and urged her to cope when she had pain. She had to manage this way, because Da was bad-tempered and always complained. Dao talked about the black magic, which her mother used to relieve pain. It is called “Song
Kraban” (Phee Tai Hong Tai Ha). She explained that if they sacrificed the soul of their ancestors who died violent deaths, they could cure Da’s illness.

Dao did everything possible, but she did not know how to help Da further. Although she appreciated the hospital treatment and recommended Da take medication and see the doctor, she still sought the better treatment for Da. She wanted doctors and nurses to do everything to relieve Da’s pain, and to advise her about diet and exercise. Dao planned to consult the nearest community hospital about getting medication there instead of the regional hospital, because it was quite a long way from their homes.

**Dao’s experience: Emerging codes**

The codes emerging from Dao’s account were: noticing sprain and pain; describing neck pain; complaining of pain; giving medication; taking her to see the doctor; assisting with herbs; finding treatment; requesting medication; appreciating taking medication and seeing the doctors; appreciating hospital treatment; accompanying her to get the treatment; doing all possible, but not knowing how to help; paying for the doctor’s services; taking care of her; visiting the doctor for medication; helping her to remain mobile; encouraging less work to stop pain; using black magic; leaving her alone when in pain; urging to cope; letting her complain; wanting doctors and nurses do everything to relieve pain; and needing advice about diet and exercise.

**Noticing sprain and pain**

*At the beginning, she sprained all of her joints and had a little pain. She was in a lot of pain later ... She showed a lot of symptoms during the Songkran Festival (Thai New Year) last year. She felt that her joints were sprained, and she had other pain at the same time ... If she took the medication and didn’t work, she would be fine ... One patient couldn’t tolerate the pain and couldn’t eat food. Fortunately my mum had only sprain and a little pain. When she had pain, she felt like a needle was pricking her skin. In my opinion, her pain would have been greater if she was older or if her disease progressed badly.*
Describing neck pain

She was in pain until she couldn’t tolerate it longer and went to the hospital … I thought she was suffering most pain in her neck.

Complaining of pain

She complained everyday when she was in pain. We didn’t like to hear it. She complained “I’m in pain” “I’m sprained” and “I feel badly.” … Yes, but not much. Her neck was the part that she always had pain in.

Giving medication

I gave the medication to her (when I saw her suffering with pain).

Taking her to see the doctor

I took her to see the doctor. He gave her some medication. Her pain decreased after she’d taken it.

Assisting with herbs

She took a lot of medications. I mean the medications that are made from herbs. They were decoctions. She boiled them before she had them … The first time that she bought an herb, she boiled it. She paid 1,000 Baht ($41.67) but she hasn’t tried it yet … She did it by herself (cooked the herb). It was easy. She put the herb and water in the earthen pot, boiled it, and drank it. A pot of the herb could be used for three months. She bought it from a temple not far from here. It cost 880 Baht ($36.67). But she did something wrong. She boiled it until it became sticky. She took it all at once and had very bad diarrhoea later (laughed).

Finding treatment

When someone suggested to her that they knew where the good doctors were, we had to go and see them. We went everywhere that anyone advised us to by renting a car. She only went to the hospital if other treatments failed. She took every medication that anyone told her was good. Some medications had many side effects after she’d been using them for a long time, such as breathing difficulty. So she’d stop taking that
medication and find a new one. She usually changed the medication if it didn’t relieve her pain ... I think that she can have many treatments together, but I have to consider her symptoms before I decide which ones. There were many places that promoted their medication by saying it could make the patients better after taking it two or three times. But I didn’t dare to get them. I worried that they might not cure her illness, and then make my mum worse. And then I would have lost time and money for some nonsense thing ... If there was a medication that could make her get better or reduced her pain, I would buy it for her. Unfortunately there is no medication like that, so she has to continue with her old treatment.

**Requesting medication**

You know that the medications for rheumatoid arthritis were expensive. They were very expensive if she got them from clinic. I will consult the nearest community hospital about getting them there instead of the regional hospital. Now she has to get this medication from the regional hospital. It’s quite a long way from our homes.

**Appreciating taking medication and seeing the doctor**

She had many kinds of medication. I hope that by taking medication and seeing the doctor, she will get better.

**Appreciating hospital treatment**

Before she was treated at the hospital, she couldn’t walk or move her body to go anywhere. She could walk from here to her home, but it was not easy. She got pain at her joints from it. She couldn’t walk to her field to work. She had to come back home and lie down. Now I think she is better than she was before. She can carry things and take care of my children. She can go anywhere by herself too. She used to ride a bike, but it made her suffer much ... I only saw her ride it once (laughed).

**Accompanying her to get the treatment**

Absolutely (I always accompanied her). But if I was very busy and had many tasks to do, my aunts accompanied her. They live near my home. They helped me as much as they could. Sometimes they helped both me and mum by renting the car.
Doing all possible, but not knowing how to help

I felt a bit bad ... I didn’t know how I can explain it (the words “I felt a bit bad.”) ... I felt bad. My heart would sink. I was nervous. I couldn’t help her and I didn’t know what I could do for her. Sometimes her pain level didn’t decrease, although she’d taken the medication already. I thought the best thing for her was to leave her to rest until she felt better ... They pitied her, but they didn’t know what they could do for her except bring her to the hospital ... But I thought everything would be all right. She would be better if she continued the treatment ... Well. I thought she would be completely cured. I wished that she didn’t suffer from pain, so I encouraged her to get continuous treatment ... She thought about thing like “Is it severe?” “Is it harmful?” If rheumatoid arthritis was not too harmful and she was only sprained, she would get treatment continually until she felt better. It was all right if she was still in a little pain, even though she took the medication continually ... We thought that she should get treatment. We would accompany her when she went to see the doctor. We tried to find out about other medication for her. We didn’t know what we could do when she was in a lot of pain. We couldn’t do anything if the doctor couldn’t do anything for her, because we were not the doctors. We didn’t know how we could support her. We tried to help her as much as we could.

Paying for the doctor’s services

They (my dad and my younger brother) gave her money when she went to see the doctor (when they saw her was in pain).

Taking care of her

I asked her “What do you want me to do to relieve your pain?” “How do you feel now?” and “What should I do if you don’t get better after taking the medication?” I wished her pain would disappear. She looked pitiful when she suffered from pain. We tried to take good care of her. We didn’t leave her alone. We took care of her, sought the best thing for her.
Visiting the doctor for medication

The thing that we always did for her was take her to see the doctor when she had pain, because we didn’t know any other way that was better than this. After she took the medication, we asked her how she felt. If it made her feel better or worse and what she thought about the medication that she’d taken... (Nodded) My younger brother worked and came back home in the evening. He asked mum “What do you think about the medication you had?” “Was it good for you?” “Did it make you feel better?”

Helping her to remain mobile

Yes (I help her when she couldn’t do things herself) ... I cooked for her if she couldn’t cook by herself. Sometimes she had to cook by herself if I was very busy. She could do that no worries. I had little free time. I was very busy. I had to feed my chickens. Sometimes she helped me to bring up my daughter too. She carried my daughter when she cried. She could do that if she was not in pain. If she got pain while I was busy, she put my daughter in the cradle ... I did too (helped her when she was in pain). We had to treat her gently, help her while she moved or changed position from lying down to sitting. We’d leave her to sit for a while, support her to stand, and prepare to walk ... We didn’t help her to do that (took a bath). She could take a bath by herself. We did for her whatever she couldn’t do for herself.

Encouraging less work to stop pain

Sure. We let her to do some things, but not much and only some times, for example cooking food for my younger brother in the morning. She loved to cook “Nham Prik”. Now I don’t let her cook it by herself, because she has to use a lot of energy to crack the ingredients and her wrists suffer. I bought a blender for her to cook with, but she was naughty. She still tried to cook it by herself. She said that it was a kind of exercise for her. You know what happened to her after she finished it? She complained that she felt worse (laughed).

Using black magic

She rode the bike to the junction where someone did some kind of black magic. We call it “Song Kraban” (Phee Tai Hong Tai Ha). Do you know it? I’ll explain it to you. We
believe in it. We sacrifice the soul of our ancestors, who died violent deaths. They will cure her of the disease (laughed). It started from her dream. She dreamed that she went to the temple. When she arrived there, someone hit her. So she made a dummy and laid it at the junction. It was a doll that was made from the soil or clay.

**Leaving her alone when in pain**

She took herself away from us when she had pain. We didn’t annoy her. We let her stay alone at her home. When she felt better, she’d come to my home to complain, complain and complain. After she finished her complaining, she went back to her home (laughed).

**Urging to cope**

She was bad-tempered and always complained. I urged her on saying “Do it! ‘You can do it’ or ‘Why didn’t you do it?’” (laughed). I let her do what she wanted and she usually complained when she got pain after she’d done it ... Do you think she did it (after I urged her on)? (laughed).

**Letting her complain**

She looked unhappy. Her face was not alive. She loved to complain (laughed). We let her complain, because we didn’t know of any way to relieve her pain except by bringing her the medication. We usually asked her about her pain level too. We also told her to take a rest if her pain was still there.

**Wanting doctors and nurses do everything to relieve pain**

I would like them do everything they can to relieve pain, for example giving injections or doing something else that can relieve pain. I’ve seen how bad it is when a patient with rheumatoid arthritis suffers from pain. In relation to the doctors, they should get close to the patients, talk to the patients as much as they can, and give them the best treatment. Nurses should do the same as the doctors too. Some ignore the patients and their relatives when they tell about their illnesses and want some help. They are very important people for patients, because they see the patients all the time.
Needing advice about diet and exercise

I need some advice about diet and exercise for my mum. I think they might have advised my mum already. My mum knew which foods she could have and which she couldn’t. For example, she had noodles without chicken. She avoided having seafood, poultry, and a strong tasting diet. She was well aware of what would happen if she took these foods. She’d have swelling later. The doctor advised her that she should try to relax when she got pain. She had a lot of pain if she was tense or her muscles contracted ... She’s never told me, but the doctor and nurses have already advised her (about exercise). I’ve no idea about this. She exercised as much as she could under the doctor’s advice. It was a good way to protect her from pain. She exercised, restricted her food, and took the medication that doctor gave her.

Aim’s experience

Background

Aim was Ead’s sister. She was a 46 years old mother and employee. She graduated from school in grade four (Prathom four). She lived with her family near Ead’s home. She said Ead was very strong and worked hard in the past. She always visited the neighbours at their homes if she knew they were sick. After she got pain from rheumatoid arthritis, she became a weak and unhealthy person. Aim said Ead never visited her place, although it was very close when she first had pain. She noticed that Ead had hand and leg pain. She also had knee pain and she walked lamely. Aim did not express how she felt when she saw her sister in pain. She said she did not know what rheumatoid arthritis pain was like, because she had only experienced stomach and back pain. Aim scolded Ead when she complained so much that she was in pain, or she just let Ead complain or sometimes avoided her, because she was complaining constantly.

Aim and Ead’s sons did everything for Ead. Their pain management included taking Ead to see the doctor, helping around the home, and encouraging her to do less work. Aim said that Ead was visited by many neighbours, some of whom believed in black magic,
and they tried to persuade her to see the shaman and find the real cause of her illness, but Ead did not. She said Ead tried a decoction from the temple, but she did not appreciate it, and she also had taken a bolus and powdered medications. Aim did not appreciate hospital care, although her sister got treatment from many health centres. She thought that nurses did not advise about things as much as they could. It was very lucky that they knew a Head of Ward, and that nurse advised Ead to see the orthopaedist, from whom Aim encouraged Ead to continue treatment. Aim wanted local health staff to visit the patients at homes, because her sister needed care from them.

**Aim’s experience: Emerging codes**

The codes emerging from Aim’s account were: noticing decreased ability to work; avoiding her because of complaining constantly; taking her to see the doctor; being urged to use black magic; being visited by neighbours; being helped by family members; encouraging less work to stop pain; getting treatments from many health centres; getting advice from a nurse to see an orthopaedist; trying a decoction from the temple; not appreciating bolus and powdered medications; doing everything for her; not appreciating hospital care; not getting advice from nurse; not getting care from local health staff; wanting local health staff to visit the patients at home; and continuing treatment from orthopaedist.

**Noticing decreased ability to work**

She always was in pain. She complained of it until we took her to see the doctors. When she first had pain, she never came to my house although it was very close. She was in pain with her hands and legs. When she walked, she got knee pain and she walked lamely. Her hands became swollen and bigger. She couldn’t use them. She got better after she’d seen the orthopaedist. In the past she was a healthy person. She worked so hard and had many jobs at the same time, such as working in the field, cutting the sugar cane, and she also took employment in the construction area. She used to work in the tapioca and white radish gardens too. She got 40-50 Baht ($A 1.67-2.08) per day for these jobs. You know she’s been employed since she only got eight Baht ($A 0.33) per day. It meant that she wasn’t able to finish her study. She only finished Prathom four
(Grade four) ... In the past she was very strong. She always visited the neighbours at their homes if she knew they were sick. After she got pain from rheumatoid arthritis, she became a weak and unhealthy person ... We knew that she had a lot of pain if she didn’t come to see me in the morning or afternoon (laughed). I always see her when we buy the food in the morning.

Avoiding her because of complaining constantly
When she complained, I scolded her about why she complained so much and talked so much (laughed). Her sons told me about the parts of her body where she had pain. You know, she complained immediately when she got pain and told us where she had it. She never kept her feelings to herself. She was open about them. I told her that her complaining wouldn’t help to relieve her pain. She would be boring to anyone (laughed). But she loved to talk about her illness. She went on so much that her sons escaped from her and came to my house (laughed).

Taking her to see the doctor
Her son took her to see the doctor in the evening. She usually saw the doctor. Her neighbours joked with her about why she loved to see the doctor so much. After she’d seen the doctor, she got better and worked hard again. She had to do household jobs by herself, because she only had two sons. The doctor advised her that she should not work hard ... Her son would take her to see the doctor in the evening ... Yes. Most times (I always accompanied her when she went to the health centres).

Being urged to use black magic
Someone who believed in black magic persuaded her to find out why this had happened to her, because they used to see her as a healthy person who worked hard. She could do everything that they employed her to do. Now she is a patient with rheumatoid arthritis, but they think that she’s had black magic performed on her. So they wanted her to see a shaman and find the real cause of her illness. She doesn’t believe in this, or in seeing a shaman.
Being visited by neighbours
Sure (her neighbours visited her when she had pain). There were many neighbours who visited her. They often visited and talked to her about her illness. She’d helped them a lot, because she’d always offered to do the catering for funerals, weddings, and priesthood ceremonies. She did it well and knew what to do.

Being helped by family members
She did housework by herself and gave her sons the clothes to wash. She let them do things when she was in pain and couldn’t do them. Now I can’t help her anymore, because I’ve just had a back operation. Unfortunately we got sick at the same time, but I can go to see her at home although I’m in my rehabilitation period. I want to know how she is. My daughter would go to see her instead of me if I couldn’t. She checked on how my sister was; if she could eat food and get things that she wanted. If she wanted to have some special food, I brought it to her.

Encouraging less work to stop pain
Sometimes her younger son told her to stop buying fresh food, and he would buy take-away meals instead. But she still did it. For example, her son scolded her, because she was making the floating basket for holding the fish in the water this morning. He didn’t want her to do it, because he worried that her pain would increase ... Her first son washed the clothes. He bought take-away meals or cooked food by himself after he finished his work. He didn’t want her to do anything, especially when she was in a lot of pain. But his mum couldn’t relax. She would come back home at 2pm to cook for them if she could.

Getting treatments from many health centres
I accompanied her when she went to many private clinics. At the beginning she went to see an orthopaedist. It wasn’t any good. She was still in pain ... She went to every place that anyone told her about. She used to go to one private clinic with her neighbours, and I used to take her to the health centre. It was not far from our homes. She got an injection from this centre. She started to get pain again after the injection wore off.
Getting advice from a nurse to see an orthopaedist

Fortunately, we knew a Head of Ward. She advised her to see another orthopaedist. She got better after she got treatment from him (orthopaedist).

Trying a decoction from the temple

She bought a decoction from a temple, but I can’t remember what the temple’s name was. She bought it on her neighbour’s advice. She used to buy powdered medications and bolus from a temple that was close to our homes too, because some neighbours told her it worked for them after they’d taken it. But after she’d finished it she was still in pain.

Not appreciating bolus and powdered medications

I think bolus and powdered medications are bad. Many people took them and got osteoporosis later. Someone had flabby, wrinkled skin, and got skin damage when they touched hot cooking oil while they were cooking. You know, after you took bolus you might take them continually ... I mean not stop taking them. They affect the trachea and the blood vessels too. They make them too dilated.

Doing everything for her

He did everything for her; as much as he could, such as washing clothes, cooking, and buying food. Sometimes he came back home at noon and bought the food for her. Last night he went to the night market and bought many kinds of desserts for her too. Her younger son wasn’t too good. He only finished Matthayom three (Grade nine). His brother wanted him to continue his study, but he rejected that idea. He rarely did things. He was totally different from his brother. My sister has a nephew, who lives with her too. He’s an older sister’s son. He’s the same as her youngest son. He didn’t take care of her very much. However, I usually tell my daughter to visit her if she doesn’t come to see me.

Not appreciating hospital care

When she met the doctors they only talked with her. I didn’t accompany her to the examining rooms. She went to the hospital to get some extra medication. I usually
accompany her when she goes to see the doctor at the private clinic ... My sister went to the hospital alone if she only needed the medication to take home, because the process of getting it was very fast. In my opinion, the nurses didn’t advise about things as much as they could. Her son always brought her to see the doctor at his clinic. When we went to the regional hospital we had to wait for the staff for a long time, especially at the change of shift time. Everyone here who gets sick has to go to the community hospital first, because we have a health insurance card (gold card). The patients are referred to the regional hospital if they are severe cases, and the staff here can’t treat them.

Not getting advice from nurses

Sometimes I asked them about what rheumatoid arthritis pain was like, the symptoms and about her illness. They told me that I should wait and ask the doctor.

Not getting care from local health staff

In the past they always visited everyone in our village at their homes. I haven’t seen them for a long time. I think they’ve stopped visiting homes.

Wanting local health staff to visit the patients at homes

Yes (I need them to visit the patients at homes). There’s been no home visiting for one or two years. They used to visit homes every fortnight or every month after women came back home after giving birth. They used to check our blood pressure, and give some medications to the patients who had high blood pressure. I think they should have home visits every one or two months. It would be better and they would know our histories of illness. Regarding some local health staff, I mean the public health volunteers and the public health reporters, they still give some vaccines to babies, rabies vaccines to the dogs in summer, and abate sand to get rid of the mosquitos’ larvae when the dengue haemorrhagic fever spreads. They do things after they got orders from the health centre.

Continuing treatment from orthopaedist

No (I don’t have any hopes about what the rheumatoid arthritis treatment will be able to do). I mean I only hope that she continues with the right treatment for her, because she is still in a lot of pain if she doesn’t take the medication. No one is against her getting
the treatment. She was very brave and did the things that her doctor advised. She’s never followed some advice, such as bathing in holy water. We want her to get treatment only from the orthopaedist.

Man’s experience

Background

Man was a 45 years old teacher at the time of the interview. He had a diploma in teaching and he was Tim’s husband. They had two sons. One son was the third year pharmacist student, and another one was applying to Army officers’ school. Man could not remember the first time his wife had pain. He only noticed her decreased driving ability, and she became moody easily when she had pain. He said she had pain if she sat in the wrong position, or sat on an unsuitable chair with no support.

Man said there was nothing different when Tim got pain from rheumatoid arthritis, because she used to get pain occasionally and she could do everything if she pain free. She always took tramal when she had pain first thing in the morning. Man and his sons managed their loved one’s pain by helping mobility, assisting her to use a wheelchair, allowing her to rest and sleep, and by enjoying holidays together. Man encouraged her to have the nutritious and good tasting food also. He always turned the air conditioner when needed, especially all the time on weekend. He said Tim could not tolerate the hot weather and her pain started immediately. Besides this, Man gave Tim holy water and herbal medication which he prepared himself. He said she tried boluses and medications from China, India, and also used a computer machine (Mae), which showed what was happening in each part of her body.

Before finishing the interview, Man said when his wife was admitted to the private and general ward. The nurses gave her medications. He said his wife always gained encouragement from their family and loving friends. Although they took care of her well, he thought he would phone his sister who lived in USA. to ask for better
medication. He appreciated his wife that she was strong-willed and patient. She was a fighter and did not get disheartened. She still maintained her work habits and always accompanied him. He told her they needed to be rich with happiness, by sharing their ideas and spending time together. They did not need to be rich from working hard and making money.

**Man’s experience: Emerging codes**

The codes emerging from Man’s account were: noticing inability to drive; maintaining work habits; gaining encouragement from friends; noticing which position caused pain; enjoying holidays; using a wheelchair; giving holy water; trying a bolus and other medication; noticing nurses give medications; feeling nothing emotionally; helping mobility; becoming moody easily; allowing rest and sleep; taking tramal to relieve pain; asking for better medication; making an herbal medication; having nutritious food; organising temperature control; and recognising the importance of happiness.

**Noticing inability to drive**

*In 1987 (she had knee operation), she could drive a car and ride a motorbike. It wasn’t a regular motorbike. It was a racing motorbike (laughed).*

**Maintaining work habits**

*She could do the work of two people. No one could do the work as effectively as her ... She works well, and contributes almost 70-80% of the work needed to do my jobs. She can arrange the bills for 30 factories, monthly and annual tax matters ... You see her like this, but do you know she used only her walker, and could walk around the department store for more than two hours. Even a healthy guy like me would want to sleep after that (laughed) ... She’s strong-willed and patient. She’s a fighter, she doesn’t get disheartened (laughed).*
Gaining encouragement from friends

Her friends came to encourage her (laughed) (when she had operation) ... Someone teased her and said “We should get some ice to drink with the Kek huay juice” (laughed).

Noticing which position caused pain

If she sat like that for only one hour (in the wrong position or sit on an unsuitable chair with no support), her pain would increase.

Enjoying holidays

I didn’t want to go to Chantaburi Province, because I didn’t like driving at night and I’d never gone that way. I had to go with my wife. Everyone who went was a teenager. They drove very fast. I drove rather slowly, because we’re old (laughed) ... I’ve been able to drive since I was 22 years old. So I could drive around Thailand ... My children dragged her to see the coral. She couldn’t swim, but there was a life preserver. My sons were very strong. They put it on her and helped her dive, but only on the surface of the sea ... While she was admitted, she sometimes asked the nurses if she could leave the hospital. She changed her clothes and went to the cinema with me (laughed) ... Besides riding to Buddhamonthon or Bangkok, we always rode to Kanchanaburi. We loved having these happy experiences. We saw this as a way to relax. I’m a humorist too (laughed).

Using a wheelchair

She couldn’t walk after she finished work yesterday. I had to put her in the wheelchair and push it to the car park.

Giving holy water

I helped her to bathe in holy water. I really prepared it for her and not the monk. You know, I can chase away some evil spirits. She told me she felt something running inside her body when she bathed in the holy water.
Trying a bolus and other medication

It (Chinese bolus) was made from antler. It was effective for renal disease and renal failure. American doctors investigated it, because it made an old rich Chinese man (Thao Kae) survive renal failure. He lived for many months after taking this medication. My wife tried it, but it was ineffective. It wasn’t suitable for rheumatoid arthritis ...

Someone gave my wife one type of medication to try. It cost 2,000 Baht ($A83.33). We almost quarrelled with him (laughed), but he guaranteed he would return my money if it was ineffective. It didn’t make her better … It (the other medication) came from India.

Noticing nurses give medications

It was the same when she was admitted to the private ward. It was no different from the general ward (nurses gave my wife the medication that the doctor prescribed).

Feeling nothing emotionally

I felt nothing (when she got pain from rheumatoid arthritis). Nothing was any different, because she used to get pain from time to time. If she was not in pain, she could do everything. For example, I had one motorbike and she had the other one. We’d ride our motorbikes to Buddhamonthon or Bangkok on weekends. We became adventurers. We each had a backpack and could stay anywhere (laughed).

Helping mobility

Sometimes my children and I had to carry her upstairs.

Becoming moody easily

I didn’t notice a lot. If her pain increased, her emotional state would change. She became moody easily, but not too much.

Allowing rest and sleep

We mostly let her rest and sleep. I always took good care of her. I served her with her meals, water, and medication. Our life style is smooth and easy, because our children go to school.
Taking tramal to relieve pain
She took tramal when she got pain first thing in the morning (laughed) ... Tramal has the least side effects. They only occur if we use it too much. I’ve no idea which medication she should take if it doesn’t relieve the pain. The doctor told her that she should take prednisolone before bedtime, but she was concerned that she would have more pain during the day if she didn’t take it in the morning. She’d take a half tablet some mornings and take the other half tablet in the evening. Some days she didn’t take it at all.

Asking for better medication
I think I will ring my sister. She lives in the USA. Her husband is a doctor. I’ll tell them about my wife’s symptoms, and ask them if there are other medications to treat rheumatoid arthritis and pain. Perhaps they can give me some drug samples for her. One place that I will take her to get treatment is the Chinese chemist. There is a pharmacist there.

Making an herbal medication
I think I’ll make her an herbal medication. I love to collect herb recipes. I have one recipe that is a medication to extend life (Ar Yu Wattana). I’ve already recorded some of the ingredients. The person who gave me this recipe was over 90 years old. He could have a young wife. But I’m not interested in his sex life. I’m interested in the fact that he is very healthy. I think I should make it for her. Perhaps it’ll make her stronger. But I have to be sure that there are no moulds in the ingredients. I’ll have to bake them before cooking. I talked with my oldest child about how I could do it, if I could bake them in the microwave after blending them and for how long. He’ll consult his teachers again. I’m worried that heat will change the ingredients.

Having nutritious food
About her food, she loves to have nutritious and good tasting food, such as food from the restaurant. She used to have nothing for two or three days. One day she only had the popcorn that I kept in the kitchen.
Organising temperature control

*I always have the air conditioner on at all times, around the clock on weekends. She can’t tolerate the hot weather. Her pain starts immediately.*

Recognising the importance of happiness

*I told her if we are rich, we need to be rich with happiness. We didn’t want to be rich from working hard and making money. We were the same people we always were. We loved to help anyone, who was more impoverished than us. We only wanted enough to get by on. We didn’t want to be rich without being happy. We loved to share our ideas and spend time together.*

Whan’s experience

Background

Whan was an 18 years old grade 11 student at the time of interview. She was Phit’s youngest child. She had one older brother and one older sister, who all lived in Bangkok. Whan became the participant, because she came back home to visit Phit and her father was not home at that time. She realised Phit had pain from rheumatoid arthritis for a long time, since she was in kindergarten school. She noticed that Phit had pain in her arms, legs, and all her joints. She was very weak and her walking was very unsteady. Her joints were swollen, and sometimes she curled up and looked like a big ball. Beside this, she noticed Phit rested the whole day when she had pain. She used some herbal treatment to relieve pain also. Whan said her mother did not admit to her pain, and she tried to make herself look well, and did not show how she was suffering. She said that her mother pretended to be well to leave hospital too. She said Phit was funny and mischievous all the time, even though she had pain.

Whan did not know what caused rheumatoid arthritis. She only knew her mother was a patient with rheumatoid arthritis that it was a chronic illness and it was difficult to cure her, so she decided to understand the disease. She, her brother, and sister helped their
mother to do activities. They used measures to relieve coldness, because their mother usually had pain when the weather became cold. Whan sometimes massaged her mother, and gave her a hot pack at the same time. She said every child had their own duty in caring for their mother when they came back home. Her older brother looked after his mother by assisting with medication. Her older sister selected all of the ingredients that she cooked for her mother. Whan encouraged her mother to drink coffee, because she said it eased her pain. Her older brother forbade mother to drink coffee, but she drank it as often as she could. She noticed her father did not care for Phit, because he usually lived in another house, in a field not far from their house. She said her brother and sister tried to persuade her mother to live with them in Bangkok. Her brother was studying in a Master degree in engineering during the day and worked in the evening. Her sister worked during the day and studied at the Bar Association in the late evening. Phit refused the offer to live in Bangkok, because she was concerned about her work and her customers. Whan was dissatisfied with nursing care she had received, because she thought nurses just did their routines, and she wished they were more interested in their patients.

**Whan’s experience: Emerging codes**

The codes emerging from Whan’s account were: noticing her reduced mobility relating to pain; using measures to relieve coldness; hiding her suffering; using massage; drinking coffee to ease pain; assisting with medication; cooking food; helping to do everything; pretending to be well to leave hospital; not noticing dad cared for her; resting all day; using some herbal treatment; acknowledging the diagnosis of rheumatoid arthritis; controlling food; trying to understand rheumatoid arthritis; working hard to support children; and being unsatisfied with nursing care.

**Noticing her reduced mobility relating to pain**

*For a long time (I saw her had pain from rheumatoid arthritis) ... Since I was in kindergarten ... She couldn’t walk or do anything. She only lay down on her bed ... She only told me a little about it; that she had pain in her arms and legs ... She had pain in all of her joints. Some parts were severe and some were not ... Yes, she was very weak...*
when she was in pain. Her walking was very bad. She couldn’t move her arms. I had to help her take her clothes off. We helped her as much as we could, because she got a lot of pain if she lifted her arms and legs or did other things ... (Laughed) Her body became swollen. It got worse if she worked hard. You know that her legs looked like elephants’ legs. Her joints and knees became swollen more than this. You can imagine. She looked like a big ball (laughed). Her hands became swollen too ... Yes (I think she’s different now) ... Her body has changed. She walks in a rigid way ... She always walks lamely, like someone who has a leg injury. Her hands curled up when she was in pain.

Using measures to relieve coldness

When the cold weather came, I laid the hot packs and hot water bottles on her joints. I’ll explain to you about the “hot water bottle”. I’d put hot water in the bottle and wrap it with cloths ... I helped her when the weather was cold. She got better if I laid them on her joints for a long time. They didn’t relieve her pain every time that we used them ... I observed her symptoms even though she didn’t tell me about them, such as swelling, inability to walk, lying down all the time, and being cold. Sometimes she was cold at noon or in the afternoon. She kept her body warm with five blankets ... Yes (I only knew she had pain from my observations). If she was cold, it meant she was in pain. She got pain and felt cold when the weather was cold.

Hiding her suffering

She tried to make herself look well and not show how she was suffering. She was funny and mischievous. Sometimes I joked with her that I had a strong piece of wood for massaging if she wanted (laughed) ... Even though she got pain she was still the same mother, who was funny all the time. I’ve seen her like this since I was young. So I never thought that she had changed ... They’ve never said anything, because we’ve always lived together. They saw what I saw and my mum tried not to show how much pain she had. My older brother usually scolded her about why she didn’t tell us how she was and why she left us to find out by ourselves.
Using massage

I massaged her and gave her a hot pack. The thing that she wanted most was to drink coffee ... I massaged her.

Drinking coffee to ease pain

Yes (she loved drinking coffee when she had pain). She told me it eased her pain. My older brother forbade her to drink it, but she drank it as much as she could (laughed) ... No. She was still mischievous. Sometimes when she got pain she wanted to lie down. She’d say “Don’t disturb me now, because I’m in pain.” She only told us that so we would let her rest ... No, (she wasn’t depressed when she had pain) we would say “Would you like a cup of coffee?”(laughed) and she’d perked up immediately (laughed) ... No (I didn’t give her a cup of coffee), my older brother wouldn’t permit her to drink it. But when I was young, I gave her some coffee behind his back ... She hid the sachets of coffee in her pants or in the cupboard. But it didn’t escape my older brother’s attention. Since I’ve lived here, I’ve seen her drink coffee everyday. My way of handling this problem was by drinking it by myself before I gave it to her. I allowed her to drink a half a cup if she begged me. I tried to drink it although I didn’t like it (laughed). She didn’t dare to drink coffee if we were around her. She was afraid of my older brother.

Assisting with medication

My older brother looked after her in relation to taking medication.

Cooking food

My older sister cooked food for her.

Helping to do everything

We tried to do everything that we could, because her hands couldn’t move or pick anything up. They were very stiff and sore ... Yes we did (her job for her). I mean my older brother, my cousin, and I did the chilli and sent it to the consumers ... Yes (she couldn’t get up from the bed at all). When she couldn’t walk well, she’d get up late. My older sister had to stay home with her. My older brother and I went to the market and sold the chilli ... Certainly (my mum stilled worked while she had pain). We helped her if
we were here ... All of us usually came back home and stayed with her at different times. If she was in a lot of pain while my older brother and older sister were home, they did everything for her and let her rest as much as she could ... I didn’t do anything much (laughed). I couldn’t do the chilli for her. It made my face and eyes burn. So she didn’t let me do it. Yesterday we went to sell the chilli at the market for her. She didn’t go, because she always had to lie down in the car.

Pretending to be well to leave hospital
Yes (I looked after her when she was admitted). The doctors did their rounds in the ward. She saw them at that time. They didn’t do anything other than this. Last time she was admitted to the hospital, they treated her the same as they did the other patients ... The doctors did their rounds according to their routines ... I think they did (talked to her), but I don’t know what they said to her ... She went to the physical therapy department and got some treatment there. The doctors and nurses didn’t do anything more for her, because she always said she was fine and everything was all right. She wanted to come back home rather than stay in the hospital. My older brother said that she pretended she was better although her hands were still swollen.

Not noticing dad cared for her
He (my dad) lived in another house. It was in the field, but not far from here. Mum and us lived here.

Resting all day
She’d sometimes lie down from the time I went to school in the morning until I came back home in the evening. We often didn’t go to school if she was in a lot of pain and couldn’t move her body at all. We had to take care of her at home ... She couldn’t walk at all at that time. She persuaded me to stay with her. We had to take it in turns to care for her at home. My brother took care of her one day and my sister took care of her next day.
Using some herbal treatment
She often got some herbs from a province in the east of Thailand. When she lived in Ban Pong District, she always went to see a doctor.

Acknowledging the diagnosis of rheumatoid arthritis
I don’t know what caused it, but I know she is a patient with rheumatoid arthritis. She should avoid having poultry and not drink too much coffee ... I know its signs and symptoms. I read about it from a brochure that my older brother got from the hospital. My uncle had gout. Some of his symptoms were similar to hers. The doctor advised her to stop drinking too much coffee, but she still did ... Yes (I knew rheumatoid arthritis was a chronic illness), because she’d suffered from rheumatoid arthritis for a long time. It was difficult to cure her.

Controlling food
Yes (everyone controlled the food that she had) ... My older sister selected all of the ingredients that she cooked for her. She usually used fish in her cooking, but my mum only had a little. She always had every kind of food but only a little ... She had a little. Sometimes she didn’t have anything. My older brother tried to force her, because she had to take her medication after having food.

Trying to understand rheumatoid arthritis
I set my mind to trying to understand about rheumatoid arthritis. I saw that she went to see many doctors. Sometimes she got better, but sometimes she didn’t.

Working hard to support children
She told us that she had to do that (work hard). My older brother tried to persuade her to live with him in Bangkok. He’s studying in the Master’s degree of engineering during the day and works in the evening. She refused this offer. She wanted to sell the chilli here. My older sister works during the day and studies at the Bar Association late in the evening. She wants to be a barrister ... We tried to persuade her to live with us in Bangkok, but she was concerned about her work and her customers.
Being unsatisfied with nursing care

*I think that they (the nurses) weren’t as interested in the patients as they could have been. They just did their routines. They didn’t ask my mum how she was, and she didn’t tell them anything more … I wish they’d be more interested in their patients … Some did. They said “How are you doing?” “How do you feel?” “Which part do you have pain?” My mum always said that everything was all right. She didn’t tell them when she was in a lot of pain, because she worried that she wouldn’t be discharged. They also gave her the same advice about diet such as avoiding poultry … They advised her to exercise in the water. We let her play in the water in the canal (laughed). They told her more than they told me. We often massaged her and she felt better after we did that.*

Poon’s experience

Background

Poon was a 55 years old farmer, who graduated from school in grade four (Prathom four). He was Ta’s husband. They had only one daughter, who was a nurse. He rarely noticed that there was anything wrong with his wife. He did not really think about the cause of the rheumatoid arthritis, except that it might be related to her working hard, because her job at that time was weaving. She used her hands to pull the weaving looms for a long time. He noticed that she could not carry a heavy bin laden with cement after she had rheumatoid arthritis and pain, as she became fatigued. He also noticed that she had pain, but not so much that she could not tolerate it. She told him when she had pain too. He did not consciously think about her pain, but at the back of his mind he knew that she had to get the treatment for her pain.

Poon was primarily responsible for taking care of Ta, because there were only three family members; Ta, his 80 years old father, and himself. Their daughter married and moved to another town with her husband. Poon helped Ta to do household jobs before he went to work in the field. He sometimes massaged her body if she had pain or fatigue. He left her alone, and let her complain without blaming her when she was in pain. He
looked for the best medication to get rid of her pain, and sought other advice from the neighbours for getting a good cure also. Their daughter always asked questions about Ta’s illness, and brought her medication from her hospital.

Poon felt untroubled when Ta told him she had rheumatoid arthritis. He did not think about the future. He and his daughter thought that she should go to see the doctors, because they hoped her illness would disappear if she continued to get treatment. It was impossible for him to think about any more than this, or to find medication that was better than the doctors gave her. Poon respected doctors as they knew more than him, because they had studied to be doctors. Although he did not know how to ask for advice, he needed to know more about suitable exercise and the effects of climate on pain. He also wanted to know more from the doctors and nurses about rheumatoid arthritis and how to manage Ta’s pain. He still needed help from the health centre in relation to rheumatoid arthritis too. Poon was concerned that patients with rheumatoid arthritis did not become disheartened about looking after themselves and continuing their treatment, because he believed they should be strong willed.

**Poon’s experience: Emerging codes**

The codes emerging from Poon’s account were: not noticing pain; helping with the household jobs; feeling she should go to the doctor; giving massage; pain related to working hard; bringing medication; deferring to the doctors’ knowledge; leaving her alone and keeping quiet; noticing changes in work habits; noticing tolerance of pain; assisting with the household jobs; acknowledging primary responsibility for care; asking about exercise and the effects of climate; not blaming and letting her complain; looking for the best medication to get rid of the pain; seeking advice from neighbours for getting a good care; wanting to know more from doctors and nurses about rheumatoid arthritis and how to manage pain; getting daughter’s advice to see the doctor only; acknowledging not knowing how to ask for advice; needing help from the health centre in relation to rheumatoid arthritis; and perceiving the need for people with rheumatoid arthritis to be strong willed.
Not noticing the pain
I didn’t notice that there was anything wrong with her. I brought her to see the doctors, and got some medication for her when she was sick ... I rarely noticed her. I didn’t consciously think about it, but at the back of my mind I knew that she had to get treatment for her pain ... Yes she did (talk to me about what was happening to her) ... She said that she had pain in her joints and things like that.

Helping with the household jobs
When she had pain in the morning and couldn’t do anything, I woke up early to do the household jobs. I helped her as much as I could from when she first had pain till now. But I don’t know what more I can do.

Feeling she should go to the doctor
I felt nothing (when she told me she had rheumatoid arthritis). I thought that she should go to see the doctors. Doctors would give her some medication. Her illness would disappear if she continued to get the treatment. I only thought this, I didn’t learn about it. So I really didn’t know how I could help her ... After I knew that she was starting to have pain, I told her to see the doctors.

Giving massage
Sometimes I massaged her body if she had pain or fatigue ... Besides these things (helping with the household jobs), I massaged her. But it didn’t relieve her pain; it made her suffer more.

Pain related to working hard
I didn’t really think about the causes (of the rheumatoid arthritis) except about her working hard, because she used her hands to pull the weaving looms for a long time.

Bringing medication
My daughter is a technical nurse. She works in the general hospital. It’s far from here. But she always asks Ta about her illness, and brings her medication from her hospital.
Deferring to the doctors’ knowledge
No. I didn’t think about the future. I thought that she should see the doctors and take the medication. It’s impossible for me to think about any more than this or to find medication that’s better than the doctors give her. They know more than me, because they’ve studied to be doctors. I haven’t studied like them, so I can’t do what they do. If I wanted to find other cures, I could only suggest decoctions and traditional medications (laughed).

Leaving her alone and keeping quiet
Of course (there have been changes since she got rheumatoid arthritis). You know sometimes when she had pain she got angry and depressed very easily, but not a lot. While she had these feelings, I left her alone, kept quiet and kept my mouth shut (laughed). Since we’ve been married, I’ve never quarrelled with her or harmed her. We understand each other.

Noticing changes in work habits
In the past she could carry a heavy bin with a lot of cement in it. Since she had rheumatoid arthritis and pain, she becomes fatigued after she’s done that.

Noticing tolerance of pain
She had pain, but not so much that she couldn’t tolerate it or that she cried. She told me if she had pain.

Assisting with the household jobs
In the morning, I got up at 4 am and did my daily routine, cooked food, and went to the field. I washed the clothes in the morning too if I had enough time. Some days I couldn’t do this, because I had a 32,000 square-metre field and had to do it by myself. Now, I leave her to rest as much as she can ... I did all the household jobs, for example cooking, washing clothes, and cleaning the house. I did everything for her if I had time. On the other hand, she did them when I couldn’t, because she always stayed home. Although I went to the field, I didn’t forget to cook and do other things for her.
Acknowledging primary responsibility for care

Yes, I’m primarily responsible for taking care of her, because there are only three of us now.

Asking about exercise and the effects of climate

I wonder about whether she can exercise, can she? … She should do aerobic dance (laughed) … Someone told me that patients with rheumatoid arthritis shouldn’t work hard … I think the cold weather will affect the RA and the pain.

Not blaming and letting her complain

When she had pain, she was easily depressed. Sometimes she complained too. At those times, I did everything as usual, I didn’t blame her and I let her complain and do what she wanted.

Looking for the best medication to get rid of the pain

We talked together that about how it would disappear if she saw the doctor and took the medication. Sometimes I thought about how I might find a good medication for her. I wanted her illness to be cured, but I didn’t know where I could find good medication. If anyone told me where I could get it, I took her to get it, anywhere and anytime. Last time, we rented a car to get some medication in Phetchaburi. I’d go anywhere if I knew I could get good medication. I really want the rheumatoid arthritis and pain to disappear.

Seeking advice from neighbours for getting a good cure

My neighbours (suggested a strategy). They had a sprain, muscle strain or something like that. When they told me, I even went to the shaman or someone, who really knew about how to clear our bodies when there is a hex on them. I generally went everywhere with my wife if I knew I could get a good cure, but sometimes her friends accompanied her.
Wanting to know more from doctors and nurses about rheumatoid arthritis and how to manage pain

I want them (doctors and nurses) to care for her and other patients with rheumatoid arthritis and pain, but I don’t know how I can say this to them ... In my opinion, the doctors don’t really advise. I want some help from the nurses too ... I mean I want them to do anything that will make my wife get better, but I don’t know how to say it ... I want them to advise me what rheumatoid arthritis is and how to care for a patient with rheumatoid arthritis and pain. I want to know more than I know now. They didn’t tell me more and they only gave her medication.

Getting daughter’s advice to see the doctor only

She (my daughter) is a technical nurse and knows a little bit about rheumatoid arthritis, because she studied nursing for two years. After she graduated, she worked at the general hospital that’s far from here. She can’t get home very often. When she’s back home, she talks with my wife and tells her “Please go to see the doctor and don’t buy medication from other places.”.

Acknowledging not knowing how to ask for advice

Perhaps I didn’t dare to ask, because I didn’t know how to say it or what I wanted to ask when I saw them. I remember that they usually asked her “How are you? and Can you grasp with your hands and please show me?” Besides these questions, they checked her joints too.

Needing help from the health centre in relation to rheumatoid arthritis

In my village, the staff from this centre came here to survey how many houses and persons in each house. They didn’t do anything for her illness. Four months ago, my wife was discharged from the hospital and was back home to rehabilitate, because she’d had a uterus operation. They told her that they would visit her. You know we’ve never seen them till now (laughed). I think that they might only visit babies or aged people. I don’t know what will happen in the future, because I know that this health centre will be under the new local council. The staff must do everything that this council orders. I’m
not sure how they can take care of our health and our illnesses, because some staffs have no knowledge about health and caring.

**Perceiving the need for people with rheumatoid arthritis to be strong willed**

*For everyone who has rheumatoid arthritis, I think that it depends on his or her attitude. They mustn’t be disheartened about looking after themselves and continuing their treatment. They should be strong willed.*

**Nhung’s and Song’s experience**

**Background**

Nhung was 21 years old and single. He graduated from school in grade six (Prathom six). He worked as an employee in a tile factory, which was not far from home. He noticed it was three years since his mother began treatment for rheumatoid arthritis and pain at the public hospital. He said she looked different after she had pain. She could not do anything that she usually did such as being unable to walk anywhere. He did not know what was happening to her. He only knew that pain affected her sleeping and eating. His mother could not sleep without a hypnotic drug when she had pain.

Nhung had his own support. He could visit his mother daily, because he moved out from Bangkok and lived with her. He said he assisted her to do household jobs as requested. He carried her to the toilet. He avoided touching her body too much. He asked her to stop crying and encouraged her to rest instead. He sometimes left her alone by walking away to his bed or the neighbours when he saw she had pain and cried. He pitied her when she had pain after activity.

Nhung said his mother received help from every family member. She did not get help from the neighbours, because she did not get along with them very well. He used to assist his mother in the hospital also. He noticed nurses’ activities and appreciated nursing care in helping and giving medications, which he valued. He said he seldom saw
the doctors while his mother was admitted to the hospital. He did not know how to ask for more help. He had just wanted the doctors to visit her frequently, and for nurses to advise the relatives on how to care better.

Song was a 16 years old grade nine student (Matthayom three). He was the youngest child of Wing. He noticed that his mother had pain in her arms and leg, that she had distended blood vessels, and that her ability to do household jobs decreased. She was unable to be humorous when his father teased her, and she usually complained and cried out when she had pain. Song gave Wing massage and encouraged her to rest and sleep. He said that it was not only him who helped his mother, but also his father, older brother, and older sister who married and lived far away.

Although Song felt upset after he knew rheumatoid arthritis was a chronic illness and his mother had to have medication all of her life, he still hoped that her pain would disappear and his mother could get better if she got treatment continually.

Nhung’s and Song’s experience: Emerging codes

The codes emerging from Nhung’s account were: perceiving the pain duration; seeing her daily; noticing decreased ability to work; noticing the differences from before and now; not knowing what happened about pain; assisting to do household jobs; carrying to the toilet; help coming from every family member; not touching her body too much; noticing her crying; leaving her alone; noticing pain affects sleeping; noticing pain affects eating; noticing her persistence in working with pain; doing household tasks as requested; encouraging rest; asking her to stop crying; not getting help from neighbours; assisting in the hospital; noticing nurses’ activities; appreciating medication; not seeing the doctor frequently; not knowing how to ask for more help; appreciating nursing care in helping and medications; not getting any advice from the health care team; and wanting visits and advice.
Perceiving the pain duration
It’s three years since she started to get treatment for rheumatoid arthritis and pain at the public hospital. I wasn’t staying at home at that time. I lived in Bangkok and I sometimes came home.

Seeing her daily
Now I don’t go back to Bangkok. I stay here and I see her everyday.

Noticing decreased ability to walk
Yes, she is better than she was before. She can walk anywhere that she wants. In the past, if she wanted to walk, she had to hold the door and walk with short steps. She usually cried out when she sat … Yes, she couldn’t walk anywhere. She always stayed at home and lay down … When she had pain, she couldn’t do anything that she usually did.

Noticing the differences from before and now
Yes, there are (any differences). … I don’t know how to explain it. (Thought and laughed) … Now, as she gets better she can do things better … She looks thin … The joints. I saw she had swelling at her wrists … and in her legs too.

Not knowing what happened about pain
I didn’t know what was happening to her. I only knew that we couldn’t touch that part of her. If we touched it, she’d cried out in pain.

Assisting to do household jobs
When my sister lived here she did everything, both cooking and household jobs. My mum usually lay down. Now, my sister’s married and lives with her husband. So mum has had to do those things by herself … I stayed home and helped her do the housework … I washed the dishes … I usually fed the pigs and my younger brother did the housework.

Carrying to the toilet
She told everyone in family when she had pain. Sometimes she told us to carry her to the toilet.
Help coming from every family member
Absolutely (everyone helped her.) ... My older sister used to do all of the housework, but she’s married and she moved out of here a year ago ... Yes (she did everything.). I helped her a little bit. She did everything from the time she woke up ... He (my younger brother) is rather weak, but he helped my sister more than me. I’m not sure what he did, because I was not home at that time. I think he did what my sister or mum asked him to do too. He knew what had happened to mum, because she’d had rheumatoid arthritis for a long time.

Not touching her body too much
But we couldn’t touch her much when she had pain.

Noticing her crying
Absolutely (that she cried when she had pain.) (laughed) ... She usually cried when she had pain.

Leaving her alone
I walked away (when she had pain and cried) ... Then I walked away to my neighbour's house. It’s over there. Sometimes I went to bed when I saw her crying.

Noticing pain affects sleeping
If she had pain, she was in pain all night. She couldn’t sleep without taking some hypnotic drug ... (she got that drug) At the health centre. It’s at the junction, a long way from here ... She couldn't sleep well when she had pain.

Noticing pain affects eating
She had only Kao Sao Nham ... First, we cook rice. After the rice is cooked, we boil water and put the rice in it and finally add fish sauce. It’s called Kao Sao Nham ... Sometimes she couldn't have anything, because she couldn’t swallow. She said the smell was too strong. It stank. She couldn’t eat it. We had to boil the rice again till it was muddy looking.
Noticing her persistence in working with pain

I pitied her. I told her “Don’t do anything”, but she didn't listen to me. She still worked and did anything that she wanted. So I let her. She always complained that she had pain when she’d finished her job and come back home ... She and my dad worked together in the same factory. She was a maid there. It wasn’t a hard job. She didn't do heavy work. She could work even though she was in pain.

Doing household tasks as requested

I did anything that I could and everything that she asked me. If she didn't ask me, I didn't do it ... Yes, she had to ask me ... I did most of the household jobs that she asked me to, for example cleaning the floor, washing clothes. If she didn’t ask me, I didn’t do them. She couldn’t wash the clothes. If she did, it was painful for her. I washed both dad’s and mum’s clothes ... I did everything that she asked of me.

Encouraging rest

I told her "If you feel badly, you should get on up your feet and stay home. If you are really unable to do that, you shouldn't. You should just stay and rest at home".

Asking her to stop crying

I asked her to please stop crying (when she cried.) ... I asked her why she cried.

Not getting help from neighbours

I usually visit them, but they didn't come here ... No, because she (my mum) doesn’t get along with them very well. They rarely visit us at home.

Assisting in the hospital

Sure (I used to take care of her when she was admitted to the hospital.) ... Yes. I could look after her the whole time, because she was admitted to a private hospital. The hospital gave me a bed and a sofa to stay the night.
Noticing nurses’ activities

They always took care of such things as her personal hygiene and her meals ... They usually rushed to see her after I told them that she was in pain. They always observed her symptoms at every mealtime, and always asked about her pain again in the evenings ... I saw them give her some medication ... They always asked her how she felt or if she was feeling better. The nurses looked after her personal hygiene. Sometimes they took her to the toilet if I was not there ... Some of the nurses advised us that we should help her as much as we could by doing things like the housework when she had pain.

Appreciating medication

She slept well and wasn’t aware of anything ... (Thought) she told me that she felt better. It relieved her pain. After that she slept. So did I.

Not seeing the doctor frequently

I’m not sure about the doctors. I seldom saw them, but I usually saw the nurses caring for her.

Not knowing how to ask for more help

(Laughed) Nothing ... (Thought) I don't know how to say it. I want the doctors to be around as much as they can ... When I accompanied her to the health centre, I waited for her outside (laughed). So I don’t know about that (how to ask some help from local health staff).

Appreciating nursing care in helping and medications

(Smiled) In my opinion, I think the nurses looked after her well. Their nursing care was enough for her. They helped her with everything that they could, such as giving her medication and caring for her when she was in pain.

Not getting any advice from the health care team

They didn't tell me, but they talked with her. So I knew when I talked with her.
Wanting visits and advice
Yes (I want the doctors to visit her frequently and nurses to advise the relatives too.)

The codes emerging from Song’s account were: noticing distended blood vessels; complaining and crying out; noticing decreased ability to do household jobs; being unable to be humorous; not knowing what to say or feel; giving massage; telling rest and sleep; hoping pain will disappear; hoping in continuing treatment; giving up the expectation that pain will disappear; looking for a job and helping to do household jobs; not knowing how to ask for more help; and seeing some help from other family members.

Noticing distended blood vessels
I saw that she had pain in her arms and legs ... I saw four or five green lines on her arms. I wasn’t sure what the lines were. Maybe they were blood vessels ... I only saw them (blood vessels) when she had pain.

Complaining and crying out
I’m not sure (when she had pain), but she always complained when she had pain. She cried out when she lifted the dishes or anything like that ... Of course (she cried and screamed out when she had pain).

Noticing decreased ability to do household jobs
As far as I could see she was as she usually was. She’d just get up, stay at home, and sometimes work in the vegetable garden ... Yes (she did her job even though she had pain) ... Yes (she did household jobs by herself) ... No, she did them (household jobs) worse ... She was different from in the past when she had no pain. Before she had pain she could do everything really well.

Being unable to be humorous
Yes, she changed emotionally. Sometimes when she had pain, my dad loved to tease her. He pulled her arms and legs. He wanted her to exercise (laughed). She yelled and went straight to bed.
Not knowing what to say or feel
I didn't know what to say or how I felt ... (Thought) Yes, I did (felt sad) ... Certainly (I pitied my mum when she had pain).

Giving massage
I massaged her arms and legs ... Sure. I pressed her like this (showed). I did it when she had pain ... I used my elbows to press down on her back ... I did it like this (showed) ...
She told me that sometimes she felt better, but sometimes the pain was still there ... No (I didn’t apply a hot compress to her). I only massaged her.

Telling rest and sleep
I told her to rest and to sleep when she had pain.

Hoping pain will disappear
I hope that her pain and the rheumatoid arthritis will disappear, because she has been getting treatment for three years.

Hoping in continuing treatment
I hope that she will get better ... At first, I thought that she could get better if she got treatment continually.

Giving up the expectation that pain will disappear
But someone told me that rheumatoid arthritis is a chronic illness. It doesn’t disappear and she has to have medication all of her life. So I stopped thinking about it ... The doctor (said that). He told my mum and she told me later ... After she told me about it being chronic, I felt upset. Now, I feel nothing.

Looking for a job and helping to do household jobs
I had to help her. I looked for a job to make money, and I did the housework instead of her ... Cooking rice, preparing the food for the pigs, cutting the banana trees, and washing the clothes.
Not knowing how to ask for more help

I didn’t know what to say. I didn’t think anything more about it at that time, because I was admitted (to the hospital at that time) too.

Seeing some help from other family members

Yes. She (my sister) always did everything for mum, for example, doing the housework. But my mum managed the medication by herself ... He (my dad) did everything that he could, such as massaging her, buying the food, and taking her to see the doctors.

Yon’s experience

Background

Yon was Boon’s husband. He was a 53 years old employee, who graduated from school in grade four (Prathom four). He worked in an ice-making factory. Since she had rheumatoid arthritis, Yon noticed that pain was the main symptom. He said Boon always had pain when the weather was cold, as it was then her joints became swollen. He observed that she cried when she could not do things for herself, and sometimes she said she wanted to die. She also was very moody. He said he just observed how she was and never asked her how she felt, because he was ‘down to earth’. He did not feel anything was different from before after he knew she was in pain with rheumatoid arthritis. He had lived with her for a long time, so everything was as usual for them.

Although Yon worked nearly everyday, he set aside the time to look after his wife well. He helped her to do things and took care her all of the time, both at home and in the hospital. He helped her in the morning, such as assisting her to get up from the bed. He cooked food and washed clothes for her. He modified the toilet to be easy for his wife to use when he was at work. He also gave her massage. He usually sought the information about rheumatoid arthritis from the newspaper and television. He avoided cooking harmful food for her such as cucumber, and he took the core out and filled it with pork instead.
Because of helping the neighbours for a long time, his wife got help from the neighbours when he was not home. Yon held no hope for cure, because he was well aware that rheumatoid arthritis was a chronic disease. He recommended that Boon get continuous treatment from the doctors, and not use herbal treatment. He appreciated doctors’ and nurses’ care. He said nurses gave his wife the medication as prescribed, and the doctors also checked her symptoms. They sometimes talked to him about rheumatoid arthritis and how to care for his wife. He said his wife got advice about food from them too. Two areas of care he wanted improved were that his wife would get more medication to relieve pain, and that nurses monitored the effects of medication after administration.

**Yon’s experience: Emerging codes**

The codes emerging from Yon’s account were: helping to do things; modifying the toilet; noticing pain is the main symptom; feeling nothing emotionally; being moody; assuming an understanding of feelings; crying and being disheartened; helping in the morning; doing the cooking; washing clothes; giving massage; recognising herbal treatment is not good for a patient with rheumatoid arthritis; caring in the hospital; appreciating doctors’ and nurses’ care; noticing patients got advice about food; noticing the harmful foods; getting help from neighbours; caring all of the time; having no hope for cure; getting information about rheumatoid arthritis from newspaper and TV; recommending continuing treatment; needing more medication to relieve pain; and wanting nurses to monitor effects of medication.

**Helping to do things**

*I’m not sure how to explain it. For the first period that she was in pain, I couldn’t go anywhere. If I went to the temple my son would call me to come back home. I had to help her with everything, including when she went to the toilet. She couldn’t do things for herself ... Exactly (everyone helped her). She couldn’t do things, but we could. I washed the dishes, cooked food, and did household jobs for her. She only did things that she could. I left them for a while if I was very tried from working. I’d do them after I felt better. I washed the clothes too. Everyone had to do things and help her together.*
Modifying the toilet
I had to modify the toilet; for example I adapted the drainpipe trap, so it was higher and tied a rope onto the ceiling. When I was not home, she could pull on the rope to support herself to stand.

Noticing pain is the main symptom
Pain. She always had pain when the weather was cold ... Wrists, knuckles, elbows, ankles, and knees (that the parts she had pain). They became swollen ... Yes (she had pain from the beginning till now).

Feeling nothing emotionally
I felt nothing (after I knew she was in pain with the rheumatoid arthritis). I’d lived with her for a long time. Nothing was different from before. Everything was as it always was ... No (I didn’t pity her), because everything was as usual for us. Sometimes I went about my business and talked with the abbot at the temple. If my son called me to come back home, it didn’t put me in a bad mood. It was all right.

Being moody
Certainly (her emotional state changed when she was in pain). (Thought)... Can you understand her feelings when after being a working woman she suddenly can’t do her job? She was very moody. That was a fact.

Assuming an understanding of feelings
No (she didn’t talk to me about how she felt), maybe because I rarely asked her. I saw what she saw and I knew what she knew, why did I need to ask her again ... I didn’t do anything (when she said that) ... (Laughed) No (I didn’t say anything to her), because I’m not romantic. I’m down to earth (laughed).

Crying and being disheartened
(Thought) She cried when she couldn’t do things for herself and when she felt disheartened. She sometimes said she wanted to die ... Yes (she was in pain and disheartened).
Helping in the morning
These days I rarely care for her in the morning, because I have to go to work. When I worked at home, I could help her more. I looked after her while she took a bath and had breakfast. I had to assist her to get up from the bed if she had a lot of pain (thought)...I supported her the best I could...going to the toilet and when she wanted things. I did everything for her.

Doing the cooking
Me (I cooked when she had pain). I could cook since I was eight years old.

Washing clothes
I helped her with everything I could such as washing her clothes, including her Thai sarong and her clothes that were stained with blood when she had her period.

Giving massage
Yes (I supported her with everything from the time she got up till she went to bed), including giving her a massage ... I massaged her and myself at the same time. You may wonder how I could do that. I massaged her legs with my right hand and myself with my left hand. While I massaged her, I always asked her how she was. I had to use my past experience while I did this ... she would get worse if I massaged her too much.

Recognising herbal treatment is not good for a patient with rheumatoid arthritis
That treatment (herbal treatment) would be good for someone who had a fever, but it was ineffective for a patient with rheumatoid arthritis.

Caring in the hospital
I looked after her every time she was admitted with a lot of pain. I always looked after her when the doctor allowed me ... I could look after her all the time when I worked at home. There was no problem ... If I had a lot of jobs to do, I visited her a few times during the day and again in the evening. I brought her medication and gave it to the nurses in the ward. I usually stayed there till 9 pm ... I had to take into account my shifts at work. I could care for her during the day if my shift was at night. On the other hand, I
could care for her in the evening if it was during the day. Sometimes I alternated with my friends, asked for leave from my employer or employed my friend to do the job instead of me.

**Appreciating doctors’ and nurses’ care**

They (doctors and nurses) took care of her well ... They (nurses) gave her tablets and injections as set out on her chart. The doctor also checked her symptoms ... Sometimes (they talked with me about her disease, and how I could care for her). They told me that she was weak and couldn’t do things by herself. That her relatives should look after her carefully ... They didn’t tell me any more than this, but I knew what I could do ... Yes (they told me general information about rheumatoid arthritis) ... Nurses asked about her symptoms, gave her medication, and advised me if I did anything wrong with her. I mean when I was giving the wrong sort of care.

**Noticing patients got advice about food**

They told the patients they should avoid having poultry, offal, lead tree, and cha-om.

**Noticing the harmful foods**

I’ll give you an example. Do you know cucumber? When I cooked it for her, I took the core out and put pork in instead.

**Getting help from neighbours**

Yes (my neighbours helped me too), because we’d helped them before. So they all helped us ... They always cared for her (when I went to work) ... We helped them for a long time doing everything that we could for them. Sometimes we stopped selling charcoal from the boat, and helped them when they had to arrange a party or funeral. We did this free of charge. We were glad to do it for them.

**Caring all of the time**

All of the time (I always looked after her). You know, when she was admitted to have the operation. I’ve never let everyone else care for her. I wouldn’t trust them. She would become worse if they’d let her drink water after the operation. The doctor prohibited her
from doing that ... I thought my injection skills would be better than some of the nurses (laughed).

**Having no hope for cure**

_I had no hopes (what the treatment would do), because I was well aware that rheumatoid arthritis is a chronic disease._

**Getting information about rheumatoid arthritis from newspapers and TV**

_I knew a lot about rheumatoid arthritis from the newspapers and books. I love reading ... At the same time (she continues treatment) I try to find out more information by reading books and watching TV. So then I can record this in the back of my mind, and use it the next time she gets pain._

**Recommending continuing treatment**

_I think so (she should continue treatment). There is no problem with that, because I know it’s a chronic illness. She has pain from rheumatoid arthritis. She should get continuous treatment._

**Needing more medication to relieve pain**

_I don’t know how to explain it (what care I need more for her when she has pain). When the patients have pain, they (nurses) should give them medication._

**Wanting nurses to monitor effects of medication**

_They didn’t do anything (nurses didn’t come back to ask my wife about her symptoms again after she’s taken the medication). One made up her face and others chatted together (laughed) ... Yes (I wanted them to come back to ask my wife if there were any changes), because they could change the medication for her if the old one was ineffective._
Ping’s experience

Background

Ping was a 60 years old farmer. He graduated from school in grade four (Prathom four). He lived with his wife and Doom, because the rest of his children married and lived with their own family. He noticed Doom had joint swelling initially then joint stiffness. She also had headache and vomiting, and she became thin, weak, and pale later. He said she could not work and move well. She cried and she was very depressed if the pain got worse.

Ping and his wife became the helpers. They visited Doom three times a day when she was admitted to hospital. He found out about herbal treatment and bought some ointment for her. She used it on the areas that were painful. Regarding treatment, he preferred home care to hospital care, because he and his wife could not sleep in hospital and worried about what was happening to her. He preferred being admitted to a hospital clinic also. He felt the staff members at the clinic were more welcoming than at the hospital. He said that Doom never got treatment from local health staff, because they usually only met the public health volunteers who surveyed the number of patients in the village, and gave out some health information.

During the interview, Ping expressed his love and empathy towards Doom. He felt that she was more important than his jobs. He explained that his wife and he had to depend on their children, or at least hope their children would help them when they were older. He referred to Buddhist the “Wheel of Fate” (Kong Kam Kong Kwain). However, he suggested that the appropriate medical treatment was better than seeing the fortune-teller. He also wanted the health care team to improve their education techniques.
Ping’s experience: Emerging codes

The codes emerging from Ping’s account were: noticing joint swelling; noticing joint stiffness; noticing headache and vomiting; becoming thin, weak and pale; noticing decreased abilities to work and move; noticing general decline; noticing tearful emotional state; expressing love and empathy towards a child; visiting her three times a day; being of assistance; preferring home to hospital care; feeling daughter is more important than job; caring according to the “Wheel of Fate”; appreciating nurses’ and doctors’ caring; not appreciating some health care staff in their caring; expressing close family ties; finding herbs or ointment; suggesting appropriate treatment is better than seeing a fortune-teller; owning personal responsibility for care; suggesting the staff should improve giving information; preferring clinic to the hospital; and getting no care from the health centre.

Noticing joint swelling
At the beginning, her joints became swollen. I mean her knuckles and ankles were swollen. She went to see the doctors, but it still got worse. Her feet, wrists, and legs were swollen later ... And her feet, they became swollen and looked as if they had been bitten by something.

Noticing joint stiffness
She couldn’t put her rings on, because her fingers were stiff; she couldn’t flex them. They were always extended. They became swollen and stiff. They looked like they couldn’t move at all. I saw that sometimes one or two fingers were strained, especially her knuckles. She couldn’t take her ring off.

Noticing headache and vomiting
She frequently had pain. She had headaches and couldn’t stand up. Sometimes she vomited too.
Becoming thin, weak and pale
She was thinner. She was weak and pale. It’s different now. Her body was wrinkled. At the same time she had other symptoms too. I can definitely say that she was thinner and paler.

Noticing decreased abilities to work and move
Doom didn’t work outdoors. And as far as household jobs, she didn’t do things such as cooking anymore. I didn’t notice much. Sometimes I saw her do the laundry. She didn’t do it well, because she had pain and fatigue. She had to stop doing it and try later. If she sat in the same position for a long time, she would have pain in her knees. In the past we said this was “bad circulation”. The blood couldn’t circulate well. It’s unusual. Sometimes I called to her “Dear! Wake up”, but she couldn’t. She was in pain and seemed very ill. She had pain and bruises all over her body.

Noticing general decline
It was as you’d expect. If our bodies aren’t strong or there’s something wrong, we don’t want to talk with others. We don’t eat well. Sometimes we can eat, but sometimes we can’t. Our bodies become run down and wrinkled.

Noticing tearful emotional state
She cried if the pain got worse. It’s in her nature to be weepy. Maybe...sometimes. If you break her, she will cry. It’s in her character ... Yes. She was very depressed (when she had pain) ... She usually cried. If the pain got worse she cried. You know her body was abnormal. She couldn’t tolerate the pain. She didn’t know what she could do to relieve it, so she cried.

Expressing love and empathy towards a child
You may not know, because you’ve never been a parent. Listen to me, parents will always love their children. If you were a parent and had children of your own, they would be the dearest things to you. You’ll hear this from every parent ... When she was admitted, I stood near her bed and saw her having convulsions. You know, I couldn’t do anything for her. I walked down to the ground floor by the stairs. I didn’t remember
anything. I got lost. I would lose the way if my wife didn’t come with me. You know I am a strong man. I’m not sensitive. I felt terrible that day. I nearly lost my mind. I loved and pitied her. I came out of the ward and sat down in the dining area for relatives … I talked with others. They told me that they noticed that patients on the fourth floor usually died in the ward. After I heard that I felt worse. I couldn’t speak. If you’d hit me at that time, I wouldn’t have felt anything. My body was numb. I was confused…very confused. I thought my daughter might die, because she was not getting better. I nearly fainted. My wife had to hold me.

**Visiting her three times a day**

I only asked her “Are you getting better dear?” or “Would you like anything?” I didn’t say anything more. I saw her three times a day; in the morning, at noon, and in the evening. I brought breakfast to her, because she didn’t eat the hospital’s food.

**Being of assistance**

I always asked her what she wanted to have. If she wanted something, I bought it for her. Sometimes my wife cooked for her too … I usually asked her the same questions, for example “Would you like anything?” “Do you want anything else?” or “How are you today?”

**Preferring home to hospital care**

She didn’t like being admitted. She preferred to be back home. Do you understand? She was born here. I am well known here. Here’s more comfortable than the hospital. We can get anything we need easily … If she was in the hospital, we couldn’t sleep and we worried about what was happening to her. These are parents’ feelings. We love her. We look after her. I couldn’t wait for the sun to rise. I had to get up and go to the hospital. I did that everyday while she was there.

**Feeling daughter is more important than job**

I felt my job was just a small part of my life. It’s farming and animal husbandry. I keep my cows in the cowshed and give them straw. When she was admitted, I looked after her during the day. I neglected my job. I only worked in the field two or three times a week. I
didn’t think of my work as necessary at that time. I cared about my daughter more than my job.

Caring according to the “Wheel of Fate”

You know children are the most important things to parents. We have to depend on them, or at least hope they will help us when we are older. In Buddhism we call this the “Wheel of Fate” (Kong Karma Kong Kwian). Parents look after their children when they’re young or sick. On the other hand, children look after their parents when they are older or sick. Parents usually hope that their children will take care of them when they are older ... I don’t know how to explain it. Well. When I’m fit and healthy I work and earn money for the future and when I’m sick ... Now, she’s sick. She needs treatment continually. I have to support her as much as I can. I’ll support her to fight the rheumatoid arthritis till she can manage things herself ... I wanted her to continue treatment. I didn’t regret spending the money. As I told you when we have children, we want them to grow and to be educated. When they’re sick, we have to look after them and find the best treatment for them. Even when they’ve grown up and become adults, we, I mean parents, still help them when they are sick. It’s the Wheel of Fate. One day when we’re older, they’ll look after us.

Appreciating nurses’ and doctors’ caring

Yes (I saw her doctors and nurses when she was admitted) ... Most of them were nice and friendly. They advised and welcomed us. It was very good. They treated me as if I was their cousin ... They didn’t say anything about the pain. When I asked them about her illness, they explained to me how to diagnose her condition and treat her ... They only told me when I asked them ... No (there weren’t any differences between the care given by the doctors and nurses). Some nurses were very good. They paid more attention to my daughter when she had a lot of pain at night. They gave her analgesic drugs and observed her pain level.

Not appreciating some health care staff in their caring

One person was not so good though. They were impolite and seemed to be uneducated. Please forgive me if my words offend you ... One (nurse) wasn’t good though. She
ignored me when I told her about my daughter’s pain. She lay down and watched TV. I know this, because I stayed there till 9pm.

Expressing close family ties
All of my children live together in a big group. They’re very loving and their relationship is very strong. I never taught them this; they did by themselves. They never quarrel. And I have many grandchildren. Some live with me and some live in their own homes. I always cook and buy things for them. If they need some help, I’m there for them as soon as I can be. We always share everything.

Finding herbs or ointment
I found out about herb treatment and bought some ointment for her. She used it on the areas that were painful ... And as far as herbs go, sometimes we used cassumunar and ointment to paint on or apply it as a fomentation. It can relieve pain. Someone had the herb and the two of them applied it to their bodies together. I always knew that she had to continue her treatment and spend more time trying to relieve the pain.

Suggesting appropriate treatment is better than seeing a fortune-teller
In relation to the fortune-teller or her horoscope, we don’t check it very often, sometimes only once a year. We don’t believe it’s 100% accurate. I think she should get the appropriate treatment from the doctor who works in the hospital. It’s like making things happen yourself. You can’t get money without working for it.

Owning personal responsibility for care
I’ve never thought about that (the health care team’s caring) before. I’ve only thought that I must take care of her as much as I can.

Suggesting the staff should improve giving information
I think there are some things they should improve. They were very poor in giving information. They didn’t tell me anything; we had to ask them before they told us anything. They should give us more details about the patient’s illness, because we are the patient’s parents. We are the caregivers. They rarely told us anything. When my
daughter was in pain, we had to ask for her medication. They then gave it to her and let her sleep. Some days the doctor didn’t do his rounds in the ward, and the nurse didn’t do anything. Some nurses only checked her vital signs … Yes. They weren’t like you (that told me what was happening to her). I had to ask them and tell them when my daughter was in pain or felt bad. The nurse would give her the medication, and then go back to the nurses’ station without re-checking her level of pain … I accompanied her four or five times. They didn’t tell me anything more. If she was admitted, I usually asked them when she would be able to come back home.

**Preferring clinic to the hospital**

When I took her to the clinic, the doctor gave her an injection and all the staff members were much more welcoming than at the hospital. My daughter went to the private hospital twice, they were also very welcoming to her. When she went to the hospital, we usually accompanied her. We had to leave home at 6am by motorbike and wait in the queues. She drank hot chocolate before leaving home. Sometimes we arrived at the hospital at 7am. And sometimes she only got the medication to take home. This meant we missed work. You know sometimes there are a lot of patients that the doctors can’t examine and treat by 11am or noon. We don’t like to go to the hospital unless we have a severe illness or we’re about to die. It’s so boring having to wait for such a long time.

**Getting no care from the health centre**

No (she didn’t get some care from the health centre), there are only public health volunteers there … They survey the number of patients in their village and give out some health information … No (they didn’t tell me what they did with this data). I’ve only seen the local health staff checking blood sugar levels for patients with diabetes mellitus. I didn’t think that they would do anything for patients who didn’t have diabetes mellitus.
Summary

This chapter introduced the caregivers’ experiences, in relation to their backgrounds and emerging codes. The caregivers described caring for relatives with rheumatoid arthritis when they had pain. The individual codes that emerged were collated into categories, which are presented in Chapter Nine of this thesis.
Chapter Seven: Nurses’ Backgrounds and Emerging Codes

Introduction

After interviewing the nurses, I transcribed the accounts of their experiences, and translated the transcriptions from Thai to English. Following this, I analysed individual accounts. This chapter relates to nurses’ backgrounds and emerging codes. The nurses were identified by the pseudonyms of Am, Anne, Khan, Luck, Meaw, Tha-nhom, Usa, Mham, Tina, and Rin. Ten nurses were between 27 and 49 years of age. They all were women. They had been caring for patients with rheumatoid arthritis, for periods ranging from seven to 24 years. Six of them were married. They all graduated with a Bachelor degree of Nursing Science, and five of them had a certificate in orthopaedic nursing training. Two hundred and seven codes emerged from these participants, involving their perceptions of pain, and how they gave nursing care to patients with rheumatoid arthritis who had pain.

Am’s experience

Background

Am was a 37 year old, single, registered nurse who worked in an orthopaedic ward in a regional hospital. She had Bachelor degree in nursing and trained in orthopaedic nursing. She was experienced with caring for patients with rheumatoid arthritis for 15 years. She saw more female patients with rheumatoid arthritis than male, and all patients were all over 40 years old. She said that the symptoms of rheumatoid arthritis were joint swelling, joint deformity, joint stiffness, and pain, especially in knees and wrists. She said the doctors used symptomatic treatment by giving antirheumatic drugs, controlling food and restricting movement. She had never observed patients with rheumatoid arthritis and acute pain. She had only observed them when they were feeling better after they had routinely taken medication as prescribed. She said some doctors gave analgesic
ointment also, because it seemed to ease the minds of patients who wanted something different, such as massage.

She managed rheumatic pain by applying hot compresses by a hot pack gel. For the patients who had severe pain, she informed the doctors and then they referred patients to the physical therapy department for some special treatment, such as soaking the painful area in paraffin. She suggested that nurses could use elastic bandages to wrap patients’ joints when there was swelling and pain in the large joints, such as the knees, by thus restricting joint movement. She assisted the patients with medications and assessed their pain after its administration. She talked to the patients about health education in terms of self-care. She suggested some of these patients change the jobs if they could. She suggested they avoid some harmful work activities. She advised them about suitable diets, keeping warm at home when the cold weather came, and the importance of resting. She talked with them about rheumatoid arthritis being a chronic illness, and explained that it did not make them different from other people. They could live a normal life and could do anything by themselves. Am felt pity for patients with rheumatoid arthritis, because rheumatic pain was chronic pain, but she did not know how to help them except her management as described.

Am said nurses should talk to the patients directly, but in cases where it was difficult to talk with the patients, they needed to talk with the relatives. Although she managed pain as she explained, she was unsure about the benefits of exercise and appropriate advice. She recognised that nurses could only give medications, and that advice, and the doctors did not control the patients’ pain. She thought pain should be controlled continually and patients with rheumatoid arthritis could care for themselves, they could also return to outpatient department (OPD) for follow up treatment.

Am’s experience: Emerging codes

The codes emerging from Am’s account were: noticing more females have rheumatoid arthritis; noticing joint swelling; noticing joint deformity and stiffness; acknowledging patients’ pain; feeling pity; recognising benefits of analgesic, food and restricted
movement; advising to rest; applying hot compresses; using paraffin soaks for pain; assisting about medication; advising about food; giving health education to relieve the pain; being unsure of the benefits of exercise; being unsure of appropriate advice; recognising nurses can only give medications and advice; advising to keep warm; feeling patients with rheumatoid arthritis can care for themselves; thinking the doctors do not control patients’ pain; thinking pain should be controlled continually; using elastic bandages; giving support and encouragement; assessing pain after medication; wanting the patients to return to OPD for follow up treatment; and communicating directly with patients.

Noticing more females have rheumatoid arthritis

I saw more female patients than male. They were all over 40 years old. I saw one case but I’m not sure how old she was. She’d had rheumatoid arthritis with pain since she was 20 years old. She had had many operations, because her joints were already deformed.

Noticing joint swelling

They had pain and swelling in many of their joints … I thought that they had these symptoms because they were lacking in exercise.

Noticing joint deformity and stiffness

Some cases had joint deformity and joint stiffness too.

Acknowledging patients’ pain

Knees and wrists (they had more pain) … No (any different symptoms between females and males). Usually they were admitted with pain and were unable to work.

Feeling pity

I pitied them, because rheumatoid arthritic pain is chronic pain. I saw in their faces that they were unhappy. I pitied them, but I didn’t know how to help them except encouraged them to rest, gave them medication and applied hot compresses to them.
Recognising benefits of analgesic, food, and restricted movement

Most of them used symptomatic treatment ... They (doctors) gave them medication and ordered them to get some rest ... Antirheumatic drugs (that the doctors gave to the patients) ... It was routine medication that they gave the patients. There is no specific medication for relieving the pain of rheumatoid arthritis ... I have never seen patients with rheumatoid arthritis and acute pain. I saw the patients that were feeling better after they had routinely taken medication as prescribed in their charts ... Most of them asked for it (balm and ointment). The doctors only gave them antipain ointment. It seemed to ease the minds of those patients that wanted something different like massage ... Taking medication continually, avoiding harmful foods and not moving the joints too much (are the best ways to manage pain).

Advising to rest

These patients could take care of themselves. They could walk, but they had inflammation where they had pain. I advised them to rest to restrict joint movement.

Applying hot compresses

If they still had pain, I applied hot compresses for them. I used hot pack gel to do that.

Using paraffin soaks for pain

In the cases that had severe pain, I informed the doctors, and then they consulted the physical therapy department to transfer patients for some special treatment, such as soaking the area in paraffin. I saw the doctors send the cases that had pain in their hands, and feet to soak in paraffin.

Assisting about medication

Besides advising them to rest, I made sure they took the medication according to the doctors’ orders.

Advising about food

I talked with them, gave them some health education, and advised them about suitable diets. I asked them what they liked to eat when they were at home. Then I advised them
what sort of food they should have, which foods to avoid. If they had the wrong idea about how to care for themselves, I advised them about the right things to do ... They had to restrict their diet. They shouldn’t have just any food that they liked if this food resulted in them having more pain, such as cha-om, bamboo shoots, and chocolate.

**Giving health education to relieve the pain**

I advised them in relation to every issue about rheumatoid arthritis, such as what rheumatoid arthritis was, the foods that they should avoid and self-care. In terms of self-care, I emphasised to them the importance of restricting their joint movement. First, I asked them what their jobs were. If their jobs made their condition worse, I suggested that they find a new career. If they couldn’t do that, I suggested that they avoid some of the harmful activities related to their work. For example, one patient was a manual worker. I told her to find a new job that paid the same wages. If she couldn’t, I advised her to be careful when she moved or did anything strenuous. Nurses have to be careful about what they say to patients with rheumatoid arthritis, because it is a sensitive point.

**Being unsure of the benefits of exercise**

I’m not sure what you mean (about exercise for patients with rheumatoid arthritis). You mean joint exercise? I didn’t want them to exercise while they had pain, because it could cause the patients to have even more pain. Before I advised them, I considered their pathology. If they had just a little pathology, I helped them to exercise to protect them from complications. If they already had deformity, I wasn’t sure whether it was good or not to suggest exercise to them. I worried that it would make them suffer more. So in my opinion, exercise doesn’t relieve rheumatoid arthritic pain.

**Being unsure of appropriate advice**

I am a ward nurse. I was never close to the patients like the local staff. They can get to see them at home. So I didn’t know what the real problems for them were, and whether they could do everything that I’d advised when they got back home. For example, I advised them to avoid some foods, but these foods might be customary in their communities. If they did as I advised and they had no more money to buy other good food, they might have become worse or malnourished. Although with educated patients,
we didn’t know whether they did what we advised or not. In my view, we can advise, but we can’t know whether they can follow the advice or not. It is a problem ... This was a problem too (their beliefs), but it depended on their educational level ... Giving them medication, information or health education, but I didn’t know if they would do what I advised or not.

Recognising nurses can only give medications and advice
It was only basic nursing care that we could give them, such as giving medication and health education. We have to work under the doctors’ orders. I think giving health education is an independent role.

Advising to keep warm
I used to ask them about this (how to manage their daily lives). They told me that they got more pain when the weather was cold. So I advised them to keep themselves warm ... I told them that they could use cloths instead of hot packs (to keep warm at home). They boiled the water, left it to cool a little, soaked the cloths in the warm water, and applied a compress.

Feeling patients with rheumatoid arthritis can care for themselves
It wasn’t a problem for me (that the fact rheumatoid arthritis is rare, and it can affect on nursing care). Most of us gave them supportive nursing care. When we saw patients with rheumatoid arthritis, we felt that it was easier to care for them than for other kinds of orthopaedic patients when they were admitted at the same time ... Patients with rheumatoid arthritis were not severely affected, but I had to assess them when they were first admitted and had arrived in the ward. I assessed what pain level they had at that time. If they were in severe pain, I gave them medication as the doctors’ prescribed and helped them to rest. Patients with rheumatoid arthritis are fine. They can take care of themselves, except for the cases that need surgery.

Thinking the doctors do not control patients’ pain
I’m thinking about medication. It’s my opinion that doctors are not really aware of patients’ pain. Different hospitals manage pain differently. Doctors in some hospitals
give patients with rheumatoid arthritis medication continually to relieve pain. They control the pain threshold to a level that the patients can tolerate. But in this hospital, we only give medication when they have pain and can’t tolerate it. It seems we don’t control their pain threshold from the first stage. When the patients have pain, the pain threshold is peaked. I think it is too late when they just take medication while they have pain. It takes longer to ease the pain.

**Thinking pain should be controlled continually**

Yes (we should not wait to start treating the pain until the patients are in acute pain), we should control the pain continually from the time the patients have a low level of pain. We used to think this just among the nurses, but we didn’t dare discuss this with the doctors. They might think that the nurses are overstepping their roles. So we still do what the doctors order us to.

**Using elastic bandages**

Nurses can use elastic bandages to wrap patients’ joints in those cases that have swelling and pain in the big joints such as the knees. We wrap and loosen the elastic bandage from time to time and lift their legs higher. By this method, we can restrict their joint movement.

**Giving support and encouragement**

I talked with them about rheumatoid arthritis being a chronic illness, and explained that it needn’t make them different from other people. They could live a normal life and do anything by themselves. But they had to avoid some activities, such as carrying heavy things as these moved their joints in a way that caused pain. If they had bone deformity, I told them to select a suitable diet, and not to carry things that were too heavy. If they could do as I told them, their pain would ease ... I’ve never seen patients who’ve tried to harm themselves. I’ve only seen patients whose pain level has stabilised.

**Assessing pain after medication**

After I’d given them medication for some time, I’d talk with them and assess how they were. If they weren’t better, I’d tell them what I could do for them, such as give them an
injection or about other treatments. In my experience, I’ve never seen patients continue to deteriorate after they’d taken oral medication.

**Wanting the patients to return to OPD for follow up treatment**

*We usually think that a patient with rheumatoid arthritis is not a severe case. So we don’t worry about home visits. We want them to attend the hospital for follow up treatment. We have outpatient department (OPD) staff to follow them up. We send a letter to them if they miss an appointment. I think that we don’t visit them at home, because there are not enough resources to support this ... I mean the vehicles and the staff (resources). Hospital staff will visit patients’ homes in some cases, such as aged people and other kinds of chronic patients, but not patients with rheumatoid arthritis. They also think rheumatoid arthritis is rare, and patients can get follow up treatment at the hospital. They think that patients can come to see them, so why do they have to go to their homes. It’s not necessary to visit their homes. It’s a waste of time. And not only that, but we don’t have enough staff to do it.*

**Communicating directly with patients**

*I talked with the patients more than their relatives. But in cases where it was difficult to talk with the patients, I talked with their relatives. I didn’t want to talk a lot with relatives, because they only sometimes tell the patients.*

**Anne’s experience**

**Background**

Anne was a 27 year old, registered nurse. She graduated with a Bachelor degree of nursing. She had not trained in specific orthopaedic care. Since she had experience with patients with rheumatoid arthritis in an orthopaedic ward for seven years, and she saw more female patients with rheumatoid arthritis than male patients, who were in the over 50 age group. In her opinion, she saw more female patients, because females encountered more risk factors associated with rheumatoid arthritis, such as self-care and
food intake. Besides joint pain, she observed that patients with rheumatoid arthritis had joint swelling in their large joints, such as wrists and shoulders that were often febrile, and could not do things for themselves while they were in pain.

Anne said her role to manage pain included giving medications as prescription. She noticed that the doctors gave colchicine tablets and tramal injection to patients with rheumatoid arthritis. She said paracetamol was not good enough to relieve their pain. She covered the patients’ bodies with the blankets, and told them to wear thick clothes to keep their joints warm. She said that patients should be in a well ventilated, but not cold place. She said that she applied hot compresses when patients had pain, but she had to be careful about the heat. In terms of giving advice, she advised patients about rest, limited activities, and using their joints effectively. She suggested patients ask their relatives to do things for them when they were in pain. She encouraged patients not be anxious or stressed, because they would feel better if they took the medication. Furthermore, she directed the nutrition staff to prepare a low uric acid and low salt diet for patients. Lastly, she informed the doctors if patients did not get better after she had followed their orders.

Although rheumatoid arthritis was rare, it was not difficult for her to give appropriate nursing care. She said nurses could learn from previous patients. She felt pity for patients with rheumatoid arthritis, but she wondered why they ignored advice and often relapsed on return to home. She said that there were many kinds of relatives, and the biggest problems were with the patients who had no relatives to take care of them. Some of their relatives thought that the patients could take care of themselves. She still had conflicting ideas about giving advice about resting and walking. She had no idea about the benefits of herb treatments. She only knew that there were steroids available in a bolus, which was in a ready-to-use pack.

Anne’s experience: Emerging codes

The codes emerging from Anne’s account were: noticing more females have rheumatoid arthritis; noticing joint pain and swelling; noticing pain causing immobility; noticing
fever; recognising the influence of food and alcohol; ignoring advice; giving analgesics; advising rest; keeping the joints warm; informing the doctor; arranging dietary requirements; applying hot compresses; relapsing on return to home; learning from previous patients’ care; advising how to use joints effectively; advising on limiting activities; recognising some patients have no relatives to help; avoiding coldness; conflicting advice on resting or walking; noticing the benefits of herb treatments; and encouraging them not to be stressed or anxious.

Noticing more females have rheumatoid arthritis

I saw more female than male patients. They were in the over 50 age group. In my opinion, I saw more female patients, because females encounter more risk factors associated with rheumatoid arthritis than males, such as self-care and food intake.

Noticing joint pain and swelling

Most of them were admitted with pain. They had pain and swelling in their big joints, such as their wrists and shoulders. Some cases had pain in their knuckles too ... If they had a little pain, they didn’t go to the hospital. Most of them came here, because their medication wasn’t relieving their pain. Many cases were admitted with severe pain, and they got better after they had injections for three days.

Noticing pain causing immobility

They couldn’t flex and extend their body parts, because there was a lot of cartilage in their big joints, and uric acid would accumulate in the big joints before the small joints. This was the reason that some patients couldn’t walk. Their symptoms meant they already had inflammation in their joints ... This movement was very poor. One couldn’t walk. She had to lie down and have absolute bed rest. Some patients couldn’t pick the spoon up when they wanted to eat, because they were in pain as soon as they moved their arms. In these cases the doctors ordered them to rest and take medication and have injections ... Yes (I pitied them), because they couldn’t do things for themselves, and they suffered when they had pain. They suffered more if they moved. Some patients couldn’t even carry a glass. Some had inflammation in every joint. That was the most
painful. They worried about what they would do if they had no relatives to take care of them when they needed to eat or move their bodies.

**Noticing fever**

*They had fever and couldn’t do things for themselves.*

**Recognising the influence of food and alcohol**

*The first thing that I thought about patients with rheumatoid arthritis was what they consumed. It’s an important factor in acquiring rheumatoid arthritis. It’s the same factor in patients with gout. They like to have high uric acid diets, such as offal and the tops of some vegetables. Drinking alcohol and smoking are the secondary factors not the main factors in leading to rheumatoid arthritis. These patients knew it was not good for them, but they couldn’t control their desires. There were many patients out in the community. They had the opportunity to select their foods and to do the right things, but they didn’t ... I also wondered why they did these things in spite of getting the right advice. If they took the advice, they got better ... There were some factors that could increase the risk of having rheumatoid arthritis, such as smoking and drinking in males. Alcohol and nicotine can affect the joints. I know from the textbook that these things lead to more crystal salt build up.*

**Ignoring advice**

*Many patients still had pain, because they didn’t believe in the advice or do what we advised. They didn’t take their medication continually. The doctors told me patients with rheumatoid arthritis should take their medication for at least six months. They often stopped taking the medication when they got better. They didn’t try to avoid things that were harmful such as the cold weather. Most of them didn’t like the hot weather. They loved to keep cool and that was the reason they got pain again ... Most of them knew the right things to do, but they didn’t do them ... They knew what they ought to do, but they didn’t it.*
Giving analgesics

They (doctors) gave them oral medication first, such as colchisine. It was the primary medication for rheumatoid arthritis and gout. There was another one, but I’ve forgotten its name. This medication irritated the stomach. They had to take antacid with it. Paracetamol didn’t relieve their pain ... Colchisine has the effect of relieving pain too. It’s an anti-inflammatory drug ... The doctors gave them Tramal injections. They didn’t give colchisine injections, because that would result in an overdose. There were some cases where they gave colchisine injections with the stat dose and told the patients to follow up later. This medication was an oil. One injection could control pain for one month. The doctors didn’t give it to the patients, because it was very expensive ... They didn’t give the patients any balm. They said not to massage any joints in patients with rheumatoid arthritis. They said there was crystal salt caught the joints which made them stiff. If they were massaged, the crystal salt would be broken up, and would get into the blood circulation. This salt would cause obstructions there and make them worse.

Advising rest

They also said the patients should rest. Taking paracetamol was good for when they had a little pain, but it couldn’t relieve severe pain ... No (there weren’t any other treatments besides the ones I’ve told you). The doctors didn’t allow the patients to get treatment from the physical therapy department, because they did range of motion (ROM) activities and that made their joints more inflamed. They emphasised to the patients that they should rest and take medication.

Keeping the joints warm

I kept their joints warm when they had pain. For example, if they had pain in their arms and body, I covered them with a blanket and told them to wear thick clothes. I advised them that they might feel hot, but that they had to be patient. I made sure they weren’t put near a window. They could get pain again if they were in a cold breeze.

Informing the doctor

I informed the doctors if the patients didn’t get better after I’d followed their orders.
Arranging dietary requirements
Furthermore, I rang the nutrition staff to prepare a low uric acid and low salt diet for them. The doctors weren’t interested in their diet, but I believed it had some effect on the body’s system and the joints especially in terms of salt.

Applying hot compresses
I also applied hot compresses when they had pain. But we had to be careful about the heat. It should be at a suitable temperature, not too high.

Relapsing on return to home
It was all right when they were admitted and stayed here. We could control the situation and handle things. They didn’t do what we’d advised when they got back home. They thought the doctors had cured their illness completely. Some patients didn’t come back for follow up treatment. The problems occurred when they lost their medication and got pain. They had to take medication continuously ... There is a socio-medical department whose staff visit the patients’ homes, but I don’t know how many responsibilities they have. They send the doctors to treat the patients at home in those cases where there are no relatives to bring the patients to the hospital. They also visit homes in severe cases. I’m not sure whether they visit patients with rheumatoid arthritis at home or not. They usually visit in medical cases that are more severe ... Many patients who didn’t attend for follow up treatment said they had no money for the cure.

Learning from previous patients’ care
I thought that if we’d seen cases before, we knew how to give nursing care. There was no problem in my opinion.

Advising how to use joints effectively
I advised them about self-care and how to use their joints effectively. For example, they should stop using the arm on the side where they had pain. They could use it a little after they got better.
**Advising on limiting activities**

*They had to limit their activities and ask for some help from their relatives.*

**Recognising some patients have no relatives to help**

*There were many kinds of relatives. The biggest problems were with the patients, who had no relatives to take care of them. Their relatives thought that they could take care of themselves. Then there were those who had some relatives to look after them, but these relatives weren’t interested in them very much. Sometimes I demonstrated to them what to do for the patients, but they often didn’t do as I advised. We couldn’t advise every patient and every relative. We didn’t advise them if they already knew what to do, but we did advise those patients whose pain increased. Most of the relatives did what the nurses advised. There were only a few of them that didn’t.*

**Avoiding coldness**

*I think it affected a lot of patients with rheumatoid arthritis. They should live in a well ventilated place. But not in a cold place. They might get pain and inflammation again. I thought that nursing care for rheumatoid arthritis was the same as for gout patients.*

**Conflicting advice on resting or walking**

*I don’t think so (that there are any other ways to relieve pain other than what I’ve told you) ... Sometimes we wanted the patients to walk a little when they got better, but we worried that that might interfere with their treatment. We were concerned about the doctors wanting them to rest, but the nurses wanting them to walk a little. The doctors often wanted them to rest to decrease the inflammation. Sometimes we felt frustrated, because nurses and patients wanted to walk a little and because the patients were able to. Everything depended on the doctors’ orders ... The patients often asked us what they could do at different times. If they didn’t ask us, we told them what they could do. We let them do what they could. Most of the doctors let us look after them and do as we thought appropriate. If we assessed them as getting better, we let them do what they could. We restricted their activities if they got worse.*
Noticing the benefits of herb treatments
I have no ideas about this (herb treatment). Most of the patients already knew about such things. One patient used oil for massage. In relation to herbs, they knew they had to use some herbs that were regraded as hot or cold herbs for each situation. One used camphor and another used some others. They put these mixed herbs into cloths. They said it made them feel hotter and relieved their pain. It was like a compress. I didn’t advise them to try massage, because they became worse if they did ... I saw some patients who took bolus with honey. Some patients took bolus in the ready-to-use packs. I believed that there were steroids in the bolus. They made them feel better, but they got worse if they stopped taking them.

Encouraging them not be stressed or anxious
I encouraged them not be anxious or stressed ... I asked them if they were stressed or anxious. If they said yes, I told them not to worry. They would get better if they took the medication that the doctors had given them, and it would take time to get better. In fact, we didn’t really know if they were anxious or not, but we had to support all of them ... No (I didn’t see any patients who complained or were disheartened). I always saw the patients that had had pain for a long time, and some of these patients were not admitted here, but went to see the doctors at the clinic.

Khan’s experience

Background
Khan was 31 years old. She was a registered nurse, who had experience with orthopaedic patients for 10 years. Khan met only female patients had rheumatoid arthritis, who were mainly aged over 40, although she met a few female patients, who were younger. She said that they had pain in many of their joints, especially the large joints, such as elbows and knees. Some patients looked pale, but she was not sure if this was related to the rheumatoid arthritis. Some patients had joint deformity, and most of them were admitted with pain. She noticed that younger patients seemed to have less
pain. Khan knew that the treatments for arthritic pain were using medication and surgery. Some patients had specific treatment, such as using hot melted paraffin. She advised patients to avoid moving or walking while they had pain, but she rarely advised them about diet, because she thought there were few direct effects from some kinds of high uric acid foods.

She sympathised with patients, because rheumatoid arthritis was a disease with an unknown cause, and they had to get treatment for the rest of their lives. When she first met patients with rheumatoid arthritis, they worried about their changed body images. Some patients expressed their fears and asked why they had rheumatoid arthritis. She pitied them, and hoped that they would learn to look after themselves as best as they could. Her preferred treatment was for them to continue taking medication rather than herbs for pain relief. Khan asserted that relatives should accept their loved ones’ illness and that the patients had real pain. She realised that relatives were carers at home, and that nursing care involved giving medication and advice. She said that another person who could help nurses to manage pain was the physical therapist. Khan also talked about a follow up system in her department, in which the staff checked when the patients were to be discharged, and when their follow up treatment at the hospital was due. The day before they were due to be discharged, staff would prepare their OPD cards and leave them in front of the examination room. They sent the letters to remind patients if they did not come to follow up treatment. Khan referred to the newest team in the hospital, the primary care unit, which would visit the patients at home in the areas for which they had responsibility. She was concerned about problems from the patients’ lack of understanding in that they did not take their medication continually, the lack of cooperation between patients and relatives, and patients having progressing symptoms although they were receiving treatment.

Khan’s experience: Emerging codes

The codes emerging from Khan’s account were: noticing more females have rheumatoid arthritis; acknowledging patients’ pain; noticing joint deformity; acknowledging patients’ pallor; noticing younger patients seem to have less pain; sympathising; using
medication and surgery for pain relief; advising about mobility; noticing patients’ feelings related to pain; agreeing that physical therapists should be involved in managing pain; advising rarely about diet; using hot melted paraffin; preferring medications to herbs for pain relief; recognising some patients do not take their medications; believing nursing care involves giving medications and advice; asserting that relatives believe the patient has pain; recognising relatives are carers at home; using follow up system in the department; and recommending a physical therapy course to relieve pain.

**Noticing more females have rheumatoid arthritis**

*I saw more female patients than male. Their ages were over 40. There were a few female patients who were younger. I’ve never in all my experience seen male patients with rheumatoid arthritis.*

**Acknowledging patients’ pain**

*They had pain in many of their joints, especially the big joints, such as the elbows and knees. Some patients had pain in every joint. I remember one case where the patient had pain in every joint … Most of them were admitted with pain more than other symptoms, except for the one case that I’ve just told you about. She had a knee operation … Most of them (the patients who are younger than 60 years old) had severe pain when they were first admitted. They got better after taking medication and weren’t readmitted. I’m not sure of the real reason for this. The doctors probably gave them the same medication as they had when they were here to take back home.*

**Noticing joint deformity**

*She had deformity in her knuckles and she also had to have a knee operation, because they’d degenerated. I’m not sure how old she was, but she was an aged person. I often found that many cases had knuckle deformity.*

**Acknowledging patients’ pallor**

*I found that some patients looked pale, but I’m not sure if this was related to the rheumatoid arthritis or not.*
Noticing younger patients seem to have less pain

I don’t think so (that there are any differences in the management of pain for aged patients and for adult patients). In cases where the patients were younger, they had a little bit of pain in their joints. They got better after taking medication. Many patients understood their illness, what the causes were, and how to relieve the pain. I had to give more support in the aged cases ... Their main occupations seem to involve light jobs. Some are housewives, but they’ve had pain for a long time.

Sympathising

I sympathised with them, because rheumatoid arthritis is a disease with an unknown cause. It’s a chronic illness. They have to get treatment for the rest of their lives. I pitied them. I wished that they would look after themselves as best they could. They needed to continue taking medication and restrict their diet to relieve their pain.

Using medication and surgery for pain relief

They usually treated them with antirheumatic drugs. If my memory serves me correctly, one of them was chloroquine. Some patients got prednisolone, but the doctors didn’t give them this medication very much ... They gave tramal injections for PRN the first time that patients with rheumatoid arthritis had severe pain. Some doctors performed a total knee operation for these patients who had pain and couldn’t walk. Besides these two treatments, I didn’t see them give other treatments or perform other operations on patients with rheumatoid arthritis who had pain in other parts of their bodies ... I often gave them medication as ordered by the doctors, gave them some PRN medication, advised them to rest as much as they could, and supported them psychologically.

Advising about mobility

I only advised them that they should avoid moving or walking while they had pain (laughed). They should rest in their beds as much as they could ... In the case that had the knee operation, she wouldn’t walk although the doctor had given her a guarantee that she could. She worried that she would be in pain again when she walked ... I talked with her and her relatives. She still didn’t believe me and wouldn’t walk. I had to encourage her to go to the physical therapy (PT) room too ... I informed the doctor
about this problem. After he knew, he gave her a guarantee again that she could walk. He said to her “Come on please, get up from your bed. We’ll teach you how to walk well without pain.” I felt that she had more confidence after we taught her.

Noticing patients’ feelings related to pain
From when I first met them, they worried about their changed body images. Some cases expressed their fears and asked why they had got rheumatoid arthritis. Some cases understood it and accepted that they would have to live with rheumatoid arthritis ... They didn’t talk much, but I could tell from their faces. They looked miserable when they had pain, because they couldn’t understand why they were in pain and why they got rheumatoid arthritis.

Agreeing that physical therapists should be involved in managing pain
Yes (physical therapists should be involved in managing pain too). Most of them will teach both the patients and their relatives. They want the relatives to accompany the patients to see the methods that they use, and they hope that they can care for the patients in the right way, especially in regard to walking, and how to use crutches, and how to take their weight on their feet. Some patients prefer to sleep rather than walk, although we give them a lot of advice against this.

Advising rarely about diet
I know that there are some kinds of high uric acid foods. I rarely advised them about diet, because I think that there are few direct effects on patients. I sometimes forgot to advise them too (laughed). Most of them usually knew about this, because they’d previously got advice from the doctor. So they were careful when they had anything to eat.

Using hot melted paraffin
Yes, I saw them (physical therapists) use hot melted paraffin with the patients. The patients soaked their hands in it for a while. Not every patient got this treatment. It depended on the doctor’s orders.
Preferring medications to herbs for pain relief

I think they (herbs and compresses) would be good, but I’m not sure that they can relieve the pain 100% or even make the patients feel better. In my experience, patients got better after taking medication. Doctors gave them more medication and supportive treatment. Nurses also gave supportive nursing care.

Recognising some patients do not take their medications

The degree of the problems and obstacles depends on the patients’ understanding and the cooperation between patients and relatives. Some patients face problems, because they don’t take medication continually. They don’t believe the doctors. Many patients don’t understand that they have a chronic disease and have to take medication continually. They don’t think that they might become worse if they don’t take the medication. I noticed that most of them still had symptoms although they received treatment. This means that treatment alone won’t stop pain or other symptoms. Their symptoms will progress continually ... I didn’t talk with them about this (why they still had pain and why they didn’t have a good prognosis). They may have talked with the doctors. I thought that the doctors had already explained to them what the causes were and why they got it. In my opinion, they got more pain, because their joints degenerated steadily. Most of them accepted this fact. At this time you don’t see patients with rheumatoid arthritis, because it’s so hot. But you see them in winter.

Believing nursing care involves giving medications and advice

It’s my view that there is little nursing care that can relieve pain, except in giving medication and advising ... People think that nurses don’t look after patients with rheumatoid arthritis enough, because they see what nurses do for these patients. Most of us don’t pay a lot of attention to them, because we think that patients with rheumatoid arthritis are not severe cases. They can do things by themselves. They will be better after taking medication. We only give them medication to relieve the pain and then health education when they are discharged. We pay more attention to other kinds of patients and elderly patients with rheumatoid arthritis, because they usually have severe pain and need surgery as well ... In the ward, I think doctors and nurses are the primary carers in managing pain. I’ve seen situations where patients have wanted injections
while they had pain, but there was no order from doctors for this. I wish doctors would consider this, and give the injection and the oral medication together. It’s inconvenient to have to ring them and ask for the injections when patients have pain after regular hours ... As for nurses, they should pay more attention to patients with rheumatoid arthritis, especially when they have pain. Nurses should take care of them, give them medication, and talk with them about their illness. I know it’s not easy, because rheumatoid arthritis is not like a bone fracture where patients can see immediate results after they get treatment. It takes a longer time to get better. It’s a chronic illness, and they don’t know when they’ll be in pain again.

Asserting that relatives believe the patient has pain
Regarding their relatives, they should accept their loved one’s illness and that the patient has real pain; they are not just being a nuisance or pretending. They should pay close attention to the patients.

Recognising relatives are carers at home
I think it would be their relatives (who care for patients at home). I have no idea about other persons or health agencies. Some orthopaedic staff used to visit paralysis cases at home. It’s good if they have a chance to visit patients with rheumatoid arthritis, and ask them about their illness, and tell them about how best to care for themselves, and how their caregivers can assist.

Using a follow up system in the department
Our staff will check when the patients were discharged, and when their follow up treatment at the hospital is due. The day before they’re due, staff will prepare their OPD cards and leave them in front of the examining room. If the patients don’t come for follow up treatment, staff will send them a letter to remind them. As home visiting, I’m not sure that all the orthopaedic staff are members of the home visiting team. There is a hospital team to visit the patients at home. It’s called the primary care unit (PCU). But this team will only visit patients’ homes in the areas that they have responsibility for.
**Recommending PT course to relieve pain**

(Other ways of relieving pain) would be taking the PT course. In my experience, no patients had treatment from the PT department. Most of them only got medication. I’m not sure why the doctors didn’t order them to go for this treatment. They may want patients to restrict their movement so that the inflammation decreases ... They gave us the records that they prepare for the patients, and they assess patients before and after they’ve had PT treatment. I don’t know anymore details about what they do. However, the doctors make the decisions about how to treat each patient with rheumatoid arthritis.

**Luck’s experience**

**Background**

Luck was the head nurse of an orthopaedic ward. She was a 46 years old mother, who graduated from a Bachelor degree in nursing. She had also trained in specific nursing care for orthopaedic patients for three months. After 23 years experience with orthopaedic patients, she was not sure about the statistics for Thailand regarding which gender was more prone to rheumatoid arthritis. In her practice, she saw more female patients than male. She said the most important symptom is pain. She noticed most patients had pain when the weather was cold, and some people had pain when they were exposed to the breeze from electric fans. She did not know the best way to help them, because as the pain was related to the weather, it was difficult to help. She recognised that the doctors controlled the treatment. They gave the patients antirheumatic drugs, and sometimes they gave paracetamol to these patients. She said there was no one to help nurses to manage pain in her ward, and that there was no critical pathway for managing pain for health care team.

She said it was easy to forget some of the nursing care, because cases of rheumatoid arthritis were rare. She sometimes rushed to read a textbook to make sure she was giving patients the right nursing care when they were admitted. The nursing care that she
usually gave to the patients included keeping them warm and arranging a suitable surrounding for them. She gave patients medication as the doctors ordered. She assisted them when they wanted help, especially when they were unable to help themselves. She left dietary advice to the doctors. Some doctors prohibited patients from drinking beer and having preservatives in their diet. Some doctors said diet was not related to rheumatoid arthritis. In her opinion, she thought the patients should not have a lot of certain foods, such as the top of some vegetables, cucumber, mushroom, and Cha-om. She was concerned that was difficult for some patients, who could not select certain foods, because of their economic status and the other social issues. She also gave them a health care brochure when they were discharged. She encouraged them to exercise after pain decreased, and gave them mental support. She brought some religious material into work to talk to the patients.

Luck thought that there were problems about treatment. The doctors needed to take time for a correct diagnosis. She recognised the need for cooperation in health team between doctors and nurses in how to care best for patients with rheumatoid arthritis. She recognised that patients knew how to care themselves, but she still worried about their beliefs, especially when they used herbal treatments with medications, and visited side effects from herbs. She also was concerned when patients did not follow up their treatment.

Luck’s experience: Emerging codes

The codes emerging from Luck’s account were: noticing more females have rheumatoid arthritis; noticing cold weather is related to pain; not knowing the best way to relieve pain; keeping warm; recognising the doctors’ control of medications; giving psychological support; assisting to move; giving medication; bringing some religious material to talk to the patients; waiting for the correct diagnosis; recognising rheumatoid arthritis care is rare; recognising the need for cooperation in health team; recognising the need for exercise after pain decreases; advising on food choices; giving health care brochure; recognising patients with rheumatoid arthritis know how to care themselves;
recognising patients’ beliefs about herbal treatment are related to pain; and noticing non-compliance to treatment in patients.

Noticing more females have rheumatoid arthritis
I’m not sure, because I’ve forgotten the statistics report for Thailand regarding which gender was more prone to rheumatoid arthritis. I personally saw more female patients than male.

Noticing cold weather is related to pain
Pain. There were many types of pain. It depended on the surroundings and the weather. Most of them had pain when the weather was cold. Some cases had pain when they were exposed to the breeze from electric fans.

Not knowing the best way to relieve pain
(Thought) I didn’t know the best way to help them, because the pain was related to the weather. It was difficult to help. If they had pain and no alkalsising, they knew how to relieve their pain. But most of them had to take medication to relieve the pain.

Keeping warm
Other things could help them a little while they were in pain. For example, we could arrange suitable surroundings for them. We could keep them warm. I knew I couldn’t help them any more than that, but it’s better than not being able to do anything for them.

Recognising the doctors’ control of medications
Doctors give them specific medication. These are called antirheumatic drugs, for example colchisine. It’s important to recognise the difference between rheumatoid arthritis and gout. Doctors spend a lot of time giving patients different medications to try, and then follow them up continually till they can be sure. If they’ve really got rheumatoid arthritis, doctors give them antirheumatic drugs. Many patients don’t follow up with the treatment. They treat themselves by buying the medication from the chemist ... They gave antirheumatic drugs and sometimes they gave paracetamol to these patients. Nurses had to take care with this and give them the medication on time ... Most
of them gave antirheumatic drugs to the patients. The patients got better after they took this medication for a while.

**Giving psychological support**

Pain is the basis of their suffering. It makes them anxious and uncomfortable. If they were in pain, I gave them psychological support, gave them religious books or other books that they were interested in. On the other hand, they had to make up their minds to be strong willed too. They should know about their condition.

**Assisting to move**

I assisted them when they wanted help especially with things they couldn’t do by themselves, such as helping them when they couldn’t walk properly or arranging comfortable surroundings for them.

**Giving medication**

I gave them medication as the doctors’ ordered.

**Bringing some religious material to talk to the patients**

I used many styles of support (laughed), but I had to assess them first. For example, I had to know what their religion or beliefs were, because I would bring them some religious material that they might be interested in and talk with them about it. Talking with them about the things that they were interested in helped me support them in appropriate ways. I could get to know what methods they used to relieve their pain, and help them to build the mental attitude to accept their illness. If they couldn’t, I would find other ways to motivate them and encourage them to have the right mental attitude. Everything that I did depended on personal differences.

**Waiting for the correct diagnosis**

I think there were problems about treatment, because at the beginning it’s not easy to detect rheumatoid arthritis from gout. Doctors had to give the patients medication to try. It took time to know what the real disease was and what medication was suitable for the patient. Everything would be all right after the patient got the right medication. Their
prognosis would be good and their pain would lessen ... We (nurses) had a few problems while the doctors were trying to establish whether the disease was rheumatoid arthritis or gout. We had to wait for the right information from them. We couldn’t give specific health education to the patients, so we gave them symptomatic nursing care during that time ... Yes (I think that the main point is in waiting for the correct diagnosis), whether it’s rheumatoid arthritis or gout. But that’s just from my experience. Doctors have told me that it takes a long time to detect the disease. Patients have to follow up continually till the doctors can tell them what their diseases are. Sometimes doctors can’t detect the disease although they get the results of the laboratory examination, and they give the patients other treatments.

**Recognising rheumatoid arthritis care is rare**

Yes (the fact that rheumatoid arthritis is rare had any effect on the nursing care), a little, because rheumatoid arthritis is rare we hardly saw patients admitted to the ward. So it was easy to forget some of the nursing care. When patients with rheumatoid arthritis were admitted, we rushed to read the textbook to make sure we were giving them the right nursing care (laughed).

**Recognising the need for cooperation in health team**

It would be good if doctors and nurses could plan together about how to care for them. Doctors have to plan what they will do. There should be cooperation between doctors and nurses. That would result in better care for the patients ... I’ve never tried them (compresses and herbs). Generally, we have to consult with the doctors who treated the patients before. That’s the easiest thing to do. We have to ask what methods nurses can use. Nurses can’t do anything independently. We have to talk with the doctors before we do anything. Doctors and nurses plan together about what we can do now and what we’ll do next. We want the patients to get the best care. Doctors are free to do more for patients than nurses, and they have many ways to relieve pain and treat the patients. Nurses can’t just guess which treatment the patients need. It depends on each doctor. As I said nurses and doctors should plan together.
Recognising the need for exercise after pain decreases

They don’t have pain all the time. If I want them to exercise, I let them do it when they are ready to. I don’t force them to exercise while they’re in pain. I encourage them to do it when they’re not in pain, because exercise can inhibit joint stiffness. In my opinion, exercise doesn’t help patients much. It can only extend the time they have without joint stiffness … I teach them one by one, because it’s ineffective to teach in a big group.

Advising on food choices

It’s up to the doctors. Some doctors prohibited them from drinking beer and having preservative in their diet. Some doctors say that it isn’t related to rheumatoid arthritis. It’s an abnormality in each patient. But I think patients with rheumatoid arthritis should not have a lot of some foods, such as the tops of some vegetables, cucumber, mushroom, and cha-om. It’s rather difficult for the patients to select the foods. There are many kinds of foods that are not suitable for patients with rheumatoid arthritis. Nurses should advise them … Yes, it’s very difficult (to advise patients with rheumatoid arthritis and pain). Some patients can’t select certain foods, because of their economic status and other social issues. Therefore, they can’t take care of themselves very well in regards to the diet that they should have.

Giving health care brochure

I give them a health care brochure when they are discharged. There’s a lot of information for the patients when they’re at home, such as which foods they can have and how to care for themselves. They have to be disciplined and pay attention to their health, so they don’t get pain.

Recognising patients with rheumatoid arthritis know how to care themselves

Yes (there’s no health agency to care for patients with rheumatoid arthritis after they’re discharged). As I’ve said, if they’re careful, they can care for themselves. They’re well aware of what foods they can or can’t have. They’re always careful.
Recognising patients’ beliefs about herbal treatment are related to pain

In terms of their beliefs, some patients not only get treatment from us, but also treat themselves with herbs. They used to tell me that they took boiled herbs and that that had the effect of relieving the pain. They learnt from advertisements that these herbs could heal joint pain, gout, and arthritis. Some patients misunderstood these words. They thought that they were the same things. They had joint pain, so they assumed that these boiled herbs could treat their illness. Some patients sought traditional treatment too, because they wanted their pain to disappear ... They may know, but not understand. You know...beliefs...it depends on their beliefs. They get a lot of information from the nurses, but they still believe in the same things. Some patients listen to other people who’ve maybe had rheumatoid arthritis or another illness. You see...it’s the Thai nature (laughed). Some educated people also get other treatment that’s not the right sort of treatment.

Noticing non-compliance to treatment in patients

Some patients don’t follow up their treatment. They change their treatment from this way to other ways, such as traditional treatment. They’re not patient enough to continue with the hospital treatment only. They say that they can’t see the results immediately. Even though we advise them that rheumatoid arthritis is a chronic illness they still hope to be healthy people, and that the rheumatoid arthritis will disappear in the future. They find out about other methods for relieving pain. Some patients are cheated. Many patients use decoctions (boiled herbs) in the form of a bolus. These are steroids. They like this, because they don’t have pain immediately after they’ve used it. They’re fine. But they don’t know that there are many side effects from steroids. When they return to get treatment from the hospital, they often don’t get well and they think that our treatment is failing them. They have to buy some steroid from the chemist and take it again when they have severe pain.
Meaw’s experience

Background

Meaw was a 31 years old, registered nurse, who had recently married. She had a nursing degree, but she had not trained in a specific orthopaedic nursing course. She had 10 years experience with orthopaedic patients. She saw more female patients with rheumatoid arthritis than males, but there were not many in total, who were aged from 20 to 30 upwards. She said that most of them were admitted with pain, and had swelling in every joint, especially in the small joints. Some patients could not walk, because of severe pain. She thought that there were many factors causing pain, but she was not sure that she would call them problems or obstacles. Factors included the cold weather, the patients’ state of mind such as being disheartened, and the duration of their suffering. She noticed that doctors controlled the treatment mainly with medication.

Meaw felt pity for patients, because rheumatoid arthritis was a disease that they had have for the rest of their lives. Therefore, she assisted them to rest and helped them to use walkers. She gave advice about the best position for sleeping by using the pillows to support where the painful joints. She emphasised that they should avoid having a high uric acid diet, because uric acid accumulated in joints. She also used discharge planning, which her Head of Ward introduced, to manage pain. She explained that discharge planning was as a guide to advise patients about important information when they were admitted until they were discharged. The advice in the discharge planning program included diet, follow up treatment, self-care, rest, and the avoidance of physical work. Besides this, Meaw thought hot compresses could relieve pain, and nurses should give psychological support to patients. Meaw did not recommend special treatment at the occupational therapy or physical therapy, because she thought it could cause more pain.

Meaw noticed problems in management pain from patients’ and nurses’ perspectives. She sometimes felt that Thai people did not really care about their health and that nurses did a routine job, rather than get involved with patients. She thought nursing care of
rheumatoid arthritis was inadequate, because there should be other things that nurses
could do, such as to know which exercises were good for patients. She was unsure about
herbs and breathing exercise to relieve pain. She said because some patients believed in
sin and karma, they did not pay attention to the advice nurses gave. She also thought that
language was important in communicating with, or advising patients. However, she
recommended patients should have the follow up treatment at the hospital. She talked
about the primary care unit (PCU) which was the new approach to team care in the
hospital. She said this team had just commenced and had started to visit people at home.
She said it was very important to give primary care, but we neglected this in the past.

**Meaw’s experience: Emerging codes**

The codes emerging from Meaw’s account were: noticing more female patients have
pain; noticing joint pain and swelling; noticing immobility; feeling pity; noticing the
doctors’ treatment is medications; recognising medication is the main treatment;
perceiving weather can affect to pain; advising the best position for sleeping; giving
psychological support; thinking hot compresses can relieve pain; assisting rest;
facilitating walking; emphasising the need to avoid some food; waiting for doctors to
confirm a diagnosis; being unsure about herbs or breathing exercises to relieve pain;
talking about the variables that cause pain; noticing disheartened feeling can cause pain;
noticing cold weather can cause pain; recognising lack of opportunity to see patients
with rheumatoid arthritis; nursing care of rheumatoid arthritis is rare; being unsure of the
use of exercise; perceiving nursing care was not enough; recognising language
difficulties; feeling special treatment at the OT and PT can make more pain;
recommending follow up system by the hospital; giving health education; using
discharge planning to manage pain; and noticing problems from patients’ and nurses’
perspectives.

**Noticing more female patients have pain**

*I saw more females than males, but there were not many. They were aged from 20 to 30 up. Last year I saw one case who was older than 20.*
Noticing joint pain and swelling

Most of them were admitted with pain. They were in a lot of pain and had swelling in every joint, especially in the small joints. They had a lot of pain in the knuckles, you could see that clearly ... I didn’t see how badly the big joints were affected. There are other symptoms and complications with rheumatoid arthritis, but they are not easy to see.

Noticing immobility

One patient had so much pain that she couldn’t walk.

Feeling pity

I pitied them, because rheumatoid arthritis is a disease that they’d have for the rest of their lives. They had to take the medication. When they had pain, they couldn’t do anything by themselves. They had to lie down or were admitted, so they could rest. I explained to them what was happening to them. There was no cure, and that I couldn’t help them any more than by what I was doing. I would encourage them to get some rest and give them psychological support.

Noticing the doctors’ treatment is medications

Most of them gave non-steroidal anti-inflammatory drugs (NSAIDs) to these patients ... Sometimes they gave the patients injections, such as Tramal. It was the PRN dose or given when the patients had acute pain. First, the doctors gave them a low dose medication to take. If patients were still in pain, they gave a higher dose to them. Patients had to take NSAIDs at all times, although the doctors gave them PRN medication as well. Last year, I saw two patients with rheumatoid arthritis who were back home and always took their medication, but their pain increased. They were readmitted. Doctors gave a revised dose to them. It was higher than the old one. The patients were fine after they took it ... One of them was Burmese and she couldn’t speak Thai, so I didn’t talk with her. The other one told me that she took the medication that the doctor gave her continually, but the pain increased with no known cause. She had pain although she had a regular diet ... They didn’t give either of them (any balm or ointment) to the patients. They gave only analgesic drugs and NSAIDs ... Most of the
doctors usually gave them medication. They didn’t consult us. When they did their rounds, they asked about patients’ symptoms and gave them a different dose or medication. The times I did rounds with them, they didn’t advise patients about exercise. Sometimes I also forgot to ask them what I should do later ... They (the doctors) advised them a bit. They usually advised them about the medication and the results to expect after the patients had taken the medication. Sometimes they suggested that it would take time to be cured and to get better. They rarely advised them about diet and exercise.

**Recognising medication is the main treatment**

I think that only medication can relieve their pain. When rheumatoid arthritis becomes worse, the pain will increase. Suggestions about their diet can help them a little. But the main treatment is giving medication. So patients should take only the medication that the doctors give them ... At the same time, we gave them NSAIDs or PRN medication too ... Yes (I gave the patients medication when they were in pain), I gave it to them routinely. If they had more pain, I gave injections and left them to get some rest.

**Perceiving weather can affect to pain**

I think it (cold) can, because some patients with rheumatoid arthritis were fine and had no more pain during the day. They could take a nap during the day as well. But at night and when the weather started to get cold, they had pain immediately. Most of them had more pain at night.

**Advising the best position for sleeping**

We talked with them and advised them about the best position to sleep in. We used pillows to support their hands or legs depending on where the pain was ... Helping them into comfortable positions when they are in pain ... I know that this way isn’t very effective in cases where the pain is severe and there is swelling. I have no other criteria, but I will give you examples. If they had pain and swelling in their hands, I used thick blankets or pillows to lift their hands higher. If they wanted to lie on one side, I would support them with a bolster, put the pillow under their knees and make their knees a little flexed. I think it helped them. At the same time, I gave them analgesic drugs as well.
Giving psychological support

I’ll tell you some examples. If they were depressed, I said to them, “You’ve already had rheumatoid arthritis for a long time. You need to spend more time being cured. Now, the medication that the doctor has given you is enough... Do you want to try a different position to sleep in? Please tell me if you have more pain, I can give you both the tablets and the injections that the doctor has ordered for you.” ... I saw a few of them (who were disheartened), but they were not too disheartened. They complained about why the rheumatoid arthritis didn’t disappear and why the pain was still there. It made them unable to work ... Many patients also complained, but not too much. I thought that they were Thai people who believed in sin, so it was not right to talk about it or complain a lot. Sometimes I told them that there were many patients who were much worse off than they were, such as patients who were paralysed. They were lucky, because they were not in pain all the time. They could be cured and their pain would ease. Since I started nursing, there has only been one patient who complained a lot ... She listened to me, talked with me, and accepted what I said. But she gave no indication about whether she was relieved or disheartened. I tried to show her some patients in the ward who were much worse off than her, and gave her some examples like the paralysed patients or those who were accident victims.

Thinking hot compress can relieve pain

I didn’t do anything other than this. I think hot compresses could have helped them, but I never used them ... I think because of the comfort. From my experience, patients got better after I gave them psychological support, arranged more comfortable positions for them, and gave them injections. So I didn’t use any other methods. In fact, if I’d given them hot compresses earlier, they would have been better off. I think this method can help a little bit.

Assisting rest

While they had pain, I wanted them to rest in their beds.
Facilitating walking
If they went to the toilet, I gave walkers to the patients, who weren’t able to walk. I advised their relatives about how to help them as they walked. In the cases that had no relatives to look after them, I would help them. Most of them used walkers to support them.

Emphasising the need to avoid some food
I didn’t suggest diet to them, but I emphasised that they should avoid having a high uric acid diet the same as gout patients, because uric acid would store in their joints.

Waiting for doctors to confirm a diagnosis
As far as I could tell there were no problems with some of the patients confusing gout and rheumatoid arthritis, because they’d met the doctors before the nurses. After they’d met the doctors, they already knew that they had a chronic illness. They knew it was rheumatoid arthritis. So they were aware that they had rheumatoid arthritis, not gout.

Being unsure about herbs or breathing exercises to relieve pain
I never tried them (herbs and breathing exercise) to relieve their pain. Perhaps these methods could help the patients. In my hospital, the doctor would give medication to the patients rather than herbs. So we lost interest in them.

Talking about the variables that cause pain
There were many factors in my opinion, but I’m not sure that I would call them problems or obstacles. They were the weather, the patients’ state of mind, and the duration of their suffering ... Sometimes I didn’t know where the disease had come from, because it occurred suddenly and I couldn’t find the cause.

Noticing disheartened feeling can cause pain
I noticed that when they were disheartened, pain increased.

Noticing cold weather can cause pain
They suffered more when the weather was cold.
Recognising lack of opportunity to see patients with rheumatoid arthritis

Another problem was that I didn’t get the opportunity to see a lot of patients with rheumatoid arthritis and pain.

Nursing care of rheumatoid arthritis is rare

Certainly (As I didn’t see rheumatoid arthritis cases frequently, this had any effects on the nursing care I gave to them). Sometimes I had to read the textbooks and try to make sense of rheumatoid arthritis again. If I didn’t do that, I couldn’t answer the patients’ questions. Because I didn’t see them frequently, I forgot a lot about the disease. I am not sure why I saw so few cases. Probably because rheumatoid arthritis is a chronic illness, and so patients can get home medication from the hospital, and go back home except for the cases that have severe pain. They were admitted to get rest and have the tablets and injections.

Being unsure of the use of exercise

I didn’t suggest it (exercise), because I was worried that it might stimulate and inflame the joints more. If they had pain and inflammation already, it could make them suffer more. On the other hand, we didn’t understand rheumatoid arthritis properly. Reading textbooks is not enough, because they only tell us about signs, symptoms, and treatments. They don’t tell us about how to exercise. It’s rather difficult to find good textbooks that tell about exercise for patients with rheumatoid arthritis, so I didn’t advise them about it.

Perceiving nursing care was not enough

I think the nursing care that I gave them was not enough. There should be other things that nurses can do. Like with exercise, I didn’t know which exercises were good for them. They didn’t exercise if they were in pain, and some didn’t do any even though they got better.

Recognising language difficulties

They still believed in sin. So some patients didn’t pay attention to the advice we gave. In the case of the Burmese patient that I told you about before, I didn’t talk with her about
her disease, because she and her relatives couldn’t speak Thai. I think that language is important in communicating with or advising the patients.

**Feeling special treatment at the OT or PT can make more pain**

I never saw them getting special treatment from these departments (OT and PT departments). Most of them were usually admitted to get bed rest and take medication or to find an effective method of pain relief. I think that above all they should get some rest while they have pain. If they take some courses in these departments, they may end up with more inflammation. When they felt better, they didn’t ask to go there, and the doctors didn’t send them to these departments either if they saw that the patients were better after taking medication. Patients with rheumatoid arthritis were usually admitted only for a short time. They were usually back home within one week.

**Recommending follow up system by the hospital**

In fact, there should be a system. It’s very important, but we neglected this in the past. Now, our hospital sets up a system to follow up many kinds of patients. We have a Rheumatology Clinic too, and I think that there is a follow up system there. Our hospital provides many departments to give health services to everybody such as the primary care unit (PCU). It has just been established.

**Giving health education**

We gave them health education before they were discharged. Now, we use discharge planning as a guide to advise them about important information. The advice includes diet, follow up treatment, self-care, rest, and the avoidance of physical work.

**Using discharge planning to manage pain**

My Head of Ward introduced it (discharge planning) here. In my ward, we use it in every case. But you’ll only find a little about discharge planning in the textbook. It’s like a form or a report. We set up the form first, and then put the important things that they have to do and to know in it. We put only the main points, but the nurses have to explain the details to the patients. We use this form from the time they are admitted until they are discharged. After we’ve advised them, we record the result on it. If they don’t
understand or do what we advise, we advise again and again till they get it or can manage well. After they are discharged, we sum up our findings about their problems and the health education that we gave.

**Noticing problems from patients’ and nurses’ perspectives**

*Sometimes I feel that Thai people don’t really care about their health and nurses do a routine job rather than get involved with the patients, especially as there are a lot of other jobs now that nurses have to do, such as the documentation and the clearing of the treatment fees. I’ve noticed that when we’ve been away from bedside care for a long time, we start to become lazy (laughed). So nurses should be more active than this. At the same time, there are some problems created by a lack of nursing staff. It affects our nursing care as well.*

**Tha-nhom’s experience**

**Background**

Tha-nhom was a 37 years old registered nurse. She graduated with a Bachelor in nursing. She attended some conferences about orthopaedic issues, but not specifically in rheumatoid arthritis. Having worked with orthopaedic patients for 16 years, she saw patients with rheumatoid arthritis, but not often. Almost of them were female and they were 50 years or more old. She said that pain was the most important symptom, and patients had pain in many of their joints, such as their hands and knees, and it was more severe when the weather was cold. She noticed that female patients had worse pain than males, but it may have been related to their tolerance levels. She felt pity for patients when they had severe pain, because the rheumatoid arthritis made them suffer badly. Hospital care became important in the lives of patients with rheumatoid arthritis, as it was difficult to treat for a cure, and the chronicity made patients feel disheartened and lose hope.
Tha-nhom noticed the doctors treated patients with rheumatoid arthritis with medications. She also noticed that injections were the best, because the patients got better after they had injections within three days, and would only need oral medication a week later. She assessed their symptoms first, gave them paracetamol as prescribed by the doctors, and followed up on how they were feeling after taking the medication. Finally, she informed the doctors and requested injections if patients still had pain. She talked to the patients about self-care, and especially the importance of following the doctors’ orders. She saw some patients who were dishheartened, but she had never seen patients who had harmed themselves. She supported their positive mental attitude to fight the illness. She also gave them the advice about rest and food, but rarely advised about exercise, because she was worried that they might exercise in the wrong position and become worse later.

Although she thought that injections were the best to relieve pain, she felt the patients should not get too many of them. She recognised that relatives were important in encouraging the patients. Regarding to health care team, she perceived the need for cooperation between the ward and the local health centre, and the need for cooperation among nurses, physical therapists or occupational therapists. She perceived OPD was helpful also. However, she talked about obstacles in managing pain, such as patients’ non-compliance to treatment, economic status problems, and beliefs about traditional treatments. On the other hand, nurses’ obstacles included giving incomplete information to patients and feeling patients thought that the information they got was unimportant. Another obstacle was lack of knowledge, because of the complexity of the disease, and infrequent chances to see rheumatoid arthritis cases. She said these factors made nurses forget how to care for patients with rheumatoid arthritis properly. In her opinion, she was unsure about the use of hot compresses, because she did not know if they could aggravate the patients’ symptoms or help them get better.

**Tha-nhom’s experience: Emerging codes**

The codes emerging from Tha-nhom’s account were: noticing more females have rheumatoid arthritis; feeling pity; perceiving hospital is important in the lives of patients
with rheumatoid arthritis; recognising traditional treatment is the other way to relieve pain; noticing doctors treat with medications; advising rest; giving analgesics; talking about self-care; advising about food; rarely advising exercise; recommending patients do not get too many injections; noticing non-compliance to treatment in patients; recognising relatives should encourage patients; perceiving the problem of economic status; recognising nurses’ incomplete information; recognising nurses’ lack of knowledge; perceiving cooperation between nurses, physical or occupational therapy departments; feeling unsure about the use of hot compresses; perceiving the need for cooperation between ward and health centre; perceiving OPD is one part to help nurses; and giving psychological support.

**Noticing more females have rheumatoid arthritis**

*I think I saw more than 10 cases both male and female. I haven’t seen them for the last few years ... Over 50 years old (in female patients). They had more pain when the weather was cold ... Pain and severe pain (are important symptoms). They had pain in many of their joints and had more pain when the weather was cold ... Hands and knees (that the parts they had pain). They had pain and swelling in both ... Some patients got injections, because the medication wasn’t relieving their pain ... They had severe joint pain, swelling, were unable to walk, and they looked pale ... There were some differences between them. Female patients had more severe pain than the male. Maybe it’s related to their tolerance levels.*

**Feeling pity**

*I pitied them when they had severe pain, because the rheumatoid arthritis made them suffer more than others. When we saw patients who suffered from fractures, they got well and it was unlikely that they would be readmitted after the doctors had treated them.*

**Perceiving hospital is important in the lives of patients with rheumatoid arthritis**

*On the other hand, hospitals became important in the lives of patients with rheumatoid arthritis, as it was not easy to treat them through till the rheumatoid arthritis had disappeared. It made them disheartened and lose hope.*
Recognising traditional treatment is the other way to relieve pain

Some patients got traditional treatment and took decoctions. These treatments made them suffer more ... Yes (the patients told me about this). They used some products, such as decoctions and bolus ... Of course (they used these products), because rheumatoid arthritis is a chronic illness. It’s not easy to cure it completely, to make the pain disappear forever. They get bored with taking the medication. If somebody advises them to try many kinds of medication or to go to places that offer good treatment, they will do that, because they don’t feel any better although they are taking the medication from the hospital. They looked worse and had complications when they were readmitted.

Noticing doctors treat with medications

They (the doctors) gave steroids to these patients. If they didn’t use these, they wouldn’t be able to control the pain ... Stomach ache (is the side effect after the patients took steroids). The doctors are well aware in this problem. They also gave them antacids such as alum mac or alum milk. They followed up patients in regards to the side effects from the steroids too. If patients had side effects after taking steroids, they decreased the dose of steroids to what was suitable for each patient. Sometimes they gave them a different medication that had few side effects ... They gave the patients injections, such as voltaren. Some doctors gave them injections for three days. Most of the patients with rheumatoid arthritis got better after they had the injections. Apart from the injections, patients also took oral medication, but the results of this were not as readily seen ... it is general supportive therapy. When the patients were in pain, they took steroids and got voltaren injections ... Yes (the doctors give them a balm or ointment), but it didn’t relieve the pain very much. The injections were better ... From my observations, injections are the best, because patients get better after they have injections for three days. If the doctors only gave them oral medication, they would be fine a week later. Some patients didn’t get better after a week of taking the oral medication. The process was very slow for them. In terms of balm or ointment, the doctors gave it to them too. They gave whatever would help each symptom. They assessed the patients first and those who just had pain were given voltaren injections, one ampule stat. They gave Voltaren injections for three days for those patients who had severe pain. Basically, the doctors didn’t prescribe balm or ointment for the patients. They gave antipain medication for
those who wanted it ... When I asked the patients, they usually told me that injections were the best. Other treatments relieve pain only for a short time.

Advising rest
First, I talked with them ... They got worse and their joints were more painful if they still walked too much. On the other hand, if they got some rest and took the medication, they would get better, because they’d stopped using their joints ... I advised them to rest in bed and stop walking, because if they still walked about and didn’t rest, their symptoms wouldn’t subside.

Giving analgesics
I gave them paracetamol as prescribed by the doctors, and followed up on how they were after taking the medication ... I’d talk with them first, assess their symptoms, and then give them medication. Finally, I’d inform the doctors and ask for injections if they still had pain ... Finally, I informed the doctors and asked for injections for the cases that weren’t getting better.

Talking about self care
I always talked with them about how to care for themselves, especially about following the doctors’ orders.

Advising about food
Regarding their diet, there are many kinds of foods that make them worse. They have to work out which foods they can have. Their symptoms won’t lessen if they take the medication, but still have a harmful diet ... I didn’t tell them about all the harmful foods that they shouldn’t eat. I told them about some meats and some strong smelling vegetables, such as lead tree and twisted cluster bean, because these foods have high uric acid content. If patients with rheumatoid arthritis have too much of these foods, uric acid is stored in the form of salt crystals and builds up their joints. Then their joints won’t move well, and later they experience joint stiffness.
Rarely advising exercise

In my opinion, patients with rheumatoid arthritis can exercise, but not too much. I rarely advised them about exercise, because I was worried that they might exercise in the wrong position and become worse later. Some patients asked me how they should exercise. I didn’t know how to answer them about the processes and methods of exercise ... I meant that I didn’t know the facts about exercise, what level of exercise those patients with rheumatoid arthritis could do, and how to advise them about it. I advised one patient telling her “Auntie... you should exercise” “OK I’ll do some running” she said. In this case, I thought after I’d advised her that running would affect her condition. So I didn’t dare to advise them without the right information. It would be better if I really knew more about it.

Recommending patients don’t get too many injections

I don’t believe patients should get too many injections, because they may become addicted to them, and ask for them every time they have pain. When they had pain, I tried them on oral medication first. After that, I told them to restrict their physical activities, to avoid using the body parts that had pain and to rest. There’s no problem in giving injections in a case that doesn’t get better after taking oral medication. If the doctors didn’t give injections in these cases, the patients would be unhappy.

Noticing non-compliance to treatment in patients

There are many problems caused by nurses and patients. Patients cause problems, I think, because of their beliefs and awareness of their illnesses, especially when they are in pain. In my past experience, they only followed the doctors’ orders and nurses’ advice when they were in pain. After their pain lessened, they thought that everything was all right. So they went back to doing the same things again. I would advise them about foods that they should not have, but they wanted to have them. They thought that it wasn’t a problem if they had just a little bit.

Recognising relatives should encourage patients

Relatives are important in this respect, because rheumatoid arthritis is a chronic illness. Relatives should take care of, pay more attention to, and encourage patients. This would
encourage the patients to take their medications, and to follow up their treatment continually. Subsequently, they should get better and be able to control their symptoms better.

**Perceiving the problem of economic status**

Another factor is the economic status of the patient. Some patients have a problem with the treatment fees, because medication for rheumatoid arthritis is so expensive. They want to continue treatment, but they need to keep their money for their families too. Some patients are both poor and live far from the hospital. It’s a problem that disrupts their treatment. In fact, there are many problems that disrupt their treatment. Somebody may have one problem, but somebody else may have many problems ... There were many problems in the past with patients having no more money for treatment or for the expensive medication. Some patients wanted to be healthy as soon as they could, but they didn’t have much money. So they couldn’t continue the treatment at the hospital, and they had to find other treatment that was cheaper. I don’t think this problem still exists, because the Government funds the patients who have little money. We call this the “health insurance card”.

**Recognising nurses’ incomplete information**

Regarding the problems that nurses create, I think that nurses give patients incomplete information. It makes them think that the information they get is unimportant. For example, when we give them health education, we give them general education, but nothing specific or we teach them in a big group not individually. So they don’t take much notice. And in term of exercise, nurses don’t have a sound knowledge of this, which exercises patients should do. It would be better if we could give them a brochure or something about the right form of exercise. They could read it and make sense of it when they back home. Right now we do nothing about this.

**Recognising nurses’ lack of knowledge**

Lack of knowledge about rheumatoid arthritis is still an important problem. Rheumatoid arthritis is a complex disease and it’s rare here. We don’t see it often. These factors make us forget how to care for patients with rheumatoid arthritis properly. Now, there is
a new problem too. It’s the changing role of nurses. In the past, we had no up to date instruments and nurses didn’t have a lot of tasks like this. We could give the patients a lot of attention. Now, there are new instruments, and nurses have to do many tasks besides giving nursing care. So nurses ignore either giving nursing care or health education. Patients get insufficient information, and don’t dare to ask about things they’re not sure of.

**Perceiving cooperation between nurses, PT or OT departments**

In the past, we had no information about the treatment that the patients had there. Now after the patients come back from these departments, the staff give us a form. They record what they’ve done for patients that day, their assessment of patients before and after treatment. Nurses can read this form and see the patients’ progress. They give us a record that looks like the nurses’ notes for example, “patient had right knee pain, she was treated with paraffin. After this treatment she felt better and her pain decreased or she still has pain today. She has to have this treatment again tomorrow”. Nurses get information from this record without having to ring them ... No, they don’t (tell us the details of how they treated the patients), unless we want to know more. Nurses can ask about the details from patients as well. Sometimes we would ask the relatives if the staff from these departments taught them how to care for the patients when they were discharged. I haven’t seen patients with rheumatoid arthritis who got treatment from these departments for a few years.

**Feeling unsure about the use of hot compresses**

I think there are many methods that nurses can use such as hot compresses. But I’m not sure whether they would aggravate their symptoms or help patients get better. Textbooks often don’t explain this. So we don’t dare to apply hot compresses to patients.

**Perceiving the need for cooperation between ward and health centre**

I think so (people or departments are needed to support nurses in managing pain). There should be good cooperation between the ward and the health centre for ongoing care of patients. Then patients would get the right sort of treatment. This would improve their health and decrease the time they needed to spend in the hospital. Spending a shorter
time in the hospital would help them save money and ease their minds about this. Unfortunately, there is no clear model for local health staff to use to follow up rheumatoid arthritis cases. I’m sure that health centres will have broader roles in the future.

**Perceiving OPD is one part to help nurses**

I also think that the outpatient department (OPD) is one of the important departments in caring for patients. They give health education to the patients, because patients with rheumatoid arthritis attend the OPD for follow up treatment more than they attend general admission. Health education at the OPD is also very important, especially about the treatment and taking medication. It helps patients control their pain. If possible, I would like health centres to be more involved in follow up treatment or visiting the patients at home. They should check on how the patients are coping.

**Giving psychological support**

I saw some patients, who were disheartened. I have never seen patients, who have harmed themselves. They were disheartened when they were in pain. After their pain eased or their relatives encouraged them, they’d feel better and attempt to fight their illness … I used psychology to talk with and encourage them. The important factor is the relative, because he or she is close to the patient. The relative is also the best person to liaise between the nurse and the patient. Patients looked good if their relatives had taken good care of them. On the other hand, they become disheartened if their relatives take poor care of them.

**Usa’s experience**

**Background**

Usa was 49 years old, a mother and head of an orthopaedic ward. She was a registered nurse who had Bachelor degree in nursing, and she was trained in specific nursing care of orthopaedic patients for three months. She had 24 years of nursing experience, and
she saw more female patients than males with rheumatoid arthritis, who were over 30 years of age. She nursed most of these patients from 1984 until 1988. She felt there was no difference between rheumatoid arthritis and other orthopaedic patients, because their suffering was the same. Therefore, she sympathised with all of them, because they all had chronic disease, and they wanted the hospital to cure them completely.

Because the doctors controlled the treatments, her management for pain was assessing and giving medication, which included analgesics as necessary. She said it was possible to use hot and cold compresses, but she could not do much, because there was limited equipment in her ward. She encouraged patients to rest also, and advised patients to take care in how they should change their behaviours, and handle their daily lives. She also encouraged patients to see the orthopaedists. In relation to psychological support, she had open and honest communication with the patients. She supported them by telling them what things they were doing right and what things they were still doing wrong. She let them chose and did things for themselves. Furthermore, she asked them which methods they had tried and what happened after they had tried them. She told patients that she and other nurses were there to help appropriately, to give hope and believe in patients’ perception of their own pain. Nurses gave hope that patients could get better, and have their disease disappear if they trusted the staff and were cooperative with treatment. Finally, she suggested that nurses had to ‘put themselves in the shoes of the patients’, and think about what they would do if they had rheumatoid arthritis.

Before finishing the interview, Usa said that nurses could have problems in managing pain if patients did not cooperate with them. The other problem was explaining the patients’ pathology, in relation to long it would take patients to get better and about their symptoms. Some patients understood that it would take time to get better and so they were not anxious, however, some counted the days and were stressed. When she saw patients with rheumatoid arthritis in the ward, she asked them if they had continued with their treatment, what the doctors had advised them, and whether they had followed instructions. She noticed they knew and remembered the things that the doctors had told them, but they did not do them, because it was in their nature to go back to their old patterns, so she stressed the importance of behaviour modification. She observed that
patients trusted doctors more than nurses, but the doctors only had a short time to talk with the patients. This meant that nurses needed to be the coordinators between doctors and patients. Regarding alternative ways to relieve pain, she thought the rehabilitation department could teach the patients how to care themselves, and she was unsure whether herbs could be effective for pain relief.

Usa’s experience: Emerging codes

The codes emerging from Usa’s account were: noticing more females have rheumatoid arthritis; encouraging patients to see the orthopaedists; noticing different responses to treatment and advice; noticing similar patterns in chronic disease and rheumatoid arthritis; advising on behavioural changes; noticing reversion to old patterns of behaviour; feeling sympathy; giving hope; creating open and honest communication; negotiating appropriate care; recognising the doctors’ control of treatments; assessing; believing patients’ perception of pain; giving medication; giving psychological support; being there to help appropriately; realising patients would get their analgesics if necessary; putting oneself in the shoes of the patients; encouraging rest; using compresses; not taking advice; recognising healing takes time; thinking the rehabilitation department can teach self care; being patients’ advocates to doctors; and being unsure about the effectiveness of herbs.

Noticing more females have rheumatoid arthritis

I saw more female patients than male. They were over 30 years old. I saw them a lot from 1984 until 1988. I rarely saw them after that, because they became outpatients. They came to the hospital to follow up their treatment at the outpatient department (OPD), take the physical therapy (PT) course, and get medication and then they went back home.

Encouraging patients to see the orthopaedists

When I saw them in other parts of the hospital, not in my ward, I asked them if they’d come to see the doctor and if they’d been treated before. I asked this, because these patients could tolerate it when they had pain, and they didn’t get pain all the time. Some
weren’t concerned when their hands were deformed. If they replied “No”, I advised them that they should go to see the orthopaedists to get treatment. They would become worse if they didn’t do that.

Noticing different responses to treatment and advice
If I saw them in my ward, I asked them if they’d continued with their treatment, what the doctors had advised them about caring for themselves, and whether they could do this or not. Most of them couldn’t remember all the things the doctors had told them. They did some things and didn’t do other things. This applied to both educated and uneducated patients.

Noticing similar patterns in chronic disease and rheumatoid arthritis
I felt there was no difference between rheumatoid arthritis and other orthopaedic patients, because their suffering was the same. They had pain and they had a chronic disease. They put up with the suffering and ignored the pain until they had joint damage. Most of the other orthopaedic patients that were not accident patients were admitted with back pain and joint pain. They had the same pain. I mean they both had joint pain. They suffered and had a chronic illness. I thought this, because I noticed that patients got better, and then worse again if they’d had the disease for five to 10 years or more. They were always up and down ... Patients with rheumatoid arthritis and other orthopaedic patients who got diseases were admitted because of pain. When I saw them all, I felt there was no difference between them.

Advising on behavioural changes
The important thing was to give them information. We needed to advise them what things they should be careful of, how they should change their behaviours, and how they could handle their daily lives. It was very difficult to change their behaviours. They got better if they could change. They often didn’t change. They reverted to doing the same harmful things when they were better. I used to advise them how to lift things.
Noticing reversion to old patterns of behaviour

They changed their behaviours at first, but they went back to doing the same old things when they were discharged. These were both educated and uneducated patients ... They knew and remembered the things that the doctors had told them, but they didn’t do them. It was in their nature to go back to their old patterns ... I stressed the importance of behaviour modification. They would still be the same if they did the same things. Some patients thought they’d got better and everything was fine. They were the same as they used to be. In fact, there was no 100% guarantee of this. An Operation would solve some of their problems and mean they wouldn’t suffer as much.

Feeling sympathy

I sympathised with all of them, because they all had chronic diseases, and they wanted the hospital to cure them completely.

Giving hope

So we had to give them hope that they could get better, and have their diseases disappear if they trusted us and gave us their cooperation. The doctors gave them medication. The nurses helped them too.

Creating open and honest communication

We advised them about what things they were doing right. They could consult us when they had problems or didn’t understand. They had to tell us, because we didn’t necessarily know what they needed or when they were disheartened. We wanted to talk with them and help them. We didn’t talk with them to be a nuisance or because we wanted to scold them. When they asked if their diseases would disappear and we said “No”, they became disheartened. We would be lying if we told them otherwise. Therefore, we had to say that it was possible to be completely cured, but there was no guarantee. Nothing was 100% sure. There was degeneration because of age. They would keep in the best state if they gave us their cooperation ... I think the nurses’ role should be about consulting, and giving patients the chance to choose their treatment. Nurses have to be willing to consult with them. They could tell us if they weren’t sure or if something they tried failed. We didn’t teach them according to the theory, but tried to
give them a chance to learn for themselves. We should find ways for them to choose. We shouldn’t tell them what they have to do. We should help them find ways to cure their illness. Nurses could learn from this what their problems are. The other important thing is that they trust the nurses. Then they ring or come to see the nurses when they have problems.

**Negotiating appropriate care**

When we have consultations with them, patients tell us what their weak points are. Nurses should support them by telling them what things they are doing right, and what things they are still doing wrong. We let them choose and do things for themselves. Furthermore, we should let them tell us which methods they've tried, and what happened after they’d tried them. Perhaps we’d told them something that was unsuitable for them, and they might find a better means for themselves ... It's a circular thing. Although nurses have many duties and things to do, the important thing is counselling. Nurses can understand that patients have other problems besides pain. Some patients have pain all day and night and their minds are troubled. They are weak the next morning. If the nurses talk to them, they can understand their problems better. Moreover, the patients want someone to know about their illness and about what care they can get. They feel better if this happens that.

**Recognising the doctors' control of treatments**

They gave them analgesic drugs, non-steroidal anti-inflammatory drugs (NSAIDs) such as naprosyn and antacid such as alum milk and alumac to protect their stomachs. Some cases were given oil or balm if they asked the doctors for it. They told the patients to get bed rest and to walk a little if they could ... Some patients got treatment there (physical and occupational department). Everything depended on the doctors. Most of them gave the patients medication and let them rest. I didn’t follow up on the cases to see what treatment they got from these departments.

**Assessing**

I assessed them and talked to them at the same time. I asked them about the history of their illness, their symptoms, and their level of pain.
Believing patients' perception of pain

The thing was to believe them when they said they had real pain and to give them medication. Some nurses didn’t give them medication. When the patients asked for it, they told the patients to wait for a while. They did that, because some patients got NSAIDs three times a day after mealtime, and had analgesic drugs when they requested them every four hours.

Giving medication

Nurses should give them medication and inform the doctors if the patients don’t get better after they’d been treated by the doctors ... Some patients had NSAIDs, analgesic injections, and drugs when they requested them. It depended on what the nurses decided in each situation. If the patients complained of pain, the nurses would tell them there were analgesic drugs and injections that they could have. Nurses could give them the injections they wanted, and then inform the doctors about what happened after they got them ... After that we gave them medication as the doctors ordered.

Giving psychological support

Nurses should support them psychologically while they wait for a new treatment from the doctors. Nurses should ask them what else they want to tell us besides their level of pain.

Being there to help appropriately

Some symptoms were cured without medication. Some patients asked for analgesic drugs to keep and take when they were in pain. We had to tell them not to worry if they had pain. We were here. They could ask for the medication every time they had pain. Nurses would know how they were. We wouldn’t know if they were getting better or worse if they kept and took the medication at home ... On the other hand, if we didn’t show interest when they complained they became disheartened. Nurses should encourage them and tell them that every patient is in the same situation. They all suffer the same. They were lucky that they had medication to take, and so they should calm down and try to relax. Everything would be all right. Their hands wouldn’t become deformed, and they’d get better after they’d taken the medication.
Realising patients would get their analgesics if necessary
If when they asked for medication we gave it to them with annoyance, they were reluctant to ask for it again. They would discharge themselves, and buy the analgesic drugs from somewhere outside. It’s hard to believe that patients would do this, but I see you know about it. At the beginning, I knew they’d got better, but I didn’t know that they’d bought the medication from somewhere else. I thought they’d got better, because they’d sometimes asked me for the medication.

Putting oneself in the shoes of the patients
Finally, nurses have to put themselves in the shoes of the patients and think about what we would do. Patients would buy the medication themselves or do something else if they were afraid that the nurses would be annoyed with them. Patients felt doctors and nurses might not cure them if they still complained about getting pain, but who could help them more than us. Therefore we should make them believe in us. It wasn’t difficult to know who believed them and who didn’t. Some child patients knew that the nurses didn’t believe them. I had to explain the situation to them.

Encouraging rest
We encouraged them to rest.

Using compresses
It’s possible to use hot and cold compresses. But we couldn’t, because there’s limited equipment here. We had one or two hot bags for patients who had chills. We had no cold packs. We had one fridge to store the medication in. We used the compresses in the cases where there was a lot of inflammation.

Not taking advice
We had problems if the patients didn’t cooperate with us. They’d get pain, but they’d still walk, not rest and not take the medication. This occurred with the patients who had pain in some of their joints.
Recognising healing takes time

The other problem was their pathology. Some had a lot of pathology and were severe cases. They hoped that their pain would disappear as soon as they were admitted to the hospital. Some patients got better after they’d been admitted for one or two weeks. The doctors and nurses should explain to them about how long it would take to get better and about their symptoms. Then they’d feel better and wouldn’t be anxious. Some understood that it would take time to get better and so they weren’t so anxious. Some counted the days and so were stressed. They became more stressed if they didn’t get better by the date that the doctors had set. Everyone was not the same.

Thinking the rehabilitation department can teach self-care

I thought the rehabilitation department could help. They could teach the patients how to care for themselves and these patients needn’t be admitted. This department and the physical therapy department (PT) could arrange a program, and teach it to the patients when they came for follow up treatment at the outpatient department (OPD). Patients could get ideas about how they could handle their daily lives, what they could do and what they should avoid doing. If they cared for themselves, they would be healthier longer. They would be able to enjoy their lives without stress. They wouldn’t have pain all the time and they could do things and go to work ... I believe the rehabilitation department could do that and teach the patients, because the patients had pathology and structural changes. It would be good if they established a program which those patients could join and then share their experiences. The patients could tell us, the other patients and the doctors how they solved problems. We thought they should do that, because we learnt it from the theory. They might find a way to cope that was suitable for them and for others.

Being patients’ advocates to doctors

Doctors have many tasks, so they only have a short time to talk with the patients. Nurses have a lot of contact with the patients. Nurses should be the coordinators between patients and doctors. We could then tell the doctors what their problems are.
Being unsure about the effectiveness of herbs

There was no thought about herbs in the past. Now it’s a very hot issue. I knew about it from some patients, but I was not sure if it was related to rheumatoid arthritis. They used crinum lily leaves to relieve muscle pain. They heated them until they became warm, laid them on the area where they had pain and massaged it. They got better. Right now herbs are a hotter issue than medication. Sometimes I think that they are not real herbs. Some patients use them more than they need to. Now many patients like to take herbs in the form of a tablet or capsule. They don’t like to take a decoction. People use them a lot, because they have many properties that can heal diseases. I didn’t use them too much. I used some herbs that made me feel refreshed, and some that quenched my thirst. I’ve never personally used herbs as a cure, because I’ve had no diseases … Nurses are more interested in how to care rather than in giving the patients herbs, because we don’t want to impinge on the doctors’ roles. Doctors have a duty to cure, but we have a duty to care and to coordinate with the doctors. We have to talk with the doctors if we have any ideas about applying herbs to patients. If the patients and their relatives want this and the doctors allow it, we let the relatives bring them in for the patients.

Mham’s experience

Background

Mham was 42 years old, and head of an orthopaedic ward. She had a degree in nursing and, she had also trained in specific orthopaedic care. She had 20 years experience in orthopaedic nursing. She usually saw more female than male patients, who were at least 40 years old. She recognised that pain was the main symptom. There were a few patients who had bone deformity. She noticed the doctors’ treatment relied on medication, such as non-steroidal medications and the patients were usually admitted to hospital for a short time for treatment.
Mham managed pain by giving patients the medications continually as prescribed. She said nurses should tell patients about two things when they give medications to patients. Firstly, nurses should tell the patients that they will need to have treatment for a long time, and whether they got better or not depended on their taking the medication. The second piece of advice was telling patients to follow up on treatment continually. She said that some Thai people did not come to see the doctors when they were sick, because they thought it was a waste of time to go to the hospital. She encouraged the patients to rest and exercise appropriately also. Mham talked to patients about adjusting their mental attitude to accept their illness. She said that nurses could say that rheumatoid arthritis was not terminal, but it usually caused suffering. At the same time, she advised the relatives about how to care for patients. Although she recognised doctors were the main advisors, nurses needed to talk to the patients more. She emphasised that nurses should try to take the patients’ minds off their illness, and try to interest them in other things.

Mham usually cared more for people with in severe cases of orthopaedic illness rather than chronic patients, because she felt she could not help patients with rheumatoid arthritis very much except to give them advice. Beside this, she did not know if there were any special arrangements for patients with rheumatoid arthritis in other hospitals. Even though she confirmed the best way to relieve pain was giving medication, she felt herbal compresses and soaking in paraffin were alternative options to relieve pain. She was unsure about the benefits of massage and soaking in warm water. Furthermore, she wanted help from occupational therapists for pain relief, and encouraged nurses to use discharge planning as part of pain management also.

**Mham’s experience: Emerging codes**

The codes emerging from Mham’s account were: noticing more females have rheumatoid arthritis; noticing bone and finger deformity; recognising pain is the main problem; helping with mental attitude; noticing the doctors’ treatment rely on medication; recognising benefits of soaking in paraffin; giving medication continually as prescribed; recognising nursing care advice on appropriate exercise; encouraging
compliance to medications; giving psychological support to accept rheumatoid arthritis; advising relatives how to care for patients; feeling unsure about soaking in warm water; encouraging appropriate rest; encouraging appropriate exercise; recognising nurses should talk to patients more; giving care only to severe cases of rheumatoid arthritis; confirming the best way to relieve pain is giving medication; recognising doctor is the main advisor; wanting help from occupational therapy department for pain relief; encouraging follow up treatment continually; encouraging discharge planning; feeling herbal compresses are an option to relieve pain; feeling unsure about massage; noticing some patients do not take advice; not knowing the special arrangements for patients with rheumatoid arthritis; and not wanting to care for chronic patients.

**Noticing more females have rheumatoid arthritis**

*I usually saw more female than male patients. They were at least 40 years old. I saw few patients that were younger than 40.*

**Noticing bone and finger deformity**

*There were a few cases that had bone deformity too ... Some patients had a little finger deformity but no dislocation.*

**Recognising pain is the main problem**

*Most of them were admitted with pain, but not too much pain. There were a few patients, who had a lot of pain and had to take medication all the time ... I’m not sure what criteria that the doctors used to admit them. I often found that they were admitted for blood test and to have their rheumatoid arthritis factor checked. These patients weren’t given an appointment at the outpatient department (OPD). Furthermore, they did the blood test to be sure which disease the patients had before they gave the patients medication. The other reason was that the patients who were in a lot of pain were admitted to get some rest ... No (there weren’t any other symptoms that I saw in them). I only saw them admitted with pain. They often had finger pain and pain in some of their joints ... The patients were admitted for a blood test on one day and got the results the next day. The doctors could reduce the dose or change their medication for them. I wondered if some cases were found to be RS negative, but the doctors treated them with*
antirheumatic drugs. They might have seen clear signs and symptoms. These patients were cured in a few days and were discharged.

Helping with mental attitude
I felt I couldn’t help them a lot, because everything depended on the doctors and the medication. Nurses could only talk to them about adjusting their mental attitude to accept their illness, attending the hospital to get treatment, continuing with the follow-up treatment at the same hospital, and not going to see a lot of different doctors. Although it was still there, they could control their illness.

Noticing the doctors’ treatments rely on medication
They gave the patients non-steroidal anti-inflammatory drugs (NSAIDs). They gave dexamethasone in some patients where pain was severe, and they gave steroids in the patients where NSAIDs were not effective. I asked the doctors about how long the patients should have the steroids. They said they had to reduce the dose, because although it made the patients better very fast, there were many side effects if it was used over a long period. I read some textbooks that said we could give gold salt to relieve pain, but I’ve never seen that here. I often saw the doctors give the patients NSAIDs and analgesic drugs ... There were a few analgesic drugs used here. I’m not sure if they gave idarac to the patients. I know they gave them paracetamol. Now we use parafon forte. It’s chlorzoxazone and paracetamol combined, therefore it’s better than paracetamol. I read in the textbooks that we could give aspirin when there was inflammation, but I’ve never seen that here either ... It (voltaren) was one kind of NSAIDs. The doctors gave NSAIDs to decrease inflammation. The pain decreased too. They didn’t give other drugs except NSAIDs, but in some patients they gave steroids as well. In my experience, the patients got better after they’d had treatment for a while, and the doctors then reduced the doses for them to a level that could control their pain.

Recognising benefits of soaking in paraffin
I used to think soaking in paraffin would be good for pain relief. I wondered why the doctors didn’t have the patients soak in warm water. I thought it would either be better for them or would have no effect. I rang the occupational therapist and asked how many
patients with rheumatoid arthritis were getting treatment there. They said there were some patients. So I asked them which was better, soaking in paraffin or warm water. They said that soaking in paraffin was better, because the heat from the paraffin was a deep heat. It could get to the joints and relieve the pain. Furthermore, they said it would be better if the patients soaked in warm water at home and before they exercised. It made their joints more flexible and decreased inflammation.

Giving medication continually as prescribed
We usually gave them the medication continually as prescribed on their chart, and gave them PRN medication as the doctors had ordered if they requested it. When I’d just started working, I didn’t give them much advice. As I told you, they had to accept their illness. If they didn’t, they suffered more. They had to know the pain wouldn’t disappear, but they could get better after they’d taken medication for a while ... In relation to giving NSAIDs, nurses had to give it as set out on their charts. These drugs were crucial in whether patients got better or worse ... Yes (nurses gave the patients medication when they had pain), but not general analgesic drugs, just anti-inflammatory drugs, because these have the indirect effect of relieving pain. We could give them both anti-inflammatory and analgesic drugs when the patients were in a lot of pain.

Recognising nursing care advice on appropriate exercise
I thought that nursing care couldn’t help them directly. Nurses just had to tell them to stop exercising and working when they had inflammation, because their tendons and ligaments would become irritated. They could exercise when the pain decreased. They had to do this on their own account, because nurses couldn’t force them to do it. They knew what they could do. They might be in a lot of pain if nurses forced them to do too much. I thought that joint pain in each patient was the same and should be managed the same. Their joints would become more irritated if they flexed and extended them while they had inflammation. They should rest during this time ... I thought our nursing care helped the patients a little.
Encouraging compliance to medications

In my view, nurses should tell patients that they would have to have treatment for a long time. Whether they got better or not depended on their taking the medication. So they needed to take it. They had to accept their illness.

Giving psychological support to accept rheumatoid arthritis

Nurses had to support them psychologically to help them accept their disease. It was not traumatic, but it did usually make them suffer. What I did was to emphasise them getting the right treatment, accepting their illness and exercising ... I saw some. I told them to accept their illness, gave them psychological support and medication. I told them the doctors would reduce the dose or change their medication after they’d taken it for a while. I asked my staff if they did the same thing. I wasn’t sure that everyone did, because most of them were new staff. So I told them to read and study from the textbook, so they could support and advise the patients well. I knew I couldn’t teach them everything. It was all right for some staff who’d worked more than 10 years. They knew rheumatoid arthritis wouldn’t disappear, and that the patients just had to accept it. The thing that I emphasise now is the danger of taking a lot of steroids. I saw many patients who’d taken them after buying them from the chemist, and some patients took the steroids that the doctors prescribed. Steroids made them pale and weak.

Advising relatives how to care for patients

The patients who were admitted always had relatives to look after them. I told them that they didn’t need to treat their loved ones as babies. They could do things for themselves, but they had to be careful about flexing and extending their joints. Patients I saw usually did things for themselves, such as having food and taking a bath. I didn’t see them in a severe stage or when they had a lot of pain. I didn’t know how their relatives looked after them at home. I know they tried to survive as Thai people abroad do. Those people have to do everything they can to survive. I believe the patients had some problems with handling their daily lives ... I think the patients have to look after themselves, try to survive their illness, take medication, and have someone in the family look after them too. Regarding the caregivers, it was fine. If there were children, they looked after mum when she got sick. There was one case where they couldn’t find a caregiver; the
housewife got sick, her husband went to work, and she had to look after her own children.

**Feeling unsure about soaking in warm water**

*I never let them soak in warm water, because I wasn’t sure that that was a decision nurses could make or whether it could make the joints more inflamed. As far as hot and cold packs went, it was fine if I applied them to the patients who had trauma and swelling. But rheumatoid arthritis was different. There was inflammation too. I didn’t dare to use them. When I was a nursing student, the teachers didn’t cover this point. I didn’t see the doctors ordering the patients to soak in paraffin, although I thought it would be good for them. I asked the occupational therapists and they said it was good, but the patients had to be patient and continue to get this treatment … We would soak them in warm water if the doctors told us it would be good for them and confirmed that we could do it. The theory said we could, but the doctors didn’t order it.*

**Encouraging appropriate rest**

*The other things were resting and not using their joints. This was the reason that the patients were admitted. They could get some rest here, and the doctors could examine them to decide on the next treatment and to manage the medication.*

**Encouraging appropriate exercise**

*We advised the patients to exercise and advised their relatives to help them in the cases where the patients couldn’t exercise by themselves. I mean they exercised as best they could. They suffered from trauma if they exercised too much. I asked one staff member who gave paraffin baths to the patients about how much the patients could exercise. She said we shouldn’t force them too much, because their ligaments and tendons would become inflamed. Paraffin could help the patients when they had inflammation. She said we shouldn’t resist the patients’ wishes, but let them do what they could.*

**Recognising nurses should talk to patients more**

*I don’t think so (that there were any problems for nurses when they managed pain). I saw some patients who complained about why they were still in pain. I talked to them for
a few minutes. I knew I could only spend a short time with them, because I had to cover two wards, and there were some patients who were accident victims. I had to care for the emergency cases first. Although I only had a short time to talk with them, I told them they had to be patient and wait until they’d taken the medication. I've never seen a case that had a lot of pain after taking medication or one where morphine was required to relieve the pain. I thought these patients needed the support of the nurses. I learned nurses should try to take the patients’ minds off their illness, and try to interest them in other things.

**Giving care only to severe cases of rheumatoid arthritis**

There were some (effects on nurses from the fact that rheumatoid arthritis cases are rare). We would forget about nursing care. When they were admitted without severe pain, we looked after them, but not very much, and we didn’t talk to them about how to exercise to prevent joint stiffness. We cared more in the cases that had a lot of pain. We did advise them to rest their joints. Sometimes we saw them and thought they were fine, we didn’t bother about giving them advice. We didn’t tell them how to protect themselves. In relation to brochures, I made 13 brochures about the diseases we saw a lot of, but we neglected to make brochures about how to care for the joints.

**Confirming the best way to relieve pain is giving medication.**

The primary method is by giving medication, and the secondary one is to stop using the joints. In fact, we don’t use our joints when we are in pain. This means that we automatically rest them. The important thing is what they should do after they get better. They would have joint stiffness if they didn’t exercise. That was the point nurses had to emphasise to them. I told them they had to exercise after the pain and inflammation were relieved.

**Recognising doctor is the main advisor**

They took bolus and bought other medication by themselves. I never knew the reason they stopped following up. Perhaps the doctors didn’t tell them whether their illness could be cured completely or not. The doctor was the main person responsible for explaining about the pathology. Anyone who advised the patients later had to follow
what the doctors did. I thought the nurses might usurp the doctors’ roles if we advised patients about those things instead of the doctors. I was sure the doctors could explain things better than the nurses could.

**Wanting help from occupational therapy department for pain relief**

There should be help from the occupational therapy department (OT), because they have paraffin treatment there. I think patients should get this treatment to relieve their inflammation and pain. I wondered why the doctors never sent them there. I asked the occupational therapists how many discharged patients came back for follow up treatment at the OPD. They said there were not many. In fact, paraffin is more suitable for the patients than warm water when they have inflammation. I don’t know why the doctors don’t allow them to do it while they’re taking medication. It can relieve their pain although it can’t cure it 100%. The occupational therapists told me they had equipment for the patients who had joint deformity. It looked like a splint to stop further deformity. Now they have a half-plastic slabs to support patients’ body parts too.

**Encouraging follow up treatment continually**

I didn’t know when the patients came back for follow up treatment after they were discharged, but I gave them appointment cards. Now the system here is that ward nurses send a list of patients that have to come back for follow up treatment to the outpatient orthopaedic department. The OPD staffs send a letter to the patients if they don’t follow up on the appointment. They send the letter three times, and then if the patients still don’t attend they cancel the cases. It’s not the hospital’s system, but it’s our system. It’s a way of improving the quality of the orthopaedic department. Some patients were not the patients from our area of responsibility. We advised them to see an orthopaedist near their home after they were discharged from here.

**Encouraging discharge planning**

I’m interested in discharge planning. It’s good if we can provide activities for the patients to do each day and at each stage. If we can do this, we need to refer to the theory. It’s like when the patients take a course or program when they are admitted. It would be good if we could do this, but our minds might become numb when we do a lot
of discharge planning. We don’t have enough staff to do it. It would be better if there was a standard form that we could use immediately. I know there is staff or someone to handle discharge planning in the hospitals abroad. They establish the discharge program for each patient, and send it to the nurses and the nurses follow that form. For us, we have to plan, organise, and do things by ourselves. Sometimes our thinking isn’t straight, and some staff are not trained in orthopaedic nursing. In my opinion, discharge planning is good, but we should have more staff who have enough knowledge to do the job.

**Feeling herbal compresses are an option to relieve pain**

I knew compresses were a way to relieve pain, because there were some herbs that could relieve pain. But if you ask me, they won’t cure the disease completely. We could do this for the patients only sometimes. It’s like the patients’ joints can absorb the heat and the medication. Someone advised me to make an herb compress, but I’ve forgotten the quantity of ingredients. She told me to crush red chillies until they became a paste and mix it with raw sugar. We had to make it like a jam. I applied it to my brother’s knees for 10 minutes and then took it off. He would feel too hot if I’d left it on his knees for more than 10 minutes. I thought the hot feeling had the same action as NSAIDs and could relieve pain. There is some substance in chilli that can relieve pain.

**Feeling unsure about massage**

About massage, I’ve never studied it, but I know traditional massage is not suitable for patients with rheumatoid arthritis. I think it’s better for someone who has some kind of sprain or strained muscles. Furthermore, I think compresses are all right for the patients, and massage would be good for them too if they applied a little force.

**Noticing some patients do not take advice**

The thing is Thai people are naughty and don’t do as we advise. This means that nurses have no control over the situation if the patients stay in the hospital for one week and are then discharged. The week’s stay would be good, because they could rest here. Some patients couldn’t find anyone in the family to look after them, because they have
household jobs to do, look after young children, and their husbands go to work. I rarely saw the patients being re-admitted so I was not sure what the reasons were.

**Not knowing the special arrangements for patients with rheumatoid arthritis**

I don’t know if the bigger hospitals have special arrangements for patients with rheumatoid arthritis; how to follow up their treatment, helping the patients, health education, and how to prepare the patients before they are discharged. I think I will ask the doctors who were trained in those hospitals. Perhaps there is something more that nurses can do for patients.

**Not wanting to care for chronic patients**

Sometimes I felt that I didn’t want to care for chronic patients, because I felt I couldn’t help them very much except to give them advice. I felt good if I treated them and I could see the results afterwards. Then I had positive reinforcement to carry on with the next step in the treatment.

**Tina’s experience**

**Background**

Tina was 44 years old, a mother and head of an orthopaedic ward. She graduated with a Bachelor in nursing and had trained for specific orthopaedic care. In her 21 years experience in caring for orthopaedic patients, she said there were not many patients with rheumatoid arthritis when she compared them with other kinds of orthopaedic patients. She saw more female than male patients. The rheumatoid arthritis symptoms were joint pain, swelling, stiffness, and deformity. She noticed that patients were admitted, because of severe pain and because they were unable to do things for themselves. She found that the doctors treated patients by using non-steroidal medications and also analgesic drugs.

In terms of pain management, Tina gave the patients medications as the doctors had ordered. Secondly, she soaked their joints in the warm water or used hot compresses.
She did not set up any motivational group or any special activities to encourage them, but she gave patients relaxation techniques. She also advised them how to rest, and restricted their activities or minimise the use of the joints when painful. She did not advise them to exercise or use their joints too much, because of the risk of further degeneration. She said that patients could have any kind of food, but they had to choose the appropriate food if they had rheumatoid arthritis with another disease. She advised the relatives how to care for patients. Because pain was all encompassing for patients with rheumatoid arthritis, Tina usually supported patients emotionally, and she sometimes showed them some patients who were worse off than they were, to make them feel better.

Tina recognised there were no real problems in managing pain for patients with rheumatoid arthritis, although she thought there were some effects on nurses. She was concerned with differences in education. She noticed that educated patients always made a point of caring for themselves, but some patients did not and they let their condition deteriorate. However, she said that there was a new product made from herbs for relieving pain. She could not guarantee that it was good for arthritic pain, because she gave it to a person to try who had general pain. Another new service was traditional massage, which might be a useful way to help patients. Furthermore, she explained about the primary care unit (PCU). There were six persons in each unit; one doctor and five nurses. They would visit patients at home and give domiciliary health services. She thought this unit might be helpful for patients with rheumatoid arthritis also.

**Tina’s experience: Emerging codes**

The codes emerging from Tina’s account were: noticing more females have rheumatoid arthritis; noticing joint swelling and deformity; noticing history of illness; noticing joint stiffness; noticing joint pain; noticing doctors’ treatment relies on medications; endorsing the use of analgesic; giving psychological support; giving medication; soaking in warm water; using herbs; advising how to rest; advising on exercise; advising good food choices; advising to relatives how to care; giving relaxation activities; comparing suffering; recognising no real problems in managing pain for patients with rheumatoid
Noticing more females have rheumatoid arthritis

Not many (patients with rheumatoid arthritis I’ve seen in my experience). I almost remember all the patients, because there were so few patients that were admitted, especially in the last two or three years. Probably not more than 50 patients. Most of them were females ... I think I saw more female patients with rheumatoid arthritis than male. I remember that I saw only one male patient with rheumatoid arthritis.

Noticing joint swelling and deformity

They had various symptoms, such as swelling in the knuckles and joint deformity.

Noticing history of illness

I remember one case. She was on the financial staff here. She got treatment from when she first had rheumatoid arthritis. She has not been readmitted for a long time, but she still takes medication and goes to work everyday.

Noticing joint stiffness

She had joint stiffness in many parts of her body too.

Noticing joint pain

They had pain in their knuckles and wrists. When they were admitted, they always had pain in many of their joints. After we read their case histories or talked with them, we found that they had pain in all their joints, such as their knuckles and knees. If they were admitted, it meant they had severe pain and weren’t able to do things.

Noticing doctors’ treatment relies on medications

After they were admitted, we let them rest, take medication, and consult the occupational or physical therapy departments for the next step of the treatment. Some patients who had pain in their knuckles might be treated with paraffin. Most of the patients were
admitted to get some rest, take medication, and be observed for any side effects after they’d taken the medication. Some patients had severe wrist pain although they already took medication.

**Endorsing the use of analgesics**

*Patients were usually admitted with chronic pain. Some patients looked disheartened. I mean, they knew that pain and suffering are a part of their illness, but they tried to find a means to get better. I don’t know what happened to them when they saw the doctors. The doctors told them whether they could treat the rheumatoid arthritis, and whether the pain would disappear. It’s impossible for the rheumatoid arthritis and pain to disappear, but they can get treatment to relieve it. I always told them that everything would be better after they’d taken the medication, and then they weren’t disheartened I knew the pain would lessen after they’d taken it for a while. Then they would be able to work or do other things that they wanted to do. In my experience, I’ve never seen patients with rheumatoid arthritis who’ve had severe pain.*

**Giving psychological support**

*We talked with them, gave them psychological support ... Pain is all encompassing for them. They always have both pain and feelings of frustration, because it’s never cured completely and it’s pain inside their joints. I usually talked and encouraged them.*

**Giving medication**

*We gave the medication as the doctors had ordered ... Firstly taking medication. That they should take medication immediately after their meal and not on an empty stomach. I emphasised this point a lot, because they would still get side effects even though they took gacida.*

**Soaking in warm water**

*I also used to let them soak in warm water. But they could only soak their hands or feet for a while, because the water would get cold. It could relieve their pain a little bit, but it couldn’t make their pain disappear. After they’d soaked their hands or feet, I applied a lotion to stop their skin from drying.*
**Using herbs**

Pharmacists in this hospital have only studied for two or three years and produced one product for relieving pain. They told me that they used herbs as the main ingredient, but I can’t remember how many ingredients were in this product. Any patient who had pain could use it, not only patients with rheumatoid arthritis. They gave it to me and a lot of patients tried it. It’s very expensive. One dose is 250 Baht ($ A10.42). It comes in a small bottle and it’s the same price as votaren gel. I got some and gave it to my neighbour who had pain in his knees to try. He felt better, but I’ve never tried it with my patients.

**Advising how to rest**

The second point is rest. If they had pain, they should restrict their activities or minimise the use of the joints where the pain was. I didn’t advise them to exercise or use their joints too much, because their joints would degenerate faster ... It depends on the parts of their bodies that have pain. Most of them had pain in their knuckles and wrists. One patient that I saw had pain in her ankles. This was one case that I failed in advising her (laughed). She worked in the market, and her work involved a lot of walking. I advised her that she should not use her joints too much and not put weight on her feet. She didn’t believe me. Her splint was damaged every time she was admitted. She said that she couldn’t stop working, because she had no money. As you know it’s in the Thai nature to keep earning money for our families and ourselves. In this case, I knew it was impossible for her to stop working and to avoid using her hands too much. It was her job. If this patient were rich or retired, she could stop working and not do anything.

**Advising on exercise**

Yes (exercise will make patients’ joints degenerate faster). I think it’s unrealistic to advise them about things that they can’t do. For example, it’s useless to advise them to exercise when they have no time even to get some rest. They really forget about it. Most of them that I saw were workers and low income earners. They couldn’t stop working. If they stopped work, they wouldn’t have any money.
Advising good food choices
If they have rheumatoid arthritis with other diseases such as hypertension, I would advise them which food is better for them. In my view, patients with rheumatoid arthritis can have any kind of food. No food is harmful to them ... I think they might be thinking about gout. For gout patients, they shouldn’t have too much of this, because it’s a high uric acid food.

Advising to relatives how to care
I told the relatives who looked after the patients in the ward to encourage them too. I often saw patients with rheumatoid arthritis admitted, who were not accompanied by relatives. They came here alone. I often asked them how they were after taking the medication and getting some rest. They told me that they felt better than when they stayed at home. It should be like that, because they always work if they are at home. They can get more rest here.

Giving relaxation activities
I didn’t set up any motivational group or any special activities to encourage them. I gave them things to do for relaxation.

Comparing suffering
Sometimes I showed them some patients, who were worse off than they were. This would make them feel better. I wanted them to know that they weren’t the only ones who had pain, and many patients had pain much worse than theirs. I’m able to do that, because my ward is a general orthopaedic ward. Patients can see a lot of different kinds of orthopaedic patients, such as patients who are injured in accidents.

Recognising no real problems in managing pain for patients with rheumatoid arthritis
There were no real problems for the nurses, because patients with rheumatoid arthritis were admitted while they could still take care of themselves and do things for themselves. They could walk although not well. The nurses weren’t burdened with more tasks. We regularly observed them and checked whether they looked better or not. So
doctors rarely admitted patients with rheumatoid arthritis to the orthopaedic ward, because they didn’t have many symptoms, and usually got some rest when they were admitted. For those taking a physical therapy course, it is probably more convenient for them to come from home rather than be admitted. They could come from home, take the physical therapy course (PT) for an hour, and go back home to work or do something else. I think that’s one reason why we hardly see patients with rheumatoid arthritis in the orthopaedic ward.

**Using hot compresses to relieve pain**

During severe periods, I mean when they are in severe pain. If they are in the ward, nurses can apply hot compresses for them. Their relatives can do it for them too, because it’s easy and there’s some equipment available to use. Some patients used to use herb compresses. Someone told me that they put cooked rice, while it was still hot, in a cloth, wrapped it, and used as a hot compress. It’s impossible to find the herbs to apply hot compresses in the ward.

**Using traditional massage to relieve pain**

I might be mistaken, but I think traditional massage is offered here. It sounds good and I think it could help patients, because they use curcuma, cassumunar and other oils. It’s good for their morale too. In my opinion, the cassumunar oil could also relieve pain. This service has only been operating for nearly a month. There are many services here such as massage, hot compresses, and also foot massage. It’s a good way to help patients.

**Advising relatives to encourage the patients**

While patients are in pain, their relatives should encourage, take care of them, and ask them about the pain. In fact, everyone wants someone to encourage them. If someone just asks about them and looks after them, they will feel better. On the other hand if no one asks them how they are or how their pain is, it’s worse than if no one takes care of them. So nurses should advise the relatives to encourage, look after and ask patients about their pain frequently. Of course, asking can’t relieve the patients’ pain, but it
eases their minds. So nurses don’t forget to advise them that their relatives should do things for them while they have pain. I think this is all I can tell you.

**Perceiving differences in education**

I think there are some effects on nurses. Those patients with rheumatoid arthritis who have enough money usually care for themselves, they get follow up treatment, see the doctors every one or two months, and have their blood tested for its rheumatoid arthritis titre. They take care of themselves continually. Some patients often attend the conferences about rheumatoid arthritis that the hospital arranges. They’re not held here, but in other hospitals, such as the big hospital in Bangkok. On the other hand, there’s the other group of patients with rheumatoid arthritis who ignores their condition and doesn’t want to know anything about rheumatoid arthritis. They only go to the hospital when they have severe pain. The educated patients always make a point of caring for themselves. But some patients don’t and they let their condition deteriorate. They take medication when they are in pain and stop taking it when they feel better. After that, they continue to work and don’t show any interest in looking after themselves when anyone reminds them.

**Valuing the follow up treatment**

Now there is a new department here, but we’ve just set it up. It’s called the primary care unit or PCU. It’s like an urban community unit. There will be at least one unit for one village, one PCU per 10,000 head of population. The staff members have responsibility for their own villages. They will take care of everyone in the village in regards to their health. Every village will have a PCU unit in the future, because it’s a part of the health policy that we called the “Project of Baht 30 All Medical Treatment”.
Rin’s experience

Background

Rin was 34 years old, a mother and a registered nurse. She had degree in nursing and attended some conferences on orthopaedic care, but not specifically in rheumatoid arthritis. In her 11 years experience, she met more female patients with rheumatoid arthritis than male, who were middle aged. They were often admitted to hospital with joint swelling and pain for a long time. She said there were many things that affected her feelings about patients with rheumatoid arthritis. Firstly, rheumatoid arthritis was rare and the patients who were admitted to her ward were trauma patients from accidents with bone fractures, as emergency cases. She paid more attention to emergency cases than rheumatoid arthritis. She was not able to explain clearly how she felt, but she usually treated pain with medication.

Rin always gave them supportive nursing care. She assessed their level of pain, the parts of their bodies that had pain, their daily activities, the joints they frequently used, their capacity to do activities, and the relatives who could take care of them during the day. After assessing and giving medication, she informed the doctors if the patients still had pain. She also advised them about the appropriate food. She gave psychological support to them as well. She talked to them frequently, and told them that there were many patients who suffered more than they did. She said that nurses should use some humour with patients, otherwise they will always only think about themselves. Furthermore, she talked to their caregivers, encouraged relatives to give the patients psychological support, and gave them family health education. She did not forget to tell the relatives to feel free to report pain.

Regarding problems in pain management, she recognised the problems that came from nurses’ lack of knowledge and experience, that made nurses unable to give adequate nursing care. The difference in nurses’ confidence and patients’ non-complaining attitude were the problems also. There were other problems, such as poor nurse-patient
ratios, poor communication between patients and nurses, and mistakes in a health brochure. Therefore, she suggested that nurses who worked in orthopaedic wards should have specific experience in caring for patients with rheumatoid arthritis. Teachers from nursing colleges need to teach ward nurses, and shared experiences with them about new innovations and knowledge. She still thought the other thing that could help nurses to give nursing care was experience.

**Rin’s experience: Emerging codes**

The codes emerging from Rin’s account were: noticing more females have with rheumatoid arthritis; noticing joint swelling; noticing joint pain; noticing hand deformity; paying more attention to emergency cases, not with rheumatoid arthritis; giving supporting nursing care; recognising lack of knowledge and experience; fixing pain with medication; perceiving non-complaining attitude is Thai nature; perceiving the problem is a difference in confidence; giving medication; being unable to give adequate nursing care; giving psychological support; informing the doctors about pain; talking to patients with humour; comparing suffering; using relatives to give psychological support; assessing; giving advice; advising on food choices; talking with the caregivers; telling the relatives to feel free to report pain; giving family health education; recognising the past experience can help nurses to give nursing care in the future; recognising lack of knowledge; needing more information on nurses’ education; confirming lack of experience; confirming communication problems between patients and nurses; confirming poor nurse-patient ratios; needing specific experience; recognising mistakes in health brochures; and recommending nurses themselves improve their knowledge and experience.

**Noticing more females have rheumatoid arthritis**

*I met more female patients than male. They were middle aged. I mean they were mostly adults. I saw only a few patients who were teenagers.*
Noticing joint swelling

They were often admitted with joint swelling. They had swelling in the small joints, such as the knuckles and had had pain for a long time ... They had pain and swelling, but not much hand deformity.

Noticing joint pain

Some patients had pain in the big joints too. It’s in the nature of Thai patients that they don’t see doctors and try to tolerate it when they have a little pain. They only go to the hospital when every medicine they’ve tried doesn’t relieve their pain.

Noticing hand deformity

In the patients that had hand deformity, their hand function was not good. They couldn’t form a fist or grasp.

Paying more attention to emergency cases, not rheumatoid arthritis

There are many things that affected my feelings about patients with rheumatoid arthritis. Firstly, rheumatoid arthritis cases are rare. They’re only one or two percent of cases in Thailand. Most orthopaedic patients who were admitted here were trauma patients from accidents and bone fractures. They were emergency patients. It was different when patients with rheumatoid arthritis were admitted. When these emergency patients were admitted to the ward, we had to give them specific nursing care and look after them more intensely than other cases.

Giving supporting nursing care

Secondly we only needed to give supportive nursing care to patients with rheumatoid arthritis when they were admitted, because they could do things for themselves. We cared more for those patients that didn’t get better after taking the medication and those patients who were anxious.

Recognising lack of knowledge and experience

Thirdly, when I’d just graduated from nursing college, I only saw a few patients of rheumatoid arthritis. That meant I had little knowledge or experience with it. I didn’t
know how to care for them other than what I knew from college. Therefore, I was lacking in experience ... Finally, I now have a lot of experience and knowledge. I’m ready to give them full nursing care, but fortunately no patients with rheumatoid arthritis have been admitted to the ward for a long time. So unfortunately for me I can’t learn from these patients. In the cases where the patients were anxious, I talked with them and informed the doctors that they weren’t getting better even though they’d taken medication. I hoped the doctors would explain to them what rheumatoid arthritis was or change the dose for them.

**Fixing pain with medication**

I might not be able to explain clearly how I felt. When they complained about their pain, we usually supported them by giving medication more than any other way. The medication was given on the doctors’ orders as set out on their charts or PRN. This meant that we might overlook trying to understand them or think about they were feelings.

**Perceiving non-complaining attitude is Thai nature**

Another thing is the Thai nature. Many patients don’t dare to tell the nurses and doctors when there is something wrong with them. They worry that we might scold them. They think it is better for them to keep quiet until they can’t tolerate it any more.

**Perceiving the problem is a difference in confidence**

And another issue is the general character of society. Patients who were not government service officers never complained or complained very little about their illnesses. On the other hand, the patients who were government service officers or educated people were confident about telling us how they felt and claimed for everything that they could get under patients’ rights. So many people think that they get better nursing care than those with a lower education.

**Giving medication**

They gave them non-steroidal anti-inflammatory drugs (NSAIDs) and advised them to get some rest. I read some books that said little about treatment from the physical
therapy department (PT) for patients with rheumatoid arthritis and pain. The doctors usually gave them medication, let them rest, and stop using their joints while they were pain. They rarely operated on these patients. They performed the operation more for gout patients. I remember there were a few patients that had operations. It was so rare I’d almost forgotten there was an operation for patients with rheumatoid arthritis too. Patients with rheumatoid arthritis usually got pain in their small joints and had swelling. Only a few patients had bone deformity. They got better after they’d taken medication for a while. When they were discharged they would go for a follow up visit at the outpatient department (OPD) ... We made sure they had NSAIDs as set out on their charts, and gave them the analgesic drugs for PRN that they wanted ... We recorded how often they took analgesic drugs, and how much pain they had, and whether they still had pain even after they’d taken this medication every four hours. We discussed what to do for them ... Nurses would give them medication and observe how they were after they’d taken it.

**Being unable to give adequate nursing care**

We rarely did fomentation or applied hot compresses for them ... There were two reasons why I rarely did these things for patients. Firstly, I wanted them to take the medication before I gave other nursing care. The second reason was my having little knowledge or experience with rheumatoid arthritis and orthopaedic diseases. So I couldn’t give complete nursing care. I was both an incharge and a leader at the same time. This meant I had to take responsibility for everything in my ward and I let my nursing care slip. At that time, I didn’t dare to assign some of my jobs to other staff members. I worried that they couldn’t do the job properly.

**Giving psychological support**

We felt supporting them psychologically and telling them the reason for their pain was important. It was the degeneration of the joints. It produced this kind of pain.

**Informing the doctors about pain**

We would inform the doctors if they still had a lot of pain.
Talking to patients with humour

There were a few patients, who complained about being fed up with this disease. Most of them said that they’d had it for a long time and had to get continuous treatment. I think I’m usually a humorous person. I told them they were lucky that they only had pain from rheumatoid arthritis and not other diseases such as bone fractures. Getting treatment for one or two days wouldn’t relieve the pain. They had to get continuous treatment and try to be patient. I made sure they learnt through humour ... Nurses have to use some humour with patients, otherwise they will always only think about themselves ... I gave them examples of comparisons between themselves and severe cases.

Comparing suffering

I talked to them frequently and told them that there were many patients, who suffered more than they did. Their anxiety would be reduced, and they thought about the many patients who suffered more than they did.

Using relatives to give psychological support

Most Thai patients have many relatives to visit them while they’re in the hospital. It makes them feel good to know that their relatives care about them.

Assessing

I assessed them for many things. First was their level of pain. Second was which parts of their bodies were painful. The third thing was the daily activities that they had to do when they were admitted. Fourth was which parts of their bodies they had to use frequently. Fifth was their capacity to do things. And the final thing was how many relatives they had who could care them during the day.

Giving advice

After I’d assessed them, I advised them to stop using the parts that were painful for a while and let them do things that they could manage.
Advising on food choices

In my opinion, rheumatoid arthritis is a chronic disease that we can give conservative nursing care for. So we advise the patients to eat appropriate food ... We used to ask them what food they wanted to eat and explain to them which food they could have, because they couldn’t have every kind of food they wanted. No one food is harmful to them. We usually checked the food they had to be sure it wasn’t harmful, and gave them adequate calories for each day. Some patients believed that some foods were not suitable for rheumatoid arthritis sufferers. If they had other food besides the hospital diet and they were fine then that was fine. We allowed them to do that. Nurses should observe this when they do their rounds ... We couldn’t provide specific nutrition programs to the catering department. We told the dietician to prepare a general diet for these patients and then assessed how much these patients, could have at each mealtime.

Talking with the caregivers

I usually talked to the relatives, who looked after the patients. I rarely talked to the relatives, who only visited. Everything related to the level of pain. Their relatives weren’t involved much if they only had moderate pain. They trusted our nursing care and treatment.

Telling the relatives to feel free to report pain

I usually told them to feel free to tell me at anytime if their loved one had pain, especially in the early morning and at night. They were reluctant to tell the nurses, because they might get angry them especially at these times. The reason I encouraged them to do this was, because they were with patients continually and so were aware of their needs. Nurses sometimes neglected to do their rounds and were preoccupied with emergency cases. After that, I told them about the things nurses would do in terms of giving medication to the patients, and informing the doctors when the patients were not getting better after finishing their medication.

Giving family health education

The other thing that I spoke to them about was preventing the patients from using their joints too much. I said this in a loud voice so the patients could hear as well. I wanted
them both to share the knowledge. After they’d shared their perceptions, they would understand the same things and feel good about it. The relatives understood their loved one and their loved one understood their relatives. It’s a good thing for nurses to be sure that they give nursing care to both patients and family.

**Recognising that past experience can help nurses to give nursing care in the future**

When I’d just graduated I was like a bird just learning to fly. I didn’t know how to give patients the best nursing care or health education. Now I have a lot of experience in how to care for them. I often reflect on why I didn’t do this or that in the past, and why I didn’t think more about who the important person was for the patients. Although I now know my mistakes, I can’t go back to the past and repair the damage. So I have to do things better in the future.

**Recognising lack of knowledge**

There were some rules that made me not dare to give the patients health education, such as a prohibition on showing X-Rays and some documents to the patients. If I were the patient, I would want to know what was happening to me and what disease I had. It showed me clear information about the patient. For example, I could see which parts of the patient were fractured from the X-Ray film. So I could explain it to them and give them the right health education. But I couldn’t do that for patients with rheumatoid arthritis, because I didn’t have enough experience or skill to see the X-Ray of patients with rheumatoid arthritis. I couldn’t give them the best health education. I could only give them a limited amount. I would like to keep learning more and more, so that I could apply this knowledge to improve my nursing care. Then I could pass on my knowledge to the patients. Now I give nursing care and health education that’s limited by my experience and the advice I get from senior nurses and some doctors. I feel that I don’t know much about new innovations and technology. Some doctors know, but they don’t talk to us. When the orthopaedic conferences were arranged, there were topics about how to use orthopaedic medication. There was no updated information about nursing care. Regarding orthopaedic textbooks, there were a few but they emphasised surgery.
Needing more information on nurses’ education

In the ten years since I graduated, I know that our nursing care has changed. Sometimes I feel frustrated when I supervise nursing students. I’m not sure if what I’m teaching them is the same of what they learn at college. It would be better if the teachers told us, and shared experiences with us about new innovations or other knowledge they have. Because the teachers study more than nurses do. It would be good for nurses and would lessen their confusion when they supervise nursing students … In my view, the first thing that I need is an awareness of new things, such as updated information and innovations, and especially an awareness of things that are different from what’s in the textbooks. I would like to see orthopaedic nursing conferences arranged frequently.

Confirming lack of experience

The first problem was my lack of experience. I have to blame myself first. I’d had little experience, and sometimes couldn’t manage the unexpected problems very well. I was only trained for a short time before the seniors appointed me as Charge Nurse.

Confirming communication problems between patients and nurses

The second problem was the communication between patients and nurses. The patients were afraid to tell us when they were in pain or when there was something wrong with them. Nurses cared for and looked after the trauma cases more than the rheumatoid arthritis cases. They thought that the patients who had rheumatoid arthritis could get treatment from the OPD. It was unnecessary that they be admitted to the ward. They weren’t sympathetic when patients with rheumatoid arthritis were admitted to the ward. They only gave them the medication as set out on their charts. Most of the patients usually got better after they’d taken medication. So nurses neglected pain management for them.

Confirming poor nurse-patient ratios

Finally, the ratio between nurses and patients was not equal. Now this problem has been solved by cutting the size of the ward, and adding more specific departments, such as the orthopaedic ward for children and two orthopaedic wards for men. Nurses have less
responsibilities than in the past and have time to look after patients more, but unfortunately there are now no patients with rheumatoid arthritis in the hospital.

**Needing specific experience**

Secondly, I would like to see the nurses who work here have specific experience in caring for orthopaedic patients. In my past, I only learned how to care for trauma cases from my seniors. We only had a chance to talk about the orthopaedic diseases when these patients were admitted. And that wasn’t often.

**Recognising mistakes in health brochures**

Thirdly, I used to see mistakes in how the health brochures were written. Someone was careless. They selected some information from the textbook and put it in the brochures. They didn’t proof them again before gave them to the patients. This led to the patients and those with less knowledge about this being confused. Someone made the brochures without considering the facts from a real life situation. The readers couldn’t get the information that they needed to apply to their own lives. So the patients were disadvantaged by us.

**Recommending nurses themselves improve their knowledge and experience**

Regarding the doctors, their emphasis was on treatment and surgery. So the nurses had to emphasise nursing care. Some nurses didn’t meet their responsibilities. They took on the doctor’s role. Problems would occur from this too ... Finally, we nurses should improve and develop ourselves before anything else. Nurses shouldn’t be satisfied with just the things they learnt from their schools. They have to continue to learn by themselves and ask others who have more experience. In my ward, there are internal academic conferences which are arranged when we see an interesting incident. We need to find a leader to lead the conference and share both knowledge and experience.
Summary

This chapter introduced the nurses’ experiences, in relation to their backgrounds and emerging codes. The nurses described caring for patients with rheumatoid arthritis especially when they had pain. The individual codes that emerged were collated into categories, which are presented in Chapter Ten of this thesis.
Chapter Eight: Emerging Theory:
Patients’ Perspectives of Rheumatoid Arthritis

Introduction

This chapter describes the analysis of patients’ perceptions. The description includes the codes, categories, concepts, and core social processes for patients’ experiences of rheumatoid arthritis.

Patients


Patients’ category: ‘Describing negative feelings’

The codes emerged from patients’ accounts of ‘feeling depressed and disheartened’, ‘feeling anger’, ‘losing of self-esteem and confidence’, and ‘feeling frightened, worse and stressed’. These codes formed the category of describing negative feelings.

The code ‘feeling depressed and disheartened’ was exemplified well by Da, who said:
I felt depressed when I couldn’t do things by myself. I felt I didn’t get what I wanted when somebody else did things for me. I was very depressed that I couldn’t have food that I liked.

The code ‘feeling anger’ was described in Tim and Wing’s accounts. Tim said:
I watched a TV program that presented a patient with rheumatoid arthritis, who used steroids and her illness disappeared. It was unbelievable and it made me wonder why. My hands and feet used to be very beautiful. They became worse, and I couldn’t flex them after I had the operation. Everyone thought I was fine when they saw me at work. They wouldn’t know I was a patient with rheumatoid arthritis if they didn’t see me walking.

Wing also said:
Yes, because I needed to (feel anger) until I was completely cured. I suffered very much when I had pain. It was all right if I could lie down. But it was painful if I moved my body. It made me suffer, but not die. Sometimes I became angry not knowing why it wouldn’t disappear. Anyone who has the disease will understand this.

The code ‘losing of self-esteem and confidence’ was exemplified by Wing, who said:
My self-esteem diminished until I almost had none, because I couldn’t do things for myself. I thought about this a lot. I couldn’t help my family. I was like someone who had lost heart and had no interest in doing anything. I used to lie down on a long bench in front of my house. I saw my neighbours going to work. I felt sad. I wanted to go to work with them. I thought about the time when I could work and then about this time that I couldn’t. I used to cry. I think I cried more than anything.

Ta described the code ‘feeling frightened’ in how she worried about care. She said:
Of course. I worried about whether I would be cured or not. I didn’t know what to say after I took the medication. Sometimes I thought I was no better, and that I still had pain. On the other hand I looked better after I took it.

The code ‘feeling worse’ was expressed by Doom. She said: “I felt worse”.
Ead explained the feeling life is nothing without mobility by saying this:
I feel that my life is nothing when I can’t do anything at all. I can’t even grasp or tighten my hair. The pain is more than I can tolerate.

Jai and Boon expressed their stress in different ways. Jai felt that:
I always told my children off everyday. It was just the general thing that happens in every family. They sometimes stressed me out, but I never told anyone if I had pain (laughed).

Boon described attempting suicide:
I know that when I was in pain it was so severe that I didn’t want to live. I suffered everyday when I had it. I tried to commit suicide by hanging myself, taking poison, and jumping into the river, but I didn’t die.

A summary for the codes within the category of describing negative feelings is shown in Table 8.1.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling depressed</td>
<td>Describing negative feelings</td>
</tr>
<tr>
<td>Feeling disheartened</td>
<td></td>
</tr>
<tr>
<td>Being stressed and depressed when in pain</td>
<td></td>
</tr>
<tr>
<td>Becoming depressed, disheartened and stressed</td>
<td></td>
</tr>
<tr>
<td>Crying with pain</td>
<td></td>
</tr>
<tr>
<td>Feeling anger</td>
<td></td>
</tr>
<tr>
<td>Losing self-esteem</td>
<td></td>
</tr>
<tr>
<td>Feeling loss of self-confidence</td>
<td></td>
</tr>
<tr>
<td>Feeling frightened</td>
<td></td>
</tr>
<tr>
<td>Worrying about cure</td>
<td></td>
</tr>
<tr>
<td>Being scared about rheumatoid arthritis</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.1 Category 1: Describing negative feelings
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling worse</td>
<td>Describing negative feelings</td>
</tr>
<tr>
<td>Feeling life is nothing without mobility</td>
<td></td>
</tr>
<tr>
<td>Feeling stressing</td>
<td></td>
</tr>
<tr>
<td>Attempting suicide</td>
<td></td>
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</tbody>
</table>

Table 8.1 (continued) Category 1: Describing negative feelings

Patients’ category: ‘Feeling unsure and dissatisfied’

The category of ‘feeling unsure and dissatisfied’ included the codes of ‘feeling unsure about staff, treatment, foods, operation, relief pain options, and exercise’.

Boon expressed being dissatisfied with some nurses and doctors, when she said:

*I wasn’t satisfied with the nurses when my blood vessels broke when they gave me injections. Some doctor manipulated my ankles with too much pressure. They should know that I had rheumatoid arthritis and it put me in a lot of pain. Someone asked me about when I could walk. I wanted to walk as soon as I could. I tried to walk around the bed, but I couldn’t do that much if they were always twisting my ankles.*

Doom was one of patients, who was unsure about treatment. She said:

*I took the medication that the doctor gave me, some herbs, and fomentation ... I’m not sure which one was the best, because I felt better after I took only the medication that the doctor gave me in the first week, but I had pain again in the second week.*

Dara wondered about poultry. She said:

*Should patients with rheumatoid arthritis avoid having poultry? ... The doctor told me that I could have it ... I don’t have it. My neighbour said that it’s harmful for patients with gout too. The doctor didn’t prohibit me from having it, but I didn’t want to take the risk and so didn’t have it.*
Dara also wondered whether an operation could relieve her pain. She explained:

*He (my neighbour) told me that I should hurry and get treatment, because I was young and maybe the doctor could operate on me. I saw many doctors, but no one told me about the operation. They said that it wasn’t necessary for me as I was only 37 years old. It’s too young for that operation. So, I wondered what a suitable age would be for me to get the operation (laughed). I talked with my neighbours about this. They told me that it’s better to have the operation while I was younger. Young folk have better immunity than older people.*

Related to relief pain options, Da and Dara were unsure whether religion can relieve pain. Da said:

*I thought only my joints and body were swollen. I had to sit with my legs extended instead of sitting with my knees bent. The doctor told me I should go to the temple and follow the Buddha's teaching. I knew someone whose tendons and ligaments in his knee had contracted. His condition disappeared after he followed the Buddha's teaching. I was not sure I could do that, because I still killed the fish when I cooked it. I set that I had to practice Buddhism for five days or one week.*

Dara agreed with Da. She also said: “(Laughed) I don’t think so. I don’t believe that that (religious activities and muscle relaxation) can relieve pain.”

Ta wondered about exercise by asking this: “*How I can do that (getting the right treatment and taking care myself)? What exercise can I do in the morning?*”

A summary for the codes within the category of feeling unsure and dissatisfied is shown in Table 8.2.
### Table 8.2 Category 2: Feeling unsure and dissatisfied

#### Patients’ category: “Noticing causes of pain”

The category of ‘noticing causes of pain’ involved the codes of ‘noticing causes from massage, weather, work, mobility, position, chemical, and karma’.

Boon noticed massage can cause her pain. She said: “No one could massage me. If they did, I had a lot of pain the next day.”

Phit felt cold weather affected pain. She recounted:

*When the cold weather came, I was in a lot of pain and I felt hot and got the sweats. Last night my daughter turned on the electric fan. I had pain late at night, because the weather became cold then. I was in such pain that I had to take a bath.*
Working caused pain, as Ead said:

*I found that the pain increased when I worked hard. For example, yesterday I sat on the ground working with my knees bent; my feet became swollen after a while ... My rheumatoid arthritis is serious in my wrists, ankles, and knees. Today the symptoms are severe, because I have been working hard for the last two days, and I was doing the laundry this morning. I realise that it’s a serious matter. The doctor gave me paracetamol, but I didn’t want to take it, because he said it could have side effects.*

Regarding mobility in Boon’s and Dara’s accounts, Boon noticed changes in stepping:

*At the beginning, he (my husband) couldn’t go anywhere. If he went out, my son would call him to come back home, because I couldn’t do anything by myself. At that time, my house had only one floor and wasn’t high from the ground. It was easy to step up from the ground, but I couldn’t even do that. It was painful if I did. No one could touch my body. It looked as though I was pretending, and needed someone to look after me all the time. I didn’t know why I was like that.*

Dara recognised walking caused her pain. She said:

*I rode my niece’s bike to go to a grocery shop that’s near my home. It would take too long if I walked. There was no problem when I rode there, but I had pain when I walked. While I had pain, I exercised my legs...lifted them both left and right side. I lifted them but not too high.*

Tim noticed her pain came from inadequate seating. She said:

*While I’m talking to you, I have no pain. I get pain when I sit in the wrong position or sit on an unsuitable chair with no support that I would fall into.*

Meanwhile, Phit thought she had rheumatoid arthritic pain from chemicals when she was hairdresser. She described:

*I’ve had pain since my first child studied in Prathom three (Grade three) and I got a lot of pain when my youngest child was very young. I’d never thought about swelling being a symptom of rheumatoid arthritis. I just thought the air inside my body wasn’t circulating well. My ankles became swollen too. I was a hairdresser before, and I*
sometimes thought I had swelling from the chemicals I used when I dressed the customers’ hair ... When I first got pain, I was a tailor and a hairdresser. I’ve dressed hair since I was 10 years old. I couldn’t roll the customers’ hair when I was in pain. I didn’t know the cause was rheumatoid arthritis.

Many patients believed their pain came from karma. Boon exemplified this by saying:

So I still get pain from rheumatoid arthritis now. I need to spend time paying for all of my sins. This means that I have to keep for my word when I say things. I don’t know how long I’ll have to do this. Regarding my niece and nephews, their parents let them be with me. Maybe I am in their debt from the past. So I will nurture them as best I can ... They should make up their minds to accept their illness. They can think that having rheumatoid arthritis is, because of their karma, but why did they have rheumatoid arthritis when there are many diseases in the world. It’s lucky that they don’t have cancer. The doctor joked with me that I was not a real patient. If I were a real patient I would have cancer. I told him that he shouldn’t challenge me, because I’ve still had any more diseases.

A summary for the codes within the category of noticing causes of pain is shown in Table 8.3.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suggesting cause of pain</td>
<td>Noticing causes of pain</td>
</tr>
<tr>
<td>Noticing massage can cause pain</td>
<td></td>
</tr>
<tr>
<td>Recognising body effects from the weather</td>
<td></td>
</tr>
<tr>
<td>Feeling cold weather affects pain</td>
<td></td>
</tr>
<tr>
<td>Recognising severe pain in the winter</td>
<td></td>
</tr>
<tr>
<td>Noticing cold weather can cause pain</td>
<td></td>
</tr>
<tr>
<td>Noticing cold weather is related to pain</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.3 Category 3: Noticing causes of pain
Table 8.3 (continued) Category 3: Noticing causes of pain

Patients’ category: ‘Noticing body changes’

The codes emerged from patients’ accounts of ‘losing weight’, and ‘having joint problems’ formed the category of noticing body changes.

Boon explained her weight loss by saying:
When I had rheumatoid arthritis, I lost weight. I couldn’t eat much, and my body became smaller ... I lost weight ... from 60 kilograms to 50. Sometimes my weight was 47 kilograms if I was in severe pain.

Boon also explained her feeling of grinding joints, while Dara explained feeling stiff joints in the morning. Boon said: “When I tried to stand, I felt something was wrong with my knee joints. They seemed to grind against each other”.

Dara said that: “I felt it change especially in the morning when I had more pain. My legs were stiff. I couldn’t get out of bed”.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting rheumatoid arthritis from working hard</td>
<td>Noticing causes of pain</td>
</tr>
<tr>
<td>Noticing increased pain from hard work</td>
<td></td>
</tr>
<tr>
<td>Recognising pain is related to working hard</td>
<td></td>
</tr>
<tr>
<td>Noticing stepping can cause pain</td>
<td></td>
</tr>
<tr>
<td>Recognising walking can cause pain</td>
<td></td>
</tr>
<tr>
<td>Noticing pain with inadequate seating</td>
<td></td>
</tr>
<tr>
<td>Thinking the causes of illness would be chemicals</td>
<td></td>
</tr>
<tr>
<td>Believing in karma</td>
<td></td>
</tr>
<tr>
<td>Being unsure about karma</td>
<td></td>
</tr>
<tr>
<td>Connecting pain to karma</td>
<td></td>
</tr>
</tbody>
</table>
A summary for the codes within the category of noticing body changes is shown in Table 8.4.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Losing weight</td>
<td>Noticing body changes</td>
</tr>
<tr>
<td>Becoming thinner</td>
<td></td>
</tr>
<tr>
<td>Noticing loss of appetite</td>
<td></td>
</tr>
<tr>
<td>Being unable to eat when having pain</td>
<td></td>
</tr>
<tr>
<td>Feeling grinding joints</td>
<td></td>
</tr>
<tr>
<td>Feeling stiff joints in the morning</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.4 Category 4: Noticing body changes

Patients’ category: ‘Recognising limiting effects of pain’

There are many codes involved in the category of recognising limiting effects of pain. Ta and Boon are very good examples of this category. Ta described feeling weak and unhappy as below:

*I always had pain and felt weak. I had no energy to do anything. My state of mind was worse too. I always thought about my pain ... I had pain, fatigue, and weakness more in the mornings. But I could still do some things ... I felt weak and unhappy, especially in the mornings. I didn’t want to wake up, because my whole body was stiff. It was all right at night. I had no pain then ... I woke up at 5.30am everyday. Even when I was in pain I didn’t get up late. After I had walked or done something, it would be better. On the other hand, if I stayed in bed the pain would stay.*

Meanwhile, Boon noticed restrictions from pain, saying:

*I don’t know how to explain it. When I was in pain I wanted to die and be born again, but I couldn’t. The pain was still there. I was in so much pain that I couldn’t even pick the medication up. I couldn’t do anything by myself, and it was painful when my husband held me too ... Sometimes when I didn’t take the medication I couldn’t do things, such as taking my clothes off.*
A summary for the codes within the category of recognising limiting effects of pain is shown in Table 8.5.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling weak and unhappy</td>
<td>Recognising limiting effects of pain</td>
</tr>
<tr>
<td>Noticing rheumatoid arthritis can cause flu or chills</td>
<td></td>
</tr>
<tr>
<td>Recognising life changed</td>
<td></td>
</tr>
<tr>
<td>Noticing decreased abilities</td>
<td></td>
</tr>
<tr>
<td>Describing how joint pain affects walking</td>
<td></td>
</tr>
<tr>
<td>Noticing restriction from pain</td>
<td></td>
</tr>
<tr>
<td>Being unable to do housework</td>
<td></td>
</tr>
<tr>
<td>Noticing decreased ability after having pain</td>
<td></td>
</tr>
<tr>
<td>Worrying about family’s problems</td>
<td></td>
</tr>
<tr>
<td>Noticing severe side effects from medications</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.5 Category 5: Recognising limiting effects of pain

**Patients’ category: ‘Describing symptoms of rheumatoid arthritis’**

The category ‘describing symptoms of rheumatoid arthritis’ is formed from the codes of ‘having joint pain, joint stiffness, joint swelling, and joint sprain’. Phit described her joint pain:

*I was in a lot of pain in my joints. It felt like something was preventing my hip joints from bending and stretching. At the beginning my fingers looked like a section of bamboo, because they became swollen and bigger. I couldn’t make a fist with my hands either. Now my wrists have been damaged for the last two years, because I grew the corn and chilli by myself.*

Wing and Dara noticed their joint stiffness together. Wing said:

*At the beginning, they were stiff before they became swollen and painful ... My wrists were stiff more than they were swollen. They were stiff and my blood vessels were green.*
Meanwhile, Dara also explained her stiff joints. She said: “My knuckles are all right, but before they were stiff and I couldn’t grasp anything”.

Beside this, Da noticed her swollen joints by saying:
I’ve had swelling since last year ... My wrists, joints, and face became swollen. My eyes looked red ... I had swelling at my wrists and knuckles. They became bigger. It felt as though a force inside my body was pushing them, making them swell. Now they look better ... Now my neck has become swollen. It looks like the energy from inside my body has been forced into my neck. This symptom subsided after I took the medication.

She also explained her sprained joints as below:
I felt sprained at my neck, wrists, and fingers. My neck felt the most sprained. I couldn’t look to the left and right. When I was admitted to the hospital, I couldn’t get up, because my whole body felt sprained. It felt worse if my muscles contracted.

A summary of the codes in the category describing symptoms of rheumatoid arthritis is shown in Table 8.6.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
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<tbody>
<tr>
<td>Noticing joint pain</td>
<td>Describing symptoms of rheumatoid arthritis</td>
</tr>
<tr>
<td>Experiencing painful hands and shoulders</td>
<td></td>
</tr>
<tr>
<td>Describing how arthritic pain is the worst kind</td>
<td></td>
</tr>
<tr>
<td>Noticing pain in the morning</td>
<td></td>
</tr>
<tr>
<td>Noticing joint stiffness</td>
<td></td>
</tr>
<tr>
<td>Noticing joint swelling</td>
<td></td>
</tr>
<tr>
<td>Noticing joint sprain</td>
<td></td>
</tr>
<tr>
<td>Describing historical information</td>
<td></td>
</tr>
<tr>
<td>Describing history illness</td>
<td></td>
</tr>
<tr>
<td>Describing the onset of rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Describing neck immobility</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.6 Category 6: Describing symptoms of rheumatoid arthritis
Patients’ category: ‘Accepting help’

The category of accepting help emerged from the involving of the codes ‘accepting help from family, relatives, neighbours, colleagues, and health care team’. Phit got more information about rheumatoid arthritis from her children. She said:

*My children usually found information about this disease by borrowing books and documents from their friends, who were medical students ... My children want me to get well from the pain. They always ask their friends about how to care for a patient with rheumatoid arthritis. They told me after they’d asked their friends that I couldn’t have preserved food, such as bamboo shoots, shrimp paste, and preserved fish with salt. I love these kinds of food. When I want to have them, I think about how I’ll be if I have them. I feel a bit frightened when I think about that (laughed).*

Boon explained advice given to her relative to her care. She said: “*They (nurses) told my husband to bathe me in my bed*”. Boon also explained how her neighbours helped her for food preparation as below:

*One person (my neighbour) cooked rice for me, and asked about buying me the food that I wanted ... If there was a funeral or wedding in this area, I would prepare everything for these events. Most of them used my home. Now I still do that, but I assign somebody else to do the things that I can’t.*

Doom got help from her colleagues. She explained that:

*While I worked for the local council, I often rang my colleagues when I couldn’t go to work ... At that time, I worked on a finance project ... I worked on office documents and tax matters. Sometimes I had to work outside with my colleagues ... Yes (I worked outside while I had pain). Fortunately, my employer allowed me to work in the office if I had pain. Sometimes he allowed me to stop work for a month. Sometimes I had sudden pain while I was working outside, and I couldn’t ride or control the motorbike, but I had to be patient (laughed) ... They didn’t say anything (when I stopped work for a long time), and they did my job for me too.*

Moreover, Phit described help she got from health care team. She said:
Most of them (doctors and nurses) talked to me and encouraged me. They didn’t want me to be worried about my illness. They always talked to me about things that made me happy.

A summary of the codes which formed to be category ‘accepting help’ is shown in Table 8.7.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receiving help from parents</td>
<td>Accepting help</td>
</tr>
<tr>
<td>Getting help from her son</td>
<td></td>
</tr>
<tr>
<td>Getting help from the children</td>
<td></td>
</tr>
<tr>
<td>Getting more information about rheumatoid arthritis from her children</td>
<td></td>
</tr>
<tr>
<td>Getting help from husband</td>
<td></td>
</tr>
<tr>
<td>Being advised by husband to accept rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Getting help for mobility from the family</td>
<td></td>
</tr>
<tr>
<td>Getting help for toileting</td>
<td></td>
</tr>
<tr>
<td>Getting help for household jobs</td>
<td></td>
</tr>
<tr>
<td>Advising relative to care</td>
<td></td>
</tr>
<tr>
<td>Gaining advice from neighbours for treatment</td>
<td></td>
</tr>
<tr>
<td>Getting help from neighbours for food preparation</td>
<td></td>
</tr>
<tr>
<td>Getting advice from the neighbours to visit masseuse</td>
<td></td>
</tr>
<tr>
<td>Getting help from the colleagues to adjust work practices</td>
<td></td>
</tr>
<tr>
<td>Receiving encouragement from doctors and nurses to not worry</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.7 Category 7: Accepting help

Patients’ category: ‘Getting advice’

The codes of ‘gaining advice about food, body movement, soaking in warm water, treatment, exercise, work, and rest’ are included in emerging the category of getting advice. Da gained advice about food. She said:
He (the doctor) advised me to restrict my food. I couldn’t have preserved food or pig bone. I had to have pork without the fat if I wanted it. I’ve been restricting my food since he advised me till now. I couldn’t straighten my body at that time. The doctor asked me if it hurt or if I had pain ... I had to be careful when I had food. I had to avoid having poultry ... I had everything except eel, birds, and mice ... Since I was admitted to the hospital, I’ve never had pork with fat at all. I felt dizzy and nearly vomited when I got the smell from the pig’s oil. I had food that was cooked in vegetable oil. The doctor asked what food I have now. I told him I have vegetables, beans, and pork without fat. My daughter cooks them for me.

Boon explained the advice she got about movement. She said:
They said that I should change positions while I was in pain and stay in bed, but avoid staying in the same position for a long time. They didn’t tell me how I could change positions. I didn’t want to do that when I was in pain, because I had pain all over my whole body. I had pain at my ribs too, but not much pain in the lower part of my body ... They (nurses) told me that I should sit on the bed, let my feet touch the floor, and try to walk ... After they’d taken the IV fluid line off. They told me to practice walking by holding the rail of the bed. I tried to walk. If I didn’t, they would check up on me and manipulate my ankles.

She also experienced getting advice about soaking in warm water. She said:
The doctor told me to soak my feet in warm water for 10 minutes when I was in pain. But it didn’t help me when the pain came. I needed to take the medication only.

Dara explained the advice about treatment that she got. She said:
I asked him how I’d got better. I wanted him to treat me till I recovered. He said that I had to take care of myself, and especially to continue with the right kind of treatment. If I did this, I would be better ... He only said that it’s a chronic illness.

Dara described the advice she got about exercise. She explained that:
He (doctor) advised me to exercise everyday. I sit on a chair, and lift my legs 10 to 20 times. Besides this, I have to flex and extend my feet up and down. I exercise everyday, because I want to get better.

Wing did not get any advice about work. She said:
No (they didn’t tell me what jobs I could do even though I had to work and do household jobs) ... No (they didn’t tell me whether I could work or not) ... They didn’t tell me about this (work may affect my body).

On the other hand, Ead got advice to decrease work. She said:
The doctor has been so kind to me; he always looks after me whatever sickness he believes I might have. He will order tests for me. The doctor scolded me, “Why do you always move around so much. You should not do too much work”.

Boon appreciated advice about bed rest. She said:
I’ll give you one example. A patient who has a knee operation should not walk immediately. They should have relatives to take care of them. They should stay in bed and ask for help.

A summary of the codes which formed the category of getting advice is shown in Table 8.8.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gaining advice about food</td>
<td>Getting advice</td>
</tr>
<tr>
<td>Getting advice for food choices</td>
<td></td>
</tr>
<tr>
<td>Gaining advice about food choices</td>
<td></td>
</tr>
<tr>
<td>Learning about harmful food</td>
<td></td>
</tr>
<tr>
<td>Getting some advice about body movement</td>
<td></td>
</tr>
</tbody>
</table>

**Table 8.8 Category 8: Getting advice**
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting advice about soaking in warm water</td>
<td>Getting advice</td>
</tr>
<tr>
<td>Being advised to see the orthopaedist</td>
<td></td>
</tr>
<tr>
<td>Getting advice to be compliant with the treatment</td>
<td></td>
</tr>
<tr>
<td>Getting advice to take pain medication continually</td>
<td></td>
</tr>
<tr>
<td>Getting advice from others about medications and supplement</td>
<td></td>
</tr>
<tr>
<td>Getting advice about exercise through walking</td>
<td></td>
</tr>
<tr>
<td>Getting advice about muscle strengthening exercise</td>
<td></td>
</tr>
<tr>
<td>Gaining advice about swimming exercise from doctors and occupational</td>
<td></td>
</tr>
<tr>
<td>therapist</td>
<td></td>
</tr>
<tr>
<td>Getting advice about exercise, supplements and self care from the doctor</td>
<td></td>
</tr>
<tr>
<td>Not getting advice about work</td>
<td></td>
</tr>
<tr>
<td>Getting advice to decrease work</td>
<td></td>
</tr>
<tr>
<td>Appreciating advice about bed rest</td>
<td></td>
</tr>
</tbody>
</table>

**Table 8.8 (continued) Category 8: Getting advice**

**Patients’ category: ‘Recognising treatment’**

The codes emerged from patients’ accounts of ‘recommending medication, operation, nursing care, realising doctor’ and nurse’s roles, and caregivers’. The codes formed the category of recognising treatment.

Wing confirmed the best way to relieve pain was seeing the doctor. She said:

*Finally, I stopped trying these other ways and just went to see the doctor ... I tried every way to relieve pain, but the best way was by seeing the doctor. I found that I could work within 3 years after the doctor had treated me.*

Tim described a knee treatment:

*I was fine when I had my knee punctured at the beginning. I felt nothing when I saw the doctor doing it for me. I lay down and saw him put the needle into my patella. He got the*
syringe out and left the needle in. I saw the fluid coming out from where the needle was. I felt nothing at that time.

Meanwhile, Dara realised nurses give medication:
They (nurses) didn’t do anything other than give me the medication that the doctor had ordered for me ... They always gave me the medication and then asked about my symptoms ... No (they didn’t tell me how to relax with the pain).

At the same time, Wing realised that the doctors prescribed medication. She explained:
I need them to see me a lot; as much as they can. I felt better after they’d seen me and given me some drugs. Nurses couldn’t do anything more, because they had to wait for the doctors. They didn’t give me the medication if the doctors hadn’t prescribed it.

Furthermore, Ta and Wing realised the importance of caregivers. Ta said:
My daughter (looked after me too). She’s a nurse, but she doesn’t get back home very often. There are three people in my family now; my husband, his dad, and me. His dad is very old. So my husband is the most important person, and he always looks after me ... My husband always did that (took care of me) ... He didn’t let me to do anything, especially in the mornings, for example he cooked for me in the mornings. I did it in the evenings, because my pain was gone. His dad couldn’t help me, because he’s over 80.

Phit agreed about the importance of caregivers as well. She said:
Patients with rheumatoid arthritis should have someone to look after them. Pain is the general thing for me. If I don’t get pain, it is abnormal. Now, I still get pain but not much. I feel like some things walking inside my joints. I talked with some friends who live in the north of Thailand. They told me I’ve got silk worms (laughed). I knew I didn’t have silk worms, because there was nothing on the X-ray, and silk worms make us feel itchy on the skin. I knew I had pain in my joints.

A summary of category ‘recognising treatment’ is shown in Table 8.9.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noticing taking medication continually</td>
<td>Recognising treatment</td>
</tr>
<tr>
<td>Recommending medications to stop pain</td>
<td></td>
</tr>
<tr>
<td>Recommending steroids as the strongest treatment</td>
<td></td>
</tr>
<tr>
<td>Preferring the doctor’s treatment of only taking medication</td>
<td></td>
</tr>
<tr>
<td>Confirming the best way to relieve pain is seeing the doctor</td>
<td></td>
</tr>
<tr>
<td>Describing knee treatment</td>
<td></td>
</tr>
<tr>
<td>Describing nursing care as giving medication</td>
<td></td>
</tr>
<tr>
<td>Realising doctors prescribe medication</td>
<td></td>
</tr>
<tr>
<td>Noticing doctors order analgesics and nurses give them</td>
<td></td>
</tr>
<tr>
<td>Noticing doctor prescribes medication and nurses them</td>
<td></td>
</tr>
<tr>
<td>Realising the most important caregiver is husband</td>
<td></td>
</tr>
<tr>
<td>Recommending patients with rheumatoid arthritis should have caregivers</td>
<td></td>
</tr>
</tbody>
</table>

**Table 8.9 Category 9: Recognising treatment**

**Patients’ category: ‘Appreciating care’**

The codes of ‘appreciating care from family, colleagues, and health care team’ involved the category of appreciating care.

Tim appreciated care from family. She said:

*I never thought about it (what might happen to me in the future), because my family, my husband, my children, and my relatives were good. Nothing had changed in my family. They took good care of me. My mum and my sister looked after me well ... I might have been more stressed if my family was unsupportive.*

Jai accepted help from her colleagues. She said:

*When I was in pain, I couldn’t do things, such as cooking and picking things up. I used to get pain when I worked the night shift. My colleagues helped me to put on a jacket*
when I was cold, because I couldn’t manage it ... I sometimes worked at night. I had to. Some colleagues worked for me when they were free. They knew I was not strong and should have plenty of rest. I looked pale the next day if I worked the night before. My body became yellow and green (laughed). I was weak too.

Da appreciated advice from other patients with rheumatoid arthritis. She explained that: Yes (I talked with other patients with rheumatoid arthritis when I was admitted). They advised me about the place that I should go to get the treatment. One gave me her telephone number too, but I didn’t ring her. I went to some place with my sister. I got one pot of medication and some balm there. The owner was a monk ... They told me I should go to the place they advised, because I’d just got rheumatoid arthritis.

Ead described appreciating care she got from health care team:

They (nurses) suggested the same things as the doctor. They read my case history and advised me. I told my neighbour about what the doctor and nurses advised me to do. Although my neighbour didn’t believe in it, I still did as they advised me ... Yes, they (doctors) were so good ... Only the doctor and the nurses at the hospital keep taking care of me. When I go to pick up the medication, the doctor asks me how I feel in order to adjust the medication until it’s suitable for my pain to respond to. The doctor said it was not too strong, but I found that when I took it, I felt better. So I kept taking it.

A summary of the codes within the category of appreciating care is shown in Table 8.10.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appreciating care from the family</td>
<td>Appreciating care</td>
</tr>
<tr>
<td>Being satisfied with family’s care</td>
<td></td>
</tr>
<tr>
<td>Accepting psychological help from family</td>
<td></td>
</tr>
<tr>
<td>Recommending getting good care from the family</td>
<td></td>
</tr>
<tr>
<td>Appreciating visits from son</td>
<td></td>
</tr>
<tr>
<td>Appreciating help from older son</td>
<td></td>
</tr>
<tr>
<td>Being visited in hospital by husband</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.10 Category 10: Appreciating care
### Table 8.10 (continued) Category 10: Appreciating care

**Patients’ category: ‘Expressing needs’**

The category ‘expressing needs’ emerged from the codes of ‘wanting to get better’, ‘needing more nursing care to relieve pain’, ‘wanting more care from health care team’, ‘wanting to know more about food and self-care’, and ‘requesting help to do things’.

Dara expressed her need to recover from pain. She said:

*I want to recover from rheumatoid arthritis and the pain and get well soon. So I have to take the doctor’s advice.*

Dara also said:

*I always asked the doctor how I was and how I could get better ... he said that I had to look after myself as best as I could.*

Boon wanted to know more about food. She explained:

*I think they (nurses) should make suggestions that are specific for the disease, and not just give us the same general information. I want them to advise us about the food that I can have and about care for a patient with rheumatoid arthritis. It’s not necessary to give much advice in some diseases. They should advise the relatives too, because there*
are some differences in each patient ... Yes, they should explain this to me (diet information).

Boon also explained what support she needed from nurses:
This disease will make you suffer pain till you feel that this is the mother of all pain. Some patients can’t accept it and get depressed. I would like the nurses to be patient while they support the patients. I thought most of the doctors were all right. Nurses were more important than them. Patients wanted nurses to listen to them, and give them encouragement when they were in pain and say things such as “Please stay in the hospital for few days till you get better.”

Da said she needed doctors and nurses to inquire about her health:
I needed them to ask me again how I was after they gave me the medication. I needed them to see me as frequently as they could.

Jai and Wing wanted more advice about self-care. Jai said:
I need them to advise me more about looking after by myself. When I went to the hospital, I always asked them about rheumatoid arthritis, and how I could manage it. I wanted to do the right thing when I was at home. I asked the doctor once about this, he said he couldn’t give me any more details about it. He told he would give me a document about it when he had updated information. I knew I could buy books from the bookstore to read about it, but I haven’t bought any yet. I often asked the nurses I knew. They advised me how I could handle my pain.

Wing described needing self-care advice at home:
I need them to advise what I can do when I come back home, how I can relieve the pain and what food I can have. I don’t know what foods are good for me and what aren’t. I need them to advise me about how to exercise ... I thought sleeping was the best thing for me. I needed them to advise me what I could do if my legs were painful, and what I could do to improve my joints. If they advise the patients, we might do it. It would be better if my pain was completely cured.
Meanwhile, Jai requested help to do things:

*I asked my children to do things for me ... I didn’t do things when I was in pain. I just left everything. I tried to use some parts of my body that had no pain, but normally there was pain at both my left and right sides. I asked my family to do things for me. They did what they could ... If I couldn’t I asked them to do them for me.*

A summary of every code which formed the category of expressing needs is shown in Table 8.11.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanting to continue treatment</td>
<td>Expressing needs</td>
</tr>
<tr>
<td>Wanting to recover from pain</td>
<td></td>
</tr>
<tr>
<td>Asking how to get better</td>
<td></td>
</tr>
<tr>
<td>Hoping to get better medication</td>
<td></td>
</tr>
<tr>
<td>Needing more advice about food</td>
<td></td>
</tr>
<tr>
<td>Wanting more nursing care to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Needing more information from nurses for self and husband</td>
<td></td>
</tr>
<tr>
<td>Needing more support from nurses in listening and pain control</td>
<td></td>
</tr>
<tr>
<td>Not getting more advice from nurses</td>
<td></td>
</tr>
<tr>
<td>Wanting more care from health care team</td>
<td></td>
</tr>
<tr>
<td>Needing home visiting from local health staff</td>
<td></td>
</tr>
<tr>
<td>Needing doctors and nurses to inquire about health</td>
<td></td>
</tr>
<tr>
<td>Needing advice on self care and pain control from the doctors and nurses</td>
<td></td>
</tr>
<tr>
<td>Needing more advice on how to do self-care</td>
<td></td>
</tr>
<tr>
<td>Wanting more advice about self-care at home</td>
<td></td>
</tr>
<tr>
<td>Requesting help to do things</td>
<td></td>
</tr>
<tr>
<td>Needing to cook</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.11 Category 11: Expressing needs
Table 8.11 (continued) Category 11: Expressing needs

Patients’ category: ‘Getting treatment from doctors’

The code in this category was seeing the doctor. Ta talked about returning to the orthopaedist’s treatment:

*I couldn’t tolerate the pain. The doctor who performed the operation on me, the nurses and my daughter all told me again that I should stop buying the medication myself. It was dangerous. My organs such as my liver and kidneys would be damaged. I should go to see the orthopaedist. My daughter filled out a requisition for rheumatoid arthritis medication for me. But the pain was still there. Even though my daughter told me, I still didn’t believe her. I still bought the medication by myself, because it made me feel fine, and my mind was at ease. However, I did go back to get the treatment from the orthopaedist again after the nurses kept telling me.*

A summary of this category is shown in Table 8.12.

Table 8.12 Category 12: Getting treatment from doctors
Patients’ category: ‘Getting treatment from the hospital’

The category of getting treatment from the hospital is formed from the codes of ‘attending, going, and being admitted to the hospital’. Wing continued hospital treatment again after she tried other treatments. She said:

*I still go there (hospital). I have to go there even though I am getting better. The next time I’m due to go there is in 2 weeks.*

A summary of the codes which emerged in this category is shown in Table 8.13.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending hospital</td>
<td>Getting treatment from the hospital</td>
</tr>
<tr>
<td>Going to the hospital</td>
<td></td>
</tr>
<tr>
<td>Being admitted to hospital</td>
<td></td>
</tr>
<tr>
<td>Continuing hospital treatment</td>
<td></td>
</tr>
<tr>
<td>Getting hospital treatment</td>
<td></td>
</tr>
<tr>
<td>Getting medication from the public and private hospital</td>
<td></td>
</tr>
<tr>
<td>Stopping physical therapy</td>
<td></td>
</tr>
<tr>
<td>Missing follow up treatment at the hospital</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.13 Category 13: Getting treatment from the hospital

Patients’ category: ‘Getting treatment from the others’

The codes of ‘getting medication from the clinic’, ‘buying medication from the chemist’, and ‘finding other treatments’ formed to the category ‘getting treatment from the others’. Jai talked about attending a special clinic:

*I went to get treatment at the special clinic in a hospital in Bangkok after I’d had two or three treatments from my orthopaedist. I went there, because I was worried that I might get more pain. I noticed that they gave me the same medication that I get here. It was a waste of money and time to go there. I had to arrived there at 3 or 4pm, get in a queue, pay a special fee and not get back home till 10 or 11pm. So I didn’t go there again, and I*
only got treatment here ... It (the special clinic) was a general clinic not a rheumatoid arthritis clinic, but it was open after hours. I paid 200 Baht ($A8.33) in out-of-hours fees, and claimed all of the medication fees from my workplace.

Phit bought medication from the chemist. She said:

I had a lot of treatments to relieve the pain. I used to buy medication that cost five Baht per pack ($A0.021). A shopkeeper refused to sell the medication to me, because her sister got rheumatoid arthritis and it left her body really bent like someone who’d been burnt. She advised me to see a doctor. I bought the medication from another chemist. I bought every medication that could relieve pain and bone and joint diseases. I bought medication myself until my body couldn’t straighten and my arms were bent. My body became bent after I had food that’s bad for rheumatoid arthritis too.

Beside this, patients looked for other treatments, which could relieve arthritic pain. Da explained how she sought many treatments:

I went everywhere that anybody advised me to go ... First, I took the decoction. Then I went to see the shaman. Then I went to see the doctor at his clinic in the other district. This is customary for people who live in the countryside. We take a decoction first when we get sick. Then I went to see the doctor at his clinic at the junction near here. Finally, I went to see the doctor in the hospital. The doctor here told me I had rheumatoid arthritis ... If one of these (decoction or bathe in holy water) was any good, I would do it. I needed my pain to disappear.

A summary of codes forming the category of getting treatment from the others is shown in Table 8.14.
Table 8.14 Category 14: Getting treatment from the others

Patients’ category: ‘Taking medication’

The codes emerged from the patients’ accounts of ‘taking medication, analgesics, and hypnotic drugs’. They formed the category of taking medication.

Tim described her experiences of taking analgesics drug, and getting gold injections. She said:

*Ten years after this operation, my hands became deformed. The treatment I got at that time was taking every analgesic drug in the hospital dispensary, getting gold injections for six months and seeing the orthopaedist ... I took tramal as well if I had a lot of pain ... If I could tolerate the pain, I’d have some food before taking the tramal in the morning. I knew myself; I took it if I felt bad.*

Wing explained how she took hypnotic drugs, by saying:

*Sometimes I couldn’t sleep, because I was so stressed. I had to take hypnotic drugs ... I bought them (hypnotic drugs) from the doctor at the hospital or the local health centre.*
They gave me 10 tablets at a time, because I was very thin and couldn’t sleep ... I didn’t take hypnotic drugs every night. I took them if I was very stressed. I was nervous and couldn’t sleep.

A summary of the codes involved in the category of taking medication is shown in Table 8.15.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking medication</td>
<td>Taking medication</td>
</tr>
<tr>
<td>Taking paracetamol to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Taking analgesics for severe pain</td>
<td></td>
</tr>
<tr>
<td>Taking analgesics drug and getting gold injection</td>
<td></td>
</tr>
<tr>
<td>Not taking analgesics drugs to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Taking prednisolone</td>
<td></td>
</tr>
<tr>
<td>Taking hypnotic drugs</td>
<td></td>
</tr>
<tr>
<td>Taking rheumatoid arthritis medication</td>
<td></td>
</tr>
<tr>
<td>Taking medication for pain relief</td>
<td></td>
</tr>
<tr>
<td>Self adjusting the dose</td>
<td></td>
</tr>
<tr>
<td>Reducing the number of doses of medication</td>
<td></td>
</tr>
<tr>
<td>Stopping medication after severe side effects</td>
<td></td>
</tr>
<tr>
<td>Managing gastric irritation from medications</td>
<td></td>
</tr>
<tr>
<td>Being compelled to take medication</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.15 Category 15: Taking medication
Patients’ category: ‘Getting rest and controlling activities’

The codes of ‘lying down’, ‘stopping work’, and ‘doing light tasks’ were grouped into the category of getting rest and controlling activities. Da laid down in bed regularly and she said:

*I always lay down in my bed during the day from 11am until 3pm. I didn’t sleep at that time. I was aware of everything that everyone did or said ... Sometimes my daughter asked her children to see if I was still alive or had died. I heard what she said, because I was keeping myself warm in the blanket ... I could get up and have food. I lay down after I finished my food.*

Beside this, Da stopped her work to get rest. She said:

*I used to work in the field before. Now I’ve stopped doing that ... I did household jobs, such as cooking rice, washing the dishes, and cleaning the house. I didn’t do them frequently. I did them once a week. I used to work in the field, and do household jobs after I came back home. Now I’ve stopped doing everything, because I get pain when my muscles contract. I used to pull the grass out in the chicken cages. I had to lie down after I’d done it for one hour.*

Ead expressed how she got rest by doing manageable tasks:

*If I do too much heavy carrying, it is painful, however if I do only small household jobs, it’s not so bad. I used to be able to do some original Thai cooking by myself. I’m no longer able to do it, because it affects my joints. I make my own judgments about things I can do or cannot do. I can’t cook or handle things with my hands, if I feel pain ... When the neighbours ask me to help them with some cooking for a party or funeral, I have to say no, because my health won’t allow me to do it.*

A summary of the category ‘getting rest and controlling activities’ is shown in Table 8.16.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lying down</td>
<td>Getting rest and controlling activities</td>
</tr>
<tr>
<td>Lying down in bed regularly</td>
<td></td>
</tr>
<tr>
<td>Lying down and resting in hospital</td>
<td></td>
</tr>
<tr>
<td>Stopping work</td>
<td></td>
</tr>
<tr>
<td>Stopping working when having pain</td>
<td></td>
</tr>
<tr>
<td>Stopping work when having pain</td>
<td></td>
</tr>
<tr>
<td>Avoiding painful activities</td>
<td></td>
</tr>
<tr>
<td>Stopping activities when in pain</td>
<td></td>
</tr>
<tr>
<td>Doing light tasks</td>
<td></td>
</tr>
<tr>
<td>Doing lighter work</td>
<td></td>
</tr>
<tr>
<td>Doing manageable tasks</td>
<td></td>
</tr>
<tr>
<td>Doing things in the evening</td>
<td></td>
</tr>
<tr>
<td>Working in spite of pain</td>
<td></td>
</tr>
<tr>
<td>Keeping up work regimes</td>
<td></td>
</tr>
<tr>
<td>Keeping work responsibilities</td>
<td></td>
</tr>
<tr>
<td>Gaining mobility</td>
<td></td>
</tr>
<tr>
<td>Staying in the same place</td>
<td></td>
</tr>
<tr>
<td>Resting</td>
<td></td>
</tr>
</tbody>
</table>

**Table 8.16 Category 16: Getting rest and controlling activities**

**Patients’ category: ‘Exercising’**

The category of exercising was explained by Jai who said:

*I only walked and got some rest. I sometimes moved my arms and legs to decrease the tension. It got bad if I didn’t move them at all. I exercised my hands and arms as the doctor advised me. He said that I should exercise a little after the pain eased. I exercised when I needed to (laughed). I ran, did aerobic dance, and sometimes exercised at home. I felt better after I’d done these things.*

A summary of category of exercising is shown in Table 8.17.
Exercising
Maintaining exercise
Exercising in the morning
Exercising when pain has gone
Needing to remain ambulant

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercising</td>
<td>Exercising</td>
</tr>
</tbody>
</table>

Table 8.17 Category 17: Exercising

Patients’ category: ‘Helping self’

The category of helping self is described by two good examples; Doom and Tim. Doom told how she helped herself to move:

*I sat and slid my body into a horizontal position. I couldn’t walk (laughed) ... I tried to move my bottom along the floor. Sometimes I yelled for mum to help me ... If I couldn’t walk, I held the bar and moved my buttocks to the next stair.*

While Tim said:

*I had to sit on the high chair that had a strong seat, especially when I had to help my husband to clear tax matters ... I felt I was very stoic, but I almost fainted when I was in a lot of pain. I felt hot and was sweating a lot. I knew I would be fine if I sat on a good chair. I changed the chair at my workplace and bought a new one by myself.*

A summary of this category is shown in Table 8.18.
### Codes

<table>
<thead>
<tr>
<th>Describing self care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helping self to walk</td>
</tr>
<tr>
<td>Helping self to move</td>
</tr>
<tr>
<td>Helping self at toileting</td>
</tr>
<tr>
<td>Using palms to drive motorbike</td>
</tr>
<tr>
<td>Persisting in helping herself to bath</td>
</tr>
<tr>
<td>Helping self in the morning</td>
</tr>
<tr>
<td>Helping self in cooking and toileting</td>
</tr>
<tr>
<td>Buying food instead of cooking</td>
</tr>
<tr>
<td>Buying take-away food instead of cooking</td>
</tr>
<tr>
<td>Having equipment to support walking</td>
</tr>
<tr>
<td>Using high chair to protect from pain</td>
</tr>
<tr>
<td>Employing others to work</td>
</tr>
<tr>
<td>Using bell to summon nurses</td>
</tr>
<tr>
<td>Getting out of bed</td>
</tr>
<tr>
<td>Waking up with pain</td>
</tr>
</tbody>
</table>

### Category

| Helping self |

---

**Table 8.18 Category 18: Helping self**

**Patients’ category: ‘Restricting food’**

The patients expressed how they restricted foods. Boon said:

*I didn’t like them (salty foods). I didn’t put any sauces on my food. I didn’t have chicken. The doctor suggested that I could have it but not much, especially not the wings.*

A summary of the category of restricting food is shown in Table 8.19 on page 332.

**Patients’ category: ‘Maintaining hygiene’**

Wing and Jai were concerned about maintaining hygiene. Wing said:

*I used to do that (washed myself with cloths instead of taking a bath) when I had a lot of pain and my daughter stayed here.*
While Jai explained:

*I avoid being around smokers too ... No (I didn’t feel uncomfortable in my place of work, because it is a prison). I didn’t have much contact with the prisoners. I worked in an area that was clean and well ventilated. I didn’t work in a factory, although there were many factories around there. Someone helped me to contact some of the staff there. There were too many chemical substances and too much dust.*

A summary of codes which formed the category of maintaining hygiene is shown in Table 8.19 on page 332.

**Patients’ category: ‘Using breathing’**

Phit was the only patient who used deep breathing to manage pain (category 21). She described:

*Sometimes I breathed in deeply, and focused on how long I’d had pain in that day. I didn’t get disheartened.*

**Patients’ category: ‘Giving massage’**

Using massage was an option to manage pain. Wing explained that:

*He couldn’t do a lot for me, because he had to work. He massaged me when he came home. He and my youngest son usually massaged me. My youngest son is a very good masseur, because he puts more pressure on and makes me feel better. The doctor gave me some balm to massage in. It was in a tube. He told me when I had pain I could still massage, but with only a light pressure ... I heard that some temples have oil for massaging, but I’ve never been there or tried their oils.*

A summary of this category is shown in Table 8.19, which follows.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controlling foods</td>
<td></td>
</tr>
<tr>
<td>Restricting food</td>
<td>Restricting food</td>
</tr>
<tr>
<td>Avoiding certain food</td>
<td></td>
</tr>
<tr>
<td>Making food and beverage choices</td>
<td></td>
</tr>
<tr>
<td>Maintain hygiene</td>
<td></td>
</tr>
<tr>
<td>Maintaining a clean environment</td>
<td>Maintaining hygiene</td>
</tr>
<tr>
<td>Using massage</td>
<td></td>
</tr>
<tr>
<td>Massaging with herbs</td>
<td></td>
</tr>
<tr>
<td>Massaging with ointment</td>
<td></td>
</tr>
<tr>
<td>Using massage and compresses</td>
<td></td>
</tr>
<tr>
<td>Using skin balm</td>
<td></td>
</tr>
<tr>
<td>Giving massage</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.19 Category 19, 20, and 22: Restricting food, maintaining hygiene, and giving massage

Patients’ category: ‘Using hot compresses’

Da used hot compresses to relieve pain. She said:

*The doctor told me to soak cloths in hot water, and put them on the area where I had pain. He said it would make me lose and relieve the pain. I rarely did that. I always took the medication and sometimes applied the oil. I got this oil from a temple. I stopped applying it, because it had a strong smell.*

A summary of codes which formed the category of using hot compresses is shown in Table 8.20 on page 333.

Patients’ category: ‘Keeping warm’

Patients also kept their bodies warm to manage pain. Doom explained her method:

*I soaked my hands in warm water when I was in a lot of pain. I felt better after I did that ... (I did it by) Myself. I boiled the water, mixed in the cold water till it was warm, and*
then soaked the parts that were more painful. Sometimes I put the warm water in a bottle and lay it on my joints. It relieved my pain.

A summary for the category of keeping warm is shown in Table 8.20, which follows.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using fomentation</td>
<td>Using hot compresses</td>
</tr>
<tr>
<td>Applying fomentation</td>
<td></td>
</tr>
<tr>
<td>Using hot compresses</td>
<td></td>
</tr>
<tr>
<td>Using hot packs</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping the body warm</td>
<td>Keeping warm</td>
</tr>
<tr>
<td>Keeping warm when working</td>
<td></td>
</tr>
<tr>
<td>Soaking in the warm water</td>
<td></td>
</tr>
<tr>
<td>Getting hot stream treatment</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.20 Category 23-24: Using hot compresses and keeping warm

Patients’ category: ‘Using decoction and bolus’

Patients used many kinds of decoction and bolus to cure their pain. Boon explained how she used decoction as below:

\textit{I tried it once (decoction). It made me more bent and stiff ... I got it from my dad. He saw someone get better after they’d taken it. But I felt I should get into the pot instead of it after I’d taken it. It gave me diarrhoea, but my ligaments were relaxed. It didn’t make me better.}

Patients’ category: ‘Using herbs and supplements’

Using herbs and supplements was the one of relief pain options. Doom experienced when she used it:
Sometimes. My mum cracked the root of bamboo (it looked like curcuma) till it was like a soft paste. After that she used it to foment or massaged it in or she applied it to the painful area. It made me feel warmer ... Yes (it relieved pain) ... After I took the herbs, I felt better at the beginning, but not in the long term.

A summary of the categories of using decoction and bolus and using herbs and supplements is shown in Table 8.21.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking bolus</td>
<td></td>
</tr>
<tr>
<td>Using decoction</td>
<td></td>
</tr>
<tr>
<td>Taking decoction and bolus</td>
<td></td>
</tr>
<tr>
<td>Using a powder medication</td>
<td></td>
</tr>
<tr>
<td>Taking bolus and steroid injection</td>
<td></td>
</tr>
<tr>
<td>Thinking about decoction and herbs</td>
<td></td>
</tr>
<tr>
<td>Using herbs</td>
<td></td>
</tr>
<tr>
<td>Taking herbs</td>
<td></td>
</tr>
<tr>
<td>Planting herbs</td>
<td></td>
</tr>
<tr>
<td>Taking herb and a spirulina supplement</td>
<td></td>
</tr>
<tr>
<td>Taking fish oil</td>
<td></td>
</tr>
<tr>
<td>Taking supplement</td>
<td></td>
</tr>
<tr>
<td>Taking a garlic supplement</td>
<td></td>
</tr>
<tr>
<td>Using the tent treatment</td>
<td></td>
</tr>
<tr>
<td>Thinking about trying a new herb</td>
<td></td>
</tr>
<tr>
<td>Taking Chinese and Thai medications</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.21 Category 25-26: Using decoction and bolus, and using herbs and supplements
Patients’ category: ‘Maintaining emotional stability’

The category of maintaining emotional stability is formed from the codes of ‘staying calm’, ‘talking to the others’, and ‘tolerating rheumatoid arthritis’. Jai said:

*I tried not to do anything except make my mind up to stay calm ... I don’t know how I can explain it. I tried to feel nothing when I saw disturbing things. It was up to me whether I could be calm or not.*

Meanwhile, Ead talked to a monk and doctor about her pain. She explained:

*I felt pain in my shoulders this time, because I helped the undertaker to carry the casket for cremation. My neighbour told me that, because I was always doing work that was associated with funerals it caused my pain or led me to have rheumatoid arthritis. I went to talk to the monk and the doctor, and they both said that what I had done was a good thing to do. But people didn’t believe what the doctor and the monk said. They said it was, because I was doing this without paying homage to the spiritual teacher. So all the bad things returned to me as side effects. But I believe that the pain I had was a part of my illness. There was no relation between my pain and the work that I did for charity or funerals. Furthermore, I also went to take care of someone in the hospital who had no one to care for them. I was always doing good things for people.*

Wing described how she tolerated rheumatoid arthritis:

*At the beginning, I thought it would disappear after I got treatment. After I’d had treatment for a while, the doctor told me that I had to accept that. Rheumatoid arthritis is a chronic disease, and it is difficult to cure completely. I had to take the medication all the time. I didn’t know what to do but tolerate it ... I didn’t know what to do. I sometimes thought I had to accept my life like this. Pain was still there and I didn’t know how to get it out of my life. This was to be my suffering. I was like a paralysis patient. I couldn’t go anywhere. My body looked bad, because I was so thin.*

A summary for the category of maintaining emotional stability is shown in Table 8.22.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staying calm</td>
<td>Maintaining emotional stability</td>
</tr>
<tr>
<td>Proving independence</td>
<td></td>
</tr>
<tr>
<td>Trying not to focus on pain</td>
<td></td>
</tr>
<tr>
<td>Controlling emotional state</td>
<td></td>
</tr>
<tr>
<td>Making mind up to be “fine”</td>
<td></td>
</tr>
<tr>
<td>Talking to self</td>
<td></td>
</tr>
<tr>
<td>Talking with friends</td>
<td></td>
</tr>
<tr>
<td>Telling the family about pain</td>
<td></td>
</tr>
<tr>
<td>Talking with a monk and doctors about pain</td>
<td></td>
</tr>
<tr>
<td>Talking with the others who had the same symptoms</td>
<td></td>
</tr>
<tr>
<td>Tolerating rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Tolerating pain</td>
<td></td>
</tr>
<tr>
<td>Tolerating illness</td>
<td></td>
</tr>
<tr>
<td>Being alone when having pain</td>
<td></td>
</tr>
<tr>
<td>Enjoying travelling</td>
<td></td>
</tr>
<tr>
<td>Going to the temple</td>
<td></td>
</tr>
<tr>
<td>Hiding pain from children</td>
<td></td>
</tr>
<tr>
<td>Hiding rheumatoid arthritis from family and acquaintances</td>
<td></td>
</tr>
</tbody>
</table>

**Table 8.22 Category 27: Maintaining emotional stability**

**Patients’ category: ‘Accepting illness’**

Patients described the codes of ‘expressing acceptance’, and ‘feeling untroubled’. Ta expressed her acceptance as below:

*I didn’t think about it (what might happen to me in the future). I made my mind up to be trouble-free and to relax. I thought to myself that it would disappear if I continued the treatment and took the medication. The doctor told me this too.*

In the same way, Phit felt untroubled with her pain. She said:
I’d never heard of this disease (rheumatoid arthritis) before, so I felt nothing. I thought it was not a serious disease. I only found out it is a most severe joint disease from which patients could have disabilities, and die sooner after I read the newspaper. I used to hear about rheumatism and I thought it was a very severe disease, but rheumatoid arthritis is even more so ... I felt nothing. I didn’t think too much.

 Patients’ category: ‘Using spiritual options’

The category of using spiritual options is exemplified well by Tim, who said:

I tried every method to relieve the pain. I used to see the shaman after someone told me I was affected by black magic. I didn’t believe it ... A Chinese shaman (Sin Sae) asked me if my neck felt like a turtle’s neck, and whether I’d done something to a turtle. I thought about it and saw that he’d told me the truth, because I used to catch a small turtle and hit it when I was young.

A summary of ‘accepting illness’ and ‘using spiritual options’ is shown in Table 8.23.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expressing acceptance</td>
<td>Accepting illness</td>
</tr>
<tr>
<td>Accepting the diagnosis</td>
<td></td>
</tr>
<tr>
<td>Expressing acceptance of rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Feeling untroubled</td>
<td></td>
</tr>
<tr>
<td>Seeing the shaman</td>
<td>Using spiritual options</td>
</tr>
<tr>
<td>Seeing traditional doctor</td>
<td></td>
</tr>
<tr>
<td>Bathing in holy water and doing good deeds</td>
<td></td>
</tr>
<tr>
<td>Doing meditation and bathing in holy water to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Rejecting spiritual and mystical remedies</td>
<td></td>
</tr>
</tbody>
</table>

Table 8.23 Category 28-29: Accepting illness and using spiritual options
From categories to concepts and core social processes

After I put codes into the same clusters of categories, I used a constant comparative method to look for concepts and core social processes. I divided them into two groups; perception and management, as shown in Figure 8.1 and 8.2.
Figure 8.1 Patients’ perception of pain
Figure 8.2 Patients’ pain management
<table>
<thead>
<tr>
<th>Categories</th>
<th>Concepts</th>
<th>Core social processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting treatment from doctors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting treatment from the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting treatment from the others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting rest and controlling activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercising</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping self</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restricting food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintaining hygiene</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using breathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving massage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using hot compresses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keeping warm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using decoction and bolus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using herbs and supplements</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Physiological factors → Bolstering physicality

Figure 8.2 (continued) Patients’ pain management
Patients’ experiences as integral to the grounded theory

After I matched the categories to concepts and core social processes, I was ready to state the grounded theory of patients’ experiences of rheumatoid arthritis. This section describes the patients’ grounded theory.

From the analysis, I concluded that patients perceived their pain in terms of dejection. They expressed negativity in relation to the limiting effects of pain, negative feelings, dissatisfied and unsure feelings about staff and the ways to relieve pain, bone and joint degeneration, and body changes. Patients attributed external and internal factors to causes of pain.

They bolstered their pain management by being receptive to therapeutic assistance including advice, treatment, care and help from family members, the health care team, and others. Patients bolstered pain management in three dimensions: physical, mental, and spiritual. In bolstering physicality, patients built up their management of physiological factors in relation to doctors’ treatments, medications, physical activities, and alternative treatments.

Patients bolstered their mentality in relation to psychological factors, by maintaining emotional stability and accepting their illness. Patients bolstered their spirituality by consulting the shaman and traditional doctors and spiritual options associated with religious practices.

Although patients have their own ways to manage their pain, they have an attitude of solicitude, seeking thoughtful attention for their needs related to treatment, nursing care, self care, and other help.
Summary

This chapter described the codes, categories, concepts and core social processes for patients’ experiences of rheumatoid arthritis. A grounded theory emerged of patients’ experiences, and this has been described in this chapter. Chapter Nine describes caregivers’ experiences of rheumatoid arthritis.
Chapter Nine: Emerging Theory:
Caregivers’ Perspectives of Rheumatoid Arthritis

Introduction

This chapter describes the analysis of caregivers’ perceptions. The description includes the codes, categories, concepts, and core social processes for caregivers’ experiences of rheumatoid arthritis.

Caregivers


Caregivers’ category: ‘Recognising the causes and effects of pain’

There were many codes in caregivers’ accounts, which formed the category of recognising the causes and effects of pain. This category was exemplified by Poon, who thought his wife got rheumatoid arthritic pain from working hard:

*I didn’t really think about the causes (of the rheumatoid arthritis) except about her working hard, because she used her hands to pull the weaving looms for a long time.*
On the other hand, A and B perceived their mother’s pain as possession.

*At first, I thought that she was possessed (laughed), because she had swelling and there seem to be no cause. She thought that someone who practiced black magic had sent an evil spirit to possess her body (Lom Pae Lom Pad) (laughed).*

Caregivers also noticed that pain can affect the patients’ lives. Nhung noticed pain affected his mother’s sleeping:

*If she had pain, she was in pain all night. She couldn’t sleep without taking some hypnotic drug ... At the health centre (she got that drug). It’s at the junction, a long way from here ... She couldn’t sleep well when she had pain.*

Nhung noticed pain also affected his mother’s eating:

*She had only Kao Sao Nham ... First, we cook rice. After the rice is cooked, we boil water and put the rice in it and finally add fish sauce. It’s called Kao Sao Nham ... Sometimes she couldn't have anything, because she couldn’t swallow. She said the smell was too strong. It stank. She couldn’t eat it. We had to boil the rice again till it was muddy looking.*

A summary of this category is shown in Table 9.1.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain related to working hard</td>
<td>Recognising the causes and effects of pain</td>
</tr>
<tr>
<td>Causing her pain from touching</td>
<td></td>
</tr>
<tr>
<td>Recognising pain is related to stress</td>
<td></td>
</tr>
<tr>
<td>Perceiving pain as possession</td>
<td></td>
</tr>
<tr>
<td>Noticing pain associated with steps</td>
<td></td>
</tr>
<tr>
<td>Noticing which position caused pain annoyance</td>
<td></td>
</tr>
<tr>
<td>Worrying that increased driving may be stressful</td>
<td></td>
</tr>
<tr>
<td>Not knowing what happened about pain</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.1 Category 1: Recognising the causes and effects of pain
Noticing pain affects eating
Noticing pain affects sleeping
Noticing the differences from before and now
Noticing general decline

Recognising the causes and effects of pain

Table 9.1 (continued) Category 1: Recognising the causes and effects of pain

Caregiver’s category: ‘Recognising body and life style changes’

The codes of ‘recognising body changes’ and ‘life style changes’ formed the category of recognising body and life style changes. Dee and Ping noticed their loved ones had joint swelling. Dee said:

*Her legs were swollen ... Her knees (were swollen). Especially in her right leg ... Her knees were the parts that I saw clearly ... Her thighs were smaller, but her knees were bigger ... I’m not sure (that her hands were also swollen.). I didn’t see this condition. She had swelling when I was young.*

Ping agreed with Dee. He noticed that:

*At the beginning, her joints became swollen. I mean her knuckles and ankles were swollen. She went to see the doctors, but it still got worse. Her feet, wrists, and legs were swollen later ... And her feet, they became swollen and looked as if they had been bitten by something.*

Patients had other symptoms of rheumatoid arthritis. Ping found his daughter had joint stiffness:

*She couldn’t put her rings on, because her fingers were stiff; she couldn’t flex them. They were always extended. They became swollen and stiff. They looked like they couldn’t move at all. I saw that sometimes one or two fingers were strained, especially her knuckles. She couldn’t take her ring off.*

Meanwhile, Yon observed that pain was the main symptom. He described:
Pain. She always had pain when the weather was cold ... Wrists, knuckles, elbows, ankles, and knees (that the parts she had pain). They became swollen ... Yes (she had pain from the beginning till now).

Ping noticed that:
Doom didn’t work outdoors. And as far as household jobs, she didn’t do things such as cooking anymore. I didn’t notice much. Sometimes I saw her do the laundry. She didn’t do it well, because she had pain and fatigue. She had to stop doing it and try later. If she sat in the same position for a long time, she would have pain in her knees. In the past we said this was “bad circulation”. The blood couldn’t circulate well. It’s unusual. Sometimes I called to her “Dear! Wake up”, but she couldn’t. She was in pain and seemed very ill. She had pain and bruises all over her body.

Caregivers were concerned with patients’ emotional states. Yon and Man noticed their wives became moody easily. Yon said: 
Certainly (her emotional state changed when she was in pain). (Thought)... Can you understand her feelings when after being a working woman she suddenly can’t do her job? She was very moody. That was a fact.

Man also said that:
I didn’t notice a lot. If her pain increased, her emotional state would change. She became moody easily, but not too much.

Patients complained about their pain. Dee described her mother’s complain as below:
Oh yes (my mum complained when she had pain), but not too much ... No (she never cried), because it was more sprain than pain.

Dao also observed that her mother often complained when she had pain. Dao said:
She complained everyday when she was in pain. We didn’t like to hear it. She complained “I’m in pain” “I’m sprained” and “I feel badly.” ... Yes, but not much. Her neck was the part that she always had pain in.
A summary of the category recognising body and life style changes is shown in Table 9.2.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noticing joint swelling</td>
<td>Recognising body and life style changes</td>
</tr>
<tr>
<td>Noticing distended blood vessels</td>
<td></td>
</tr>
<tr>
<td>Noticing muscle tightness</td>
<td></td>
</tr>
<tr>
<td>Noticing joint sprain and pain</td>
<td></td>
</tr>
<tr>
<td>Noticing joint stiffness</td>
<td></td>
</tr>
<tr>
<td>Noticing headache and vomiting</td>
<td></td>
</tr>
<tr>
<td>Becoming thin, weak, and pale</td>
<td></td>
</tr>
<tr>
<td>Noticing her body colour changed to green</td>
<td></td>
</tr>
<tr>
<td>Noticing pain is the main symptom</td>
<td></td>
</tr>
<tr>
<td>Perceiving of pain duration</td>
<td></td>
</tr>
<tr>
<td>Noticing tolerance of pain</td>
<td></td>
</tr>
<tr>
<td>Not noticing the pain</td>
<td></td>
</tr>
<tr>
<td>Noticing unable to drive</td>
<td></td>
</tr>
<tr>
<td>Noticing changes in work habits</td>
<td></td>
</tr>
<tr>
<td>Noticing decreased ability to work and move</td>
<td></td>
</tr>
<tr>
<td>Noticing decreased ability to do household jobs</td>
<td></td>
</tr>
<tr>
<td>Noticing decreased ability to walk</td>
<td></td>
</tr>
<tr>
<td>Noticing her reduced mobility relating to pain</td>
<td></td>
</tr>
<tr>
<td>Maintaining work habits</td>
<td></td>
</tr>
<tr>
<td>Working hard to support children</td>
<td></td>
</tr>
<tr>
<td>Noticing her persistence in working with pain</td>
<td></td>
</tr>
<tr>
<td>Being moody</td>
<td></td>
</tr>
<tr>
<td>Complaining of pain</td>
<td></td>
</tr>
<tr>
<td>Noticing her crying</td>
<td></td>
</tr>
<tr>
<td>Noticing tearful emotional state</td>
<td></td>
</tr>
<tr>
<td>Crying and being disheartened</td>
<td></td>
</tr>
<tr>
<td>Being unable to be humorous</td>
<td></td>
</tr>
<tr>
<td>Becoming stressed from inadequate help</td>
<td></td>
</tr>
<tr>
<td>Noticing her emotions not change</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.2 Category 2: Recognising body and life style changes
Caregivers’ category: ‘Expressing reactions after having pain’

Patients expressed reactions to having pain. Whan said her mother hid her suffering when she was in pain. She said:

She tried to make herself look well and not show how she was suffering. She was funny and mischievous. Sometimes I joked with her that I had a strong piece of wood for massaging if she wanted (laughed) ... Even though she got pain she was still the same mother, who was funny all the time. I’ve seen her like this since I was young. So I never thought that she had changed ... They’ve never said anything, because we’ve always lived together. They saw what I saw and my mum tried not to show how much pain she had.

Whan also found that her mother pretended to be well to leave hospital. She explained:

Yes (I looked after her when she was admitted). The doctors did their rounds in the ward. She saw them at that time. They didn’t do anything other than this. Last time she was admitted to the hospital, they treated her the same as they did the other patients ... She wanted to come back home rather than stay in the hospital. My older brother said that she pretended she was better although her hands were still swollen.

Caregivers’ category: ‘Expressing feelings’

Caregivers felt pity and sympathy to patients with rheumatoid arthritis. B expressed how they felt pity to their mother: “I pitied her, but I didn’t know how I could help her”.

Dee felt sympathy when seeing her mother in pain. She said: “I sympathised with her ... I don’t know how to explain the sympathise feeling”.

Yon said that he and his wife assumed they understood her feelings:

No (she didn’t talk to me about how she felt), maybe, because I rarely asked her. I saw what she saw and I knew what she knew, why did I need to ask her again ... I didn’t do anything (when she said that) ... (Laughed) No (I didn’t say anything to her), because I’m not romantic. I’m down to earth (laughed).
Caregivers’ category: ‘Motivation to care’

Caregivers showed their motivation to care for patients with rheumatoid arthritis. Ping expressed his love and empathy towards his daughter:
You may not know, because you’ve never been a parent. Listen to me, parents will always love their children. If you were a parent and had children of your own, they would be the dearest things to you. You’ll hear this from every parent ... When she was admitted, I stood near her bed and saw her having convulsions. You know, I couldn’t do anything for her. I walked down to the ground floor by the stairs. I didn’t remember anything. I got lost. I would lose the way if my wife didn’t come with me. You know I am a strong man. I’m not sensitive. I felt terrible that day. I nearly lost my mind. I loved and pitied her.

Man recognised the greatest importance in their lives was happiness:
I told her if we are rich, we need to be rich with happiness. We didn’t want to be rich from working hard and making money. We were the same people we always were. We loved to help anyone, who was more impoverished than us. We only wanted enough to get by on. We didn’t want to be rich without being happy. We loved to share our ideas and spend time together.

A summary for the codes which involved in the category of motivation to care is shown in Table 9.3 on page 351.

Caregivers’ category: ‘Expressing hopes’

The codes which formed the category of expressing hopes included ‘hoping pain will disappear’, and ‘hoping in treatment’. Song said: “I hope that her pain and the rheumatoid arthritis will disappear, because she has been getting treatment for three years”.

While Dee hoped treatment can cure pain: “I hope she will be completely cured and that her pain disappears”.
On the other hand, Yon had no hope for cure. He said: “I had no hopes (what the treatment would do), because I was well aware that rheumatoid arthritis is a chronic disease”.

A summary of the category expressing hopes is shown in Table 9.3.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expressing close family ties</td>
<td>Motivation to care</td>
</tr>
<tr>
<td>Feeling daughter is more important than job</td>
<td></td>
</tr>
<tr>
<td>Expressing love and empathy towards a child</td>
<td></td>
</tr>
<tr>
<td>Recognising the importance of happiness</td>
<td></td>
</tr>
<tr>
<td>Hoping pain will disappear</td>
<td>Expressing hopes</td>
</tr>
<tr>
<td>Hoping in continue treatment</td>
<td></td>
</tr>
<tr>
<td>Having no hope for cure</td>
<td></td>
</tr>
<tr>
<td>Giving up the expectation that pain will disappear</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.3 Category 5-6: Motivation to care and expressing hopes

Caregivers’ category: ‘Being unsure’

This category emerged from Song, who was unsure about his reactions to pain. He said: I didn't know what to say or how I felt ... (Thought) Yes, I did (felt sad) ... Certainly (I pitied my mum when she had pain).

Caregivers’ category: ‘Accepting’

The category of accepting is created from the caregivers’ accounts of ‘feeling nothing emotionally’, and ‘trying to understand rheumatoid arthritis’. Man And Yon felt nothing emotionally. Man said: I felt nothing (when she got pain from rheumatoid arthritis). Nothing was any different, because she used to get pain from time to time. If she was not in pain, she could do everything.
Yon said:
I felt nothing (after I knew she was in pain with the rheumatoid arthritis). I’d lived with her for a long time. Nothing was different from before. Everything was as it always was ... No (I didn’t pity her), because everything was as usual for us. Sometimes I went about my business and talked with the abbot at the temple. If my son called me to come back home, it didn’t put me in a bad mood. It was all right.

Whan tried to understand rheumatoid arthritis. She said:
I set my mind to trying to understand about rheumatoid arthritis. I saw that she went to see many doctors. Sometimes she got better, but sometimes she didn’t.

A summary for these codes is shown in Table 9.4.

**Caregivers’ category: ‘Offering suggestions’**

Caregivers offered the suggestions for patients with rheumatoid arthritis. Aim emphasised that patients should continue treatments from the orthopaedist:
No (I don’t have any hopes about what the rheumatoid arthritis treatment will be able to do). I mean I only hope that she continues with the right treatment for her, because she is still in a lot of pain if she doesn’t take the medication. No one is against her getting the treatment. She was very brave and did the things that her doctor advised. She’s never followed some advice, such as bathing in holy water. We want her to get treatment only from the orthopaedist.

Ping agreed with this suggestion:
In relation to the fortune-teller or her horoscope, we don’t check it very often, sometimes only once a year. We don’t believe it’s 100% accurate. I think she should get the appropriate treatment from the doctor who works in the hospital. It’s like making things happen yourself. You can’t get money without working for it.

Dao and Aim encouraged less work to stop pain. Dao said:
We let her to do some things, but not much and only some times, for example cooking food for my younger brother in the morning. She loved to cook “Nham Prik”. Now I don’t let her cook it by herself, because she has to use a lot of energy to crack the ingredients and her wrists suffer. I bought a blender for her to cook with, but she was naughty. She still tried to cook it by herself. She said that it was a kind of exercise for her. You know what happened to her after she finished it? She complained that she felt worse (laughed).

Aim recounted:

Sometimes her younger son told her to stop buying fresh food, and he would buy take-away meals instead. But she still did it … For example, her son scolded her, because she was making the floating basket for holding the fish in the water this morning. He didn’t want her to do it, because he worried that her pain would increase.

Beside this, Poon perceived that patients with rheumatoid arthritis should be strong willed:

For everyone who has rheumatoid arthritis, I think that it depends on his or her attitude. They mustn’t be disheartened about looking after themselves and continuing their treatment. They should be strong willed.

A summary of the category of offering suggestions is shown in Table 9.4.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nothing emotionally</td>
<td>Accepting</td>
</tr>
<tr>
<td>Trying to understand rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Acknowledging the diagnosis of rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Recommending continuing treatment</td>
<td>Offering suggestions</td>
</tr>
<tr>
<td>Feeling she should go to the doctor</td>
<td></td>
</tr>
<tr>
<td>Continuing treatment from orthopaedist</td>
<td></td>
</tr>
<tr>
<td>Recognising the inefficiency of traditional medicines</td>
<td></td>
</tr>
<tr>
<td>Recognising herbal treatment is not good for a patient with rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Suggesting appropriate treatment is better than seeing a fortune-teller</td>
<td></td>
</tr>
<tr>
<td>Encouraging less work to stop pain</td>
<td></td>
</tr>
<tr>
<td>Preferring clinic to the hospital</td>
<td></td>
</tr>
<tr>
<td>Preferring home to hospital care</td>
<td></td>
</tr>
<tr>
<td>Perceiving the need for people with rheumatoid arthritis to be strong willed</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.4 Category 8-9: Accepting and offering suggestions

Caregivers’ category: ‘Needing’

Although caregivers have their own ways to help patients, they still need more information, care, medication and help. Poon needed more information from nurses and doctors about RA and how to manage pain:

*I want them (doctors and nurses) to care for her and other patients with rheumatoid arthritis and pain, but I don’t know how I can say this to them ... In my opinion, the doctors don’t really advise. I want some help from the nurses too ... I mean I want them to do anything that will make my wife get better, but I don’t know how to say it ... I want them to advise me what rheumatoid arthritis is and how to care for a patient with rheumatoid arthritis and pain. I want to know more than I know now.*

He also needed help from health care staff:
In my village, the staff from this centre came here to survey how many houses and persons in each house. They didn’t do anything for her illness. Four months ago, my wife was discharged from the hospital and was back home to rehabilitate, because she’d had a uterus operation. They told her that they would visit her. You know we’ve never seen them till now (laughed). I think that they might only visit babies or aged people. I don’t know what will happen in the future, because I know that this local health centre will be under the new local council. The staff must do everything that this council orders. I’m not sure how they can take care of our health and our illnesses, because some staffs have no knowledge about health and caring.

Dao wanted doctors and nurses to do everything to relieve pain:
I would like them to do everything they can to relieve pain, for example giving injections or doing something else that can relieve pain. I’ve seen how bad it is when a patient with rheumatoid arthritis suffers from pain. In relation to the doctors, they should get close to the patients, talk to the patients as much as they can, and give them the best treatment. Nurses should do the same as the doctors too. Some ignore the patients and their relatives when they tell about their illnesses and want some help. They are very important people for patients, because they see the patients all the time.

Man and Yon needed better medication to relief pain. Yon said:
I don’t know how to explain it (what care I need more for her when she has pain). When the patients have pain, they (nurses) should give them medication.

Man also expressed:
I think I will ring my sister. She lives in the USA. Her husband is a doctor. I’ll tell them about my wife’s symptoms, and ask them if there are other medications to treat rheumatoid arthritis and pain. Perhaps they can give me some drug samples for her. One place that I will take her to get treatment is the Chinese chemist. There is a pharmacist there.

A summary for these codes is shown in Table 9.5.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needing advice about diet and exercise</td>
<td>Needing</td>
</tr>
<tr>
<td>Suggesting the staff should improve giving information</td>
<td></td>
</tr>
<tr>
<td>Wanting to know more from doctors and nurses about rheumatoid arthritis and how to manage pain</td>
<td></td>
</tr>
<tr>
<td>Wanting nurses to monitor effects of medication</td>
<td></td>
</tr>
<tr>
<td>Wanting doctors and nurses do everything to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Wanting visits and advice</td>
<td></td>
</tr>
<tr>
<td>Wanting more support for pain relief from health care team</td>
<td></td>
</tr>
<tr>
<td>Wanting local health staff to visit the patients at homes</td>
<td></td>
</tr>
<tr>
<td>Needing help from the local health centre in relation to rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Not appreciating hospital care</td>
<td></td>
</tr>
<tr>
<td>Not seeing the doctor frequently</td>
<td></td>
</tr>
<tr>
<td>Deferring to the doctors’ knowledge</td>
<td></td>
</tr>
<tr>
<td>Not getting advice from nurses</td>
<td></td>
</tr>
<tr>
<td>Being unsatisfied with nursing care</td>
<td></td>
</tr>
<tr>
<td>Not getting care from local health staff</td>
<td></td>
</tr>
<tr>
<td>Not getting any advice from the health care team</td>
<td></td>
</tr>
<tr>
<td>Not appreciating some health care staff in their caring</td>
<td></td>
</tr>
<tr>
<td>Getting no care from the health centre</td>
<td></td>
</tr>
<tr>
<td>Asking for better medication</td>
<td></td>
</tr>
<tr>
<td>Needing more medication to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Not noticing dad cared for her</td>
<td></td>
</tr>
<tr>
<td>Not getting help from neighbours</td>
<td></td>
</tr>
<tr>
<td>Not appreciating bolus and powered medications</td>
<td></td>
</tr>
<tr>
<td>Not knowing how to ask for more help</td>
<td></td>
</tr>
<tr>
<td>Acknowledging not knowing how to task for advice</td>
<td></td>
</tr>
</tbody>
</table>

**Table 9.5 Category 10: Needing**
Caregivers’ category: ‘Appreciating present treatment’

The category of appreciating present treatment emerged from the caregivers’ accounts about ‘appreciating medication, doctors’ and nurses’ care, and information from others’.

Nhung appreciated medication. He said:

*She slept well and wasn’t aware of anything ... (Thought) she told me that she felt better. It relieved her pain. After that she slept. So did I.*

Dee also appreciated the effects of medication. She explained:

*It’s really good, because she looks better after taking it (medication). She should get treatment like this continually.*

Yon appreciated doctors’ and nurses’ care.

*They (doctors and nurses) took care of her well ... They (nurses) gave her tablets and injections as set out on her chart. The doctor also checked her symptoms ... Sometimes (they talked with me about her disease and how I could care for her). They told me that she was weak and couldn’t do things by herself. That her relatives should look after her carefully ... They didn’t tell me any more than this, but I knew what I could do ... Yes (they told me general information about rheumatoid arthritis) ... Nurses asked about her symptoms, gave her medication, and advised me if I did anything wrong with her. I mean when I was giving the wrong sort of care.*

A and B felt the health care team did all they could. They said:

*I think rheumatoid arthritis is a rare disease. There are few patients with rheumatoid arthritis. I noticed that mum had pain from the stress. When she saw the doctors, they gave her home medication. I think our family is the most important factor in easing her tension. The doctors and nurses can’t do anything more than what they do now. We have to help her as much as we can ... I don’t think so (that the local health staff was concerned about this and visited her at home).*
Yon appreciated information about rheumatoid arthritis he got from newspaper and television:

*I knew a lot about rheumatoid arthritis from the newspapers and books. I love reading... At the same time (she continues treatment) I try to find out more information by reading books and watching TV. So then I can record this in the back of my mind, and use it the next time she gets pain.*

A summary for codes which formed the category of appreciating present treatment is shown in Table 9.6.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appreciating medication</td>
<td></td>
</tr>
<tr>
<td>Appreciating the effects of medication</td>
<td></td>
</tr>
<tr>
<td>Appreciating doctors’ and nurses’ care</td>
<td></td>
</tr>
<tr>
<td>Noticing doctors’ and nurses’ activities</td>
<td></td>
</tr>
<tr>
<td>Noticing nurses’ activities</td>
<td></td>
</tr>
<tr>
<td>Noticing nurses give medications</td>
<td></td>
</tr>
<tr>
<td>Appreciating nursing care in helping and medications</td>
<td></td>
</tr>
<tr>
<td>Appreciating nurses’ and doctors’ caring</td>
<td></td>
</tr>
<tr>
<td>Feeling the health care team are doing all they can</td>
<td></td>
</tr>
<tr>
<td>Appreciating hospital treatment</td>
<td></td>
</tr>
<tr>
<td>Daughter’s advice to see the doctor only</td>
<td></td>
</tr>
<tr>
<td>Getting advice from a nurse to see an orthopaedist</td>
<td></td>
</tr>
<tr>
<td>Noticing patients got advice about food</td>
<td></td>
</tr>
<tr>
<td>Getting treatments from many health centres</td>
<td></td>
</tr>
<tr>
<td>Getting information about rheumatoid arthritis from newspapers and TV</td>
<td></td>
</tr>
</tbody>
</table>

**Table 9.6 Category 11: Appreciating present treatment**

**Caregivers’ category: ‘Giving support to get the treatment’**

The category of giving support to get the treatment emerged from the codes of taking the patients to see the doctor. Dao exemplified this code well. She said: *“I took her to see the doctor. He gave her some medication. Her pain decreased after she’d taken it”*. 
A summary of this category is shown in Table 9.7.

**Caregivers’ category: ‘Leaving alone and letting complain’**

One of the pain management strategies caregivers used was leaving the patients alone, and letting them complain. Poon explained how he left her alone and he kept quiet:

*Of course (there have been changes since she got rheumatoid arthritis). You know sometimes when she had pain she got angry and depressed very easily, but not a lot. While she had these feelings, I left her alone, kept quiet and kept my mouth shut (laughed). Since we’ve been married, I’ve never quarrelled with her or harmed her. We understand each other.*

Dao let her mother complain when she was in pain:

*She looked unhappy. Her face was not alive. She loved to complain (laughed). We let her complain, because we didn’t know of any way to relieve her pain except by bringing her the medication. We usually asked her about her pain level too. We also told her to take a rest if her pain was still there.*

A summary for these codes is shown in Table 9.7.

**Caregivers’ category: ‘Assisting in the hospital’**

Yon described how he cared his wife when she was admitted to hospital:

*I looked after her every time she was admitted with a lot of pain. I always looked after her when the doctor allowed me … I could look after her all the time when I worked at home. There was no problem … If I had a lot of jobs to do, I visited her a few times during the day and again in the evening. I brought her medication and gave it to the nurses in the ward. I usually stayed there till 9 pm … I had to take into account my shifts at work. I could care for her during the day if my shift was at night. On the other hand, I could care for her in the evening if it was during the day. Sometimes I alternated with my friends, asked for leave from my employer or employed my friend to do the job instead of me.*
A summary of this category is shown in Table 9.7.

Table 9.7 Category 12-14: Giving support to get the treatment, leaving alone and letting complain, and assisting in the hospital

Caregivers’ category: ‘Assisting coping’

A and B exemplified how they assisted coping to their mother:

*I tried to talk about funny things with her, but she thought I was just annoying her ... I did that to try and cheer her up and to ease her stress, but she wouldn’t play along with me ... When she had pain, I tried to cheer her up. I loved her so much when she had pain and didn’t complain about it. After she felt better, she started to complain again. Sometimes I thought it was good that she got sick, because then she didn’t complain too much.*

A summary for codes which formed the category of assisting coping is shown in Table 9.8.
**Caregivers’ category: ‘Assisting with eating’**

Caregivers assisted with eating by focusing on how to control food and notice harmful food. Whan explained how she and her siblings controlled food for their mother:

_Yes (everyone controlled the food that she had) ... My older sister selected all of the ingredients that she cooked for her. She usually used fish in her cooking, but my mum only had a little. She always had every kind of food but only a little ... She had a little. Sometimes she didn’t have anything. My older brother tried to force her, because she had to take her medication after having food._

At the same time, Yon noticed which food was harmful.

_I’ll give you an example. Do you know cucumber? When I cooked it for her, I took the core out and put pork in instead._

A summary of the category of assisting with eating is shown in Table 9.8.

**Caregivers’ category: ‘Giving massage’**

Six caregivers gave massage to relieve pain for their loved ones. Yon described how he gave massage to his wife:

_Yes (I supported her with everything from the time she got up till she went to bed), including giving her a massage ... I massaged her and myself at the same time. You may wonder how I could do that. I massaged her legs with my right hand and myself with my left hand. While I massaged her, I always asked her how she was. I had to use my past experience while I did this ... she would get worse if I massaged her too much._

A summary of the category giving massage is shown in Table 9.8.
### Assisting coping

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urging to cope</td>
<td></td>
</tr>
<tr>
<td>Attempting to provide cheer</td>
<td>Assisting coping</td>
</tr>
<tr>
<td>Asking her to stop crying</td>
<td></td>
</tr>
<tr>
<td>Enjoying holidays</td>
<td></td>
</tr>
<tr>
<td>Not supporting her emotions</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing food</td>
<td>Assisting with eating</td>
</tr>
<tr>
<td>Cooking food</td>
<td></td>
</tr>
<tr>
<td>Controlling food</td>
<td></td>
</tr>
<tr>
<td>Doing the cooking</td>
<td></td>
</tr>
<tr>
<td>Having nutritious food</td>
<td></td>
</tr>
<tr>
<td>Noticing the harmful foods</td>
<td></td>
</tr>
<tr>
<td>Drinking coffee to ease pain</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving massage</td>
<td>Giving massage</td>
</tr>
<tr>
<td>Using massage appropriately</td>
<td></td>
</tr>
</tbody>
</table>

### Table 9.8 Category 15-17: Assisting coping, assisting with eating and giving massage

**Caregivers’ category: ‘Assisting with orthodox medication’**

The category of assisting with orthodox medication focused on looking after patients to take medication. Dao said: "I gave the medication to her (when I saw her suffering with pain)."

Poon said his daughter brought the medication to his wife:

*My daughter is a technical nurse. She works in the public, general hospital. It’s far from here. But she always asks Ta about her illness, and brings her medication from her hospital.*

A summary for these codes is shown in Table 9.9.
Codes | Category
--- | ---
Giving medication | Assisting with orthodox medication
Bringing medication | 
Assisting with medication | 
Looking after medications | 
Taking tramal to relieve pain | 
Visiting the doctor for medication | 
Appreciating taking medication and seeing the doctor | 
Requesting medication | 
Looking for the best medication to get rid of the pain | 

Table 9.9 Category 18: Assisting with orthodox medication

Caregivers’ category: ‘Assisting with natural medication’

This category emphasised herbal treatment. Man explained how he made an herbal medication for his wife:

*I think I’ll make her an herbal medication. I love to collect herb recipes. I have one recipe that is a medication to extend life (Ar Yu Wattana). I’ve already recorded some of the ingredients. The person who gave me this recipe was over 90 years old. He could have a young wife. But I’m not interested in his sex life. I’m interested in the fact that he is very healthy. I think I should make it for her. Perhaps it’ll make her stronger. But I have to be sure that there are no moulds in the ingredients. I’ll have to bake them before cooking. I talked with my oldest child about how I could do it, if I could bake them in the microwave after blending them and for how long. He’ll consult his teachers again. I’m worried that heat will change the ingredients.*

A summary of this category is shown in Table 9.10.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making an herbal medication</td>
<td>Assisting with natural medication</td>
</tr>
<tr>
<td>Using some herbal treatment</td>
<td></td>
</tr>
<tr>
<td>Finding herbs or ointment</td>
<td></td>
</tr>
<tr>
<td>Assisting with herbs</td>
<td></td>
</tr>
<tr>
<td>Trying a decoction from the temple</td>
<td></td>
</tr>
<tr>
<td>Trying a bolus and other medication</td>
<td></td>
</tr>
</tbody>
</table>

**Table 9.10 Category 19: Assisting with natural medication**

**Caregivers’ category: ‘Helping’**

Caregivers managed patients’ pain by helping and doing everything for their loved ones. Aim noticed what Ead’s son did for Ead:

*He did everything for her; as much as he could such as washing clothes, cooking, and buying food. Sometimes he came back home at noon and bought the food for her. Last night he went to the night market and bought many kinds of desserts for her too.*

Whan also explained how she and her siblings helped their mother:

*We tried to do everything that we could, because her hands couldn’t move or pick anything up. They were very stiff and sore ... Yes we did (her job for her). I mean my older brother, my cousin, and I did the chilli and sent it to the consumers ... Yes (she couldn’t get up from the bed at all). When she couldn’t walk well, she’d get up late. My older sister had to stay home with her. My older brother and I went to the market and sold the chilli ... Certainly (my mum stilled worked while she had pain). We helped her if we were here ... All of us usually came back home and stayed with her at different times.*

A summary for these codes is shown in Table 9.11.
Table 9.11 Category 20: Helping

Caregivers’ category: ‘Encouraging rest’

Caregivers encouraged patients to rest when they were in pain. Whan said:

She’d sometimes lie down from the time I went to school in the morning until I came back home in the evening. We often didn’t go to school if she was in a lot of pain and couldn’t move her body at all. We had to take care of her at home ... She couldn’t walk at all at that time. She persuaded me to stay with her. We had to take it in turns to care for her at home. My brother took care of her one day and my sister took care of her next day.

A summary for codes which formed this category is shown in Table 9.12.
**Caregivers’ category: ‘Helping mobility’**

Caregivers helped patients about their mobility. Man helped his wife by using a wheelchair:

She couldn’t walk after she finished work yesterday. I had to put her in the wheelchair and push it to the car park.

Meanwhile Yon modified the toilet to suit his wife:

I had to modify the toilet; for example I adapted the drainpipe trap, so it was higher and tied a rope onto the ceiling. When I was not home, she could pull on the rope to support herself to stand.

A summary of the category of helping mobility is shown in Table 9.12.

**Caregivers’ category: ‘Facilitating comfort’**

The codes of caregivers’ accounts included ‘not touching her body too much’, ‘organising temperature control’, and ‘using measures to relieve coldness’. Nhung said:

“We couldn’t touch her much when she had pain”. Man said:

I always have the air conditioner on at all times, around the clock on weekends. She can’t tolerate the hot weather. Her pain starts immediately.

Whan also had her own way to facilitate comfort:

When the cold weather came, I laid the hot packs and hot water bottles on her joints. I’ll explain to you about the “hot water bottle”. I’d put hot water in the bottle and wrap it with cloths ... I helped her when the weather was cold. She got better if I laid them on her joints for a long time. They didn’t relieve her pain every time that we used them ... I observed her symptoms even though she didn’t tell me about them, such as swelling, inability to walk, lying down all the time, and being cold. Sometimes she was cold at noon or in the afternoon. She kept her body warm with 5 blankets ... Yes (I only knew she had pain from my observations). If she was cold, it meant she was in pain. She got pain and felt cold when the weather was cold.
Caregivers’ category: ‘Encouraging exercise’

A and B described the way to encourage their mother to exercise:

*And we also took her to do aerobic exercise, because we wanted her to exercise continually. We bought exercise equipment for her, but it’s become a place to hang things on already (laughed). She just exercised for a few days, because she wasn’t used to it. We bought a sand sack for her to exercise with. She only used it two or three times, because she had pain all over her body after she used it (laughed).*

A summary for the category is shown in Table 9.12.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resting all day</td>
<td>Encouraging rest</td>
</tr>
<tr>
<td>Encouraging rest</td>
<td></td>
</tr>
<tr>
<td>Telling rest and sleep</td>
<td></td>
</tr>
<tr>
<td>Allowing rest and sleep</td>
<td></td>
</tr>
<tr>
<td>Helping mobility</td>
<td>Helping mobility</td>
</tr>
<tr>
<td>Helping her to remain mobile</td>
<td></td>
</tr>
<tr>
<td>Using a wheelchair</td>
<td></td>
</tr>
<tr>
<td>Modifying the toilet</td>
<td></td>
</tr>
<tr>
<td>Carrying to the toilet</td>
<td></td>
</tr>
<tr>
<td>Encouraging exercise</td>
<td>Encouraging exercise</td>
</tr>
<tr>
<td>Asking about exercise and the effects of climate</td>
<td></td>
</tr>
</tbody>
</table>

**Table 9.12 Category 21, 22, and 24: Encouraging rest, helping mobility, and encouraging exercise**

Caregivers’ category: ‘Getting help from others’

Caregivers got help from others to look after the patients. Aim explained the help from family:

*She did housework by herself and gave her sons the clothes to wash. She let them do things when she was in pain and couldn’t do them. Now I can’t help her anymore,*
because I’ve just had a back operation. Unfortunately we got sick at the same time, but I can go to see her at home although I’m in my rehabilitation period. I want to know how she is. My daughter would go to see her instead of me if I couldn’t. She checked on how my sister was; if she could eat food and get things that she wanted. If she wanted to have some special food, I brought it to her.

She also told about the help Ead got from the neighbours:
Sure (her neighbours visited her when she had pain). There were many neighbours, who visited her. They often visited and talked to her about her illness. She’d helped them a lot, because she’d always offered to do the catering for funerals, weddings, and priesthood ceremonies. She did it well and knew what to do.

Man said his wife got help from her friends also:
Her friends came to encourage her (laughed) (when she had operation) ... Someone teased her and said “We should get some ice to drink with the Kek huay juice (laughed)”.

A summary of ‘getting help from others’ is shown in Table 9.13.

**Caregivers’ category: ‘Seeking spiritual support’**

Caregivers focused their spiritual support by using black magic and praying. B described her praying:
I never spoke to her about it. I was praying for her, but if she didn’t hear me, she didn’t know. It was my secret that I would never speak about it, and I didn’t want to speak about it (laughed). I didn’t dare to say anything and I was ashamed too (laughed). She may have thought that I didn’t care about her. But when I did this, she didn’t know. I loved to say the “Chin Na Ban Chon” prayer. It’s the most popular prayer in Buddhism. I prayed every day while she was in pain. I prayed for her and wished her to be healthy.

Dao believed in using black magic to relieve pain:
She rode the bike to the junction where someone did some kind of black magic. We call it “Song Kraban” (Phee Tai Hong Tai Ha). Do you know it? I’ll explain it to you. We believe in it. We sacrifice the soul of our ancestors, who died violent deaths. They will cure her of the disease (laughed). It started from her dream. She dreamed that she went to the temple. When she arrived there, someone hit her. So she made a dummy and laid it at the junction. It was a doll that was made from the soil or clay.

A summary of the category seeking spiritual support is shown in Table 9.13.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being helped by family members</td>
<td>Getting help from others</td>
</tr>
<tr>
<td>Help coming from every family member</td>
<td></td>
</tr>
<tr>
<td>Seeing some help from other family members</td>
<td></td>
</tr>
<tr>
<td>Being visited by neighbours</td>
<td></td>
</tr>
<tr>
<td>Getting help from neighbours</td>
<td></td>
</tr>
<tr>
<td>Employing a neighbour to help</td>
<td></td>
</tr>
<tr>
<td>Seeking advice from neighbours for getting a good cure</td>
<td></td>
</tr>
<tr>
<td>Gaining encouragement from friends</td>
<td></td>
</tr>
<tr>
<td>Using black magic</td>
<td>Seeking spiritual support</td>
</tr>
<tr>
<td>Being urged to use black magic</td>
<td></td>
</tr>
<tr>
<td>Giving holy water</td>
<td></td>
</tr>
<tr>
<td>Praying for her every day</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.13 Category 25-26: Getting help from others and seeking spiritual support
From categories to concepts and core social processes

Constant comparative method was used to find concepts and core social processes after I distinguished codes into suitable clusters of categories. They are shown in figure 9.1 and 9.2.
<table>
<thead>
<tr>
<th>Categories</th>
<th>Concepts</th>
<th>Core social processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognising the causes and effects of pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recognising body and lifestyle changes</td>
<td>Attention</td>
<td>Intimacy</td>
</tr>
<tr>
<td>Expressing reactions after having pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressing feelings</td>
<td>Compassion</td>
<td>Close understanding</td>
</tr>
<tr>
<td>Motivation to care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressing hopes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 9.1 Caregivers’ perception of pain
<table>
<thead>
<tr>
<th>Categories</th>
<th>Concepts</th>
<th>Core social processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving support to get treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leaving alone and letting complain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisting in the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisting coping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being unsure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offering suggestions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appreciating present treatment</td>
<td>Psychological support</td>
<td>Mental succour</td>
</tr>
<tr>
<td>Getting help from others</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 9.2 Caregivers’ pain management
<table>
<thead>
<tr>
<th>Categories</th>
<th>Concepts</th>
<th>Core social processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assisting with eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving massage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisting with orthodox medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisting with natural medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping</td>
<td>Physiological support</td>
<td>Physical succour</td>
</tr>
<tr>
<td>Encouraging rest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping mobility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facilitating comfort</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encouraging exercise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking spiritual support</td>
<td>Spiritual support</td>
<td>Spiritual succour</td>
</tr>
</tbody>
</table>

Figure 9.2 (continued) Caregivers’ pain management
Caregivers’ experiences as integral to the grounded theory

After I matched the categories to concepts and core social processes, I was ready to state the grounded theory of caregivers’ experiences of rheumatoid arthritis. This section describes the caregivers’ grounded theory.

Caregivers’ experiences perceived their role as intimacy, by paying attention to the body and lifestyle changes, and causes and effects of their relative’s pain. They had a close understanding, based on compassion for their relatives, a motivation to care, and hopes for positive outcomes.

Caregivers gave succour to relatives with rheumatoid arthritis in three dimensions: physical, mental, and spiritual. They provided physical succour by giving physiological support, assisting in the activities of daily living of patients, such as eating, resting and exercising, and comfort measures, such as orthodox and natural medication.

Caregivers provided mental succour to their relatives by giving psychological support, accepting their illness, supporting them to get treatment, and assisting them during hospitalisation. They allowed their loved ones to be alone, to be free to complain, and assisted them to cope with their problems as they arose. Although caregivers appreciated treatments and help from others, they also offered some suggestions themselves to relatives to relieve pain. The last dimension was spiritual succour, in which caregivers supported their relatives spiritually by using religious activities and some black magic.

Summary

This chapter described the codes, categories, concepts and core social processes for caregivers’ experiences of rheumatoid arthritis. A grounded theory emerged of caregivers’ experiences, and this has been described in this chapter. Chapter Ten describes nurses’ experiences of rheumatoid arthritis.
Chapter Ten: Emerging Theory:
Nurses’ Perspectives of Rheumatoid Arthritis

Introduction

This chapter describes the analysis of nurses’ perceptions. The description includes the codes, categories, concepts, and core social processes for nurses’ experiences of rheumatoid arthritis.

Nurses


Nurses’ category: ‘Recognising the incidence of rheumatoid arthritis’

The first category from nurses emerged from the code ‘noticing more females have rheumatoid arthritis’. Every nurse agreed that they met more female patients than male. Anne said:
I saw more female than male patients. They were in the over 50 age group. In my opinion, I saw more female patients, because females encounter more risk factors associated with rheumatoid arthritis than males, such as self-care and food intake.

Rin agreed:
I met more female patients than male. They were middle aged. I mean they were mostly adults. I saw only a few patients, who were teenagers.

Nurses’ category: ‘Recognising causes of pain’

Nurses perceived that there were many factors can cause pain. Luck explained:
There were many types of pain. It depended on the surroundings and the weather. Most of them had pain when the weather was cold. Some cases had pain when they were exposed to the breeze from electric fans.

Other factors which can cause pain were patients’ feeling and beliefs. Regarding feeling, Khan said:
From when I first met them, they worried about their changed body images. Some cases expressed their fears and asked why they had got rheumatoid arthritis. Some cases understood it and accepted that they would have to live with rheumatoid arthritis ... They didn’t talk much, but I could tell from their faces. They looked miserable when they had pain, because they couldn’t understand why they were in pain and why they got rheumatoid arthritis.

Meaw noticed disheartened feelings can cause pain. She said: “I noticed that when they were disheartened, pain increased”.

Luck recognised patients’ beliefs about herbal treatment are related to pain. She said:
In terms of their beliefs, some patients not only get treatment from us, but also treat themselves with herbs. They used to tell me that they took boiled herbs and that that had the effect of relieving the pain. They learnt from advertisements that these herbs could heal joint pain, gout, and arthritis. Some patients misunderstood these words. They
thought that they were the same things. They had joint pain, so they assumed that these boiled herbs could treat their illness … Some educated people also get other treatment that’s not the right sort of treatment.

A summary of codes, which formed the category of recognising causes of pain is shown in Table 10.1.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about the variables that cause pain</td>
<td>Recognising causes of pain</td>
</tr>
<tr>
<td>Noticing pain causing immobility</td>
<td></td>
</tr>
<tr>
<td>Noticing cold weather can cause pain</td>
<td></td>
</tr>
<tr>
<td>Noticing patients’ feelings related to pain</td>
<td></td>
</tr>
<tr>
<td>Noticing disheartened feeling can cause pain</td>
<td></td>
</tr>
<tr>
<td>Recognising patients’ beliefs about herbal treatment are related to pain</td>
<td></td>
</tr>
</tbody>
</table>

Table 10.1 Category 2: Recognising causes of pain

Nurses’ category: ‘Recognising symptoms of rheumatoid arthritis’

The category of recognising symptoms of rheumatoid arthritis came from the codes ‘noticing joint pain, joint swelling, joint deformity, and joint stiffness’. Mham recognised pain was the main problem for patients with rheumatoid arthritis:

Most of them were admitted with pain, but not too much pain. There were a few patients, who had a lot of pain and had to take medication all the time … I’m not sure what criteria that the doctors used to admit them. I often found that they were admitted for blood test and to have their rheumatoid arthritis factor checked. These patients weren’t given an appointment at the OPD. Furthermore, they did the blood test to be sure which disease the patients had before they gave the patients medication. The other reason was that the patients who were in a lot of pain were admitted to get some rest … No (there
weren’t any other symptoms that I saw in them). I only saw them admitted with pain. They often had finger pain and pain in some of their joints.

Rin and Am noticed the symptoms of joint swelling. Rin said:
They were often admitted with joint swelling. They had swelling in the small joints such as the knuckles and had had pain for a long time ... They had pain and swelling, but not much hand deformity.

Am said:
They had pain and swelling in many of their joints ... I thought that they had these symptoms, because they were lacking in exercise.

Khan found that patients had joint deformity:
She had deformity in her knuckles and she also had to have a knee operation, because they’d degenerated. I’m not sure how old she was, but she was an aged person. I often found that many cases had knuckle deformity.

The last symptom which nurses realised the patients with rheumatoid arthritis had, was joint stiffness. Tina explained: “She had joint stiffness in many parts of her body too”.

A summary of codes is shown in Table 10.2.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noticing joint pain</td>
<td>Recognising symptoms of rheumatoid arthritis</td>
</tr>
<tr>
<td>Acknowledging patients’ pain</td>
<td></td>
</tr>
<tr>
<td>Recognising pain is the main problem</td>
<td></td>
</tr>
<tr>
<td>Noticing joint swelling</td>
<td></td>
</tr>
<tr>
<td>Noticing joint deformity</td>
<td></td>
</tr>
<tr>
<td>Noticing joint stiffness</td>
<td></td>
</tr>
<tr>
<td>Noticing fever</td>
<td></td>
</tr>
<tr>
<td>Noticing immobility</td>
<td></td>
</tr>
<tr>
<td>Acknowledging patients’ pallor</td>
<td></td>
</tr>
<tr>
<td>Noticing history of illness</td>
<td></td>
</tr>
<tr>
<td>Noticing younger patients seem to have less pain</td>
<td></td>
</tr>
</tbody>
</table>

**Table 10.2 category 3: Recognising symptoms of rheumatoid arthritis**

**Nurses’ category: ‘Recognising the value of hospitalisation’**

Tha-nhom perceived hospital was important in the lives of patients with rheumatoid arthritis. She perceived:

*On the other hand, hospitals became important in the lives of patients with rheumatoid arthritis, as it was not easy to treat them through till the rheumatoid arthritis had disappeared. It made them disheartened and lose hope.*

**Nurses’ category: ‘Expressing pity and sympathy’**

The nurses’ accounts formed the codes of feeling pity, sympathy, and being there to help appropriately. Meaw felt pity for patients with rheumatoid arthritis.

*I pitied them, because rheumatoid arthritis is a disease that they’d have for the rest of their lives. They had to take the medication. When they had pain, they couldn’t do
anything by themselves. They had to lie down or were admitted, so they could rest. I
explained to them what was happening to them. There was no cure, and that I couldn’t
help them any more than by what I was doing. I would encourage them to get some rest
and give them psychological support.

Khan felt sympathy for patients.
I sympathised with them, because rheumatoid arthritis is a disease with an unknown
cause. It’s a chronic illness. They have to get treatment for the rest of their lives. I pitied
them. I wished that they would look after themselves as best they could. They needed to
continue taking medication and restrict their diet to relieve their pain.

Usa expressed that she was there to help patients appropriately:
Some symptoms were cured without medication. Some patients asked for analgesic
drugs to keep and take when they were in pain. We had to tell them not to worry if they
had pain. We were here. They could ask for the medication every time they had pain.
Nurses would know how they were. We wouldn’t know if they were getting better or
worse if they kept and took the medication at home … On the other hand, if we didn’t
show interest when they complained they became disheartened. Nurses should
encourage them and tell them that every patient is in the same situation.

Nurses’ category: ‘Preferring to nurse emergency cases’

Three nurses expressed some feeling to patients with rheumatoid arthritis. Mham felt
that she did not want to care for chronic patients:
Sometimes I felt that I didn’t want to care for chronic patients, because I felt I couldn’t
help them very much except to give them advice. I felt good if I treated them and I could
see the results afterwards. Then I had positive reinforcement to carry on with the next
step in the treatment.

Rin said that she paid more attention to emergency cases, not rheumatoid arthritis, when
they were admitted to hospital.
There are many things that affected my feelings about patients with rheumatoid arthritis. Firstly, rheumatoid arthritis cases are rare. They’re only one or two percent of cases in Thailand. Most orthopaedic patients who were admitted here were trauma patients from accidents and bone fractures. They were emergency patients. It was different when patients with rheumatoid arthritis were admitted. When these emergency patients were admitted to the ward, we had to give them specific nursing care and look after them more intensely than other cases.

On the other hand, Usa noticed similar patterns in chronic disease and rheumatoid arthritis:

I felt there was no difference between rheumatoid arthritis and other orthopaedic patients, because their suffering was the same. They had pain and they had a chronic disease. They put up with the suffering and ignored the pain until they had joint damage. Most of the other orthopaedic patients that were not accident patients were admitted with back pain and joint pain. They had the same pain. I mean they both had joint pain. They suffered and had a chronic illness.

**Nurses’ category: ‘Feeling unsure about the ways to relieve pain’**

The category of feeling unsure about relieving pain was shown in three codes; ‘being unsure of appropriate advice’, ‘not knowing the best way to relieve pain’, and ‘being unsure of the benefit of exercise’. Am said:

*I am a ward nurse. I was never close to the patients like the local staff. They can get to see them at home. So I didn’t know what the real problems for them were and whether they could do everything that I’d advised when they got back home. For example, I advised them to avoid some foods, but these foods might be customary in their communities. If they did as I advised and they had no more money to buy other good food, they might have become worse or malnourished.*

Luck said that she did not know the best way to relieve pain.
(Thought) I didn’t know the best way to help them, because the pain was related to the weather. It was difficult to help. If they had pain and no alkalosing, they knew how to relieve their pain. But most of them had to take medication to relieve the pain.

Nurses were unsure about how to advise about exercise. Am confessed:
*I’m not sure what you mean (about exercise for patients with rheumatoid arthritis). You mean joint exercise? I didn’t want them to exercise while they had pain, because it could cause the patients to have even more pain. Before I advised them, I considered their pathology. If they had just a little pathology, I helped them to exercise to protect them from complications. If they already had deformity, I wasn’t sure whether it was good or not to suggest exercise to them. I worried that it would make them suffer more. So in my opinion, exercise doesn’t relieve rheumatoid arthritis pain.*

A summary of the codes which formed the category of feeling unsure about the way to relieve pain is shown in Table 10.3.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being unsure of appropriate advice</td>
<td>Feeling unsure about the ways to relieve pain</td>
</tr>
<tr>
<td>Not knowing the best way to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Not knowing the special arrangements for patients with rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Being unsure of the benefits of exercise</td>
<td></td>
</tr>
<tr>
<td>Conflicting advice on resting or walking</td>
<td></td>
</tr>
<tr>
<td>Feeling unsure about massage</td>
<td></td>
</tr>
<tr>
<td>Being unsure about the effectiveness of herbs</td>
<td></td>
</tr>
<tr>
<td>Feeling unsure about soaking in warm water</td>
<td></td>
</tr>
<tr>
<td>Feeling unsure about the use of hot compresses</td>
<td></td>
</tr>
<tr>
<td>Being unsure about herbs or breathing exercises to relieve pain</td>
<td></td>
</tr>
</tbody>
</table>

**Table 10.3 Category 7: Feeling unsure about the ways to relieve pain**
Nurses’ category: ‘Expressing obstacles’

There were the obstacles from doctors, nurses, and patients which nurses noticed in their pain management. Usa and Luck described the obstacles from the doctors. Usa recognised healing took time:

_The other problem was their pathology. Some had a lot of pathology and were severe cases. They hoped that their pain would disappear as soon as they were admitted to the hospital. Some patients got better after they’d been admitted for one or two weeks. The doctors and nurses should explain to them about how long it would take to get better and about their symptoms. Then they’d feel better and wouldn’t be anxious. Some understood that it would take time to get better and so they weren’t so anxious. Some counted the days and so were stressed. They became more stressed if they didn’t get better by the date that the doctors had set. Everyone was not the same._

Meanwhile, Luck described waiting for doctors to confirm a diagnosis:

_I think there were problems about treatment, because at the beginning it’s not easy to detect rheumatoid arthritis from gout. Doctors had to give the patients medication to try. It took time to know what the real disease was and what medication was suitable for the patient. Everything would be all right after the patient got the right medication. Their prognosis would be good and their pain would lessen ... We (nurses) had a few problems while the doctors were trying to establish whether the disease was rheumatoid arthritis or gout. We had to wait for the right information from them._

Related to obstacles from nurses, Luck recognised rheumatoid arthritis care was rare.

_Yes (the fact that rheumatoid arthritis is rare had any effect on the nursing care), a little, because rheumatoid arthritis is rare we hardly saw patients admitted to the ward. So it was easy to forget some of the nursing care. When patients with rheumatoid arthritis were admitted, we rushed to read the textbook to make sure we were giving them the right nursing care (laughed)._
Meaw agreed with Luck:

Certainly (As I didn’t see rheumatoid arthritis cases frequently, this had any effects on the nursing care I gave to them). Sometimes I had to read the textbooks and try to make sense of rheumatoid arthritis again. If I didn’t do that, I couldn’t answer the patients’ questions. Because I didn’t see them frequently, I forgot a lot about the disease. I am not sure why I saw so few cases. Probably because rheumatoid arthritis is a chronic illness and so patients can get home medication from the hospital, and go back home except for the cases that have severe pain. They were admitted to get rest and have the tablets and injections.

Rin recognised that obstacles came from lack of knowledge and experience:

Thirdly, when I'd just graduated from nursing college, I only saw a few patients of rheumatoid arthritis. That meant I had little knowledge or experience with it. I didn’t know how to care for them other than what I knew from college. Therefore, I was lacking in experience ... Finally, I now have a lot of experience and knowledge. I’m ready to give them full nursing care, but fortunately no patients with rheumatoid arthritis have been admitted to the ward for a long time. So unfortunately for me I can’t learn from these patients. In the cases where the patients were anxious, I talked with them and informed the doctors that they weren’t getting better even though they’d taken medication. I hoped the doctors would explain to them what rheumatoid arthritis was or change the dose for them.

Usa explained another obstacle from nurses. She said:

Doctors have many tasks, so they only have a short time to talk with the patients. Nurses have a lot of contact with the patients. Nurses should be the coordinators between patients and doctors. We could then tell the doctors what their problems are.

Nurses also expressed the obstacles from patients. Anne said:

Many patients still had pain, because they didn’t believe in the advice or do what we advised. They didn’t take their medication continually. The doctors told me patients with rheumatoid arthritis should take their medication for at least six months. They often stopped taking the medication when they got better. They didn’t try to avoid things that
were harmful such as the cold weather. Most of them didn’t like the hot weather. They loved to keep cool and that was the reason they got pain again ... Most of them knew the right things to do, but they didn’t do them.

Tha-nhom noticed non-compliance to treatment in patients:

There are many problems caused by nurses and patients. Patients cause problems, I think, because of their beliefs and awareness of their illnesses, especially when they are in pain. In my past experience, they only followed the doctors’ orders and nurses’ advice when they were in pain. After their pain lessened, they thought that everything was all right. So they went back to doing the same things again. I would advise them about foods that they should not have, but they wanted to have them. They thought that it wasn’t a problem if they had just a little bit.

Tha-nhom also perceived that obstacles came from economic status:

Another factor is the economic status of the patient. Some patients have a problem with the treatment fees, because medication for rheumatoid arthritis is so expensive. They want to continue treatment, but they need to keep their money for their families too. Some patients are both poor and live far from the hospital. It’s a problem that disrupts their treatment. In fact, there are many problems that disrupt their treatment. Somebody may have one problem, but somebody else may have many problems ... There were many problems in the past with patients having no more money for treatment or for the expensive medication.

A summary of this category is shown in Table 10.4.
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognising no real problems in managing pain for patients with rheumatoid arthritis</td>
<td>Expressing obstacles</td>
</tr>
<tr>
<td>Recognising mistakes in health brochures</td>
<td></td>
</tr>
<tr>
<td>Recognising healing takes time</td>
<td></td>
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<tr>
<td>Waiting for the correct diagnosis</td>
<td></td>
</tr>
<tr>
<td>Waiting for doctors to confirm a diagnosis</td>
<td></td>
</tr>
<tr>
<td>Thinking the doctors do not control patients’ pain</td>
<td></td>
</tr>
<tr>
<td>Nursing care of rheumatoid arthritis is rare</td>
<td></td>
</tr>
<tr>
<td>Recognising rheumatoid arthritis care is rare</td>
<td></td>
</tr>
<tr>
<td>Recognising lack of knowledge and experience</td>
<td></td>
</tr>
<tr>
<td>Recognising lack of opportunity to see patients with rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Recognising language difficulties</td>
<td></td>
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<tr>
<td>Recognising nurses’ incomplete information</td>
<td></td>
</tr>
<tr>
<td>Being unable to give adequate nursing care</td>
<td></td>
</tr>
<tr>
<td>Being patients’ advocates to doctors</td>
<td></td>
</tr>
<tr>
<td>Confirming poor nurse-patient ratios</td>
<td></td>
</tr>
<tr>
<td>Noticing problems from patients’ and nurses’ perspectives</td>
<td></td>
</tr>
<tr>
<td>Confirming communication problems between patients and nurses</td>
<td></td>
</tr>
<tr>
<td>Noticing some patients do not take advice</td>
<td></td>
</tr>
<tr>
<td>Recognising some patients do not take their medications</td>
<td></td>
</tr>
<tr>
<td>Noticing non-compliance to treatment in patients</td>
<td></td>
</tr>
<tr>
<td>Noticing different responses to treatment and advice</td>
<td></td>
</tr>
<tr>
<td>Perceiving differences in education</td>
<td></td>
</tr>
<tr>
<td>Perceiving the problem of economic status</td>
<td></td>
</tr>
<tr>
<td>Perceiving the problem is difference in confidence</td>
<td></td>
</tr>
<tr>
<td>Perceiving non-complaining attitude is Thai nature</td>
<td></td>
</tr>
<tr>
<td>Relapsing on return to home</td>
<td></td>
</tr>
<tr>
<td>Noticing reversion to old patterns of behaviour</td>
<td></td>
</tr>
<tr>
<td>Recognising some patients have no relatives to help</td>
<td></td>
</tr>
</tbody>
</table>

**Table 10.4 Category 8: Expressing obstacles**
Nurses’ category: ‘Assessing’

The codes of assessing came from Rin, Usa, and Am’s accounts. Rin exemplified this code well. She said:

*I assessed them for many things. First was their level of pain. Second was which parts of their bodies were painful. The third thing was the daily activities that they had to do when they were admitted. Fourth was which parts of their bodies they had to use frequently. Fifth was their capacity to do things. And the final thing was how many relatives they had who could care them during the day.*

Nurses’ category: ‘Informing the doctors’

Anne and Rin informed the doctors about patients’ pain. Anne explained: “*I informed the doctors if the patients didn’t get better after I’d followed their orders*”.

Rin also said: “*We would inform the doctors if they still had a lot of pain*”.

Nurses’ category: ‘Managing medication’

Nurses agreed that giving medication was the common way to relieve pain. Tina explained:

*We gave the medication as the doctors had ordered ... Firstly taking medication. That they should take medication immediately after their meal and not on an empty stomach. I emphasised this point a lot, because they would still get side effects even though they took gacida.*

Nurses gave analgesics to relieve pain. Tha-nhom explained:

*I gave them paracetamol as prescribed by the doctors, and followed up on how they were after taking the medication ... I’d talk with them first, assess their symptoms, and then give them medication. Finally, I’d inform the doctors and ask for injections if they still had pain ... Finally, I informed the doctors and asked for injections for the cases that weren’t getting better.*
Nurses’ category: ‘Using discharge planning’

Mham and Meaw encouraged discharge planning to manage pain. Mham said:
*I’m interested in discharge planning. It’s good if we can provide activities for the patients to do each day and at each stage. If we can do this, we need to refer to the theory. It’s like when the patients take a course or program when they are admitted. It would be good if we could do this, but our minds might become numb when we do a lot of discharge planning. We don’t have enough staff to do it. It would be better if there was a standard form that we could use immediately.*

Meaw agreed:
*My Head of Ward introduced it (discharge planning) here. In my ward, we use it in every case. But you’ll only find a little about discharge planning in the textbook. It’s like a form or a report. We set up the form first, and then put the important things that they have to do and to know in it. We put only the main points, but the nurses have to explain the details to the patients. We use this form from the time they are admitted until they are discharged. After we’ve advised them, we record the result on it. If they don’t understand or do what we advise, we advise again and again till they get it or can manage well. After they are discharged, we sum up our findings about their problems and the health education that we gave.*

Nurses’ category: ‘Using herbs’

Tina talked about using herbs. She said:
*Pharmacists in this hospital have only studied for two or three years and produced one product for relieving pain. They told me that they used herbs as the main ingredient, but I can’t remember how many ingredients were in this product. Any patient who had pain could use it, not only patients with rheumatoid arthritis. They gave it to me and a lot of patients tried it. It’s very expensive. One dose is 250 Baht ($A10.42). It comes in a small bottle and it’s the same price as voltaren Gel.*
Nurses’ category: ‘Using relaxation’

Tina offered advice about relaxation. Related to relaxation activities, she said:
*I didn’t set up any motivational group or any special activities to encourage them. I gave them things to do for relaxation.*

She also suggested that traditional massage would relieve pain:
*I might be mistaken, but I think traditional massage is offered here. It sounds good and I think it could help patients, because they use curcuma, cassumunar and other oils. It’s good for their morale too. In my opinion, the cassumunar oil could also relieve pain. This service has only been operating for nearly a month. There are many services here such as massage, hot compresses, and also foot massage. It’s a good way to help patients.*

Nurses’ category: ‘Keeping warm’

The category of keeping warm emerged from the codes ‘keeping the joints warm’, ‘applying hot compresses’, and ‘using paraffin soaks for pain’. Anne explained how she kept the patients’ joints warm:
*I kept their joints warm when they had pain. For example, if they had pain in their arms and body I covered them with a blanket and told them to wear thick clothes. I advised them that they might feel hot but that they had to be patient. I made sure they weren’t put near a window. They could get pain again if they were in a cold breeze.*

Am applied hot compresses to patients. She said: “*If they still had pain, I applied hot compresses for them. I used hot pack gel to do that*”.

Am also suggested soaking in hot paraffin. She perceived:
*In the cases that had severe pain, I informed the doctors and then they consulted the physical therapists to transfer patients for some special treatment, such as soaking the area in paraffin. I saw the doctors send the cases that had pain in their hands and feet to soak in paraffin.*
A summary of this category is shown in Table 10.5.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping the joints warm</td>
<td>Keeping warm</td>
</tr>
<tr>
<td>Avoiding coldness</td>
<td></td>
</tr>
<tr>
<td>Using elastic bandages</td>
<td></td>
</tr>
<tr>
<td>Soaking in warm water</td>
<td></td>
</tr>
<tr>
<td>Applying hot compresses</td>
<td></td>
</tr>
<tr>
<td>Using paraffin soaks for pain</td>
<td></td>
</tr>
</tbody>
</table>

**Table 10.5 Category 15: Keeping warm**

**Nurses’ category: ‘Using medication as the main treatment’**

Nurses recognised that the doctors controlled the treatment, and their treatment relied on the medications. Usa explained:

_They gave them analgesic drugs, non-steroidal anti-inflammatory drugs, such as naprosyn and antacid, such as alum milk and alumac to protect their stomachs. Some cases were given oil or balm if they asked the doctors for it._

Meaw agreed that the doctors’ treatment was giving medication;

_Most of them gave non-steroidal anti-inflammatory drugs (NSAIDs) to these patients ... Sometimes they gave the patients injections, such as tramal. It was the PRN dose or given when the patients had acute pain. First, the doctors gave them a low dose medication to take. If patients were still in pain, they gave a higher dose to them. Patients had to take NSAIDs at all times, although the doctors gave them PRN medication as well._

**Nurses’ category: ‘Recognising nurses’ roles in managing pain’**

Nurses realised that their pain management was giving medication and advice. Am explained that:
It was only basic nursing care that we could give them, such as giving medication and health education. We have to work under the doctors’ orders. I think giving health education is an independent role.

Meanwhile, some nurses felt that patients with rheumatoid arthritis can care for themselves. Luck said:

Yes (there’s no health centre to care for patients with rheumatoid arthritis after they’re discharged). As I’ve said, if they’re careful, they can care for themselves. They’re well aware of what foods they can or can’t have. They’re always careful.

A summary of codes which formed the category of recognising nurses’ roles in managing pain is shown Table 10.6.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving care only to severe cases of rheumatoid arthritis</td>
<td>Recognising nurses’ roles in managing pain</td>
</tr>
<tr>
<td>Recognising nurses can only give medications and advice</td>
<td></td>
</tr>
<tr>
<td>Believing nursing care involves giving medications and advice</td>
<td></td>
</tr>
<tr>
<td>Feeling patients with rheumatoid arthritis can care for themselves</td>
<td></td>
</tr>
<tr>
<td>Recognising patients with rheumatoid arthritis know how to care themselves</td>
<td></td>
</tr>
</tbody>
</table>

Table 10.6 Category 17: Recognising nurses’ roles in managing pain

Nurses’ category: ‘Offering suggestions’

Nurses confirmed that the best way to relieve pain was giving medication. Mham said:
The primary method is by giving medication, and the secondary one is to stop using the joints. In fact, we don’t use our joints when we are in pain. This means that we automatically rest them. The important thing is what they should do after they get better. They would have joint stiffness if they didn’t exercise. That was the point nurses had to emphasise to them. I told them they had to exercise after the pain and inflammation were relieved.
Beside this, Meaw felt special treatment at the occupational and physical therapy department cause pain:

_I never saw them getting special treatment from these departments (occupational and physical therapy departments). Most of them were usually admitted to get bed rest and take medication or to find an effective method of pain relief. I think that above all they should get some rest while they have pain. If they take some courses in these departments, they may end up with more inflammation. When they felt better, they didn’t ask to go there, and the doctors didn’t send them to these departments either if they saw that the patients were better after taking medication. Patients with rheumatoid arthritis were usually admitted only for a short time. They were usually back home within one week._

Furthermore, Am recognised benefits of analgesics, food, and restricted movement:

_Most of them used symptomatic treatment ... They (doctors) gave them medication and ordered them to get some rest ... Antirheumatic drugs (that the doctors gave to the patients) ... It was routine medication that they gave the patients. There is no specific medication for relieving the pain of rheumatoid arthritis ... I have never seen patients with rheumatoid arthritis and acute pain. I saw the patients that were feeling better after they had routinely taken medication as prescribed in their charts ... Most of them asked for it (balm and ointment). The doctors only gave them antipain ointment. It seemed to ease the minds of those patients that wanted something different like massage ... Taking medication continually, avoiding harmful foods and not moving the joints too much (are the best ways to manage pain)._
<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferring medications to herbs for pain relief</td>
<td>Offering suggestions</td>
</tr>
<tr>
<td>Confirming the best way to relieve pain is giving medication</td>
<td></td>
</tr>
<tr>
<td>Recommending patients don’t get too many injections</td>
<td></td>
</tr>
<tr>
<td>Realising patients would get their analgesics if necessary</td>
<td></td>
</tr>
<tr>
<td>Feeling special treatment at the OT or PT can make more pain</td>
<td></td>
</tr>
<tr>
<td>Recognising benefits of analgesic, food, and restricted movement</td>
<td></td>
</tr>
</tbody>
</table>

Table 10.7 Category 18: Offering suggestions

Nurses’ category: ‘Using religion to relieve pain’

Luck used religion to relieve pain:

*I used many styles of support (laughed), but I had to assess them first. For example, I had to know what their religion or beliefs were, because I would bring them some religious material that they might be interested in and talk with them about it. Talking with them about the things that they were interested in helped me support them in appropriate ways. I could get to know what methods they used to relieve their pain, and help them to build the mental attitude to accept their illness. If they couldn’t, I would find other ways to motivate them and encourage them to have the right mental attitude. Everything that I did depended on personal differences.*

Nurses’ category: ‘Giving advice’

The nurses’ accounts showed the codes ‘giving advice about foods, behaviours, resting, health education, mobility, and exercise’. Rin was a good example of the code of advising on food choices. She said:

*In my opinion, rheumatoid arthritis is a chronic disease that we can give conservative nursing care for. So we advise the patients to eat appropriate food ... We used to ask them what food they wanted to eat and explain to them which food they could have, because they couldn’t have every kind of food they wanted. No one food is harmful to*
them. We usually checked the food they had to be sure it wasn’t harmful, and gave them adequate calories for each day.

Usa gave advice on behavioural changes:

_The important thing was to give them information. We needed to advise them what things they should be careful of, how they should change their behaviours, and how they could handle their daily lives. It was very difficult to change their behaviours. They got better if they could change. They often didn’t change. They reverted to doing the same harmful things when they were better._ I used to advise them how to lift things.

Nurses advised patients about how to rest. Tha-nhom explained:

_First, I talked with them … They got worse and their joints were more painful if they still walked too much. On the other hand, if they got some rest and took the medication, they would get better, because they’d stopped using their joints … I advised them to rest in bed and stop walking, because if they still walked about and didn’t rest, their symptoms wouldn’t subside._

Health education was important advice to give to patients with rheumatoid arthritis. Meaw said:

_We gave them health education before they were discharged. Now, we use discharge planning as a guide to advise them about important information. The advice includes diet, follow up treatment, self-care, rest, and the avoidance of physical work._

Nurses also advised about mobility. Luck assisted the patients to move:

_I assisted them when they wanted help especially with things they couldn’t do by themselves, such as helping them when they couldn’t walk properly or arranging comfortable surroundings for them._

Nurses advised patients about exercise. Mham encouraged appropriate exercise to patients:

_We advised the patients to exercise and advised their relatives to help them in the cases where the patients couldn’t exercise by themselves. I mean they exercised as best they
could. They suffered from trauma if they exercised too much. I asked one staff member who gave paraffin baths to the patients about how much the patients could exercise. She said we shouldn’t force them too much, because their ligaments and tendons would become inflamed. Paraffin could help the patients when they had inflammation. She said we shouldn’t resist the patients’ wishes, but let them do what they could.

A summary of the category of giving advice is shown in Table 10.8.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advising on food choices</td>
<td></td>
</tr>
<tr>
<td>Advising rarely about diet</td>
<td></td>
</tr>
<tr>
<td>Arranging dietary requirements</td>
<td></td>
</tr>
<tr>
<td>Emphasising the need to avoid some food</td>
<td></td>
</tr>
<tr>
<td>Recognising the influence of food and alcohol</td>
<td></td>
</tr>
<tr>
<td>Advising on behavioural changes</td>
<td>Giving advice</td>
</tr>
<tr>
<td>Advising rest</td>
<td></td>
</tr>
<tr>
<td>Advising the best position for sleeping</td>
<td></td>
</tr>
<tr>
<td>Giving health education</td>
<td></td>
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<tr>
<td>Giving health care brochure</td>
<td></td>
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<tr>
<td>Giving family health education</td>
<td></td>
</tr>
<tr>
<td>Assisting to move</td>
<td></td>
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<tr>
<td>Facilitating walking</td>
<td></td>
</tr>
<tr>
<td>Advising about mobility</td>
<td></td>
</tr>
<tr>
<td>Advising on limiting activities</td>
<td></td>
</tr>
<tr>
<td>Advising how to use joints effectively</td>
<td></td>
</tr>
<tr>
<td>Encouraging appropriate exercise</td>
<td></td>
</tr>
<tr>
<td>Recognising the need for exercise after pain decreases</td>
<td></td>
</tr>
<tr>
<td>Recognising nursing care advice on appropriate exercise</td>
<td></td>
</tr>
<tr>
<td>Rarely advising exercise</td>
<td></td>
</tr>
</tbody>
</table>

Table 10.8 Category 20: Giving advice
Nurses’ category: ‘Giving psychological support’

The category ‘giving psychological support’ was formed from many codes. Rin and Tina gave psychological support by comparing suffering. Rin explained:

I talked to them frequently and told them that there were many patients, who suffered more than they did. Their anxiety would be reduced, and they thought about the many patients, who suffered more than they did.

Tina said:
Sometimes I showed them some patients, who were worse off than they were. This would make them feel better. I wanted them to know that they weren’t the only ones who had pain, and many patients had pain much worse than theirs. I’m able to do that, because my ward is a general orthopaedic ward. Patients can see a lot of different kinds of orthopaedic patients, such as patients who are injured in accidents.

Luck supported patients emotionally:
Pain is the basis of their suffering. It makes them anxious and uncomfortable. If they were in pain, I gave them psychological support, gave them religious books or other books that they were interested in. On the other hand, they had to make up their minds to be strong willed too. They should know about their condition.

Usa suggested a way to give the patients hope:
So we had to give them hope that they could get better, and have their diseases disappear if they trusted us and gave us their cooperation. The doctors gave them medication. The nurses helped them too.

She also suggested other two things for nurses. One was to believe in patients’ pain:
The thing was to believe them when they said they had real pain and to give them medication. Some nurses didn’t give them medication. When the patients asked for it, they told the patients to wait for a while. They did that, because some patients got non-steroidal anti-inflammatory drugs three times a day after mealtime, and had analgesic drugs when they requested them every four hours.
The last suggestion was to put oneself in the shoes of patients: 

*Finally, nurses have to put themselves in the shoes of the patients and think about what we would do. Patients would buy the medication themselves or do something else if they were afraid that the nurses would be annoyed with them. Patients felt doctors and nurses might not cure them if they still complained about getting pain, but who could help them more than us. Therefore, we should make them believe in us.*

A summary of codes, which formed the category of giving psychological support, is shown in Table 10.9.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comparing suffering</td>
<td>Giving psychological support</td>
</tr>
<tr>
<td>Giving psychological support</td>
<td></td>
</tr>
<tr>
<td>Helping with mental attitude</td>
<td></td>
</tr>
<tr>
<td>Giving support and encouragement</td>
<td></td>
</tr>
<tr>
<td>Giving psychological support to accept rheumatoid arthritis</td>
<td></td>
</tr>
<tr>
<td>Encouraging them not be stressed or anxious</td>
<td></td>
</tr>
<tr>
<td>Giving hope</td>
<td></td>
</tr>
<tr>
<td>Communicating directly with patients</td>
<td></td>
</tr>
<tr>
<td>Creating open and honest communication</td>
<td></td>
</tr>
<tr>
<td>Believing patients’ perception of pain</td>
<td></td>
</tr>
<tr>
<td>Putting oneself in the shoes of the patients</td>
<td></td>
</tr>
</tbody>
</table>

**Table 10.9 Category 21: Giving psychological support**

**Nurses’ category: ‘Giving encouragement’**

Usa and Mham gave accounts of the ‘giving encouragement’. Usa encouraged patients to see the orthopaedists:

*When I saw them in other parts of the hospital, not in my ward, I asked them if they’d come to see the doctor and if they’d been treated before. I asked this, because these patients could tolerate it when they had pain, and they didn’t get pain all the time. Some weren’t concerned when their hands were deformed. If they replied “No”, I advised*
them that they should go to see the orthopaedists to get treatment. They would become worse if they didn’t do that.

Mham encouraged patients to get the follow up treatment continually:

I didn’t know when the patients came back for follow up treatment after they were discharged, but I gave them appointment cards. Now the system here is that ward nurses send a list of patients that have to come back for follow up treatment to the outpatient orthopaedic department. The OPD staffs send a letter to the patients if they don’t follow up on the appointment. They send the letter three times, and then if the patients still don’t attend they cancel the cases.

She also said she encouraged compliance to medications:

In my view, nurses should tell patients that they would have to have treatment for a long time. Whether they got better or not depended on their taking the medication. So they needed to take it.

Nurses’ category: ‘Using humour to manage pain’

Rin talked to patients with humour to manage pain:

There were a few patients, who complained about being fed up with this disease. Most of them said that they’d had it for a long time and had to get continuous treatment. I think I’m usually a humorous person. I told them they were lucky that they only had pain from rheumatoid arthritis and not other diseases, such as bone fractures. Getting treatment for one or two days wouldn’t relieve the pain. They had to get continuous treatment and try to be patient. I made sure they learnt through humour … Nurses have to use some humour with patients, otherwise they will always only think about themselves … I gave them examples of comparisons between themselves and severe cases.

Nurses’ category: ‘Providing nursing care’

Usa and Rin talked about providing nursing care to manage pain. Usa said:
When we have consultations with them, patients tell us what their weak points are. Nurses should support them by telling them what things they are doing right, and what things they are still doing wrong. We let them choose and do things for themselves. Furthermore, we should let them tell us which methods they’ve tried, and what happened after they’d tried them. Perhaps we’d told them something that was unsuitable for them, and they might find a better means for themselves ... It’s a circular thing. Although nurses have many duties and things to do, the important thing is counselling. Nurses can understand that patients have other problems besides pain. Some patients have pain all day and night and their minds are troubled. They are weak the next morning. If the nurses talk to them, they can understand their problems better. Moreover, the patients want someone to know about their illness and about what care they can get. They feel better if this happens that.

Meanwhile, Rin said:
Secondly, we only needed to give supportive nursing care to patients with rheumatoid arthritis when they were admitted, because they could do things for themselves. We cared more for those patients that didn’t get better after taking the medication and those patients, who were anxious.

Nurses’ category: ‘Recommending additional help’

The category of recommending additional help involved nurses’ accounts which focused on follow up treatment, cooperation from others, nurses’ experience and alternative treatment.

Khan recommended using a follow up system to manage pain:
Our staff will check when the patients were discharged, and when their follow up treatment at the hospital is due. The day before they’re due, staff will prepare their OPD cards and leave them in front of the examining room. If the patients don’t come for follow up treatment, staff will send them a letter to remind them. As home visiting, I’m not sure that all the orthopaedic staff are members of the home visiting team. There is a
hospital team to visit the patients at home. It’s called the primary care unit (PCU). But this team will only visit patients’ homes in the areas that they have responsibility for.

Meanwhile, Luck suggested the cooperation of health team to manage pain:

*It would be good if doctors and nurses could plan together about how to care for them. Doctors have to plan what they will do. There should be cooperation between doctors and nurses. That would result in better care for the patients ... I’ve never tried them (compresses and herbs). Generally, we have to consult with the doctors who treated the patients before. That’s the easiest thing to do. We have to ask what methods nurses can use. Nurses can’t do anything independently. We have to talk with the doctors before we do anything. Doctors and nurses plan together about what we can do now and what we’ll do next. We want the patients to get the best care. Doctors are free to do more for patients than nurses, and they have many ways to relieve pain and treat the patients. Nurses can’t just guess which treatment the patients need. It depends on each doctor. As I said nurses and doctors should plan together.*

Nurses’ experience was also important to manage pain. Rin suggested:

*When I’d just graduated I was like a bird just learning to fly. I didn’t know how to give patients the best nursing care or health education. Now I have a lot of experience in how to care for them. I often reflect on why I didn’t do this or that in the past, and why I didn’t think more about who the important person was for the patients. Although I now know my mistakes, I can’t go back to the past and repair the damage. So I have to do things better in the future.*

Tha-nhom recognised traditional treatment was another way to relieve pain:

*Some patients got traditional treatment and took decoctions. These treatments made them suffer more ... Yes (the patients told me about this). They used some products, such as decoctions and bolus ... Of course (they used these products), because rheumatoid arthritis is a chronic illness. It’s not easy to cure it completely, to make the pain disappear forever. They get bored with taking the medication. If somebody advises them to try many kinds of medication or to go to places that offer good treatment, they will do*
that, because they don’t feel any better although they are taking the medication from the hospital. They looked worse and had complications when they were readmitted.

A summary of codes, which formed the category of recommending additional help, is shown in Table 10.10.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thinking pain should be controlled continually</td>
<td>Recommending additional help</td>
</tr>
<tr>
<td>Valuing the follow up treatment</td>
<td></td>
</tr>
<tr>
<td>Using a follow up system in the department</td>
<td></td>
</tr>
<tr>
<td>Recommending follow up system by the hospital</td>
<td></td>
</tr>
<tr>
<td>Wanting the patients to return to OPD for follow up treatment</td>
<td></td>
</tr>
<tr>
<td>Recognising the need for cooperation in health team</td>
<td></td>
</tr>
<tr>
<td>Perceiving the need for cooperation between ward and local health centre</td>
<td></td>
</tr>
<tr>
<td>Perceiving cooperation between nurses, PT or OT departments</td>
<td></td>
</tr>
<tr>
<td>Recommending PT course to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Agreeing that physical therapists should be involved in managing pain</td>
<td></td>
</tr>
<tr>
<td>Wanting help from occupational therapy department for pain relief</td>
<td></td>
</tr>
<tr>
<td>Thinking the rehabilitation department can teach self care</td>
<td></td>
</tr>
<tr>
<td>Perceiving OPD is one part to help nurses</td>
<td></td>
</tr>
<tr>
<td>Learning from previous patients’ care</td>
<td></td>
</tr>
<tr>
<td>Recognising that past experience can help nurses to give nursing care in the future</td>
<td></td>
</tr>
<tr>
<td>Needing specific experience</td>
<td></td>
</tr>
<tr>
<td>Recommending nurses themselves their knowledge and experience</td>
<td></td>
</tr>
<tr>
<td>Needing more information on nurses’ education</td>
<td></td>
</tr>
<tr>
<td>Recognising nurses should talk to patients more</td>
<td></td>
</tr>
<tr>
<td>Noticing the benefits of herb treatments</td>
<td></td>
</tr>
<tr>
<td>Feeling herbal compresses are an option to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Thinking hot compress can relieve pain</td>
<td></td>
</tr>
<tr>
<td>Recognising traditional treatment is the other way to relieve pain</td>
<td></td>
</tr>
<tr>
<td>Recognising relatives should encourage patients</td>
<td></td>
</tr>
</tbody>
</table>

Table 10.10 Category 25: Recommending additional help
Nurses’ category: ‘Dealing with relatives’

The category of dealing with relatives emerged from the accounts of advising relatives how to care patients with rheumatoid arthritis. Mham exemplified how to talk to relatives:

_The patients, who were admitted, always had relatives to look after them. I told them that they didn’t need to treat their loved ones as babies. They could do things for themselves, but they had to be careful about flexing and extending their joints. Patients I saw usually did things for themselves, such as having food and taking a bath. I didn’t see them in a severe stage or when they had a lot of pain. I didn’t know how their relatives looked after them at home._

A summary of this category is shown in Table 10.11.

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking with the caregivers</td>
<td>Dealing with relatives</td>
</tr>
<tr>
<td>Telling the relatives to feel free to report pain</td>
<td></td>
</tr>
<tr>
<td>Asserting that relatives believe the patient has pain</td>
<td></td>
</tr>
<tr>
<td>Recognising relatives are carers at home</td>
<td></td>
</tr>
<tr>
<td>Advising to relatives how to care</td>
<td></td>
</tr>
<tr>
<td>Advising relatives how to care for patients</td>
<td></td>
</tr>
<tr>
<td>Using relatives to give psychological support</td>
<td></td>
</tr>
<tr>
<td>Advising relatives to encourage the patients</td>
<td></td>
</tr>
</tbody>
</table>

Table 10.11 Category 26: Dealing with relatives

From categories to concepts, and core social processes

After I categorised 208 codes into categories, I looked for concepts and core social processes by using a constant comparative method. The related categories, concepts and core social processes are shown in Figure 10.1 and 10.2.
Recognising the incidence of rheumatoid arthritis
Recognising symptoms of rheumatoid arthritis
Recognising causes of pain
Recognising the value of hospitalisation

Recognising nurses’ roles in managing pain
Expressing obstacles
Feeling unsure about the ways to relieve pain

Expressing pity and sympathy
Empathy
Connectedness

Observation → Vigilance
Chronicity → Difficulties associated with chronicity

Figure 10.1 Nurses’ perception of pain
<table>
<thead>
<tr>
<th>Categories</th>
<th>Concepts</th>
<th>Core social processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessing</td>
<td>Physiological care</td>
<td>Promoting physicality</td>
</tr>
<tr>
<td>Informing the doctors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keeping warm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using discharge planning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using herbs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using relaxation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using medication as the main treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offering suggestions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing nursing care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using religion to relieve pain</td>
<td>Spiritual care</td>
<td>Promoting spirituality</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving advice</td>
<td>Psychological care</td>
<td>Promoting mental health</td>
</tr>
<tr>
<td>Giving psychological support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving encouragement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dealing with relatives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using humour to manage pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommending additional help</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 810.2 Nurses’ pain management
Nurses’ experiences as integral to the grounded theory

After I matched the nurses’ categories to concepts and core social processes, I was ready to state the grounded theory of nurses’ experiences of rheumatoid arthritis. This section describes the nurses’ grounded theory.

Nurses perceived that rheumatoid arthritis was related to difficulties associated with chronicity. They also emphasised obstacles and their own uncertainty about the ways to relieve pain in caring for patients with rheumatoid arthritis. Although they preferred acute nursing care, nurses had a sense of connectedness and empathy with these patients. Therefore, they provided nursing care involving vigilance with knowledgeable observation, and they were mindful of the causes of pain, the value of hospitalisation, and the incidence and symptoms of rheumatoid arthritis.

In terms of pain management, nurses provided care to patients with rheumatoid arthritis in three dimensions: physical, mental and spiritual. The first dimension was promoting physicality. Nurses gave physiological care by assessing, keeping joints warm, managing medication, using discharge planning, informing the doctor of changes, and by using alternative strategies, such as herbs and relaxation. The second dimension was promoting mental health. Nurses provided psychological care through psychological support and encouragement. They also used humour, dealt with the relatives, and offered advice and suggestions including recommendations for additional help. The third dimension was promoting spirituality through providing spiritual care by using religious practices.
Summary

This chapter described the codes, categories, concepts and core social processes for nurses’ experiences of rheumatoid arthritis. A grounded theory emerged of nurses’ experiences, and this has been described in this chapter. Chapter Eleven is the final chapter of the thesis, as it deals with a discussion of the grounded theory and a conclusion.
Chapter Eleven: Discussion and Conclusion

Introduction

This chapter discusses the grounded theory. Insights and implications are offered to patients, caregivers, and nurses.

The Grounded Theory of Participants’ Experiences of Rheumatoid Arthritis.

Through a grounded theory analysis procedure, the middle range theory was induced as follows:

Patients, caregivers and nurses perceived pain and effects of the pain of rheumatoid arthritis in terms of degeneration, the need for intimacy, and vigilance respectively. Patients expressed their negativity to pain as dejection, and they acknowledged their solicitude and receptivity towards care. Caregivers and nurses felt close understanding and connectedness respectively. Patients emphasised attribution and nurses focused on the difficulties associated with chronicity. Pain management was in terms of physical, mental, and spiritual dimensions for patients, caregivers and nurses.

The grounded theory is shown in Figure 11.1.
Figure 11.1 The Grounded Theory of Participants’ Experiences of Rheumatoid Arthritis
Discussion

The grounded theory proposes that perceptions of pain of patients with rheumatoid arthritis, caregivers, and nurses are different. This is a similar finding to Muhlenkamp and Joyner (1986), who found differences between the perceptions of arthritis patients about self-reported affective states, and nurses’ perceptions of patients’ affective states. In my Ph.D. study, patients perceived their pain in terms of degeneration, which involved abnormality in body changes and symptoms of rheumatoid arthritis, such as losing weight, joint degeneration, and having pain in the morning. They expressed their dejection by showing their negativity with pain, by being depressed, disheartened, angry, and losing self-esteem and confidence. This negativity included dissatisfaction and uncertainty with the health care team, lack of knowledge of effective ways to relieve pain, and how pain effected and limited their daily lives. Patients believed in many external and internal factors causes of pain, such as the weather, working, and karma.

Although caregivers attended to their relatives’ body and lifestyle changes, causes and effects of pain, and reactions to pain, they perceived their attention in terms of intimacy. This means that they had a close understanding, based on compassion for their relatives to express feelings of pity and sympathy, a motivation to care, and hopes for positive outcomes. Meanwhile, nurses were vigilant in perceiving pain by observing accurately the incidence and symptoms of rheumatoid arthritis, causes of pain, and the value of hospitalisation. Nurses expressed their empathy towards these patients in a sense of connectedness. They perceived rheumatoid arthritis in terms of difficulties associated with chronicity. Nurses also identified issues involving chronicity, such as nurses’ roles in managing pain, obstacles and the feelings of uncertainty in how to relieve pain, and why nurses preferred to care for emergency and acute care cases.

In relation to pain management, patients, caregivers, and nurses perceived that it covered three dimensions; physical, mental, and spiritual. Although they agreed on the nature of those dimensions, they focused on different details. Patients perceived their pain management as bolstering. To bolster physicality, they concerned themselves with the physiological factors affecting pain. They considered seeking treatment from doctors,
medications, physical activities, and alternative therapies such as decoction and herbs. Patients bolstered their mentality by addressing psychological factors, such as maintaining their emotional stability, and accepting illness, seen in the codes of ‘expressing acceptance’, and ‘feeling untroubled’. Patients bolstered their spirituality by consulting the shaman and traditional doctors, and by seeking spiritual options associated with religious practices. Furthermore, they were receptive to therapeutic assistance, such as getting advice, treatment, help, and care from their families, healthcare team, and others. They expressed in solicitude in seeking thoughtful attention for their needs for better treatment, nursing care, self care, and further help.

Caregivers perceived pain management as succour. They provided physical succour by giving physiological support, assisting in the activities of daily living of patients, such as eating, resting and exercising, and comfort measures, such as orthodox and natural medications. They provided mental succour to patients through psychological support to help them seek treatment, cope with the problems, accept their illness, and to assist them during hospitalisation. Caregivers allowed their loved ones space to be alone, to be free to complain, and they assisted them to cope with their problems as they arose. Although caregivers appreciated treatments and help from others, they also offered some suggestions themselves to relatives to relieve their pain. For spiritual succour, caregivers supported their relatives by using religious activities and some black magic.

Nurses promoted physicality by giving physiological care in assessing patients’ conditions, keeping their joints warm, managing medication, using discharge planning, informing the doctor of changes, and by using alternative strategies, such as herbs and relaxation. To promote mental health, nurses provided psychological care through psychological support and encouragement. They also used humour, dealt thoughtfully with the relatives, and offered advice and suggestions, including recommendation for additional help. Nurses promoted spirituality through providing spiritual care by using religious practices.
Insights and implications

Insights and implications from the grounded theory extend to patients, caregivers and nurses.

For patients with rheumatoid arthritis

Patients need accurate knowledge and understanding about rheumatoid arthritis, as differentiated from other types of arthritis. This research showed that patients perceived pain in terms of degeneration and dejection. These negative feelings can affect patients and their illness directly. Therefore, patients in this research encourage other people with rheumatoid arthritis to accept their illness reasonably, and maintain positive attitudes to their illness. Self esteem, self confidence, and self efficacy are important factors in quality of life. Patients require appropriate self care based on different backgrounds, such as their educational and economic status. Explanations of treatments and disease progression need to be directed at an appropriate level of understanding. In relation to treatment, patients require appropriate treatment continually, which should not be based on medications only. Alternative therapies such as herbs, physical therapies or occupational therapy, are other treatment choices. By using a variety of treatments, the health care team can provide choices and treat patients effectively. Patients need help to develop effective approaches in expressing their needs to relatives and the health care team.

For caregivers

Caregivers are the most important support persons for patients, because patients need help and support from their caregivers at home and at hospital. Caregivers need sufficient information from the health care team about their loved ones’ illness. This information includes the nature and effects of illness, and the kinds of care to be provided by caregivers. In this way, caregivers are able to support patients in their physical, mental, and spiritual needs, based on the right understanding in their illness. Talking directly and observing patients attentively are effective tools for relatives to help
patients handling the pain, as this research demonstrated. Caregivers need to value their worth as helpers, through the acknowledgement of nurses, and the health care team.

**For nurses**

There are many issues to concern nurses in relation to caring patients with rheumatoid arthritis, including practice, education, research, and administration dimensions.

**Practice implications**

Because rheumatoid arthritis is rare in Thailand, it is very easy for nurses to be confused about this disease. Nurses need to recognise rheumatoid arthritis as separate and special in terms of patients’ needs. Nurses also need to listen to the patients and relatives as important partners in giving effective care. Nurses are also one of the main sources of information for patients and relatives, so they need to give health education to patients and families, as a professional responsibility.

**Education implications**

Nurses require undergraduate and continuing education programs to build and refresh their knowledge and practice of caring for people with rheumatoid arthritis. An effective education strategy is discussing and sharing their experiences and knowledge among the health care team, based on actual practice issues in caring for patients.

**Research implications**

The main research in rheumatoid arthritis is about the effects of treatment. More research is needed about patients’ perspectives. Lambert (1991) suggested issues to be studied about arthritis, including increasing longitudinal studies of rheumatoid arthritis as a chronic disease; educational methods for patients; health promotion; factors effecting well-being and quality of life; effects of severity; multiple assessments, specific nursing interventions involving physiologic and psychosocial care;
identification of patients’ and their important persons’ needs; and examining physiologic responses. These projects could be undertaken using quantitative, qualitative, or mixed method designs, depending on the research aims and objectives.

Administration implications

Nurses require adequate resources for continuing education and research, which they can access directly, including workplace computer access to publications, such as websites, or rheumatoid arthritis organisations. Nurse administrators can ensure that nurses in practice, education, and research receive all the resources they require to gain knowledge, and skills to care more effectively for people with rheumatoid arthritis.

Summary

Rheumatoid arthritis is a chronic disease, which is complex and has unknown causes, and it affects patients’ well being and quality of life. It also affects patients’ relatives, by causing them to feel distress, at the pain and disability their loved ones experience. Rheumatoid arthritis is very difficult for the health care team to deal with, especially in how to control pain decisively. Although nurses have not always had at their disposal the best ways to relieve pain, they can attain nursing care goals by listening to what patients and their relatives need, maintaining knowledge relating to the specificity of rheumatoid arthritis, and by taking appropriate professional actions. This research has shown that the perceptions of patients, caregivers, and nurses differ in relation to their perceptions of pain and pain management in rheumatoid arthritis. Even so, patients, caregivers, and nurses can work together to ensure that the best possible care is given to patients with rheumatoid arthritis.
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Appendices
CONSENT FORM

I, ______________________ of ______________________
Hereby consent to be a participant in the research project being carried out by Benjawan Sriyotin entitled

Perceptions of Female Patients, Caregivers and Nurses of Pain and Pain Management in Adult Patients with Rheumatoid Arthritis, Ratchaburi Province, Thailand.

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 interviews. This will involve me in relating stories of my experiences and perceptions about pain and pain management in adult patients with rheumatoid arthritis. I will be given a transcribed interview so that I may make changes and corrections to my contributions. If I experience uncomfortable emotions in relating my stories, at any stage, the tape recorder will be turned off and 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 any details that may identify me will be altered to protect my privacy and anonymity.
* I voluntary 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 this 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 ________________________________
PLAIN LANGUAGE STATEMENT FOR PARTICIPANTS

Perceptions of Female Patients, Caregivers and Nurses of Pain and Pain Management in Adult Patients with Rheumatoid Arthritis, Ratchaburi Province, Thailand

My name is Benjawan Sriyotin. I am a nurse lecturer at Boromarajonani College of Nursing, Ratchaburi who is currently studying towards a Doctor of Philosophy in Nursing at Southern Cross University in Australia. I am interested in finding out more about how female patients, caregivers and nurses perceive pain and pain management in adult patients with rheumatoid arthritis. I wish to invite you to join me in this project. I hope that by doing this research a more helpful knowledge about rheumatoid arthritis and perceptions in pain and pain management will be developed especially in adult patients. This has the potential to maintain caregivers’ and families’ understanding for caring their loved ones who have rheumatoid arthritis pain. In the same way, it has the potential to increase nurses’ the health care team’s understanding, and improve the way they support patients with rheumatoid arthritis.

If you agree to participate in the project I will meet you to explain more about the research, answer any of your questions and go through 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 the information will be destroyed. All participants will be asked to maintain the confidentiality of what they say in the interviews.

The research will involve you in an interview for an hour to share your experiences about perceptions of pain and pain management in adult patients with rheumatoid arthritis. Interviews will be managed at your home, ward or any place that is comfortable for you. I will be taping all the interviews and transcribing them myself. Copies of the transcripts will be given back to you to check your contributions and allow for corrections. You may ask for the tape to be turn off at any stage during the interviews.
As rheumatoid arthritis is a chronic disease, the interview may be an emotional experience and bring up unhappy memories. If you have any unsettling emotions during the interview, you will be free 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, Prof. Bev Taylor (see list attached).

I would be happy to discuss any questions you make have about the research, so feel free to contact me on (032) 323290 between 9 AM. and 5 PM.

Thank you.

Benjawan Sriyotin