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**UNIVERSITY OF SOUTHAMPTON**

**FACULTY OF HEALTH SCIENCES**

**Self-management for pain control in Thai patients who have  
cervical cancer in a Thai Regional Cancer Centre**

by

**Thitiwan Yothathai**

Thesis for the degree of Doctor of Philosophy

December 2014



UNIVERSITY OF SOUTHAMPTON

## **ABSTRACT**

FACULTY OF HEALTH SCEINCES

Doctor of Philosophy

### **SELF-MANAGEMENT FOR PAIN CONTROL IN THAI PATIENTS WHO HAVE CERVICAL CANCER IN A THAI REGIONAL CANCER CENTRE**

by Thitiwan Yothathai

Cervical cancer is one of the most common cancers in Thailand with around 10% of these women experiencing persistent pain. One third of those are under treated and it is claimed that programmes of self-management may contribute to better managing this pain. However, self-management is a Western concept and it is not clear whether this concept is helpful to Thai people or how it might be conceptualised or how Thai people self-manage their pain.

The aim of this study to explore the way in which Thai women with cervical cancer manage their pain with specific reference to the potential for self-management in hospital and at home and how they might be supported in this activity by their family and health professionals. A single embedded case study design was adopted over six months in a regional cancer centre located in the North-East of Thailand. The participants were purposively sampled for the phenomenon under investigation. Six patients with cervical cancer experiencing moderate to severe pain, six identified family caregivers and seven health care providers were interviewed and observed. Framework analysis was used to analyse the observational and interview data.

The finding revealed six main themes of self-management including problem solving, decision making, information finding and utilisation, forming patient/health care professionals partnership, taking action and, especially, perception. These themes are influenced by Thai family and culture resulting in a revision self-management model for This is developed. The model explains relationship between two main aspects, thinking and behaving that people behave self-management. Thinking and behaving influence each other

and can be changeable due to the real situation. Factors influence these two aspects including backgrounds of experience, knowledge, and social context of Thailand.

Conclusion, the patients developed their ability to self-manage their pain in their everyday life. To improve self-management in Thai patients, the individual circumstance of family and Thai culture are important factors to be aware.

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# DECLARATION OF AUTHORSHIP

I, Thitiwan Yothathai,

declare that the thesis entitled

Self-management for pain control in Thai patients who have cervical cancer in a Thai Regional Cancer Centre

and the work presented in it are my own and has been generated by me as the result of my own original research. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- None of this work has been published before submission.

Signed: .....

Date: .....



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# Abbreviations

CPST	The Cancer Pain Self-management Training programme
DM	Decision making
Dx	Diagnosis
FM	Family caregiver
HCP	Health care provider
IASP	The International Association for the Study of Pain
Int	Interview
L	Line
MoPH	The Ministry of Public Health
NCI	The National Cancer Institute
Obs	Observe
PS	Problem solving
PT	Patient
RCT	Randomised controlled trial
SIGN	The Scottish Intercollegiate Guidelines Network
SM	Self-management
TA	Taking action
WHO	The World Health Organisation



# Chapter I

## Introduction

### 1.1 Introduction to the thesis

Chapter one presents an overview of cancer pain and its management in Thailand in order to provide general background of this area. Relevant literatures, including literature relating to cancer, cancer pain, and self-management in patients with various kinds of chronic disease will be discussed in an intention to set a context for this study. In addition, the current knowledge around self-management in patients with cancer pain in Thailand will be provided in order to justify reason to study as well as to identify the research questions and aim of the thesis.

### 1.2 Prevalence of cancer and cancer pain in Thailand

Cancer is an important disease worldwide, registering increasing incidence and mortality each year. The World Health Organisation (WHO) reported an estimated 12.7 million new cancer cases globally in 2008, and the incidence is predicted to increase to 22 million by 2030 (Feylay et al. 2008). Cancer is a leading cause of death across the world; an estimated 7.6 million deaths due to cancer (around 13% of all deaths) occurred in 2008, with a predicted mortality of 83.2 million in 2015 (Feylay et al. 2008). Cancer has also been debated as an important issue in Thailand, where the mortality rate due to cancer has increased from 73.3 per 100,000 population in 2002 to 84.9 in 2007 (Khuhaprema et al. 2008). In addition, the Ministry of Public Health (MoPH) of Thailand reported that the admission rate of patients with cancer, in health service units, rose from 34.7 per 100,000 population in 1994 to 124.4 in 2006 (Attasara 2007).

The most common cause of cancer incidence is breast cancer, among women globally and in Thailand, with 23% of all new cases in women globally and 20.2% amongst Thai women (Feylay et al. 2008). However, cervical cancer, the second incidence, is a vital problem amongst Thai women, resulting in an increase in the admission rate and the premature death rate of many women (Attasara 2007).

Nearly ten thousand Thai women were diagnosed with cervical cancer in 2008, and there were an estimated 5,200 deaths from cervical cancer in 2008, accounting for 15% of female cancer deaths (Feylay et al. 2008). The number of inpatient admissions as a result of cervical cancer has risen from 12.37 per 100,000 population in 2002 to 22.48 in 2007 (Attasara 2007). The number of patients with cervical cancer in the North-East of Thailand has been rising, from 10.17 per 100,000 population in 2002 to 20.5 in 2007 (Health Information Unit 2008) and the prevalence of cancer has increased every year (Attasara 2007). The progression in the number of cervical cancer patients is, therefore, contributing to the public health problem in Thailand. It has not only caused an increase in premature death rates of Thai women but it is also the cause of considerable distress and suffering which needs to be addressed in order to diminish the burden of cervical cancer and its consequences.

## **1.3 Cancer pain**

### **1.3.1 Definition and mechanism of pain**

There are various definitions of pain from scientists and psychologists. However, the most widely accepted, established by the International Association for the Study of Pain (IASP) in 1986, is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (IASP 2008 ).

The Gate Control Theory, proposed by Ronald Melzack and Patrick Wall in 1965, is commonly theory to described mechanisms underlying pain perception (Moayedi and Davis 2013). This theory states that nerve impulses, evoked by injury, are influenced in the spinal cord by other nerve cells that act like gates, either preventing the impulses from getting through, or facilitating their passage. In other words, the brain is not a passive receiver of pain information but can influence the information received, deciding whether it is important enough to be registered.

The gate control theory suggested that psychological and cognitive variables influenced by socio-cultural learning and experience play a role in the perception of pain. These three dimensions are not independent but rather, interact with one another (Bendelow and Williams 1995).

### 1.3.2 Prevalence of cancer pain

Pain is a common consequence of cancer, both as a result of the disease itself and its treatment (Ferrell & Grace 1995; Peng et al. 2006). A meta-analysis by van den Beuken-van Everdingen et al. (2007) reported that the prevalence of pain in cancer survivors is 33%, with more than one third experiencing moderate to severe pain. A review study by Fukshansky et al. (2005) argued that 33% of cancer patients experienced severe pain. Peng et al. (2006) reported from their retrospective survey of 722 patients with advanced cancer in Taiwan, that pain is increased along with the progressive of disease, through to the end stage. In addition, 24% and 32% of patients with end-stage cancer suffered moderate and severe pain respectively. Approximately 50% of patients with cancer experience pain at the time of their cancer diagnosis and early in the course of disease, and the prevalence of pain increases to 75% at advanced stages of the disease (International Association for the Study of Pain (IASP) 2008).

Pain is also an important problem in cervical cancer (Attasara 2007). The prevalence of pain in women with cervical cancer is around 10% and nearly one third of those experience severe pain (Beck & Falkson 2001; RustØen et al. 2003). Previous Thai studies reported that more than 30% of patients with an advanced stage of cancer in a gynaecological organ experience moderate to severe pain (Petpichetchian 2001; Rattanasukhon 2001; Khounnikhom 2007). It is clear that, although pain is not a common symptom in the early stage, it ultimately causes severe pain in the advanced stage of the disease.

The cause of pain includes the disease itself, which may be attributed to an invasion by cancer of bone, soft tissue, muscle and nervous system. Pain associated with direct tumour involvement is the most common cause of cancer pain (Foley 1999). Approximately 90% of patient with cancer experience bone pain (Patal, Anthony and Dickenson 2012). In cervical cancer the prevalence of pelvic pain gradually increases and persists with the disease's progression and becomes a typical symptom as cancer metastasis to surrounding tissues and organs (Rattanasukhon 2001). In addition, localised pain may be a consequence of treatment of cervical cancer (Rattanasukhon 2001; Peng et al. 2006). Treatment-related pain includes from chemotherapeutic agents caused peripheral neuropathy, radiation-induced neuronal damage, postsurgical pain syndromes (Peng 2006).

### **1.3.3 Impact of cancer pain**

Cancer pain can have a major impact on an individual's life and on their family (Davis 2000). The impact of cancer pain on the individual can potentially be positive and/or negative. Acute cancer pain may lead to an increase in the problem solving capability of the patient (Davis 2000). It can also lead to a positive sense of responsibility in decision making (Davis 2000). On the other hand, persistent pain, a common feature in patient with cancer (IASP 2008), may lead to depression as a result of unsuccessful pain control. It can make people frustrated and induce a sense of loss or bereavement, feeling of worthlessness or feeling of hopelessness and helplessness (Davis 2000).

Cancer related pain may also impact on family structure and its function. Providing care for a person with cancer experiencing persistent pain is an unfamiliar and stressful task that usually falls to one particular member in a family, such as a person's spouse, child, parent or another relative (Given et al. 2001). The family caretaker may feel tired due to prolonged caring for a patient with cancer and may become isolated from normal social activities (Tsigaropoulos et al. 2009). The family is a witness to pain being experienced by one of its members which may result in anguish, tension and depression among family members (IASP 2008). Cancer pain may also affect sexual relationships, possibly leading to sexual dysfunction, with the potential of depression for both the person with pain and their spouse or partner (Davis 2000). In addition, pain may cause role changes, not only within the family but also in the wider community; for example by loss of employment and resulting financial worries (Davis 2000).

### **1.3.4 Cancer pain management**

There is convincing evidence that the vast majority of cancer pain can be controlled by pharmacological strategies. Cancer pain management has been transformed following guidelines outlined by the World Health Organization (WHO), describing the analgesic ladder and the use of adjuvant drugs for pain control (WHO 1996). In addition, there is some evidence that non-pharmacological treatments, including complementary and alternative strategies, as well as other local control techniques such as radiation therapy and neurosurgery, are supportive to patients in coping with the consequence of pain (Scottish Intercollegiate Guidelines Network, 2008; Chang et al. 2007).

Although there numerous strategies used to control pain, pain remains a critical problem for people with cancer; evidence of inadequate pain control is still reported (Scottish Intercollegiate Guidelines Network (SIGN) 2008; Jacobsen et al. 2008; Bennett et al. 2009). Nearly half of patients who experience cancer pain worldwide were likely to receive inadequate analgesia (Deandrea et al. 2008). The multivariate analysis undertaken by Deandrea et al (2008) showed that a lack of specific education in pain management for physicians and a failure of physician-patient communication explains some of the undertreatment reported (Deandrea et al. 2008). Furthermore, there is specific evidence in Japan, Korea and Thai studies, that patients are dissatisfied with pain management and the extent of pain remaining after analgesics have been prescribed (Okuyama et al. 2004; Lee 2007, Khounnikhom 2007). For example, a study in Thailand by Vatanasapt et al. (2008), reported that a substantial number of patients with cancer, with moderate to severe pain, received sub-optimal medication, including sub-optimal levels of treatment with non-opioid analgesics (80%). In addition, one-third did not receive any intervention or pain control during admission to the hospital (Vatanasapt et al. 2008).

There is evidence from a systematic review that patient education can positively benefit cancer pain management but there was insufficient evidence to determine how much and for how long these programmes are effective (Bennett et al. 2009). In addition, patient education programmes appear to be more effective in those persons recently diagnosed, while the benefit for patients with advanced cancer is not clear (Bennett et al. 2009). Thus, although education and pain management programmes may be of benefit there are still questions to be asked about the nature of these programmes and whether they will be effective in Asian communities that contain cultural diversity far different from the Western circumstances.

### **1.3.5 Barrier to cancer pain management**

The fact that effective analgesics and other strategies are available to manage pain suggests that it is not a lack of treatment options that results in inadequate pain control. The sub-optimal treatment reported in the above studies is likely to be due to inadequate prescription and other factors, such as a lack of knowledge and misconception about pain medication (Berry 2007). In addition, patient, family, and health care systems also influence the effectiveness of pain management (IASP 2008).

### 1.3.5.1 Barriers related to patients and families

One of the major factors influencing cancer pain management is patients' and their family's beliefs and appraisal of cancer pain, and their consequent behaviour (Bandura 2002). Thus, the way patient and family think about cancer pain influences the way they express their pain and cope with pain.

It is clear that the experience of pain is unique, influenced by the individual's personal, social and cultural experiences (Ferrell and Grace 1995; Berry 2007). Patients may not complain of pain because they want to be a 'good patient' or they are reluctant to distract the physician from treating the primary disease, leading to a potential lack of communication about pain to health care providers. The fear of addiction and worry about unmanageable side effects, such as constipation, often lead to reluctance to take pain medication, resulting in poor adherence to the prescribed analgesic regimen (IASP 2008).

Psychological and cognitive factors may influence pain perception and pain expression (Davis 2000; Petpichetchian 2001; Lukkahatai 2004; Lewandowski et al. 2007). Patients with cancer may interpret increasing pain as a signal of progression of the disease. Some patients frame their meaning of pain as a metaphor of death (Berry 2007). These perceptions of cancer pain may lead to a greater perception of the intensity of the pain, and lead to a belief that pain control is not possible.

Individual beliefs also influence pain management. For example, a review of relevant literature found that half of older patients, who experience cancer pain, do not take their medication in full therapeutic doses, resulting in a reduction of effective pain management (Chatwin et al. 2009). The reasons underpinning this behaviour are complex. It may be related to the patients' belief of cancer pain and psychosocial influences (Chatwin et al. 2009). Beliefs about the cause of cancer and its outcome, as well as expectations about the ability to control the disease and its symptoms, affect the patients experience their disease and its management (Weihs et al. 2002). A systematic review of barriers to cancer pain management by Jacobsen et al. (2008) indicated that maladaptive beliefs of the patient have a negative influence on pain intensity, emotion and analgesic adherence.

Family members construct their own view of the meaning of cancer pain (Berry 2007). Their individual beliefs influence their behaviour when caring for their patients, such as their decisions for giving pain medicine (Weihs et al. 2002; Duhamel and Dupuis 2003). Cancer pain may cause distress to family members because they may view pain as a metaphor for illness and eventually death (Berry

2007). This appraisal may affect their reluctance to continue the care and may be an obstacle to pain management (Berry 2007). It can be seen that identifying the meaning that pain has to family members may be one way of understanding their impact on cancer pain management.

It is clear that individual psychology and cognition are associated with personal perceptions of pain and govern behaviour in the management of pain. Addressing patients and family beliefs and appraisal about disease and pain management should therefore be a central component in the development of a pain management education programme (Bandura 2002).

#### **1.3.5.2 Barriers related to health care professionals**

Health care professionals' beliefs directly affect the delivery of effective pain management (Chatwin et al. 2009). Health care professionals can believe that they have a better grasp of the disease management resulting in a reluctance to listen to patients' and families' human stories (Duhamel and Dupuis 2003). Health professionals may put the emphasis on solving an actual pain rather than taking time to address issues that may be of more concern to the patient and family; for example the impact of cancer pain on their lives (Polomano and John 2006; van den Beuken-van Everdingen et al. 2007). They may well try to relieve pain directly rather than working with an individual and their family to find the most appropriate way for the patient to manage their own pain. This may result in inappropriate care to meet the patients' needs and thus ineffectiveness of pain management.

A major barrier to poor pain management is poor assessment of pain and inadequate knowledge of a pain regimen prescriptions (IASP 2008). Anxiety about regulations regarding controlled substances, concerns about the side effects of analgesics and fear of patients becoming addicted or tolerant to analgesics have been identified as barriers to adequate pain management (IASP 2008). Training in cancer pain management, at all levels of professional education, is required. Education on these issues and on pain assessment for health care professionals may result in adequate analgesic prescription and better pain management (IASP 2008; Chatwin et al. 2009).

#### **1.3.5.3 Barriers related to the health care system**

An impractical analgesic regulatory system and problems of availability of pain treatment may become barriers to pain control (IASP 2008). The limitation of variety of analgesics, lack of coverage and uneven distribution of medicine and equipment, as well as a lack of professional services, may be important barriers to

the effectiveness of cancer pain management. These barriers are also illustrated in the Thai literature. There is a high prevalence of inadequate analgesia in Thai patients with cancer, which may be due to the limitation of pain medications in the health care system. In addition, a lack of pain management specialists or pain clinics to be directly responsible for caring for patients with pain, may aggravate the pain problem in the health care system, especially in the rural areas of Thailand (Petpichetchian 2001).

In addition, there is a lack of availability and access to textbooks and pain control guidelines, and to training in pain management (IASP 2008). These health policy matters need to be addressed.

In summary, cancer pain is an important problem worldwide, including Thailand. There is evidence of inadequate pain management and that there are several barriers to improving pain management experience. Cancer pain is an ongoing condition which people need to manage on a day to day basis. Therefore, it is important that people with pain gain the ability to take care of themselves and are encouraged to play a central role in managing their own condition by promoting self-management (Lorig and Holman 2003; Kralik 2004).

## **1.4 Cancer pain experience and its management of Thais**

In Thailand, there were 3 main papers that illustrated pain experience and pain management of Thai patients with cancer (Petpichetchian 2001; Rattanasukon 2001; Lukkahatai 2004). Petpichetchian (2001) developed a model synthesising gate control theory and Lazarus's theory to be used as a guide for the descriptive study. The model consists of cognitive pain appraisals, perceived meaning of cancer pain and perceived control over pain in order to describe cancer pain experiences of the patient. The situational factors influencing the patient's pain experience include stage of cancer and personal characteristics. Rattanasukon (2001) studied pain experience in terms of meaning of cancer pain, factors influencing pain, impact of cancer pain and pain management, by using a phenomenology design. The neuromatrix theory of pain (refers to multidimensional phenomenon of pain) and theory of stress appraisal and coping (considers cognitive dimension of pain including perception, coping, culture and spiritual beliefs) are theoretical guides for a cross-sectional study by Lukkahatai (2004). The finding of all studies can explain cancer pain experience and its management in the Thai patients, as follows.

### **1.4.1 Perception of cancer pain**

It is found that perception about cancer pain is categorised into 2 dimensions: perceived meaning of cancer pain and perceived control over pain. Perceived meaning of cancer pain mainly affects pain intensity, pain interference and mood, whereas perceived control over pain directly affects coping strategy selection and use (Petpichetchian, 2001). Perceived meaning of cancer pain also affects pain coping but the effect of that is less than perceived control over pain. Perceiving the sense of control affects pain coping efforts and directs the use of pain coping strategies, which independent of patients perceive the meaning of cancer pain (Petpichetchian, 2001).

Cancer pain belief is a main factor of perceiving meaning of cancer pain that influences pain experience. Patients who had negative pain beliefs reported greater pain intensity and interference of pain with their daily activity. In addition, there is a direct effect of religious beliefs, a negatively significant effect, on perceived control over pain (Lukkahatai, 2004). This situation may be explained by the fact that the major religion of Thais is Buddhism. It was found that the religious belief within Buddhism effects patients' pain appraisal (Petpichetchian 2001). Buddhist tradition may play a role in shaping Thai patient's appraisals of their cancer pain situation. A previous study indicated that older people tend to report strong beliefs about the importance of religion and existence of a supernatural power than do younger people. This may lead older people readily accepting the limitation on their activities and perceive themselves as more vulnerable to the disruptive effects of cancer pain, compared to younger people (Lukkahatai 2004).

The role of beliefs and Thai culture also influences the use of coping strategies by the cancer population (Lukkahatai, 2004). Patients who report the negative meaning of pain as loss, threat or spiritual awareness often report high pain intensity, greater pain interference with activity and using catastrophising as a coping strategy; whereas those who perceive pain in a positive way, such as personal challenge, report decreases in pain intensity and also high scores on perceived control over pain, use active coping and decreased catastrophising that could improve pain outcome (Lukkahatai, 2004).

### **1.4.2 Dealing with pain in Thai patients with cancer**

Thai patients with cancer pain report their coping strategies that include self-statements (tell oneself to be brave and carry on despite the pain, tell oneself "I can

control the pain”), praying, distraction, ignoring sensation, catastrophising (worry all the time about whether it will end), distancing (image the pain is outside the body) (Lukkahatai, 2004). Some patients use cognitive control in dealing with pain. The strategies for cognitive control are religious principles, distraction and relaxation in order to change attention of pain to other focal points and hence decrease perceived levels of pain. Religious beliefs are closely related to spiritual well-being in the Thai context. The practice of meditation can decrease elevated pain levels and generate deep relaxation. Practicing merit or reciting the Buddhist principles are ordinal means in dealing with pain in Thais (Rattanasukon 2001).

Karma may play an important role in patient’s coping with cancer pain (Junda 2004; Get-Kong 2010). In Thai patients, the aim of coping is not to increase the sense of the ability to control but instead the purpose of coping is to bear the pain (Lukkahatai 2004). This perception may be explained by the religion beliefs of Buddhism. For Buddhists, the truth of life is that birth, aging, sickness and death are four unavoidable events for humanity. In addition, Thai people believe in karmic law (the law of cause and effect) which may cause patients to accept cancer diagnosis and suffering due to previous bad karma (Lukkahatai 2004). The feeling of uncontrollability is generated as a result of these beliefs.

There are some regional differences about cancer pain characteristics and pain management. Patient’s perception and local beliefs about health, illness and care in different areas also reflect potential factors influencing the way people take care of themselves (Petpichetchian 2001). Some older people may have a belief of animism which perceives the cause of disease is a malicious spirit, therefore rites related to the belief in spirits and occultism can be scatteringly observed, especially in Thai rural areas (Rattanasukon 2001).

Pain medicine is necessary for a patient who has cancer pain. Every patient has got at least one kind of pain medicine (Rattanasukon 2001). Analgesic is also a vital medicine to relieve pain at home. Patients use Paracetamol mostly based on knowledge that it is safe and easy to access. Taking a patient to a hospital is necessitated when the pain cannot be dealt with by self-managing of taking medicine. Patients start by trying to deal with the pain on their own; however, when the pain cannot be controlled by self, seeking help from the health care provider will be actioned (Rattanasukon 2001).

Pain medication is designed to have a direct effect on decreasing pain intensity and pain interference. However it is likely that patient who takes pain medicine is decrease in using other pain coping strategies (Petpichetchian 2001).

This shows a controversial effect of using drug to perform self-management capability.

The traditional medicine is included in the pharmacological approach for dealing with symptoms in Thai patients. Knowledge of herbs is conveyed from generation to generation in local Thai society. Using herbs to treat patients is an approach that is modified based on the experience of the user and variation of illness. Some patients who have cancer pain prefer to use herbs without any guarantee of the treatment's effectiveness (Rattanasukon 2001).

### **1.4.3 Factors influence pain management behaviours**

The Thai cultural concept called 'Kreng-Jai', the concept that teaches Thais to be considerate of another's feeling and to be reluctant to express feeling to others, may influence how Thais respond to pain. Many Thai patients particularly hesitate to ask for help or pain medication at night, because they think that the request would bother the nurses or caregivers (Lukkahatai 2004). In consequence, some patients may adopt successful ways to deal with the pain. On the other hand, some patients have to be patient with pain due to their lack of communication to others.

Enhancing factors of pain management are feelings of being a burden (patients do not wish to be a burden and so try solving their problems by themselves), family's hope (as an effort to recover) and knowledge (increase ability to choose pain relieving strategies). On the other hand, inhibiting factors of pain management are surrendering to the pain, a crowded environment, poor physical health over and above cancer and feelings of hopelessness (Rattanasukon 2001). Failure to use coping strategies to deal with pain causes patients to develop feelings of hopelessness and helplessness. Such patients may just give in to the pain and end up doing nothing (Rattanasukon 2001).

Thinking that nothing can relieve cancer pain, fear of side effects of drugs, fear of addiction, fear of becoming a drug-dependent patient; these issues are all barriers to pain management. Financial concern is a major factor affecting both patients and family feelings and also interferes with the quality of illness management choices (Rattanasukon 2001).

Patient's educational background might be related to the way patients cure and care for their illness and their ability to manage their daily symptoms. The

research recommends that an educational programme is still necessary to be provided for patients and family caregivers (Petpichetchian 2001).

Perceiving attention and encouragement are potential factors that help to relieve pain. Social support is a psychological strategy, in that it increases a feeling of certainty, reduces stress and improves health behaviour as a result (Rattanasukon 2001). Family members and health care providers are recommended as being the main sources of social support. In the Thai culture, one's family is often involved in providing care and making decisions for their ill family member (Get-Kong 2010). Previous studies showed that the family can provide support for the patient, such as daily activity, monitoring sleeping, eating and bathing. Searching for ways to care for and cure the patient covers many activities, including facilitating travelling for treatment. In addition, the family also provides financial help as well as emotional support by offering encouragement to the patient (Rattanasukon 2001). Family members are an integral part of the health care team, defined as a major source of support for patients.

Health professionals can provide support by prescribing pain medicine, as well as providing knowledge about pain and its management (Rattanasukon 2001). Nurses are found to be major source of information and providers of care for people, especially in regards to their psychological care, because there is easy access to the nurse and nurses, in general, can provide counselling and information as needed (Rattanasukon 2001; Get-Kong 2010).

The role of both the family and health care providers in the pain management support of cancer pain is complicated and there is a need for research in this area. The application of a pain management programme to the particular group of cancer patients of interest to this research, as well as a variety of factors including patients, their context, their personal thoughts, their family, as well as their health care circumstances, require careful consideration.

Up to the present, the reason for ineffective pain management may be due to the fact that the intervention strategy applied to a patient is not tailored to the unique, specific needs of that given individual. There is, therefore, an immediate requirement for an alternative, more efficient technology to lessen the pain in each individual. It is suggested that self-management may be a novel strategy suitable for people who are experiencing persistent pain due to cancer.

There is evidence indicating that self-management strategies to control symptoms can be effective in chronic illnesses (Barlow et al. 2002; Blyth et al. 2005)

and some studies have suggested self-management to be beneficial for people in pain (Kralik 2004; Closs et al. 2007). In addition, the effectiveness of self-management strategies in dealing with fatigue in Thai people with cancer was reported by Lundberg and Rattanasuwan (2007).

Self-management may therefore be a strategy helpful to people with cervical cancer experiencing pain in Thailand. The researchers argued that the self-management ability developed by the patients were not a consistent process. The development of self-management was grounded by the personal and individual social context (Kralik 2004). This emphasised that development of self-management depended more on individual approaches and more attention to the particular context of the patients (Blyth et al. 2005; Closs et al. 2007). However, there is very little research-based evidence related to this topic; more studies are needed to understand self-management behaviour in particular, and to validate self-management strategies before their general implementation in practice.

## **1.5 Self-management**

### **1.5.1 Self-management overview**

Self-management refers to an ability to manage oneself by using various necessary skills. It is a dynamic-active process of learning, trailing and overcoming the boundaries (Kralik 2004). Self-management is problem-based, in other words the problems and concerns of patients have to be considered along with applying a self-management approach. The important consideration in self-management should be focused on an individual needs assessment for each new topic (Lorig and Holman 2003).

Koch, Jenkin and Kralik (2004) explained a model of self-management that consists of medical model, collaborative model and self-agency model. In the medical model, health professionals are in the central role to manage the patient's condition. Patients learn to trust medical knowledge and management. This model can generally be located at first diagnosis or condition change. The collaborative model is centred on collaboration between doctor and patient, with both of them providing management. The self-agency model is found in long-term conditions because of the patients' life experiences have informed them about managing themselves.

Chronic patients are the experts at dealing with their own condition in everyday life. The researchers also suggest that health providers can facilitate people toward self-agency, by embracing new understandings of self-management in the context of long-term illness.

Lorig and Holman (2003) define a set of 5 core self-management skills as follows:

1. **Problem solving:** patients are taught basic problem solving skills including problem definition, generation of possible solution, solution implementation and evaluation of results.
2. **Decision making:** this skill is part of problem solving. Patients must make day-to-day decisions in response to changes in their disease condition. They need sufficient and appropriate information.
3. **Resource utilisation:** the patient has to learn how to seek and utilise resources from many sources available via health providers.
4. **Forming of a patient/health care provider partnership:** patients must be able to communicate details of their condition and their needs via an accurate report. Moreover, they should make informed choices about treatment and discuss these with their health providers.
5. **Taking action:** patients have to learn how to change behaviour by using a short-term action plan and pursue their task to reach the goal. This skill depends on patients' confidence (self-efficacy). There is a tendency to succeed based on high efficacy, On the other hand, it has to involve some problem solving in order to make the plan more realistic and to avoid failure in the case of low confidence.

The key component of self-management is self-tailoring; in other words using self-management skills and knowledge and applying them to oneself as appropriate. The best means to self-tailoring is done by patients who learn the principles for changing behaviours and self-management (Lorig and Holman 2003).

### **1.5.2 Self-management for chronic illness**

There is conflicting evidence about the benefit of self-management in chronic illness. A number of studies have demonstrated the positive outcomes of self-management programmes as they increase knowledge of symptom management

and improving health status in people with chronic disease. A systematic review by Barlow et al. (2002) indicated that self-management provides benefit for patients with various kinds of chronic illnesses. It can improve the patients' health status and increase the efficacy of patients' skills for living with their chronic disease. However, the effectiveness of self-management is uncertain. Other systematic reviews argued that self-management programmes had only small to moderate benefit in several but not all sample studies of chronic disease (Warsi et al. 2004, Newman et al. 2004). One researcher suggested a self-management educational programme is of benefit to people with asthma but cannot improve conditions in arthritic or diabetic patients (Warsi et al. 2004). In addition, a Cochrane review by Coster and Norman (2008) claimed that there is inadequate evidence to support the effectiveness of intervention of self-management on chronic illness. Therefore, the further study of self-management on chronic illnesses should be addressed. Moreover, researchers argued that self-management programmes should be developed specifically for the particular subgroups, based on the patients' needs (Warsi et al. 2004). Moreover any such initiatives involving personalised-type programmes would need long-term follow-up evaluation (Barlow et al. 2002).

### **1.5.3 Self-management for pain**

A few studies have examined patients' experiences of pain and the effectiveness of self-management in patients with pain (Kralik, 2004; Blyth et al. 2005; Closs et al. 2007). The findings demonstrated that conventional analgesia is the primary method to manage pain. However, patients often reported poor effectiveness and unpleasant side effects of analgesics (Closs et al. 2007). Most patients develop their ability to self-manage their pain in their everyday lives. They attempted to self-manage pain in their everyday life, through active and passive strategies (Blyth et al. 2005). The active strategies include massage, exercise, cognitive therapy and alternative interventions whereas the passive strategies are resting, prayer and taking medicines. The result of a research claims that patients who use active strategies had less pain duration and less pain medication, compared with the passive group (Blyth et al. 2005). However, this finding did not demonstrate factors that were able to influence the active strategies' effectiveness and it cannot be assumed that these strategies will be effective in all or even the majority of patients. The researcher argued that the self-management developed by the patients is not a linear, consistent process. It is grounded by the personal and individual social context (Kralik 2004). There is a strong argument to support the notion that

development of self-management ability needs to take far more account of the individual approach and pay more attention to the particular context and circumstances of patients (Blyth et al. 2005; Closs et al. 2007).

#### **1.5.4 Self-management for chronic illness in Thailand**

The effectiveness of self-management in Thai people has been studied in various chronic diseases. A study of self-management was established in patients with end stage renal disease receiving haemodialysis (Methakanjanasak 2005). The findings showed that self-management was correlated with improving health status. However, in patients who have poor health status, they could not perform self-management. For this group of patients, therefore, social support provided by family members and health care providers may be an important factor to improve the patients' self-management and their health status. This suggests that to improve the patients' self-management ability a researcher should consider the patient at an individual level and the support provided by family and health care provider; a more holistic approach.

In addition, a quasi-experimental study of chronic obstructive pulmonary disease (COPD) by Kumpanut (2007) showed that patients on a self-management programme that included education and training self-management skills such as goal setting, self-monitoring, self-reinforcement and self-evaluation, had improved pulmonary function test scores, as well as lower dyspnea and anxiety than those in a control group. However, the results may need further study over a long-term period and in the larger sample size to confirm the effectiveness of this programme.

Wattana et al. (2007) reported that a self-management programme was effective in Thai diabetic patients, with the patients randomised to intervention showing greater glycaemic control. Tookeaw (2007) investigated the effectiveness of a self-management promotion programme with type 2 diabetic patients. The findings illustrated that better self-management skills were shown in the experimental group but the HbA1C of both groups was no different. This uncertain result may need further investigation in particular factors and long-term evaluation.

#### **1.5.5 Self-management for cancer in Thailand**

There are only three published papers focusing on problems related to self-management in Thai patients with cancer (Buranaraungrote 2006; Lundberg and

Rattanasuwan 2007; Somrarnyart 2006). The studies demonstrated that a variety of self-management strategies used by those patients, such as practicing religion, doing meditation, rest and exercise, was effective in relieving fatigue related to treatment. However, the effectiveness of each strategy cannot apply to every patient because of the differences in the severity of their problems, the patients' health status and their unique individual abilities. There is, therefore, a need for more studies with larger sample sizes in particular populations.

In summary, the theoretical basis of the self-management is based on the principle of behavioural change (Lorig & Holman 2003) which, in turn, is influenced by personal thoughts and beliefs (Bandura 2002). Previous literature shows that most self-management programmes provide benefit to day-to-day management in chronic diseases (Barlow et al. 2002). However, self-management education programmes had only small to moderate benefits in several but not all in chronic diseases. Therefore, it needs further studies to be carried out to examine their effectiveness with various chronic conditions (Warsi 2004; Somrarnyart 2006). Furthermore, most studies report only the short-term benefits, whereas the results may vary in the long time period. Despite this, the programme should be demonstrated show it' effectiveness in long-term (Barlow 2002; Protheroe 2008). The study claimed that the single theory of self-management may not be suitable for all patients. It may necessary to use more than one means, depending on a patient's condition, as well as their efficacy (Newman, Steed and Mulligan 2004).

Whether self-management might be a suitable strategy to implement for patients who have cancer pain, it can be seen that the self-management of Thai patients with cancer pain is complicated. There is insufficient evidence to explain what self-management of cancer pain in the Thai context involves. It is important to understand the patients' self-management in order to generate an appropriate intervention for improving their self-management of cancer pain.

The principle of behavioural change, including personal thoughts and beliefs, is clear to be the theoretical basis of self-management (Bandura 2002; Lorig and Holman 2003). In addition, the context of self-management of the patients, including family and health professionals, is also important to address. An application of a self-management programme to the particular group and a variety of factors, including patients and their context such as personal thoughts, family context as well as health care circumstances, are required to be carefully considered

when attempting to improve cancer pain control, particularly via a self- management programme.

## **1.6 Thai context**

### **1.6.1 Thai society**

Buddhism has taken root in Thai society for a long time, has influenced Thai attitudes and social values. The present social structure reflects much of such religious teaching; for example, the relationship between younger and the senior, belief in re-incarnation, the law of causality, making merit in the hope of a better life in the next incarnation, and lifelong monkhood as the greatest merit (Siriwan 2000).

The relationship between the younger and the senior in Thai society is hierarchical (Siriwan 2000). The junior must pay respect to the senior, while the latter must be generous to the former in return. The good point of this characteristic is to keep the society stable and united. Besides, the juniors dare not express their opinions, which might lead to many Thais being unassertive.

### **1.6.2 Thai culture and personal belief**

Thai culture influences personal perceptions and beliefs which affect the way people express themselves and behave. Thai cancer patients do not appraise the meaning of their pain to be association with their stage of cancer, number of pain sites, duration, age or gender. However, a study by Lukkahatai (2004) showed that elderly people who report strong beliefs about the importance of religion and the existence of a supernatural power are readily accept limitations on their activities and perceive themselves that they are vulnerable to the disruptive effects of cancer pain.

The role of culturally related factors and religious beliefs in the cancer pain experience was clearly set out. Spiritual beliefs did not have an effect on perceived meaning of pain but did have a negatively significant effect on perceived control over pain. Patients who reported strong beliefs about the importance of religion in their lives, the existence of a supreme being and the importance of religious practices did not perceive pain as a challenging event; such patients also perceived themselves as having less ability to control pain (Lukkahatai 2004). This mind set can be explained in relation to the law of Karma, which states nobody can avoid

their Karmas, their fate. Therefore, patients who believed in external control may believe less their own sense of control.

Patients who had high scores in spiritual beliefs reported low pain interference with daily activities, because the teaching of Buddha about the Law of Karma leads patients to accept their burden, a condition that they have to bear. Moreover, these patients were also reported as frequently using coping strategies such as distraction, distancing, self-statement, ignoring sensation and praying. These coping strategies did not increase the sense of ability to control but were only aimed to enable the person to bear the pain because of their belief in the teaching of Buddha about the Law of Karma, which stated that a person must take responsibility for his/her past life Karma. However, the belief in the idea of Karma may affect the report of less interference of pain with their daily activities (Lukkahatai 2004).

### **1.6.3 Social support**

Social support is revealed as a psychological strategy designed to increase a feeling of certainty, decrease feelings of stress and improve health behaviour as a result (Rattanasukon 2001). Family members and health care providers are recommended as being the main source of social support.

A previous study showed that family can provide support for the patient, such as daily activity, sleeping, eating and bathing. Ways to care for and cure the patient include facilitating the travelling for treatment, as well as the family providing financial help and emotional support by encouraging the patient (Rattanasukon 2001).

Cultural differences influence how people express, use and seek social support. Asians prefer to use implicit social support. In addition, the tendency not to seek any social support is found in many countries of Asia (Kim et al. 2008). Asian culture believes that one should not ask for support, because people should anticipate helping before it is explicitly sought. Moreover, people should be responsible for dealing with and solving their own problems. Asian people would be concerned about the potentially negative relational consequences of support seeking; some might perceive their performance as inadequate and lose face if asking for community support (Kim et al. 2008). This situation can be found generally in Thai society. Moreover, some Thais perceive that any problem should be kept confidential. Asking for help from people, especially who are not members of

the family, is an activity to be avoided in order not to receive negative reactions from people who will see the requestor as pitiful, to be looked down on. Only when it is found that the problem cannot be solved solely by the family would it be thought acceptable to seek support from people outside the family.

However, there is some distinction about social support in Thai culture. There are two particular concepts describing personality of Thais related to expressing personal requests. The concept of 'kreng-jai' (a concept that teaches Thais to be considerate of another's feeling and to be reluctant to express feelings to others) and concept of 'feeling of burden' (a concept that means patients prefer not to be a burden and prefer to try solving their problem on their own) may influence how Thais respond to pain (Rattanasukon 2001; Lukkahatai 2004). Many Thai patients particularly hesitate to ask for help from another due to the thought that the request would bother them (Lukkahatai 2004). In consequence, some patients may adopt successful ways to deal with the pain by themselves. On the other hand, some patients will endure pain due to their lack of communication to others, which may result in a feeling of hopelessness, if the use of coping strategies to deal with pain is ineffective (Rattanasukon 2001). These two concepts may explain the diversity in the willingness and readiness to express the need for support in Thais.

#### **1.6.4 Thai family**

In Thai culture, because of the intimate relationship among family members, all family members will sense their responsibility of solving problems for everyone in the family (Lundberg and Rattanasuwan 2007). Therefore, family is a crucial source of psychological, financial and material support which is a key to success of self-management for chronic illness, particularly in patients with cancer pain.

Family is a unique setting with powerful continuing relationships that assume levels of complexity and organisation that go beyond the individual people involved. Family members create a shared social reality that is linked to health, and it is in this environment that most disease management takes place. Parents, spouses, and other family members are assumed to be the primary source of support, and their ability to meet the needs of the patient is often confounded by the distress that illness generates in other family members.

Family relationships have greater emotional intensity than do most other social relationships, and research suggests that there is a substantive, positive correlation between the specific bonds within families and chronic-disease

management and outcomes (Primomo et al. 1990). Stable, secure, and mutual family relationships enhance consistent disease management behaviour by permitting a sharing of the burdens associated with disease.

Thai cultural norms demand gratitude and care of the family. It is important to understand the different role of social support in different cultures. Moreover, it is necessary to be aware of individual cues to detect the needs of people whether in similar cultural backgrounds.

The family would take responsibility for all members who have problems and those problems would be handled within the family (Lundberg and Rattanasuwan 2007). All family members willingly participate in the discussion and provide choices of the solution. However, the decision making is depended on the person who is the most powerful in the family (Get-Kong, 2010). In most Thai families it is the men who take primary responsibility of family finances, so they are asked to be the leaders, while women traditionally fulfilled the roles of homemaker and carer. It is generally found that the decision making belongs to a man, who may be husband, father, grandfather or the eldest son. This can explain how the Thai family influences the patient's self-management. However, the relationship between family support and patients' appraisal of cancer pain and/or patients' self-management of cancer pain needs clarification.

### **1.6.5 Family and self-management**

Family members play the prime role in offering care and comfort in order to maximise the quality of pain control for the cancer patients (Duhamel and Dupuis 2003). They can assist patients to deal with cancer pain in many ways, including in deciding what pain medication to give and when to give it, monitoring and recording the patients' symptoms and communicating with health professionals. In addition, they also remind and encourage the patient to follow the prescriptions and find alternative ways in order to help patients in relieving pain (Given and Given 1994). It can be argued that family members may be an important factor to encourage the patient in performing self-management in order to increase the quality of pain control. However, research studying the effectiveness of family support on increasing self-management capability in cancer patients does not seem to have been published.

Most previous studies focused on the role of family and the family's role in providing care for the various kinds of patients such as patients with HIV/AIDS or

cancer, patients with cognitive problems and patients with psychological problems (Kahana et al. 1994). The findings of Kahana et al. (1994) showed the benefits of family in helping to improve the patients' health status. However, the role of family members related to the patients' self-management was not investigated. In previous Thai literature, researchers described Thai culture and norms among family members in taking responsibility to care for the patients with chronic disease, including patients with cancer (Methakanjanasak 2005; Burararaungrote 2006; Somrarnyart 2006; Lundberg and Rattanasuwan 2007). However, they did not explore the role of the family providing support related to self-management of cancer pain. Further study to investigate the relationship between social support provided by family caregivers and self-management, may be useful to develop programmes designed to increase the effectiveness of pain control in cancer patients.

## **1.7 Justification for the study**

It can be seen that cancer pain is a crucial concern in health care service. There are many complicated issues emanating from cancer pain management, including the barriers related to an individual patient, family caregiver and health care providers, as well as the barriers related to the health care system (IASP 2008). Careful consideration of how these factors contribute to the effectiveness of pain control in cancer patients is required.

It was found that self-management was beneficial to the day-to-day management of chronic diseases (Barlow et al. 2002). This might be a suitable strategy to implement for patients who have cancer pain. However, previous studies indicated that there was insufficient evidence to evaluate the effectiveness of self-management programmes (Coster & Norman 2008). The application of a self-management programme to a particular group, taking into account a variety of factors such as patients and their personal thoughts, their family context, as well as their health care circumstances, requires careful consideration.

There is a shift in focus within cancer care towards the outpatient and home setting, resulting in the family becoming more actively involved in cancer care at home (Given et al. 2001). Family members are convinced to be an integral part of the health care team, being defined as a major source of support for patients, especially in the terminal stage of the disease (Kahana et al. 1994; Duhamel & Dupuis 2003). The collaboration between family and health care providers may

improve patient outcomes (Kahana et al. 1994). Most of the previous studies of home based cancer patients focused on social support in pain management (Berry 2007) and on patients who had chronic diseases, including cancer (Given et al. 2001; Weihs et al. 2002; Methakanjanasak 2005; Lundberg & Rattanasuwan 2007). Some previous studies showed a positive correlation between the care provided by family members and the patients' outcomes (Weihs et al. 2002). However, the influence of family support on cancer pain control was still questionable (Tsigaropoulos et al. 2009). Moreover, the role of both the family and other health care providers, in the self-management support of cancer pain, is complicated and there is still a need for research in this area.

In conclusion, the prevalence of cancer in Thailand has risen each year. One of the most common cancers in Thai women is cervical cancer (Attasara 2007). Amongst these patients, pain is an important problem, in which inadequate pain control is still reported (Khounnikhom 2007). Therefore, there is an increasing pain-related problem, as a consequence of the growing number of Thai patients with cervical cancer, which needs to be addressed. The literature accessed in the last fifteen years was reviewed, revealing that there was insufficient evidence in relation to self-management experiences of Thai patients who have cancer pain; there being only one study investigating the effectiveness of a self-management programme in patients with cancer pain. While the finding of the study showed the positive outcomes of the programme, some limitations of the programme were also discussed.

The self-management of patients with cancer pain is complicated. It is important to understand the patients' self-management strategies in order to generate an appropriate intervention for improving the self-management of cancer pain. The principle of behavioural change, including personal thoughts and beliefs, is the theoretical basis of self-management (Bandura 2002; Lorig & Holman 2003). In addition, the context in which the self-management of the patients occurs, including family and health professionals, is also important to address. Thus, to develop and to apply self-management of cancer pain in Thai patients, a variety of factors, including the patients' perspectives, family context as well as health care circumstances, requires careful consideration. An appropriate research approach investigating the self-management of pain control in Thai patients with cancer is needed to further the construction of knowledge.

## **1.8 Research questions and purpose**

Cancer pain is an important problem worldwide, including Thailand. There is evidence of inadequate pain management which needs further study in order to improve pain control. There are many complicated obstacles of cancer pain management. Careful consideration of how these factors influence pain control in cancer patients is required.

Given the persistent nature and prevalence of pain in cervical cancer, it is important to develop strategies to enable individuals to manage their pain on a day to day basis. This is the focus of this thesis, to understand how people manage their pain and how they can be supported to develop effective self-management strategies.

### **1.8.1 Research questions**

#### **1.8.1.1 Main question**

How is cancer pain experienced by Thai women with cervical cancer managed in hospital and at home and what is the potential for self-management?

To answer these questions, some further sub-questions were developed using the key concepts of self-management as a guide

#### **1.8.1.2 Sub questions**

- How do these women conceptualise and perceive their cancer pain?
- When pain is perceived to be a problem what process do patients undertake to solve this problem?
- What decisions do patients make to manage their pain and how do they make those decisions?
- What resources do patients use to manage their pain and how do they utilise these resources?
- What relationships do patients make with their health care providers and what impact does this have on their pain management?
- What action do people with cancer take to manage their cancer pain?

- How do these self-management activities differ between hospital and home?
- What action do health care professionals take which enhance or hinder self-management of pain?
- In what ways do family members support or hinder self-management of cancer related pain?

### **1.8.2 Purpose**

The purpose of the research is to gain an understanding of self-management for pain control in patients who have cervical cancer, specifically in relation to Thai women, their families and health care providers. An in-depth exploration of the experience of cancer pain would lead to constructing an understanding of 'how' and 'why' participants respond to pain in the way that they do and the consequences for how they manage their pain. The results of this study would provide information which can be used to develop appropriate education programmes of self-management of cancer pain for the patient, for the family caregivers and for the healthcare providers, in order to improve pain control in Thai women with cervical cancer.



# Chapter II

## Literature Review

### 2.1 Introduction

Following the general overview of cancer pain and self-management provided in the previous chapter, chapter three considers these issues in more depth, specifically in relation to the Thai context. Gaps in the evidence relating to cancer pain management and previous self-management programmes in Thailand are identified to inform the development of research questions and subsequent research objectives.

The overall purpose of this chapter is to review the literature relevant to the self-management of pain control in Thais. This chapter will report the literature search strategy, databases available to conduct the search, and then the results. The findings, strengths and limitations of each study will be discussed in order to draw conclusions about the current state of evidence. In addition, the gaps in cancer pain management knowledge will be identified, enabling justification of this research project. The chapter ends by presenting the research questions and objectives of this study.

### 2.2 Literature search strategy

Conducting a literature search is an essential stage of the research process, undertaken in order to identify the relevant literature underpinning the topic of interest. The initial stage, which should include thinking about specific information, is needed in order to focus the search. Then, locating of information sources including the relevant databases, identifying search terms, combining relevant topics and selecting relevant material will follow.

### 2.2.1 Literature sources

Literature sources need to be identified in order to conduct a literature search. A variety of sources are recommended including both paper and electronic. Journals, books, reports, theses and computer databases are generally used. Searching using electronic bibliographic databases, hand searching, citation tracking from referenced lists and grey literature is also recommended (Voorde and Laonard 2007).

Electronic databases were employed as the main information sources because of their academic credibility, effectiveness, specificity and convenience and also because they provide the researcher the opportunity to employ a systematic approach (Boagy and Glasper 2012).

Electronic databases including CINAHL, AMED, EMBASE, MEDLINE, Pubmed, PsycINFO, Web of Knowledge are available from the University of Southampton. Using these sources enables access to significant amounts of information, particularly from published journals, dissertations and theses. These electronic databases generally enabled a systematic search of relevant international literature but were limited in their ability to identify literature conducted in Thailand. Therefore, databases and sources in Thailand, including the Thailand Library Integrated System (ThaiLIS)(<http://tdc.thailis.or.th/tdc/basic.php>), Thai Theses Online (<http://www.theses.stks.or.th/>), TKC e-thesis (<http://www.tkc.go.th/index.php/tkc-e-thesis>), and the Research Library of the National Research Council of Thailand ([http://www.riclib.nrct.go.th/index\\_e.html](http://www.riclib.nrct.go.th/index_e.html)) were searched. These sources were helpful and allowed the use of Boolean operators for searching. Most research reports and theses could be downloaded as full text, but some documents were unable to access the full paper in which asking for the paper from the author had been conducted.

It was acknowledged that some Thai literatures might not be published on electronic databases. Find out relevant literatures by visiting web page of Thai universities' library as well as asking the universities' librarian was done.

## 2.2.2 Defining the search term, search strategy and exclusion criteria

The Thai literature was searched by using the keywords in relation to the research question as ‘what is self-management for pain control in Thai patients with cervical cancer’. This topic area had been investigated from a range of professional and theoretical contexts; therefore both health care databases and psychosocial databases were accessed.

To begin searching the literature, it is necessary to choose appropriate search terms, or key words, which are dependent on an awareness and understanding of the research area and of the investigator thinking laterally. Then the Boolean operator OR, AND, and NOT was used to organise the concepts of the literature search (Fitzpatrick 2007).

There were 3 steps used in conducting literature searching:

Step 1: Identifying search terms and related key words of each concepts by using \* after any search term in order to find possible word related to the original key words. Then combining any term with OR to retrieve all relative words.

Search term	Key words
Concept 1: To identify the self	sel*
Concept 2: To identify the pain	pain* OR suffer*
Concept 3: To identify the cancer	cancer* OR carcinoma* OR malignan*
Concept 4: To identify the management	manag* OR control* OR regulat* OR Car* OR tailor* OR evaluat* OR treat*
Concept 5: To identify the programme	program* OR educat* OR teach* OR train* OR coach* OR develop*

Step 2: Combining each concept with AND to narrow and focus on the specific concept, the results consisted of 4 main concepts

Concept 6: Self-management: C1 and C4

Concept 7: Cancer pain: C2 and C3

Concept 8: Self-management programme: C5 and C6

Concept 9: Self-management programme for cancer pain: C7 and C8

Step 3: Limit the results with inclusion and exclusion criteria

Inclusion criteria: full text research articles, dissertations or theses conducted in English or Thai language only; published or conducted from 1995 to 2012 in order to cover all relevant and contemporary literature.

Exclusion criteria: books, reports, conferences papers, literature reviews; those relating to students, pupils, children, infants, new born, adolescents; those relating to post-operation, psychological problems, dental problems, pregnancy and postpartum

### **2.2.3 Searching results**

It was found that there was only one paper resulting from this search strategy, perhaps because there has been little research conducted in this area or there research had not been published in these online databases. There was evidence that self-management had been studied in patients with various kinds of chronic diseases such as diabetes mellitus, chronic obstructive pulmonary disease and heart disease. Therefore, to generate an understanding and an overview of self-management in Thailand, the search term was modified to 'self-management programmes for chronic disease'. The number of literature sources that resulted from this search, including the modified and broader search approach, was illustrated in the table as followed.

Table 2.1 Search strategy result

Search term/Concepts (C)	International databases						Thai databases			
	CINHAL	AMED	EMBASE	MEDLINE	Web of Knowledge	PsycINFO	ThaiLIS	TKC e- Thesis	Thai Theses Online	Research Library of National Research Council of Thailand
C1: Self	19218	2665	47763	66737	>100,000	82872	71	58	323	166
C2: Cancer	62141	5830	523090	689062	>100,000	14094	647	22	2001	464
C3: Pain	37561	9919	83681	105306	>100,000	22927	297	12	616	74
C4: Management	398233	43049	>1,000,000	>1,000,000	>100,000	299009	7956	128	9419	440
C5: Programme	143692	16780	342466	596207	>100,000	283437	20905	1124	2271	382
C6: Self-management: (C1 and C4)	6381	829	9284	13651	41987	15197	65	30	143	106
C7: Cancer pain: (C2 and C3)	2117	692	4463	5033	7846	990	143	22	24	2
C8: Self-management programme: (C5 and C6)	346	43	332	523	1436	1093	65	30	18	0
C9: Self-management programme for	11	2	9	13	20	7	2	0	0	0

Search term/Concepts (C)	International databases						Thai databases			
	CINHAL	AMED	EMBASE	MEDLINE	Web of Knowledge	PsycINFO	ThaiLIS	TKC e-Thesis	Thai Theses Online	Research Library of National Research Council of Thailand
cancer pain: (C7 and C8)										
Included by conducting in Thailand	1	0	0	1	1	0	2	2	0	0
<b>Final result</b>	<b>2</b>									
C10: Self-management programme for chronic disease (modified C8)	2	0	0	1	2	0	38	12	6	0
Excluded by reading through articles	2	0	0	1	2	0	25	8	6	0
<b>Final result (Excluded duplication)</b>	<b>28</b>									

The results were mostly found in the ThaiLIS database because this database collected the theses from most universities in Thailand; theses that were unlikely to be published in international journals. The search strategy managed to identify 28 relevant literature references. There were 8 studies conducted with patients who have chronic obstructive pulmonary disease (COPD) (Buathongjan 2005; Unchit 2005; Pisanbowornsri 2007; Kumpanut 2007; Prombutr 2007; Duangpang 2005); 2 articles focused on patients with asthma (Lohasarn 2007; Sae-Tae 2008); 9 references involving patients with diabetes mellitus (Tookaew 2007; Keeratiyutawong 2005; Kongsakul 2009; Deeseang 2006; Johnjumrut 2007; Chodchoi et al. 2007; Konyai 2007; Suttharattanakun 2006; Sanjaithum 2006); 4 studies of patients with urinary problem (Muangmaitong 2008; Pradujkanjana 2006; Santayopas 2001; Methakanjanasak 2005); 1 article about patients with arthritis (Duangklai 2003); 2 involving patients with heart disease (Tangwichitsakun 2007; Tudtheang 2010), 1 article concerning patients with hypertension (Wongputtakham 2007); and 3 studies of patients with cancer (Somrarnyart 2006; Buranaruangrote 2006; Lundberg and Rattanasuwan 2007). The summary of this literature is illustrated in the table below.

Table 2.2 Summary of reviews included (n=28)

Author	Title	Aim	Design	Sample	Outcomes	Findings
Buathongjan J Master Thesis, Chulalongkorn University, 2005	The effect of self-management program on dyspnea in patients with chronic obstructive pulmonary disease, lower southern region	To examine the effect of the self-management program on dyspnea in patients with chronic obstructive pulmonary disease (COPD)	Quasi-experimental study  The control group received conventional care  The experimental group received a 6-week self-management program  Data collecting: 2 times at pre-intervention and the 6 <sup>th</sup> week after finish the program	40 outpatients with COPD in a community hospital  Homogeneous patients were randomised into the control group (n=20) and the experimental group (n=20)	Perceive dyspnea by the Modified Borg Scale  Data analysis: descriptive analysis and T-test	Tobin's conceptualisation of self-management and Kanfer's notion of self-monitoring was the framework for developing the program  The program comprised of patient self-assessment and goal setting, individualised education of dyspnea management strategies, pulmonary rehabilitation and self-monitoring skill teaching)  The experimental group was significantly decreasing in dyspnea ( $p < .001$ ) and lower ( $p < .05$ ) than the control group
Unchit P Master Thesis, Burapha	The effectiveness of promoting competency in	To determine the effect of promoting competency in a chronic dyspnea	Quasi-experimental study  Pre and post-test	42 outpatients with COPD in a tertiary hospital	Perceived competency in chronic dyspnea SM scale	The experiment group significantly increased competency scores and decreased dyspnea status ( $p$

Author	Title	Aim	Design	Sample	Outcomes	Findings
University, 2005	a chronic dyspnea self- management program on self- management outcomes in people with chronic obstructive pulmonary disease	self-management program on self- management outcomes in people with COPD	design	Homogeneous patients were randomised into the control group (n=21) and the experimental group (n=21)	Dyspnea Visual Analogue Scale (DVAS)  Data analysis: descriptive analysis and T-test	< .05).  The experiment group had significant higher competency score and lower dyspnea status than the control group ( $p < .05$ ).
Pisanbowornsr i N Master Thesis, Burapha University, 2007	Development of the model for promoting competency in chronic dyspnea self- management for patients with chronic obstructive pulmonary disease	To develop a model for promoting competency in chronic dyspnea self-management for patients with COPD	Action research (in-depth interview, participant observation, field notes)  The study was conducted for 8 months	20 patients with COPD  Purposive sampling	Perceived competency in chronic dyspnea self-management scale  Dyspnea Visual Analogue Scale (DVAS)  Data analysis: qualitative coding,	The developed model consists of building therapeutic relationships, continuing teaching chronic dyspnea self- management skills, mutual participation among the patients with COPD, family and health care team, emotional support, practice of self-management, coordinating care and helping from a health care team, and enhancing confidence in

Author	Title	Aim	Design	Sample	Outcomes	Findings
					<p>developing themes and a model development</p> <p>Quantitative: descriptive analysis and Wilcoxon Signed Rank test</p>	<p>patient's own capacity.</p> <p>The model affected the patient to perceive the high competency in chronic dyspnea and decrease dyspnea status.</p>
<p>Kumpanut J Master thesis, Burapha University, 2007</p>	<p>Effects of self-management promotion program on self-management practice, dyspnea, pulmonary function and anxiety in the elderly with chronic obstructive pulmonary disease</p>	<p>To determine the effects of self-management promotion program on self-management practice, dyspnea, pulmonary function and anxiety in elderly with COPD</p>	<p>Quasi-experimental study</p> <p>The control group received regular training</p> <p>The experimental group received an 8-week promoting self-management program</p> <p>The program included goal setting, self-monitoring, self-evaluation, self-reinforcement</p>	<p>16 elderly people with COPD in a community hospital</p> <p>Homogeneous patients were purposive sampling and placed into 2 groups</p>	<p>Self-management practice</p> <p>Dyspnea Visual Analogue Scale</p> <p>Auto-spirometer</p> <p>Spiel Berger State Anxiety Inventory Form X-1</p> <p>Data analysis: Two-way analysis of variance: repeated measure; Newman-</p>	<p>Social cognitive theory (Bandura) and self-monitoring (Kanfer and Gaelich) was the framework of study.</p> <p>The experimental group had significantly higher self-management practice and pulmonary function (<math>p &lt; .05</math>), lower dyspnea and anxiety (<math>p &lt; .05</math>) at post program and 8 weeks follow-up than the control group.</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
			Data collecting: week0 (pre-test), 8 (post-test), 16 (follow up)		Keuls method	
Prombutr R Master Thesis,  Chulalongkorn University, 2007	The effect of self-management program on reducing acute exacerbations in persons with chronic obstructive pulmonary disease	To study the effect of self-management programme on reducing acute exacerbations in persons with COPD and to compare acute exacerbations with COPD	Quasi-experimental research  The control group received conventional nursing care  The experimental group received a 6-week session of self-management program  First 3 weeks received group educational and training program (10 patients per group), 1 hour, once a week in hospital  Last 3 weeks received	40 outpatients with COPD in a community hospital  Matched pair technique to the control group (n=20) and the experimental group (n=20)  Power of test was 0.80 equal to 11 samples	Lung function test  Peak flow rate by Wright Peak Flow Metre  Data analysis: Descriptive analysis and T-test	The programme includes self-assessment, education-demonstration- training, evaluation program (modified from Bourbeau et al 2003 which reference to the Chronic Care Model (CCM))  The experimental group showed significantly reducing acute exacerbations ( $p < .05$ ) and higher peak flow rate ( $p < .05$ ) than the control group.  The experimental group had greater self-management behaviour resulting in better findings.  Self-assessment provided

Author	Title	Aim	Design	Sample	Outcomes	Findings
			<p>individual home visit for reviewing and discussion (1 hour)</p> <p>Data collecting: Week 0 and week 7</p>			<p>specific problems of the patients resulting in developing an appropriate education for particular.</p> <p>The practice could increase the confidence and improve skill.</p> <p>Home visits provided understanding the patient and family.</p>
<p>Kangchai W Thai Journal of Nursing Research (2002) 6(3), 101-114)</p>	<p>Efficacy of self-management promotion program for elderly women with urinary incontinence</p>	<p>To test the efficacy of a self-management promotion program for elderly women with urinary incontinence</p>	<p>A quasi-experimental pre-test and post-test, non-equivalent comparison group design</p> <p>The experimental group received 4 phases of self-management promotion program 1) assessment and planning (week0)</p>	<p>60 elderly women from home who afflicted with urge or mixed urinary incontinence</p> <p>Random sampling the participants into the experiment group (n=30)</p>	<p>Self-management questionnaire for UI</p> <p>SM Incontinence psychological impact scale</p> <p>Monitoring sheet</p> <p>Incontinence questionnaire</p> <p>Chula mental test</p>	<p>The program was based on the self-management concept (Bartholomew) and self-regulation model (Kanfer).</p> <p>The experiment group was significantly increased (<math>p &lt; .001</math>) and higher self-management practice mean scores than the control group (<math>p &lt; .01</math>).</p> <p>The experimental group had significant decreased frequency</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
			<p>2) preparation: received short lecture, group discussion, demonstrations, practice and a booklet (week1)</p> <p>3) self-management practice (week2-8)</p> <p>4) evaluation: 30-45 minutes home visit once a week for 7 weeks (week2-8)</p> <p>Data collection: by a research assistant at week0,8,12,16</p>	<p>and the control group (n=30)</p> <p>The power of test was 0.80.</p>	<p>Modified Barthel activities daily living index (BAI),</p> <p>Geriatric depression scale (GDS)</p> <p>Data analysis: T-test, repeated measures ANOVA</p>	<p>of urinary incontinence (<math>p &lt; .001</math>) and negative psychological impact mean scores and had significantly lower scores than the control group (<math>p &lt; .01</math>).</p>
<p>Tookaew R Master Thesis, Burapa University, 2007</p>	<p>Effects of self-management promotion program on self-management practice and haemoglobin</p>	<p>To investigate the effects of self-management practice and hemoglobin a1c (HbA1c) level among the elderly patients with type2</p>	<p>Quasi-experimental study</p> <p>Self-management program : self-management plan, handbook of self-management in DM,</p>	<p>20 outpatients with diabetes mellitus in a university hospital</p> <p>Simple random</p>	<p>Self-management questionnaire and interview</p>	<p>The experiment group had higher self-management score than the control group, HbA1c had no significant different.</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
	A1c level among the elderly patients with type 2 diabetes mellitus	diabetes mellitus (DM)	self-recording  Pre-post and 12 weeks follow-up	sampling		
Keeratiyutawong P et al. Thai Journal of Nursing Research  (2006),10(2), 85-97.	Effectiveness of a self-management program for Thais with type 2 diabetes	To test the effect of a self-management program on diabetes knowledge, self-care activities, quality of life and glycosylated hemoglobin A1c (GHb) in persons with type 2 diabetes	Randomised controlled trial (RCT) study  The control group attended diabetes education as the routine nursing and watched 5 videotapes about diabetes care.  The experimental group received a small group (9-13 patients) self-management programme.  The programme included 5 sessions (2 hours per session);	81 outpatients with type2 DM in a community hospital  Homogenous patients were randomly assigned to the control group (n=41) and the experimental group (n=40)	The diabetes knowledge scales  The summary of diabetes self-care activities measure (SDSCA)  The diabetes quality of life measure (DQOL)  Glycosylated hemoglobin A1c (GHb)  The instruments were test reliability	Theoretical framework : Orem's self-care theory and cognitive therapy  The experimental group had significant higher in knowledge, SDACA and DQOL than the control group at 3 and 6 months.  The experimental group had lower, but not significant different, in GHb than the control group.

Author	Title	Aim	Design	Sample	Outcomes	Findings
			<p>1) a pathology of DM, cognitive restructuring and goal setting, 2) dietary control and communication skills, 3) diabetic medication and problem solving skills, 4) foot care and self-monitoring, 5) exercise; watched 5 videotapes about diabetes self-care</p> <p>Follow-up telephone calls 3 and 5 months post intervention</p> <p>Both group received a set of written diabetes material</p> <p>Data collecting : pre-intervention, 3 and 6 months post</p>		<p>by the use of K-R 20 and Cronbach's coefficient</p> <p>Data analysis: repeated measures ANOVA for knowledge, SDACA and DQOL, repeated measures ANCOVA for GHb</p>	

Author	Title	Aim	Design	Sample	Outcomes	Findings
			intervention			
Kongsakul S Master Thesis, Thammasat University, 2009	The effects of a self- management skill training program on self- management behaviours regarding glycemic control and blood sugar level among persons with type 2 diabetes mellitus	To determine the effects of a self- management skill training program on self-management behaviour regarding glycemic control and blood sugar among persons with type 2 DM	Quasi-experimental study  The control group received routine nursing care  The experimental group received a self- management program; Week1,2 received self- management education (2 hours per week covering all 6 skills) Week3-6 received home visit, reviewed and counselling, telephone followed up 2 times, and written material about diabetes self- management	60 outpatients with type 2 DM in a community hospital  Homogeneous patients were randomised into the control group (n=30) and the experimental group (n=30)  Sample size was calculated following by Schiesselman that was equal to 26 patients	Evaluation form of self-management behaviours in relation to glycemic control, fasting blood sugar (FBS) level  Reliability of the instruments was 0.926 by Cronbach's Alpha coefficient  Data analysis: descriptive analysis, T-test, and Chi- square	Conceptual framework of the study involved in social learning theory and self-management (Creer) consisting of goal setting, information collection, information process and evaluation decision making, action and self-reaction  The experimental group had a significantly higher level of self- management behaviours regarding the glycemic control score ( $p < .05$ ) and lower level of FBS ( $p < .01$ ) than the control group.

Author	Title	Aim	Design	Sample	Outcomes	Findings
			Data collecting: baseline, then 4 and 8 weeks after entering the program			
Deeseang W Master Thesis,  Chulalongkorn University, 2006	Effects of self- management program on hemoglobin A1c and LDL- cholesterol level of type 2 diabetic patients	To compare HbA1c and LDL-cholesterol level of patients with type 2 DM in the experimental group before and after received the self-management program and between the experimental group and the control group	Quasi-experiment study  The control group received conventional nursing care.  The experiment group received self- management program (self-evaluation, goal setting, self- management strategies and review)	40 outpatients with type 2 DM in a community hospital  Homogeneous patients randomised into the control group (n=20) and the experimental group (n=20)	HbA1c and LDL- cholesterol record form	In the experiment group, HbA1c had significant lower in than before but LDL-cholesterol did not different.  No significant different between the experiment group and the control group.
Johnjumrut C Master Thesis, Mahidol University,	Individualized empowerment approach to dietary self- management	To test the effectiveness of the individualised empowerment approach in dietary	Quasi-experiment study  The experimental group received 16- a	30 participants with DM	Anthropology measurement Biochemical analysis	The individualised empowerment-based approach offers benefits to participants  Positive change in problem

Author	Title	Aim	Design	Sample	Outcomes	Findings
2007	to improve metabolic control in patients with type 2 diabetes	self-management education to improve metabolic control in patients with type 2 DM	<p>week intervention program:</p> <p>Week -1 : baseline measurement</p> <p>Week 0,2,4,12 : educational material (healthy eating for DM, food exchange package guide), provided educational and counselling with step-by-step empowerment approach (5 steps consisted of identify problem, identify feeling, set goal, make action plan, evaluate the plan)</p> <p>Week 8: same as week 0, and included biochemical test</p> <p>Week 16 : repeat all tests</p>		<p>The problem solving dietary scenario (PSDS)</p> <p>Semi-quantitative food frequency questionnaire (FFQ)</p>	<p>solving ability</p> <p>Positive coping strategies led to understand dietary self-management</p> <p>Goal setting led to change in food habit both quality and amount of food consumption</p> <p>Decline in body composition and improved glycaemic control</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
Wattana C et al. Nursing and Health Sciences (2007), 9, 135-141	Effects of a diabetes self-management program on glycemic control, coronary heart disease risk, and quality of life among Thai patients with type 2 diabetes	To determine the effects of a diabetes self-management program on glycemic control, coronary heart disease (CHD) risk, and quality of life (QOL)	Randomised controlled trial design  The control group received usual nursing health education  The experiment group received a small group diabetes education class (120 min), and then 4 small group discussions to promote self-efficacy (90 min/group), 2 individual home visits (45 min)  Period of intervention was 6 months  Data collection: pre-test week0 and post-test week 24±1	147 people with type 2 DM who met the research criteria were randomly to the control group (72) and the experimental group (75)  Sample size was calculated based on a significant level of 0.01 and a power of 0.90 (55 were required and 8-10% of attrition rate)	Laboratory testing (HbA1c, lipid profile)  SF-16 Thai version for QOL  The Framingham Heart Study Coronary Heart Disease Risk Profile  The reliability coefficient was 0.94  Data analysis: descriptive statistics, T-test, Fisher's Exact test, rank sum Mann-Whitney u-test, ANCOVA, and Chi-square	The programme of this study was based on the theory of self-efficacy (Bandura) and self-management (Creer).  Glycaemic control : HbA1c and lipid profile in the experimental group had significantly lower than pre-test and greater than the control group at 24 weeks ( $p < .05$ )  Coronary heart disease : lipid profile and BP in the experiment group had significantly greater decrease than the control group ( $p < .05$ )  QOL : the experimental group had significant greater increase than the control group ( $p < .001$ )

Author	Title	Aim	Design	Sample	Outcomes	Findings
Tangwichitsakun S Master Thesis, Mahidol University, 2007	Effects of self-management program on quality of life among heart failure patients	To examine the effect of a SM program on the quality of life among heart failure patients	Quasi-experimental research  The control group received conventional care  The experiment group received a 5-day (30-60 minutes per day) self-management program consisting of education of the disease, SM practice and evaluation  Data collecting: Week0 (pre-test) and week6 (post-test)	30 heart failure patients who admitted to the medical wards in a university hospital  Purposive sampling assigned to the experimental group (n=15) and the control group (n=15)	The Minnesota Living with Heart Failure Questionnaire by Rector, Kubo and Cohn (1987) (Thai version)  The reliability was obtained by Cronbach's Alpha coefficient with the value of 0.95  Data analysis: Descriptive statistics, T-test	The program was developed based on theory of self-management (Creer).  QOL after received program was significant better than before ( $p < .001$ )  QOL of the experimental gr was better than control group ( $p < .001$ )  Self-management program can enhance the QOL in HF patients
Wongputtakham S Master Thesis, Mahidol	Effects of self-management on health behaviours and blood pressure	To examine effects of self-management on health behaviours and blood pressure	Quasi-experiment study  The control group received routine care	30 outpatients from the hypertensive clinic in a community	Health behaviour recording form	Health behaviour in the experimental group was significantly higher than the control group, and after was higher than before.

Author	Title	Aim	Design	Sample	Outcomes	Findings
University, 2007	among hypertensive patients	among hypertensive patients	The experiment group received self- management plan, handbook for self- management	hospital  Homogeneous patients were randomised into the control group (n=15) and the experimental group (n=15)		Blood pressure was significant lower in the experimental group than in the control group, and after was lower than before.
Lohasarn W Mater Thesis, Khon Kaen University, 2007	The effect of a self- management education program on knowledge and self- management skills in patients with asthma	To study the effect of a self- management education program on knowledge and self-management skills of patients with asthma	Quasi -experimental research  The control group received routine care  The experimental group received a self- management educational program (duration 45 min)  The study was implemented within 1	30 patients with asthma  Homogeneous patients were randomised into the control group (n=15) and the experimental group (n=15)	An asthma knowledge questionnaire  An asthma self- management skill questionnaire  The reliability equalled to 0.75 and 0.82, respectively	The program was based on the concept of participant learning among the PT and nurse educator, adult learning. The content was about knowledge of asthma and self-management skills; one week warning letter emphasizing the awareness of self-management.  The experimental group had significant higher in knowledge ( $p < .01$ ) and self-management skills ( $p < .005$ ) than before

Author	Title	Aim	Design	Sample	Outcomes	Findings
			<p>month.</p> <p>Data collecting: Pre-test and post-test 1 month after receiving the program</p>			received educational program.
Sae-Tae N Master Thesis, Prince of Songkla University, 2008	Effect of discharge planning program on self-management ability of asthmatic patients attending emergency unit in unrest area of southern Thailand	To test the effect of discharge planning program on self-management ability of asthmatic PTs attending an emergency unit in the unrest area of southern Thailand	<p>Quasi-experimental research</p> <p>Discharge planning program covering self-management in live ability of asthmatic attack</p>	<p>64 asthmatic PT who attended the emergency unit of a community hospital</p> <p>Homogeneous patients were assigned into the control group (n=30) and the experimental group (n=32)</p> <p>Systematic random</p>	A self-management ability of asthmatic PT questionnaire and 48-hr readmission record	<p>Self-management ability of the experimental group was at moderate level, higher than control group.</p> <p>Percentage of 48-hr readmission of the experimental group was lower than the control group</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
				sampling for the experimental group		
Duangkhai P Master Thesis, Burapha University, 2003	Effectiveness of self-management program in the elderly with osteoarthritis of the knee	To determine the effect of the self-management program on self-management practice, knee pain and stress in the elderly with osteoarthritis of the knee	Quasi-experimental study  The control group received regular training  The experimental group received self-management program (provide knowledge about osteoarthritis of the knee, practice necessary skills in dealing with knee pain and promotion SM practice comprising goal setting, self-monitoring, self-evaluation and self-reinforcement)	20 outpatient elderly with knee osteoarthritis in a community hospital  Simple random sampling	Self-management practice and a perceived stress interview form with numerical rating and visual analogue scale	The experimental group was higher self-management practice, lower knee pain and stress level than the control group at immediate post program and 4-week follow up.  No different of self-management practice between immediate post-programm and 4-week follow up in the experimental group.

Author	Title	Aim	Design	Sample	Outcomes	Findings
			4 weeks follow up			
Somrarnyart M Doctoral Thesis, Chiang Mai University, 2006	Effectiveness of self-management training program among Thai cancer patients with pain.	To evaluate the effect of self-management training on pain intensity, pain interference and pain control among cancer patients	Randomised controlled trial  The control group received conventional nursing care and booklets  The experiment group received a cancer pain self-management training (CPST) program Phase1 : session 1-4 Phase2 : session 5-8 and home visit (week 6,8)(1 session per week)  Individually program took time for 4 weeks of intervention and 4 weeks for follow up	72 outpatient with cancer in a university hospital  Mixed cancer patients were randomised to the control group (37) and the experiment group (35)  Power of analysis: based on sample size estimates by Polit and Beck; with significant of .05, desired power of .08 and effect size	Brief Pain Inventory Short Form (BPI-SF)  Pain control Scale (PCS)  Survey of Pain Attitudes (SOPA)  Semi-structure Interview Guide  Pain Self-Monitoring Form (daily record)  Evaluation forms of program session (after finish each session)  Reliability: internal consistency reliability was 0.81-	Average and right now pain intensity, pain interference in the intervention group was significant less, but greater pain control than the control group.  The control group trended to have drug error; both less and more than prescription, time error. The drug serum level was not enough during night time. The patients were reluctant to take analgesic and had more anxiety.  Both groups found similar side effect such as sleepiness and constipation.  CPST program has effectiveness in decreasing pain intensity, pain interferences and increasing pain control

Author	Title	Aim	Design	Sample	Outcomes	Findings
			<p>The whole study was 12 months</p> <p>Data collecting: by research assistants, week0 and week8</p>	of .47	<p>0.86</p> <p>Data analysis: descriptive analysis, Chi-square, ANCOVA</p>	
Suttharattanakun S Mater Thesis, Khon Kaen University, 2006	Factors influence self-management of type 2 diabetic patients	To study factors influencing self-management of type 2 diabetic patients	<p>Descriptive research</p> <p>Data were collected for 3 months.</p>	200 outpatients with type 2 DM who followed up at medical department in a university hospital	<p>The illness identity questionnaire; the timeline questionnaire; the consequences questionnaire; the controllability or curability questionnaire; the cause questionnaire</p> <p>Self-management behaviours questionnaire</p>	<p>Conceptual model of the study used the Common Sense model of illness representation</p> <p>PT perceived their illness as controllability or curability (belief that DM can control, the effective of DM control depend on the PT more than doctor), hereditary casual attribution, physical casual attribution, karma casual attribution, age and occupation which together predicted self-management behaviours</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
					<p>Reliability was tested by K-R 20, and Cronbach's Alpha coefficient.</p> <p>Data analysis: Pearson's product moment correlation coefficient and Stepwise Regression Analysis</p>	<p>The prolonged patients and patients who failed in controlling DM had less motivation for seek way to cure or change behaviour to control DM</p>
<p>Konyai J Master Thesis, Khon Kean University, 2007</p>	<p>Patient's perception of diabetes mellitus, foot complications and self-management of the condition in diabetic type 2 patients</p>	<p>To explore patient's perception of diabetes mellitus, foot complications and self-management of the conditions</p>	<p>Qualitative research  In-depth interview</p>	<p>20 patients with type 2 diabetes and received medical care of a community health care centre</p>	<p>The patients' perception of self-management</p>	<p>The patient's perception could be categorized into 4 stages: 1) getting the diagnosis 2) reacting to the diagnosis (negotiated feeling of believe or not believe in the diagnosis of DM), 3) checking for sure (search information about DM from different source, then compare information and own experience) 4) accepting the disease (manage their condition by</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
						changing health behaviours and taking medicine, following both medical advice and their own perception)
Sanjaithum K Master Thesis, Mahidol University, 2006	Factor influencing nutritional self- management among older adults with diabetes mellitus	To examine the factors influencing nutritional self- management among older adults with DM	Descriptive cross- sectional study  Interview following a developed questionnaire	230 older adults aged 60 and older who had DM diagnosis at least 1 year	The instrumental activities of daily Living (IADL) questionnaire  An accessibility of food information support questionnaire  A nutritional self- management questionnaire	Positive correlation between self- management behaviour and knowledge of DM.  The major source of information was health professionals (nurse, doctor, pharmacist, respectively).  Family provided information about food (but mainly by nurse and doctor)  Most patients bought food by themselves and more than half were also provided by caregivers.  Good food consumption, fair food selection but poor means

Author	Title	Aim	Design	Sample	Outcomes	Findings
						of cooking (oil, coconut milk, MSG)
Pradujkanchan a N Master Thesis, Mahidol University, 2006	Prevalence, type, severity, self- management and consequence of urinary incontinence in late adult and elderly	To explore the prevalence, type, severity, self- management strategies and consequence of urinary incontinence in late adult and elderly	Cross-sectional descriptive research	185 member of a Metropolitan Hospital Senior Citizen club  Purposive sampling	The Set-Test (screen mental status of participants)  The General Information Questionnaire  The Incontinence Questionnaire  The Self- management of Urinary Incontinence Questionnaire  The Consequence of Urinary Incontinence Questionnaire	The study based on the conceptual framework of the Revised Symptom Management Conceptual Model of Dodd and colleagues  First 5 self-management strategies were urinate before going outside/go to bed, clean genital area after each urination, allow urine to wet clothes and change clothes if feel uncomfortable, wear the clothes that are easily to remove when needing to void and get enough water intake  The finding revealed that most patients did not seek to cure their incontinence because they did not think that it had been their problem, majority of them

Author	Title	Aim	Design	Sample	Outcomes	Findings
						used supportive intervention and life style management
Duangpaeng S Doctoral Thesis, Mahidol University, 2002	Chronic dyspnoea self- management of Thai adults with COPD	To explain the process of chronic dyspnoea management and to describe the factors influencing the process of chronic dyspnoea management of Thai adults with COPD who live in a province in the eastern region of Thailand	Grounded theory; In-depth interviews, observations (families, communities, action/interaction, relationship, events, incident at home and hospital) and reviews of health records.  Study duration of 9 months	31 participants with COPD, recruited from outpatient department of tertiary hospital.	The patients' self- management  Data analysis: constant comparative method	The process to becoming an expert in chronic dyspnoea self- management was composed of 4 sequential stages (entering as a novice, developing in self- management competency, developing expertise and becoming an expert).  Self-learning (self-perception, self-awareness, self-efficacy) and self-management (cognitive process to understand the meaning of disease, monitoring, planning) were the important action or interaction strategies of this process.  2 major factors influencing the process were 1) personal factors: perception and response to illnesses which

Author	Title	Aim	Design	Sample	Outcomes	Findings
						<p>related to experience, knowledge, social support, self-efficacy, self-awareness, hope and course of illness</p> <p>2) contextual factor: remission and exacerbation period of illness, and supportive environment: physical and social environment including family, community and health service system: related to family member relationship, responsibility to each other, availability for support, beliefs or values, the family's relationship with other resources outside the family and location of the household</p>
Santayopas P Doctoral Thesis, Mahodol University, 2001	Related factors and self-management methods of urinary incontinence in	To investigate the prevalence of urinary incontinence (UI), related factors, psycho-social	Cross-sectional study  Interview and case comparison study	720 elderly females who live in a community in Bangkok	An epidemiologic model to obtain data about human biology and environment factors, life-style	Most common methods for self-management were changing their wet cloths, frequently urinating, avoid going outside and urgency toileting.

Author	Title	Aim	Design	Sample	Outcomes	Findings
	Thai female elderly	impacts and self-management methods in Thai elderly females			and the access to health systems for factors related to UI	Factor related to UI were overweight body mass index, present illness, heart disease, respiratory disease, constipation and depression
Methakanjanasak N Doctoral Thesis, Chiang Mai University, 2005	Self-management of end-stage renal disease patients receiving haemodialysis	To examine a developed model which described casual relationships among illness representations, self-efficacy, social support, self-management and the quality of life of ESRD patients receiving haemodialysis	Cross-sectional study  descriptive analysis  Structured, face-to-face, interview; 1 hr 30 min (one time)  Data analysis: Path analysis by using multiple regression analysis Descriptive statistics	110 patients who have ESRD receiving haemodialysis twice a week in the Northern region of Thailand  Sample size was calculated by SAS programme with a level of power of 0.70 which equal to 100 patients	Personal data questionnaire  Illness Representation of ESRD questionnaire  Haemodialysis Self-management self-efficacy questionnaire (HSMEFQ)  Social support questionnaire  Hemodialysis Self-management questionnaire, SF-	Conceptual framework of the study was developed by integration the theory of illness representation, self-efficacy and social support in order to predict self-management and quality of life.  The level of self-management was positively influenced by the level of social support and self-efficacy, but negatively influenced by comorbidity and identity.  Self-efficacy is the most important predictor of self-management whereas social support is the least significant

Author	Title	Aim	Design	Sample	Outcomes	Findings
					<p>36 version 2</p> <p>Interdialytic weight gain (IWG)</p> <p>Serum potassium (K+)</p> <p>Reliability: test by Cronbach's alpha coefficient at 0.87</p>	<p>predictor.</p> <p>Social support positive was related to self-management and QOL.</p> <p>Social support is the predictor of self-efficacy.</p> <p>The most significant predictor of the mental component score were identity and social support.</p>
Tudtheang S Doctoral Thesis, Mahodol University, 2004	The experience of heart disease illness : self, meaning and self-management	To explore patients' experience of heart disease illness, their defining of the meaning of illness, the alteration of self, the management of the altered self and social contexts of self-management	Qualitative research  In-depth interviews	12 patients with heart disease at a provincial hospital in the northern region of Thailand	Self-meaning and self-management	<p>Patients believed heart disease to be a life-threatening condition causing fear of death and involving severe distress and suffering and restrictions of lifestyle.</p> <p>The cracked self: feeling of uncertainty, incompetence and dependency causing the sense of losing freedom and independence</p>

Author	Title	Aim	Design	Sample	Outcomes	Findings
						<p>The crumbling self: sense of complete loss, despair about the future and regaining the former self, feel of worthless, meaningless, useless, undignified and ashamed</p> <p>2 ways to manage:            1) through stabilizing the self by controlling the illness and planning one's life consistent with its various conditions and            2) through raising hope by leaving the past, constructing a new self and changing one's goal.</p>
Buranaruangrote S Master Thesis, Mahidol University, 2005	Experience and self-management for fatigue in breast cancer patients receiving	To investigate fatigue experience, fatigue management strategies, depression and anxiety and their	Descriptive study  Participants completed questionnaires and were interviewed at baseline (day 0), telephone interview	100 outpatients with CA breast who received chemotherapy at a university hospital and a tertiary hospital	A set of 5 self-administered questionnaire : 1) demographic characteristic2) sickness and health status	Conceptual framework : the model of revised symptom management proposed by Dodd  Fatigue experience increased in accordance with the frequency of chemotherapy.

Author	Title	Aim	Design	Sample	Outcomes	Findings
	chemotherapy	relationship	day 14, were evaluated fatigue and were interview on fatigue management strategies at the next appointment	in Bangkok, Thailand	3) Fatigue Symptom Inventory (FSI) 4) Hospital and Anxiety Depression Scale (HADS) 5) fatigue management strategies  Data analysis: Descriptive statistics, Pearson's product moment correlation coefficient	Fatigue management strategies: more rest and sleep followed by exercising.  Fatigue experience was significantly positive related to depression and anxiety ( $p < .01$ ).  A balance between exercises and sufficient rests should be taken into careful consideration.
Lundberg PC and Rattanasuwan O Cancer Nursing (2007) 30, 146-155.	Experiences of fatigue and self-management of Thai Buddhist cancer patients undergoing radiation	To describe a)the subjective feelings of fatigue of Thai Buddhist cancer patient undergoing radiation therapy (RT) and identify possible gender	Descriptive study  Time : 1 week	133 outpatients with cancer who were receiving external RT, 55 men and 78 women  Simple random sampling from	The Revised Piper Fatigue Scale (Thai version)  The reliability was 0.97 by using Cronbach's Alpha coefficient	The conceptual framework based on the Piper Integrated Fatigue Model.  Beliefs regarding the main cause of fatigue (1) RT, (2) anxiety, depression and fright/fear, (3) cancer, (4) long travel to hospital and long waiting time for RT, (5)

Author	Title	Aim	Design	Sample	Outcomes	Findings
	therapy	different b) their beliefs about the main cause of fatigue c) their ways of self-management for relief of fatigue		the eligible patients visiting the outpatient RT clinic of the hospital in the last 6 months before study.	Data analysis: Descriptive statistics, T-test, qualitative content analysis	difficult to sleep and weak body, respectively.  Ways of self-management for relief fatigue - 5 categories : (1) getting moral support from family and friend (2) practicing religion, reciting prayers, doing merit and meditation (3) practicing self-care for symptomatic problem (rest, using drugs, physical exercise, drink water frequently, receiving massage) (4) accepting the situation and doing the best of one's life (5) counselling with doctor and nurse

## 2.3 Critique of the study

Parahoo's guideline was employed as a critical appraisal tool to critique all studies (Parahoo 2006). This tool was specifically designed for beginners, in order to look through and examine the processes involved in both quantitative and qualitative research. In addition, it was a step-by-step guide and provided just seven main headings which directly related to the structure of the research studies most often reported.

Table 2.3 Illustrate the key strengths and limitations of the studies critiqued

Studies	Strengths	Limitations
Buathongjan J Master Thesis, Chulalongkorn University, 2005	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Proposed frame work/model to explain the results</li> <li>• Employed data analysis measurement</li> <li>• Experimental design : experimental group and control group</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide power of test of the sample size</li> <li>• No clear discussion in relation to self-management</li> </ul>
Unchit P Master Thesis, Burapha University, 2005	<ul style="list-style-type: none"> <li>• Experimental design : experimental group and control group</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• The study report did not provide the conceptual framework for research.</li> <li>• Lack of detail of the programme</li> <li>• Limited details reported regarding data collection procedures</li> <li>• Did not provide power of test of the sample size</li> </ul>
Pisanbowornsri N Master Thesis, Burapha University, 2007	<ul style="list-style-type: none"> <li>• Reported ethical approval</li> <li>• Consent obtained from the participants</li> <li>• Qualitative approach related to the design</li> <li>• Used quantitative data and qualitative data to reach the</li> </ul>	<ul style="list-style-type: none"> <li>• The study report did not provide the conceptual framework</li> <li>• The study did not provide clear description of the process of action research.</li> <li>• Did not provide</li> </ul>

Studies	Strengths	Limitations
	<p>proposed of the study</p> <ul style="list-style-type: none"> <li>• Employed a standard questionnaire</li> <li>• Employed data analysis measurement</li> </ul>	<p>measurement tools' reliability</p> <ul style="list-style-type: none"> <li>• Did not provide the statistical analysis of the quantitative data</li> </ul>
<p>Kumpanut J Master thesis, Burapha University, 2007</p>	<ul style="list-style-type: none"> <li>• Proposed frame work/model to explain the results</li> <li>• Provided explanation of research background, aim, finding, and discussion</li> <li>• Experimental design : experimental group and control group</li> <li>• Used standard outcome measures to collect data</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide detail of the programme</li> <li>• Did not provide clear in detail of how to sampling patients into the experimental group and the control group</li> <li>• Small sample size</li> <li>• Did not provide power of test of the sample size</li> <li>• Did not provide measurement tools' reliability</li> <li>• Did not provide clear discussion about self-management practice measurement</li> </ul>
<p>Prombutr R Master Thesis, Chulalongkorn University, 2007</p>	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, research design, data collection, finding and discussion</li> <li>• Proposed frame work/model to explain the results</li> <li>• Used standard outcome measures to collect data</li> <li>• Experimental design: experimental group and control group</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide clear discussion about self-management practice measurement</li> </ul>
<p>Kangchai W Thai Journal of Nursing Research (2002) 6(3), 101-114)</p>	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Proposed frame work/model</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide what the control group received</li> <li>• Did not provide measurement tools' reliability</li> </ul>

Studies	Strengths	Limitations
	<p>to explain the results</p> <ul style="list-style-type: none"> <li>• Employed a standard questionnaire</li> <li>• Employed data analysis measurement</li> </ul>	
<p>Tookaew R Master Thesis, Burapa University, 2007</p>	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, data collection, finding, and discussion, and strength and limitations</li> <li>• Qualitative approach included to evaluate the programme</li> <li>• Experimental design : one group pre-test and post-test design</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide the detail of the programme</li> <li>• Did not provide power of test of the sample size</li> </ul>
<p>Keeratiyutawong P et al. Thai Journal of Nursing Research (2006),10(2), 85-97.</p>	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, design, data collection, and discussion</li> <li>• Proposed frame work/model to explain the results</li> <li>• Experimental design : experimental group and control group</li> <li>• Used standard outcome measures to collect data</li> <li>• Employed a standard questionnaire</li> <li>• Provided measurement tools' reliability</li> <li>• Employed data analysis measurement</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide power of test of the sample size</li> <li>• Did not clearly explain findings related to data collection</li> <li>• Did not provide statistical analysis of quantitative data</li> </ul>
<p>Kongsakul S Master Thesis, Thammasat University,</p>	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, data collection, finding</li> <li>• Proposed frame work/model</li> </ul>	<ul style="list-style-type: none"> <li>• Did not give clear discussion in relation to self-management</li> <li>• Should evaluate a longer follow-up by using HbA1C as</li> </ul>

Studies	Strengths	Limitations
2009	<p>to explain the results</p> <ul style="list-style-type: none"> <li>• Provided clear details of experimental design : experimental group and control group</li> <li>• Employed a standard questionnaire</li> <li>• Provided measurement tools' reliability</li> <li>• Employed data analysis measurement</li> </ul>	<p>an indicator</p>
Deeseang W Master Thesis, Chulalongkorn University, 2006	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Used standard outcome measures to collect data</li> <li>• Experimental design : experimental group and control group</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide the detail of the programme</li> </ul> <p>Did not provide power of test of the sample size</p> <ul style="list-style-type: none"> <li>• Did not provide the statistical analysis of the quantitative data</li> <li>• Did not provide clear discussion about self-management practice</li> </ul>
Johnjumrut C Master Thesis, Mahidol University, 2007	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Used standard outcome measures to collect data</li> <li>• Qualitative approach included to evaluate the programme</li> <li>• Provided experimental design : one group experimental design (pre-test and post-test)</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide the detail of the programme</li> <li>• Did not provide what the control group received</li> <li>• Did not provide detail how to sampling</li> <li>• Did not provide power of test of the sample size</li> <li>• Did not provide measurement tools' reliability</li> </ul>

Studies	Strengths	Limitations
Wattana C et al. Nursing and Health Sciences (2007), 9, 135-141	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, data collection, finding, discussion, and strength and limitations</li> <li>• Proposed frame work/model to explain the results</li> <li>• Used standard outcome measures to collect data</li> <li>• Employed a standard questionnaire</li> <li>• Experimental design : experimental group and control group</li> <li>• Provided discussion on self-efficacy and home visiting to perform diabetes self-management behaviours</li> </ul>	<ul style="list-style-type: none"> <li>• Long duration of intervention sessions (2 hours of education and additional small group)</li> </ul>
Tangwichitsakun S Master Thesis, Mahidol University, 2007	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Proposed frame work/model to explain the results</li> <li>• Experimental design : experimental group and control group</li> <li>• Employed the Minnesota Living with Heart Failure Questionnaire</li> <li>• Provided measurement tools' reliability</li> <li>• Employed data analysis measurement</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide power of test of the sample size</li> </ul>
Wongputtakham S Mater Thesis, Mahidol	<ul style="list-style-type: none"> <li>• Proposed frame work/model to explain the results</li> <li>• Experimental design : experimental group and</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide clear details</li> </ul>

Studies	Strengths	Limitations
University, 2007	control group	<p>of the programme</p> <ul style="list-style-type: none"> <li>• Did not provide detail how to sampling</li> <li>• Did not provide power of test of the sample size</li> <li>• Did not provide data analysis method</li> <li>• Did not provide clear discussion about self-management practice</li> </ul>
Lohasarn W Mater Thesis, Khon Kaen University, 2007	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, and finding</li> <li>• Proposed frame work/model to explain the results</li> <li>• Experimental design : experimental group and control group</li> <li>• Employed a standard questionnaire</li> <li>• Provided measurement tools' reliability</li> </ul>	<ul style="list-style-type: none"> <li>• There was no statistical method provided in the study.</li> <li>• There was no statistical comparison between groups.</li> <li>• Did not provide clear discussion about self-management practice</li> </ul>
Sae-Tae N Master Thesis, Prince of Songkla University, 2008	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide clear details of the programme</li> <li>• Did not provide power of test of the sample size</li> <li>• Did not provide measurement tools' reliability</li> <li>• Did not provide data analysis method</li> <li>• Did not provide clear discussion about self-management practice</li> </ul>
Duangklai P Master Thesis,	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim,</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework</li> </ul>

Studies	Strengths	Limitations
Burapha University, 2003	<p>ethics approval, data collection, finding, and discussion</p> <ul style="list-style-type: none"> <li>• Employed a standard questionnaire</li> </ul>	<p>for research.</p> <ul style="list-style-type: none"> <li>• Small sample size</li> <li>• Did not provide measurement tools' reliability</li> <li>• Did not provide data analysis method</li> <li>• Did not provide clear discussion about self-management practice</li> </ul>
Somrarnyart M Doctoral Thesis, Chiang Mai University, 2006	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, design, data collection, finding, discussion, and strength and limitations</li> <li>• Reported ethical approval</li> <li>• Consent obtained from the participants</li> <li>• Proposed frame work/model to explain the results</li> <li>• Qualitative approach included to evaluate the programme</li> <li>• Experimental design : experimental group and control group</li> <li>• Employed a standard questionnaire</li> <li>• Provided measurement tools' reliability</li> <li>• Employed data analysis measurement</li> </ul>	<ul style="list-style-type: none"> <li>• Heterogeneous nature of sample (mixed cancers)</li> </ul>
Suttharattanakun S Mater Thesis, Khon Kaen University, 2006	<ul style="list-style-type: none"> <li>• Provided explanation of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Proposed frame work/model to explain the results</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide clear details of research design</li> <li>• Did not provide power of test of the sample size</li> <li>• Needed some clarification about DM control and encouragement from health</li> </ul>

Studies	Strengths	Limitations
	<ul style="list-style-type: none"> <li>• Employed a standard questionnaire</li> <li>• Provided specific finding on beliefs of controllability or curability</li> </ul>	<ul style="list-style-type: none"> <li>care professionals.</li> </ul>
Konyai J Master Thesis, Khon Kean University, 2007	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide clear details of research design</li> <li>• Did not provide qualitative data analysis method</li> <li>• Needed study for DM especially those who have less access to information resource</li> </ul>
Sanjaithum K Master Thesis, Mahidol University, 2006	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide power of test of the sample size</li> <li>• Did not provide measurement tools' reliability</li> <li>• Did not provide data analysis method</li> </ul>
Pradujkanjana N Master Thesis, Mahidol University, 2006	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Proposed frame work/model to explain the results</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide power of test of the sample size</li> <li>• Did not provide measurement tools' reliability</li> <li>• Specific age group and setting which limited generalisation</li> <li>• The purposive selection could not reflect all older adults and elderly</li> </ul>
Duangpaeng S Doctoral Thesis,	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, data</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> </ul>

Studies	Strengths	Limitations
Mahidol University, 2002	<p>collection, finding, discussion, and strength and limitations</p> <ul style="list-style-type: none"> <li>• Qualitative approach included to evaluate the programme</li> <li>• Qualitative research: grounded theory</li> <li>• Provided analysis method</li> <li>• Emphasised on competence and confidence in self-management in order to be an expert in chronic dyspnoea self-management</li> </ul>	<ul style="list-style-type: none"> <li>• Should conduct study in other areas or different socio-economic status and educated group to increase transferability of the finding</li> <li>• May need quantitative study to test the relationship among concepts</li> <li>• May need study to test the nursing intervention related to this process of becoming an expert</li> </ul>
Santayopas P Doctoral Thesis, Mahidol University, 2001	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Used standard outcome measures to collect data</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework for research.</li> <li>• Did not provide clear details of research design</li> <li>• Did not provide data analysis method</li> <li>• Did not provide power of test of the sample size</li> </ul>
Methakanjanasak N Doctoral Thesis, Chiang Mai University, 2005	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, data collection, finding, discussion, and strength and limitations</li> <li>• Reported ethical approval</li> <li>• Consent obtained from the participants</li> <li>• Proposed framework/model to explain the results</li> <li>• Used standard outcome measures to collect data</li> <li>• Employed a standard questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• Power of test of the sample size seemed low, need re-test with larger sample and in other setting</li> </ul>
Tudtheang S Doctoral	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim,</li> </ul>	<ul style="list-style-type: none"> <li>• The study did not provide the conceptual framework</li> </ul>

Studies	Strengths	Limitations
Thesis, Mahodol University, 2004	<p>ethics approval, data collection, finding, discussion, and strength and limitations</p> <ul style="list-style-type: none"> <li>• Used standard outcome measures to collect data</li> <li>• Employed a standard questionnaire</li> <li>• The study showed the power in the context of the hospital and family affected self-management</li> </ul>	<p>for research.</p> <ul style="list-style-type: none"> <li>• Did not provide clear details of research method</li> <li>• The study did not provide data analysis method.</li> </ul>
Buranaruangrote S Master Thesis, Mahidol University, 2005	<ul style="list-style-type: none"> <li>• Provided explanations of research background, aim, ethics approval, data collection, finding, and discussion</li> <li>• Proposed frame work/model to explain the results</li> <li>• Employed a standard questionnaire</li> <li>• Employed data analysis measurement</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide clear details of research design</li> <li>• The research did not provide the participants' opinions /attitudes/perceptions about self-management in their own views.</li> <li>• Did not discuss on impact or relation to self-management as mention in the objective</li> </ul>
Lundberg PC and Rattanasuwan O Cancer Nursing (2007) 30, 146-155.	<ul style="list-style-type: none"> <li>• Provided clear explanations of research background, aim, ethics approval, data collection, finding, discussion, and strength and limitations</li> <li>• Consent obtained from the participants</li> <li>• Proposed frame work/model to explain the results</li> <li>• Employed a standard questionnaire</li> <li>• Provided measurement tools' reliability</li> <li>• Employed data analysis measurement</li> <li>• Emphasised on family as play</li> </ul>	<ul style="list-style-type: none"> <li>• Did not provide clear details of research design</li> <li>• Small sample size with heterogeneous of samples</li> <li>• Did not provide power of test of the sample size</li> </ul>

Studies	Strengths	Limitations
	the central role in providing emotional, financial and material support	

## 2.4 Analysis and synthesis of the literature

### 2.4.1 Content component

It was found that most research papers (18 papers) were conducted to test the effectiveness of self-management in various kinds of chronic disease. The self-management programmes involved the education and training of patients, including home visiting, in order to review the self-management practices and to provide discussion about the problems and counselling for the patients (Buathongjan 2005; Unchit 2005; Kumpanut 2007; Prombutr 2007; Lohasarn 2007; Sae-Tae 2008; Tookaew 2007; Keeratiyutawong 2005; Kongsakul 2009; Deeseang 2006; Johnjumrut 2007; Chodchoi et al. 2007; Muangmaitong 2008; Duangklay 2003; Tangwichitsakun 2007; Wattana et al. (2007); Wongputtakham 2007; Somrarnyart 2006).

Wattana et al. (2007) reported that a self-management programme was effective for Thai diabetic patients with the patients randomised to intervention showing greater glycaemic control. Tookeaw (2007) investigated the effectiveness of a self-management promotion programme for type 2 diabetic patients. The findings illustrated that better self-management skills in the experimental group were shown but the HbA1C of both groups was no different. This uncertain result may need further investigation relating to particular factors, as well as a longer term evaluation.

There are two studies focusing on problems related to cancer. There are cross-sectional studies by Buranaraungrote (2006), involving 100 patients with breast cancer undergoing chemotherapy, and by Lundberg and Rattanasuwan (2007), researching 133 patients with various types of cancer undergoing radiation therapy. Both descriptive studies demonstrated that a variety of self-management strategies used by those patients, such as practicing religion, doing meditation, rest and exercise, was effective in relieving fatigue related to treatment. However, the effectiveness of each strategy cannot apply to every patient, because of the difference of the severity of their problem, the patients' health status and their

abilities. There is, therefore, a need for more studies with larger sample sizes and in a particular population

There is only one study investigating the effectiveness of a self-management programme on pain control with various kinds of cancer patients (Somrarnyart 2006).

#### **2.4.2 Methodology component**

The majority of research designs (16 papers) are quasi-experimental study. All of the literature illustrated that the self-management programmes developed self-management practice in relation to symptoms or diseases, enhanced competency scores of self-management, improved health status, and provided a greater quality of life.

A quasi-experimental study in chronic obstructive pulmonary disease (COPD) by Kumpanut (2007) showed that patients on a self-management programme that included education and training self-management skills such as goal setting, self-monitoring, self-reinforcement and self-evaluation, resulted in improved pulmonary function tests and lower dyspnea and anxiety levels than those in a control group. However, the results may need further study for a long-term period and with a larger sample size to validate the effectiveness of this programme.

Nine descriptive cross-sectional researches were conducted to explore the self-management strategies, factors affecting self-management behaviours and to examine relationships among self-efficacy, social support and self-management (Konyai 2007; Suttharattanakun 2006; Sanjaithum 2006; Pradujkanchana 2006; Santayopas 2001; Methakanjanasak 2005; Tudtheang 2010; Buranaruangrote 2006; Lundberg and Rattanasuwan 2007).

A descriptive study of self-management was established in patients with end stage renal disease receiving haemodialysis (Methakanjanasak 2005). The findings showed that self-management was correlated with improving health status. However, in patients who have poor health status, they could not perform self-management. For this group of patients, therefore, social support provided by family members and health care providers may be an important factor to improve the patients' self-management and their health status. This can demonstrate that to improve the patients' self-management ability, researchers should consider the

patient at an individual level, together with the support provided by family and health care providers.

There was a study conducted by using action research, aimed at developing a model for prompting competency in chronic dyspnoea self-management for patients with COPD (Pisanbowornsri 2007). The model emphasised building relationships and coordinating between patient, family and health care team. Moreover, enhancing confidence with support from family, including emotional support, was also added in the model.

A grounded theory was applied in Thai adults with COPD by Duangpang (2005). The study aimed to explain the process of chronic dyspnoea management and describe the factors influencing the process. The process generated from the study was composed of entering as a novice, developing in self-management competency, developing expertise and becoming an expert. Two of the important characteristics of becoming an expert were seen to be competence and confidence in self-management. In addition, external factors such as a supportive physical, social and emotional environment were major factors influencing the process.

### **2.4.3 Discussion by the key literature**

In Thailand, there is only one randomised controlled trial (RCT) study investigating the effectiveness of a self-management programme on pain control with various kinds of cancer patients (Somrarnyart 2006). The study was based on a theoretical framework that is integrated between self-control and self-regulation. Self-control refers to an ability to face and control the event about which the programme intends to build a belief that the patients have the ability to control pain. Self-regulation is a process for the attainment and maintenance of personal goals, in which the programme teaches the patients how to reach and manage those goals. As a result, a cancer pain self-management training (CPST) programme was developed by the researcher. The programme consisted of five key educational training processes, including self-monitoring, self-evaluation, goal setting and self-contract, decision making and action, as well as self-reinforcement.

An RCT design (four weeks of intervention and four weeks of follow up with home visits and telephone counselling) was applied in heterogeneous (mixed cancer diagnosis) 35 cancer patients and 37 controls. The purposive sampling was used to recruit participants from the out-patients department of the pain clinic of a tertiary university hospital. In addition, the inclusion criteria were limited to the patients

who lived in a location not more than 2 hour's drive from the clinic and their family caregivers were willing to support the patients during the training sessions and also at home.

The four-week intervention through the Cancer Pain Self-management Training (CPST) programme includes 90 minutes education and practice weekly, with booklets covering the topic of cancer pain and introduction to self-management, cancer pain self-management specifically to medication management, cancer pain self-management specifically to non-pharmacological intervention, and cancer pain self-management specifically to foot massage and reflexology. The audiocassette tape on muscle relaxation and folk music was provided in the intervention group to use at home. This programme also provided counselling and support, via home visiting and telephone contact, during the next four weeks. The data collection included the demographic data, Brief Pain Inventory-short form (BPI-SF), and Pain Control Scale (PCS). These data were collected in the first approach before attending the training, and collected again after completing the programme. An interview was conducted before starting the programme, about methods that participants normally used to manage their pain, and after completion of the programme, to explore how participants managed their pain whilst engaging in the study. During the training, all participants in the investigated group were asked to complete the Pain Self-monitoring form weekly. An evaluation form, for both participants and investigator, was completed in the last session of the training.

The findings demonstrated that the programme was effective in decreasing the pain intensity, decreasing pain interferences and increasing pain control. The comparison of mean scores of the pain intensity, pain interference, and pain control between the control group and the intervention group was done by using ANCOVA. There were significant differences in all aspects of outcomes between the control group and the investigation group. The programme also increased the understanding of the patients regarding their own condition, their sense of control and a feeling of confidence.

There are some other interesting findings. There was no significant difference between the control and intervention group in taking the daily pain medication as prescribed. In addition, in the use of non-pharmacological methods, there were some similarities in the use of distraction methods, breathing relaxation and herbs, but differences in quality between the control group and the intervention group.

Although this study demonstrated the benefits of the self-management programme in various aspects, it still contains some issues that need to be further considered.

Firstly, such a programme is likely to be beneficial in the limited group. It is likely that the terminally ill patients with limited social support and resources can join the self-management programme, due to the fact that all participants taking part in the programme were out-patients with full support from their families in all issues. It means that some difficulties, for example the patients with complicated conditions such as severe pain, patients who have admission in the hospital, as well as patients with financial problems, result in such patients being excluded from, or failing to complete, the training programme.

The CPST programme was quite time consuming, the 8 weeks training programme needed force of energy for both the trainer and also the trainees to continue and complete the programme. It might not be a suitable model to provide in the clinical setting, due to the limited time of the patients. In addition, the participant or participants who had an advanced stage of disease might not be able to concentrate during a long period of time due to their pain severity and other symptoms, resulting in a 14% drop-out rate from this study. Therefore, the programme might not suit patients with complicated conditions and also in some health care services that lack personnel and facilities.

Secondly, the theoretical framework employed to develop this programme may not be suitable in the Thai context. The programme was developed based on previous literatures, which were mostly reporting investigations in the Western context. It is not grounded in the particular patients' beliefs and Thai culture, which are both important factors influencing Thai behaviour. The context of Thai belief affects cancer pain appraisal and the use of pain coping strategies. The programme focused on improving the patients' control ability by building a sense of confidence. This may not be beneficial to patients with some limitations and patients with strong spiritual beliefs that may have their own ways to manage their pain. In addition, the context of family is a vital part of caring in the Thai culture and will be a mainstay supporter for Thai patients. In this study, the programme focuses on the patients, while the family members do not participate in the programme. Therefore, the programme may not apply to some complicated families, in which there may exist unique self-management circumstances. It might be better to examine self-management of cancer pain from either the patient's or their family's perspective.

This may generate a greater understanding of the patients' self-management experience and help to improve pain management in the family context.

Thirdly, according to the programme, it was found that the nurse (the researcher) acted in an active role to encourage the patients in all aspects, including giving knowledge, training skills, and motivating the patients to do self-management activities following the programme. The findings appeared to illustrate the improvement of self-management behaviour, but the patients seemed to sustain a passive role in managing their own problems. The possible explanation would be the particular context of care and Thai culture, which leads people to communicate or interact with others, especially those with higher status. This issue needs to be of concern when considering reasons or perspectives of the patients' behaviour in relation to self-management; the finding may have identified important barriers to the generation of self-management skills in Thai patients. To clarify the background of behaviours, an appropriate study is needed that would enable a deeper exploration, which the present study could not provide.

Fourthly, there was no significant difference in the use of medication between 2 groups. However, some similarities in the use of non-pharmacological strategies such as herbs, distraction, and breathing relaxation technique in both groups, were noted, based on data emerging from the interviews. It could be seen that all patients had their own management of pain in some level but the effectiveness might be different, based on how to practice those strategies. It is interesting to explore how people from different backgrounds manage their own problems in the real life context, including the problem of pain due to cancer. It might be of benefit to understand the situation of patients' self-management behaviour, in order to find the most appropriate way to optimise that behaviour, such as an education self-management strategy and a training self-management programme for people who have particular problems, to improve their own ability to self-manage.

Finally, implementing this programme in other situations may be a challenge because this programme was executed in a university-based hospital which was full of professional and facilities' support. This generates a question of the effectiveness of the programme, when considering other local/small hospitals that lack such fully equipped facilities. Studying the context of each patient's setting, before applying any self-management programme, may be helpful to optimise the effectiveness of the self-management programme in practice.



# Chapter III

## Research Methodology

### 3.1 Introduction

This chapter provides a coherent research methodology of this thesis which complies with the research questions and objectives in chapter 3. This chapter begins with a discussion of the justification for selecting a qualitative case study approach. The boundedness of the case, exploration of sampling, access, recruitment process, as well as data collection and analysis will then be considered. The discussion of the rigour of the study will be presented at the end of the chapter.

### 3.2 Justification for adopting a qualitative case study approach

According to the literature review in the previous chapter, the effectiveness of self-management programme in various kinds of chronic disease worldwide, including Thailand, was examined; for example increasing knowledge of care, improving health status and enhancing self-management competency. Most studies employed a quantitative research model including cross-sectional design, quasi-experimental design, and randomised controlled trial research. One noticeable gap in the researchers' areas of interest was people with cancer pain.

In Thailand, the number of studies focusing on self-management in relation to pain control in patients with cancer was limited to just one study found in the Thai databases. Although the self-management programme was significantly effective for the patients, such evidence seemed not enough and it was found that there were some issues emerging in the findings that needed to be considered. An 8-week programme for individuals seemed inappropriate when applying it in other health care settings, due to unequal facilities and man power in other hospitals, especially in rural areas. Nurses who conducted the programme always took active roles, whereas the patients seemed to prefer to be

passive. The findings showed some degree of improvement in communication between patients and nurses but this seemed not to reach a competency level needed for effective self-management skills. In addition, patients who participated in the programme still prefer to use their own strategies additionally, such as alternative or local treatment, to relieve pain, regardless of whether they are in the training. This finding may suggest that there were individual strategies that people used to take care of themselves. The previous study was unable to identify with any degree of certainty what reasons and beliefs were underpinning those behaviours. A constructive qualitative research model may be an appropriate approach to fill these gaps.

To construct the reality or knowledge about beliefs and reasons underpinning the Thai cancer patients' behaviour requires a flexible, open approach to these dynamic and unique experiences. In addition, human behaviour cannot be understood without reference to the meaning, context and purpose of those activities (Guba & Lincoln 1994). The constructivist paradigm meets these criteria and firmly focuses on the examination of subjectivity and value of individual experience. In addition, it is found that a study focusing on self-management for pain control in patients with cancer has never been conducted by using a qualitative approach. To fill the gaps of interest, the case study, a constructivist approach, was selected.

The selection of a qualitative case study research model in the current study stemmed from the research questions that demand close examination of pain experience in patients with cervical cancer, in real life settings. The ultimate research aim was to conceptualise self-management in patients who experience cancer pain. The qualitative case study model was characterised by the researcher spending extended time on sites, personally in contact with activities and operations of the case, reflecting and revising the descriptions of what was observed and continuously interpreting the meaning of what was going on (VanWynsberghe & Khan 2007). The qualitative approach allows the discovery of meaning and purpose of human behaviours that exist in a particular context (Guba & Lincoln 1994). The reality of patients' cancer pain experiences was studied in a contemporary situation, addressing both *how* and *why* questions in order to obtain a rich insight into that self-management experience. The real life phenomenon of pain experience, perspective and behaviour could not be explained separately from its context. Therefore, the use of a qualitative case study paradigm, as the research methodology, was suitable for this study.

### 3.3 Qualitative case study methodology

Given that the literature review stressed the importance of taking account of the social dynamics and context in which pain is experienced and managed, the case study was selected as the methodology for this study. Stake (1995) claims that case study is well suited to a constructive paradigm as it provides a powerful story that illustrates the experience of the phenomenon under examination by enriching and potentially transforming a reader's understanding of a phenomenon by extending their experience (VanWynsberghe & Khan 2007).

A case study can be operationally defined as the empirical study of human activity in a natural context. It is useful in the study of human affairs and resembles the understanding of the naturalistic world, through personal experiences (Stake 2000). To study human behaviour in a natural setting, a unique situation involving complex phenomenon, the researcher cannot control or manipulate the behaviour of participants involved in the study. The behaviour unfolds naturally without intervention from the researcher.

Yin (2000, p18) states "a case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life contexts; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used". Since the phenomenon cannot be separated from the context of the case, the case study draws on many real life variables and multiple sources of evidence in order to enable an in-depth understanding of the issue being investigated.

Case study can embrace both qualitative and quantitative approaches to information gathering (Stake 2006; Yin 2009). Qualitative case study research has a tendency to look at process, dynamics and development as a compound phenomenon, whereas quantitative research focuses on such variables at a certain point in time. Quantitative study examines variables detached from their context, resulting in examining the case in specific aspects, without considering its whole function (Verschuren 2003). However, researchers can use both methods in a case study, whenever appropriate (Yin 2009).

#### 3.3.1 Boundedness of the case

One of the important features of case study is that it is characterised by a specific temporal and spatial boundary (VanWynsberghe & Khan 2007). As Denzin and Lincoln (2005) explain time and space create a 'bounded system' for investigation. Attending to place and time brings context to the structures and

relationships that are of interest (VanWynsberghe & Khan 2007). The boundaries indicate what will and will not be studied in the scope of the research project and also indicate the breadth and depth of the study (Merriam 1998). The boundary also defines the 'naturalistic setting' within which the research examines whatever is under scrutiny, in its own habitat. It is therefore important to define the boundaries of the case in order to construct a detailed, holistic understanding of the case (VanWynsberghe & Khan 2007).

In case study, the case may be a unit, entity, or phenomenon with defined boundaries that the researcher can demarcate (Merriam 1998).

The 'bounded system' of this case study was defined as the system of pain management experienced by Thai women with cervical cancer. Thus, while the study examined pain and pain management (medical and self-management) it was not concerned with other symptoms, such as the psychological consequences of diagnosis.

The boundary of this case study, in order to investigate pain management and optimal understanding of self-management for pain control of the patient, consists of the perspectives of patient's pain management, family caregivers' management of pain and health care providers' management of pain.

The specific issues around the pain management system which were explored were:

1. Meaning and belief about cervical cancer pain which might influence pain experience, pain management, and self-management capabilities.
2. Meaning and belief about self-management in controlling cancer pain, strategic-related cancer pain management, as well as the characteristic of self-management in controlling cancer pain.
3. Social support, including family caregiver and health care provider, which may be an important contributing factor in developing the capability of self-management in controlling cancer pain, as well as increasing the effectiveness of pain management in patients with cervical cancer.

The setting boundary examined was hospital and home. This boundary provided different aspects of pain experience from various contexts. The hospital setting was one of cancer centres in Thailand. This specific service hospital was selected because it was the newest cancer centre under the control of the National Cancer Institute (NCI). This hospital had no pain specialist and pain centre service for dealing directly with the pain problems of cancer patients. This cancer centre context provided a unique situation for pain management and self-management development. Home settings can reveal the particular context details from the patients' homes, in order to examine pain management

undertaken by patients and their families in their homes. It was important to study the real situation of pain management from these two different contexts to gain knowledge and understanding of pain management in a natural situation. The boundary of time was restricted by the time set aside for data collection: observations, interviews and documents over a period of six months. The sources of data were six patients and for each patient a designated family caregiver and a health care provider.

To summarise, the boundedness of this case is shown in figure 1 as follows:

Case Study :  
Self-management for pain control in Thai women who have cervical cancer

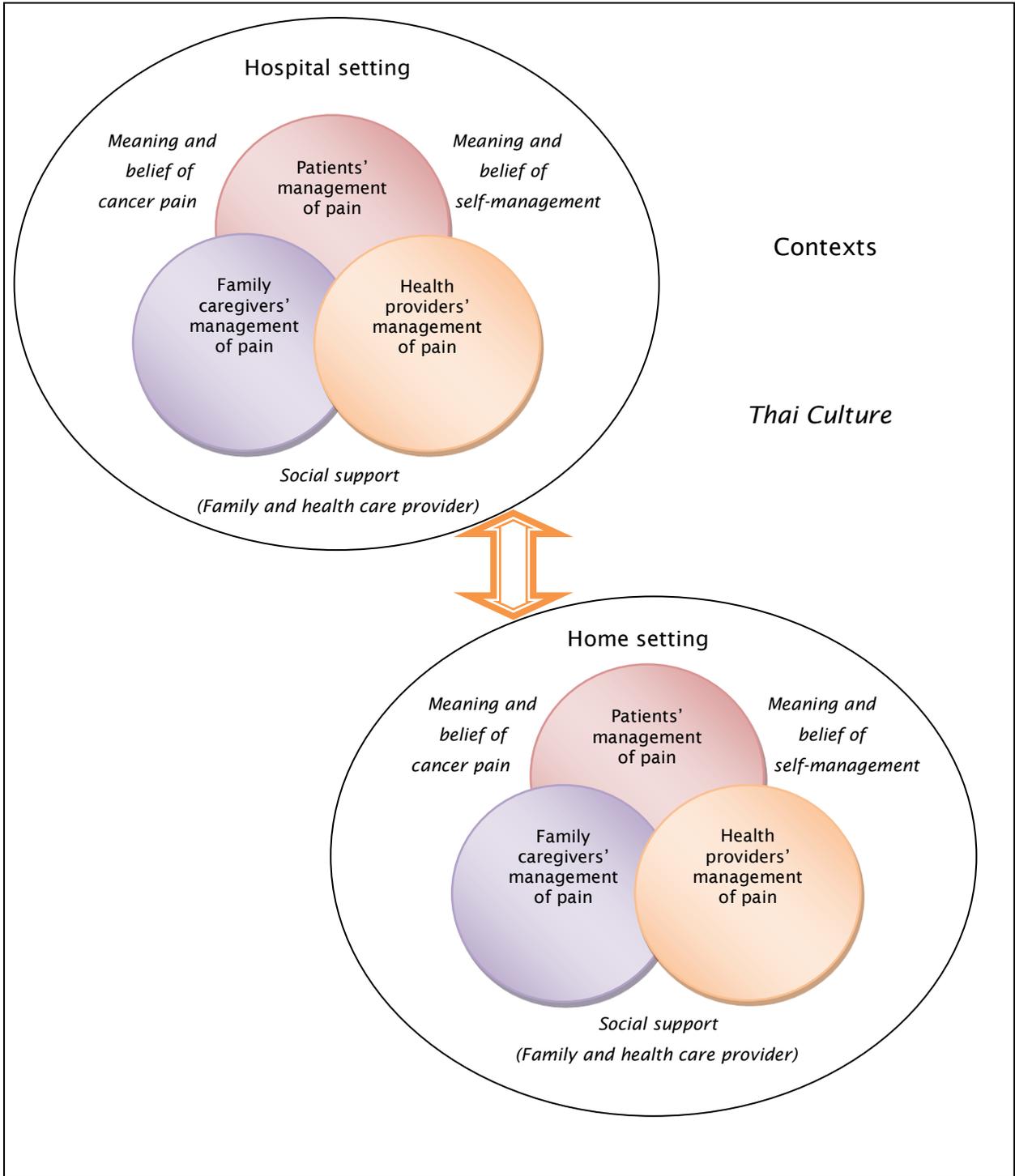


Figure 3.1 The boundedness of the case

### 3.3.4 Case study design

The design of case study research can be differentiated by the way in which it is constructed, to focus either on a single case or multiple cases. These designs can be further divided, based on the purpose of analysis, into holistic design (single unit of analysis) and embedded design (multiple units of analysis) (Yin 2009). The holistic design examines only the global view of interest, whereas the embedded design aims to discover a set of subunits and later describe units of analysis as a whole (Yin 2009).

A single embedded case study design was selected for this research because of its capabilities in representing a unique case of cancer pain experience in a particular circumstance. Furthermore, such a design can establish a holistic picture, as well as revealing in-depth understanding of the whole unit of analysis (Yin 2009).

The 'whole unit of analysis' of the current study refers to cancer pain experience and its self-management in Thai patients. The main interest in this research was to understand pain experience, including cognitive and behaviour related pain and pain management, and also to understand self-management in controlling pain in the particular case of women with cervical cancer. In addition, family caregivers and health care providers were also important factors in the health care system, as supporting facilitators who provided effective self-management in controlling pain in this group of patients.

The structure is conducted from six embedded cases. Each case consisted of a woman with pain as a consequence of cervical cancer, the key family caregiver who took responsibility for co-managing that person's pain and the health care provider. Each embedded case described the pain experience, pain management and self-management in detail. Then analysis across all cases, to address the research questions, would be undertaken in order to understand the characteristics of self-management for cancer pain control in the Thai context.

Data gathering over six months by observations and interviews, on both past and present pain experience, enabled a description of cancer pain experience and its management of both an individual participant and also the whole case.

Each embedded case was initially identified in the hospital so that the person's current pain experience could be understood and so that it was considered in relation to the interactions between people involved with pain management. Data about current pain experience, pain management and

cooperation between patients, family caregiver and health care provider during the period of admission, was collected by various means including observation, interview and documentation. Data relating to pain experience and pain management in the past and current contexts was gathered by asking the people involved to clarify their perspectives and purpose underpinning their behaviour in relation to cancer pain and its management.

Then the case study setting moved to the patient's home. This research design provided information about pain experience and management from the perspectives of both patient and family. This design also provided information about the interaction among family members, when dealing with the issue of pain management. The research design enabled an understanding of the whole circumstance of pain management in the real life context.

### **3.3.5 Participants and sample size**

Many constructivist qualitative researchers employ theoretical or purposive sampling models (Denzin & Lincoln 2005). An intensive and in-depth focus on the specific unit of analysis will result in a pragmatic exploration of issues involving a small number of individuals (VanWynsberghe & Khan 2007). The literature suggests that a sample is of an adequate size when it can support the desired analysis (Patton 2002; Denzin & Lincoln 1994). To reach the pragmatic criteria that fit in the period of study between March and August 2011, six patients with an identified family caregiver, and seven health care providers who had responsibility for taking care of the patients, were recruited to take part in the study. Recruiting a small number of research participants facilitated an in-depth inquiry designed to yield an understanding of the reality of home based pain management of six females with cervical cancer.

### **3.3.6 Ethical approval process and gaining access**

The research proposal was approved by the peer review and the research governance process of the university. Then the proposal was presented for approval from the ethics committee of the National Cancer Institute (NCI), Thailand. Once the process was completed, a request for permission from the hospital administrative committee, to study in the hospital, was submitted.

Once the research was approved by the hospital committee for the researcher to conduct the case study in the hospital, discussion with a potential nurse of the hospital in order to ask her to be a gatekeeper for this research, and to find the most appropriate way to promote my research project to all the staff,

was arranged. A plan for setting a formal meeting to introduce the project in the ward was provided, aiming to promote the research project and to begin forming a relationship with the staff. The target in this meeting was those physicians and nurses who would be most affected by the study. An 'information sheet for the health care provider' was also distributed in the meeting. The meeting provided an open discussion between the researcher and all the staff, to clarify any concerns about the proposed research project and to find solutions to any difficulties, in order to limit or decrease those difficulties in practice as much as possible. Once mutual agreement was established, the researcher began conducting the project.

### **3.3.7 Recruitment and identification of the participants**

The research participants would be selected, based on their ability to provide relevant data related to the research aims of obtaining information on cancer pain experience and its management

#### **3.3.7.1 Identification of patients**

In the recruitment process, patients who could participate in the research were identified, based on the criteria discussed with the ward nurses. This identification process was conducted during the first period of observation. The researcher initially approached the potential participants under the approval of the consultant. There was a mutual agreement that the researcher would have to take full responsibility for initially approaching the potential participant. The criteria for recruitment are listed below.

#### ***Inclusion criteria***

1. Patients with diagnosis of cervical cancer
2. Patients who are admitted in the hospital
3. Patients experiencing moderate to severe pain requiring analgesia
4. All participants are at least 18 years of age
5. All participants are able to communicate in Thai

#### ***Exclusion criteria***

1. Patients identified by their physician as unsuitable for the study
2. Patients who have had major surgery within the last two weeks
3. Patients who have serious physical or psychological problems
4. Patients who are unlikely to be able to be involved throughout the study

### **3.3.7.2 Identification of the family caregiver**

Each research participant was asked to indicate her key caregiver. The caregiver could be the spouse, parent, child or someone who the patient felt would provide the most care for her when she was in pain.

### **3.3.7.3 Identification of health care provider**

Health care providers, who provided the most care for the patients, were identified to be participants by the researcher based on an opinion from the ward charge nurse. A criterion of caring the most for the patients involved with pain management was the key to selecting health professionals to be research participants.

### **3.3.8 Consent process**

Prior to commencing the research, seeking written consent for general observation needed, for ethical reasons, to be obtained from all the health care staff who normally worked in the wards. Some of them expressed that they felt uncomfortable to sign the consent form for observation. This issue was discussed with the gatekeeper and the hospital committee and it was agreed that the researcher could conduct observation under the approval given by the ethics committee and the hospital committee. However, verbal consent from the health care staff had still been sought and they were informed that the opportunity to withdraw from the project was available to them. To obtain permission to interview the identified health care providers, a full explanation of the purpose of this interview was given to them and a written consent was obtained from them (see Appendix II).

The patients were individually informed about the project and were invited to participate. They received an information sheet that described the aims and methods of the study (see Appendix I). They were informed of the way the researcher would collect data about their experience of cancer pain and its management by observation (in the ward and at home) and about the interview process. They were offered further opportunities to ask questions or seek clarification on any matter related to the study. They were advised that they could refuse participation if they so wished; they might withdraw from the study at any time without any negative impact on receiving health care service. All patients were given at least 48 hours to consider their decision to take part in this study. When the patients agreed to take part, a written consent was obtained

by the researcher for observations, interviews, audio-recording, note taking and accessing their medical records (see Appendix II).

A family caregiver who provided the most care for the patient, identified by the patient, was asked to be a participant. An information sheet for the family caregiver was distributed (see Appendix I) and the consent form was processed: a similar procedure to that experienced by the patient.

### **3.3.9 Data collection methods**

Case study research usually requires multiple sources of evidence to ensure systematic data collection (Yin 2009). It is necessary to study the case in its real-life context, as it is important to overview the broad range of factors relating to human behaviour and to capture the complexity of the interaction between people resulting in an understanding of details of the case study in particular (Simons 1996). Data, not only relating to the person's present state, but also to past experiences and the situational context, in other words *relevant to the topic of research*, are collected (Polit 2008, p235). Data to describe the behaviour related to pain in patients who have cervical cancer, in the Thai context, would be gathered from multiple sources, but particularly patients, family caregivers and health care providers.

Methods commonly used to collect data in case studies were interviewing and observing (Simons 1996). These methods suit qualitative case study research because of their tendency to look at the dynamics of behaviour in the compound phenomenon. The data collection method to facilitate a comprehensive understanding of the current research was carefully designed, based on the purpose of the study and the present research paradigm. This current case study aims to describe the behaviour related to pain in Thai patients who have cervical cancer. This aim will be achieved by the use of various information gathering methods such as observation and interviewing. These various approaches to information acquisition can provide an in-depth understanding of the complexity of the case, with which to address the research purpose.

#### **3.3.9.1 Participant observation**

Participant observation generates in-depth information about issues of potential interest in a natural setting (Holloway 1996). A participant observer, over a period of time, can gain a comprehensive 'picture' of the study site. Participant observation can develop a 'sense of the setting' as a result of creating appropriate meaning and insight in a particular situation and context (Simons

2009). Observation may take time and also be difficult in making sense of reality (Simons 2009) but it has the power to elicit the nuances of incidents and relationships in the 'live experience' of people in particular situations. This researcher intends to apply this method to reach a comprehensive understanding of the pain experiences of women with cervical cancer.

In case study research, it was recognised (Simons 2009) that observation seems to be a highly subjective data source. In addition, Merriam (1998) contended that the relationship of the researcher with the setting will change as the research is undertaken. These concerns were addressed carefully in the observation process and also in the analysis process.

### ***Forming a researcher's role***

The researcher's role is an important factor determining successful access into the research field. It is important for the observer to establish an excellent rapport and trust with those being observed (Polit 2008) in order to gain access into the setting and to enable the researcher to be seen as credible to, and accepted by, the research participants. To form the role of a health oriented researcher, I wore the health care uniform of a nurse instructor, similar to the health care uniform of the hospital, which was familiar to both patients and hospital staff. I indicated my position as a researcher by a name tag. This role play could create the impression of familiarity and gain credibility from patients and hospital staff.

The good relationship between me and the hospital's staff had been established and continued since I had previously supervised students in the ward. However, once I took on the role of researcher the situation appeared to alter: health care staff became worried due to thinking that they were being assessed by me. Patients and family caregivers also wondered about my position and role in the ward. However, this feeling was mitigated as a result of developing an excellent rapport with the case study participants.

I spent five full days (0800-1600) in the first month in the ward in order to familiarise all parties concerned with my presence there. I tried to join various activities in the ward, such as providing care for the patients, having lunch with the nurses and making conversation with the staff, patients and caregivers, in an attempt to generate a comfortable feeling about my ward-based presence. One month later, I felt that a more relaxed atmosphere had been established. Only then was the observation phase commenced.

### ***Forming the observer's role***

The role of the observer is important when the goal (of research) is to gain information on human behaviour, based on excellent rapport and trust within the social relationship context (Polit 2008). There are various kinds of researcher-observer's role; complete participant, participant as observer, observer as participant and complete observer; such classifications depending upon the participatory level of the observer (Holloway 1996).

In this study I adopted the role of 'observer as participant' to reach the valuable data. Although the basis of this role is that of an observer who is only marginally involved in the situation and does not directly participate as part of the work force, such a role provides the possibility for the researcher to ask questions and be accepted as both colleague and researcher (Holloway 1996). This role of 'observer as participant' provided me with the opportunity to be accepted as a nurse-researcher, in the hospital ward setting, in order to develop the researcher-participant relationship (Holloway 1996). In addition, this role allowed me to look freely around the study setting with permission to generate the optimal position to obtain the desired information. During undertaking this role, I did not take on nursing activities, which allowed me more freedom to move around the study setting and which enhanced the opportunities for data collection. I had participated with, and had undertaken general help for, the patients and nurses in the ward based on the initial negotiation about my position in the ward. This seemed an excellent means to approach people in the ward, which resulted in a rapport with patients and staffs being developed sooner than I expected.

### ***Stages of observation***

Observation in fieldwork is typically divided into three levels. The first level is 'descriptive observation', its purpose tends to be broad and it is used to help observers try to figure out what is going on, as when looking at people's patterns of behaviour. Then 'focused observation', where the observer will carefully observe interesting events and interactions relative to what has been learned from the descriptive observation. Finally, 'selective observation' is the most highly systematic focus and is undertaken to facilitate comparisons between categories or activities (Spradley 1980).

The observation occurring in my study consisted of three stages based on those typical levels of fieldwork observations, as outlined above (Spradley 1980). The first stage was descriptive observation, in which the purpose was to make

broad observations of pain management procedures taking place in the ward. The second stage was focused observation, in which the careful observation around pain management of the potential participant patients was arranged. Finally, selective observations, focusing on specific interactions related to pain, were made in order to clarify important issues emerging from previous observations (see guideline Appendix IV\_4.1). These observations were conducted in various locations, such as adjacent to the patient's bed, the nurse's station, the corridor and the nurse's rest room. Each observation was recorded immediately, detailing time, place, actors and event in a small notebook. Full field notes were completed at the end of each observation period.

In the first, fieldwork research stage, I spent five days a week observing activities in relation to pain, in order to understand the scope of pain management in the ward. Documents, including guidelines for pain management and record forms, were also studied. Time spent in the ward was divided into two periods; the first period was in the morning (0700-1300), allowing observation of nursing handover and initial patient interactions; the second period was in the afternoon (1300-1900), allowing observation of the transition between day and night time carers. The precise duration of each observation depended upon the situation.

The second stage of observation was to identify patients to be the research participants. The observations were conducted around four to five times within one month. I observed the patients', caregivers' and nurses' activities in relation to pain management and observed how these participants interact in the pain management process. I paid attention to conversations about pain management during the physician's round and the nursing round. I followed nurses in delivering care to the patients to observe their activities and interactions. I also discussed relevant issues with patients and health professionals to clarify the significant behaviours of pain management. This stage enabled the gathering of data about an individual patient and identified issues to be explored and clarified in further observations.

The third stage of observation selectively focused on the significant behaviours noted from previous observations. These observations took place two to three times during the ward-based research period, in order to clarify understanding of those behaviours, especially on the potential for self-management of pain. In addition, I have looked for different behaviours among the participants which could provide information relevant to a variety of activities around the self-management of cancer pain.

Observations also took place in the patient's home, in order to gain information on how they coped with pain at home. The home visit took place when the patients were allowed home on weekends or when they were discharged from hospital. All details about the conduct of a home visit were agreed with the patients in advance and the date was confirmed two days before the actual visit was made.

All patients and family caregivers would be informed that the aim of the home visit was to observe their natural daily activities in the real situation at home and that they can and should do everything at home as usual. I explained that my role was as a visitor who was interested in their daily living and their activities relating to pain management at home.

### ***Managing the practical risk in the field***

The purpose of the observation was to describe behaviour in a natural context, as it occurred; it cannot be supposed that the practice of all hospital staff always represented 'best practice'. It is essential that the safety of the patients is prioritised. This issue was discussed with the ward staff prior to the commencement of my observations and it was agreed that the researcher should not, in any way, influence the care that was being delivered. The researcher would intervene in practice only if that practice was perceived to threaten patient safety. The researcher would discuss the practice with the staff member and the matter will subsequently be reported to the charge nurse of the ward following an initial mutual agreement.

### **3.3.9.2 Semi-structured in-depth interview**

Interviews enable researchers to get to key issues and to elicit a great depth of information in order to construct an understanding of the issues being investigated by a case study (Simons 2009). The advantages of interviews include facilitating individuals to tell their stories, the flexibility to change direction in order to pursue emergent issues and to probe a topic or go deeper into a response. In addition, the interview offers potential for uncovering and representing unobserved feeling and events that cannot be discerned elsewhere by the researcher (Simons 2009).

A semi-structured interview guideline was used to explore cancer pain management and self-management strategies used to deal with cancer pain, including factors which affect pain management, from the perspectives of patients, family caregivers and health care providers. The open-ended and probing questions, following the specific interview schedule (Appendix IV\_4.2),

were used to explore pain experience, pain management, self-management and social support in controlling cancer pain.

To ensure that the interview guides were appropriate, several pilot interviews were conducted with patients who met the inclusion criteria and with professional colleagues. As a result of these trials, the problems that might have become obstacles to the interviews could be explored and dealt with. A potential problem was that the language used by the researcher during the interviews seemed formal and, as a result, the participants could not fully understand the questions. Changes to the interview technique and language were made to solve this formal language issue, while the structure and content of the interview guide experienced no significant changes.

The nurses' and family caregivers' interviews took place in a small meeting room which provided privacy and reduced levels of disruption (Gubrium & Holstein 2001). One on one, face to face interviews were arranged for each participant, in order to address the research questions. The interview lasted from one to one and a half hours, taking place at a mutually convenient time. Overall, the interviews were conducted in a friendly atmosphere and flowed smoothly throughout the period of the interview. All the participants were willing to answer all the questions and allowed the use of their information in the study. There were some issues that a nurse had asked to be deleted from the transcript for personal reasons after she had read the primary analysed transcript. The data was then removed from the transcript.

The plan for interviewing the patients was similar to the plan for interviewing the family and nurses. But in practice, patients preferred to lie on their bed for the interview. It was found that the patients' symptoms were changeable and they were not able to sit and talk for a long time because of their pathology. It was the responsibility of the researcher to assess and prevent all risks that might occur with the participants during the research project. Therefore the interview of each patient was arranged at her bed. Even though the patients said that they did not mind that their information might be disclosed, the participants' privacy and confidentiality were emphasised during the interviews. I had conducted the interview in an environment of privacy as much as possible, such as when adjacent patients were not in bed due to having appointments for treatment or meeting physicians.

The complete interview was divided into 2-3 shorter interviews. This organisation was balanced between the research inquiry and the patients' risk management. It was found that this arrangement was suitable to seek in-depth clarification in the following interview session. I managed the time for interviews

to take place mostly in the morning in order to refrain from any disturbance, such as unscheduled daily radiation and unplanned visits by the patient's relatives. The overview of the interview atmosphere was quite good. Most interviews flowed smoothly but sometimes patients preferred not to talk, due to post radiation fatigue, pain, or emotional concerns. Those interviews were postponed and rearranged.

Audio-recording was used, with the permission of all participants, in order to ensure accuracy of information provided. Moreover, it enabled me to concentrate on the interpersonal nature of the interview and fully respond to participants (Simons 2009). However, some participants appeared worried about the audio-recording but none of them asked for the recording to be stopped. Note taking was not done during the interview because some participants seemed uncomfortable when I had taken some notes. This might be an obstacle to gaining valuable information. Therefore, I made notes immediately after each interview.

### **3.3.10 The fieldwork process summary**

The fieldwork was conducted for approximately nine months; the first three months for accessing the setting and piloting the research tools (interview and observation guidelines) and the next six months for collecting data. The process is summarised in figure 2, from permission being granted for doing research by the hospital to the end of data collection.

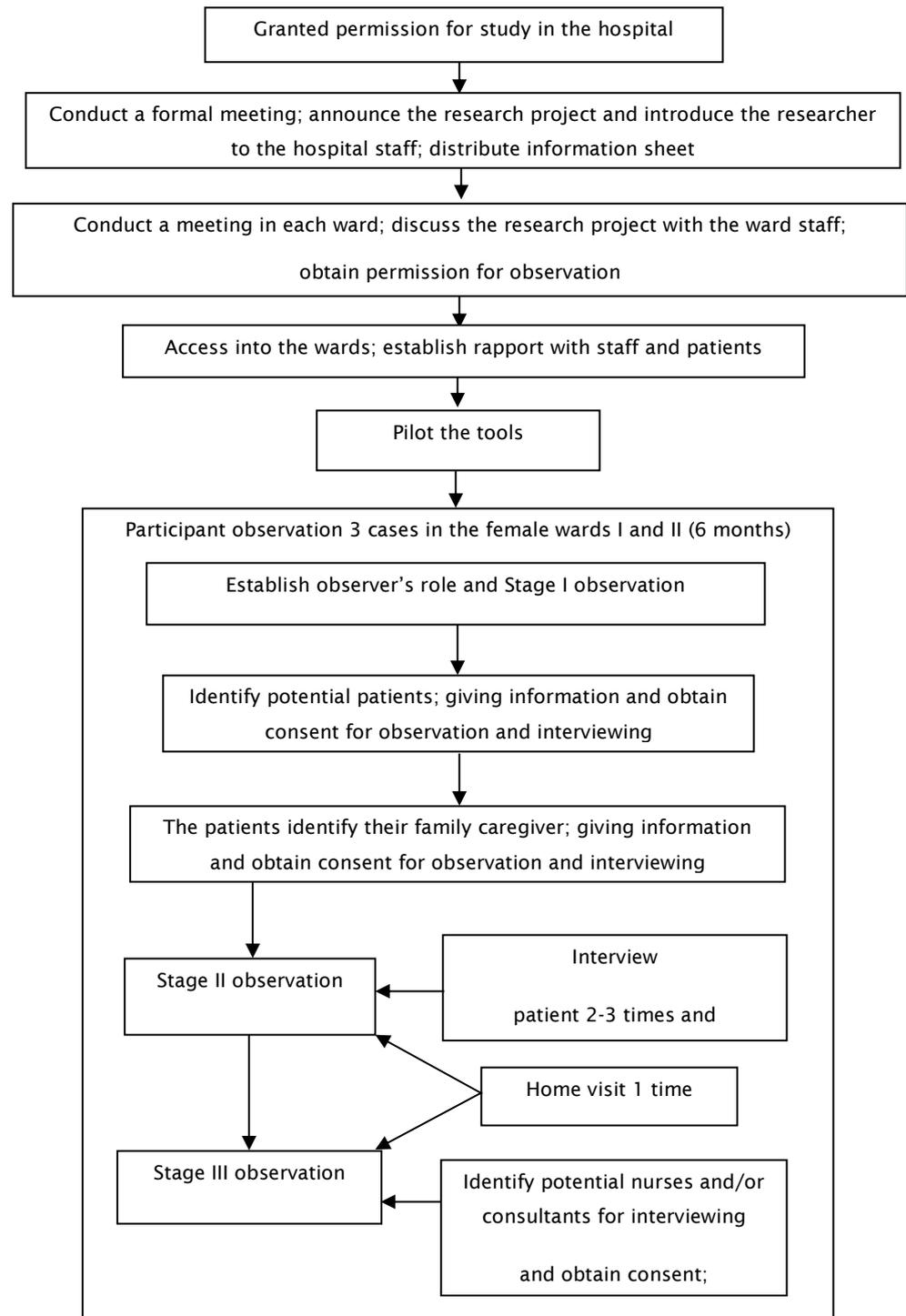


Figure 3.2 The study process summary

### 3.3.11 Risk management

The risks to both participants and the researcher have been addressed. It is not anticipated that participants would, in any way, be at risk by taking part in this research. The participants may think that topics about sexual organs and serious illness such as cancer or pain are sensitive and/or personal (Gubrium & Holstein 2001) and as a consequence become reluctant to disclose information. I, as a researcher, had recognised my responsibility to ensure that the study caused no harm to the participants and that the needs of participants had been prioritised over the needs of the researcher. A good rapport at the beginning of the research period could reduce the sense of being a stranger between myself and the participants, so that a sense of trust and safety could be developed during the fieldwork period.

Emotional and physical concerns of all participants had been emphasised throughout the study. Participants had been carefully observed and encouraged to discuss those matters about which they felt uncomfortable. The participants were informed that they could withdraw from the study without penalty and appropriate manners were employed to minimise that concern. The contact details of the researcher and helpful clinics were given to all participants, to make sure that they could find support regarding any matter. It was found that most patients and caregivers had major concerns about their disease and its symptoms. Some of them felt frustrated with the health care service and family care. These concerns were discussed between me and the participants in the first instance. However, some of those matters had been referred to ward nurses, subject to the patients' agreement. Those matters were then dealt with by the ward nurses, leading to the problems being managed appropriately.

The research team had been concerned with risk as a result of locating one component of the research at the patient's home. Prior to fieldwork being carried out, risk assessment and an action plan to deal with any risk were conducted following the 'risk assessment guidelines' of the University of Southampton. All necessary documents, including home visit guidelines, fieldwork map, contact details of both participants and research team, as well as emergency contact details, were compiled. This information was kept by both the researcher and an authorised research assistant who acted as a coordinator whenever the researcher was engaged with fieldwork. During home visits, all processes including travelling and visiting strictly followed the home visit guidelines. Evaluation of the guidelines and process was conducted after each home visit. There were minor revisions of the procedure, such as the note taking, that could not be conducted

due to an inappropriate situation or environment. My colleague and I recalled and recorded data immediately after each home visit. No adverse incidents happened during the home visits.

### **3.3.12 Data protection**

Participants in this study were informed that any information they provided would be kept confidential. The demographic data was coded with a participant number. All data from note taking, audio-recording and documents were labelled anonymously. The reference index for all participants' records was labelled by using the alphanumeric system. 'PT' was used for patient, 'FM' for family caregiver and 'HCP' for health care provider. An abbreviation of 'Int' referred to the interview and 'Obs' referred to the observation. The number 1, 2 or 3 identified the ordinal number of interview and observation. Therefore, for example, the first interview of the first patient was referenced as 'PT1\_Int1' and the first observation record of the first patient was referenced as 'PT1\_Obs1'. Pseudo-names were allocated to the direct quotes contained in the findings, to ensure none of participants could be identified.

All data has been typed and kept on the researcher's computer and is also backed up on a University of Southampton network computer, protected with the researcher's password. Access to the electronic database is controlled by the university network protection system. All hard copies of research data, including the written field notes and all printed documents, have been kept in a locked cabinet which can only be accessed by the researcher.

Personal data will be held no longer than necessary. The data which fall into disuse will be destroyed by appropriate measures to ensure that the data cannot be reconstructed and processed by third parties. After completing the study, the retained data will be kept for ten years in accordance with the Faculty's storage policy, University of Southampton; however such data can be accessed by permission of the university.

### **3.3.13 Data analysis**

Qualitative data are a source of rich descriptions and explanations regarding a particular phenomenon. The mass of words, generated by interviews or observations of behaviour located in a real-life context, need to be described and summarised. To seek understanding of the reality derived from the data, an

appropriate analytical strategy is needed, in which a qualitative analysis approach is useful.

It is recognised that there is no right way to analyse qualitative data and hence numerous approaches to the analysis of qualitative data are available (Ritchie & Lewis 2003). To decide on the choice of analysis needs careful consideration by the researcher. This qualitative case study is mainly descriptive and aims to construct understanding of a particular case in the real-life context. The analysis, therefore, would follow the 'framework' approach based on ethnographic accounts. This 'framework' analysis provides for a systematic process and design transparency, via which the reader can assess and construct an understanding of the case study in question.

The preliminary analysis during the data collecting period was established. This illustrated the broad picture of the case and its context and provided for relevant issues to be further addressed. The comprehensive analysis was constructed when all data had been collected. It is important to state that, at this initial stage of data analysis, only the patients' perspectives would be addressed. The findings from the perspectives of family caregivers and health care providers are not presented in this upgrade thesis.

### ***Data preparation***

Qualitative raw data is rich in detail in several forms, therefore it is essential to organise those data to become more manageable. All interview audio-records were referenced by the researcher before transcription. The referenced interview records were transcribed verbatim by the research assistants. The researcher checked any errors and made appropriate amendments to ensure accurate interview transcription. The notes which were recorded after the interview were added to the corresponding issues in the transcripts by the researcher. The interview files of each participant have been kept in separate individual folders.

The observation field notes were typed by the researcher every day, after each completed observation period. Each observation from each participant was referenced by using the alphanumeric system and has been kept in the corresponding folder. The documents have been typed and kept in a separate folder.

## ***Framework analysis***

The method for analysis of cancer pain experience and its management for this research is the 'framework' model (Ritchie & Lewis 2003). Framework analysis classifies and organises data according to key themes, concepts and emergent categories, resulting in a theoretical depiction of the case (Ritchie & Lewis 2003). This 'framework' method was selected to clarify the understanding of pain experience, pain management and self-management in this case study, because the visible matrix of themes and categories assists the analysis of each aspect of the case from the perspectives of patient, family caregiver and health care provider and across all cases. Moreover, this is a systematic process of analysis, which the reader can follow throughout the study (Ritchie & Lewis 2003).

The analysis process following this choice would be used for data resulting from interviews and observations. Documentation will be dealt with by following its specific analysis guidelines. The relevant and/or related issues from all data sources will be considered, interpreted and generated into themes.

The framework process of data analysis applied in this study has been divided into two key stages: (1) the stage of data management and (2) the stage of data description and data explanation (Ritchie & Spencer 2003). Data management has been employed in order to illustrate the broad picture of the cases. It helps to reduce the mass of unwieldy data to make them more manageable. Then, the stage of description and explanation has been addressed in order to make sense of the case (Ritchie & Spencer 2003; Green & Thorogood 2009).

### ***Stage of data management***

To manage data in this study, the five stages of familiarisation, identifying a thematic framework, indexing, charting and summarising or synthesising (Ritchie & Spencer 2003) were applied to the patients' interview data.

Stage of gaining an overview of data through data management

1. *Familiarisation*
2. *Identifying a thematic framework*
3. *Indexing*
4. *Charting*
5. *Summarising or Synthesising*

***Familiarisation:*** this is a crucial activity at the start of analysis, designed to gain an overview of the data and to begin listing key ideas and recurrent themes (Ritchie & Lewis, 2003). I had achieved familiarisation by dealing with the data several times, listening to the interviews, reviewing the field notes and noting down my comments and key emerging issues (Pope & Mays 2006). This process was continued until I felt that a comprehensive understanding of the diversity of the data had been encompassed (Ritchie & Spencer 2003; Green & Thorogood 2009).

***Identifying a thematic framework:*** many codes were developed from the raw data. I had identified the codes in language as close as possible to the original terms or in actual word used by the participants. This was to prevent any missing and/or misinterpretation of the data (Ritchie & Spencer 2003). Then sub-concepts and concepts were developed from the codes. The concepts also came as a result of reflection upon previous literature sources and my research aims (Pope & Mays 2006). Then, these concepts were constructed into themes and the themes were labelled by using alphanumerical forms to become a manageable index.

***Indexing:*** the developed index was applied to the raw data (Ritchie & Spencer 2003). I had carefully read each phrase, sentence and paragraph and decided to apply the corresponding index. An indexing reference was constructed in order to determine that the applied index would ensure labelling consistency (Ritchie & Spencer 2003). This index would be continuously refined and modified throughout the period of data analysis.

***Charting:*** this was conducted by using headings from the thematic framework to create thematic matrices or charts of the data, hence ensuring a summary of the whole dataset was constructed (Ritchie & Spencer 2003). The matrices were created with the themes in rows and participants' views in columns. Then, the data was entered into the appropriate parts of the thematic framework. Line references, relating to the passages were enclosed in brackets; in addition, some text such as key words and original terms were also included to remind the reader of what is being referred to (Pope & Mays 2006). The end result was a set of data structured within an analytical framework that was grounded in the participants' own accounts. The thematic charts for observations and interviews were created separately with consistency in form and order. This enabled me to analyse both in the flexible dimensions of individuals and across all data sources (Ritchie & Spencer 2003).

***Summarising or Synthesising***: this is the final stage of the data management process, which uses the charts referred to above to define concepts and find the preliminary patterns, associations and explanations relating to cancer pain experience and its management (Pope & May, 2006; Green & Thorogood 2009). To reach the achievement of summarising, I considered each theme, carefully regarding the meaning of personal opinions and their contexts. This enabled me to begin making sense of the broad view of the case.

In the thesis, the analysis was done case by case; each case consists of interview and observation of a patient, an identified family caregiver and health care professionals. Interview data and observational data were analysed by using framework analysis, separately, in the same way. The themes of each source were merged. Then the key themes from the two data sources were summarised.

The process of this step was illustrated in the figure below.



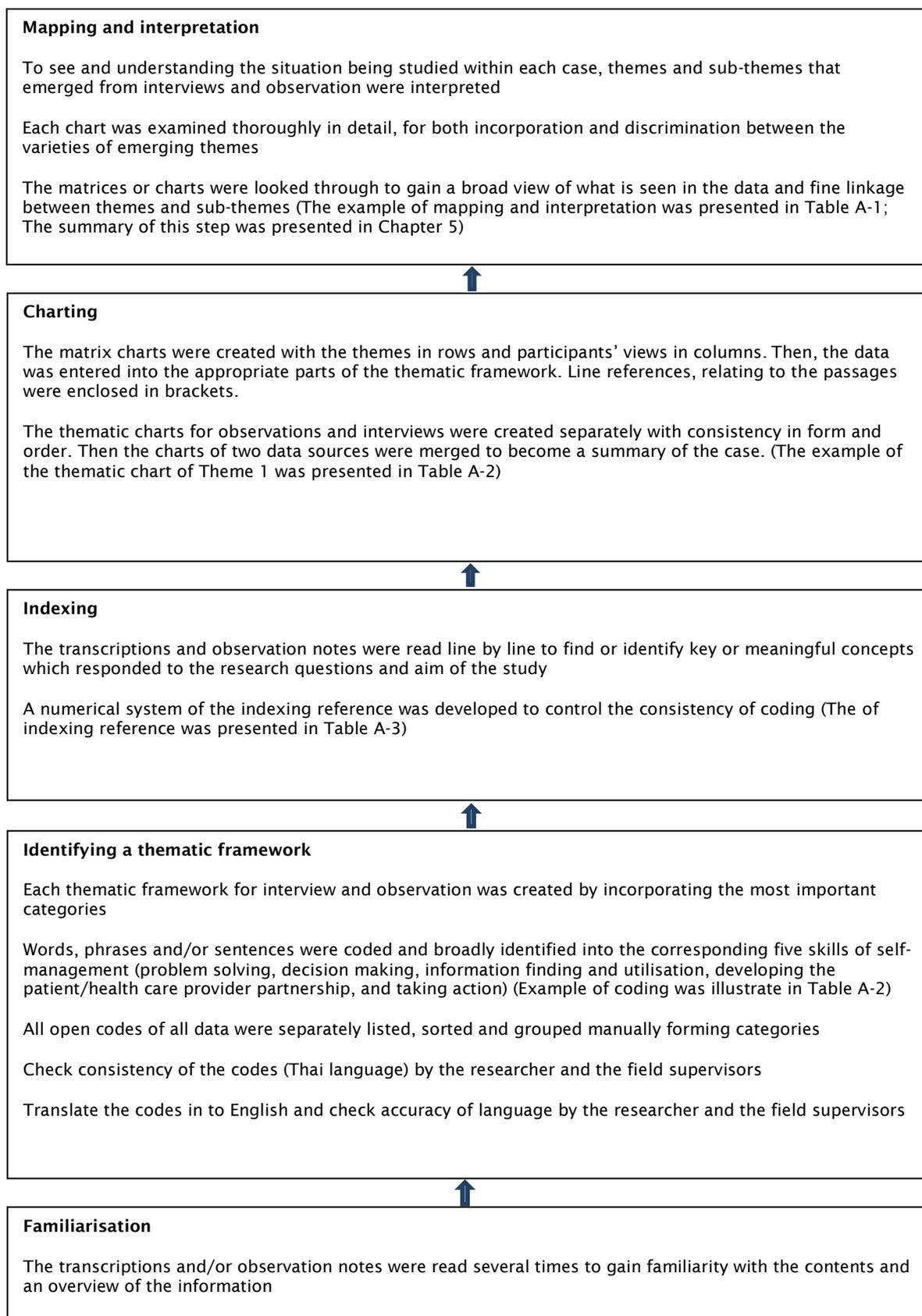


Figure 3.3 Stage of data management

### ***Stage of data description and explanation***

The emerged themes in each row of the chart, the developed categories and all content revealed the overview of the data. Careful consideration of both incorporates and discriminates between the varieties of emerged themes had been conducted. Then the similar themes were grouped and the new descriptive and higher abstract categories were generated. The developing new category process had been repeated until it seemed that meaningful and unique classifications were developed (Ritchie & Spencer 2003).

Then the connection and the differentiation had been considered, within and across the classification, in order to explain the whole case study. The pattern of behaviour related to pain management had been verified and the 'match linkage' of the pattern has been identified across all cases (Ritchie & Spencer 2003). This link helped to explain 'how' and 'why' issues underpinning the participants' behaviour. In addition, comparison between participants, assists the explanations of behaviour in relation to individual thought and context. The explanations were supported by both explicit accounts from the participants and implicit accounts by the emerging themes of analysis (Ritchie & Lewis 2003).

In the thesis, this stage was developed in a table next to the narrative story of each case (as shown in Chapter 4). This enabled me to present a greater understanding of individual embedded case in relation to self-management of cancer pain, addressed in the research questions. Then all themes of each case would apply to interviews and observation allowing comparison of the data across six cases. This stage of the analysis could lead to develop the empirical conclusion and a descriptive model of the phenomena being studied. The results of this step were presented in Chapter 5. Finally, the revised-themes were grouped and mapped in order to find relationships between themes, and then the self-management for this case study was developed. The developed self-management model was illustrated in Chapter 6.

### **3.4 Rigour of the study**

The quality of case studies varies. The case study offers opportunities for researchers to learn from the evidence, to expand the scope of inquiry,

to reconstruct their own understanding in order to inform the reader's judgements on the evaluation (Simons 1996). In this study, the quality of research has been considered, based on the criteria of validity, triangulation and generalisation.

### 3.4.1 Validity

There are various ways of improving validity, each of which requires the exercise of judgement on the part of the researcher as well as, ultimately, the reader of the research (Pope & Mays 2006). The distinct exposition of method, of data collection and of analysis provides readers with a way to judge conclusions based upon the evidence. In this study, a detailed research design has been conducted to provide sufficient information for the reader to be able to understand vicariously.

Using multiple sources of evidence to encourage the line of inquiry, a chain of evidence has been provided to achieve validity of the case study (Yin 2009). The sufficient data allows the reader to judge whether the interpretation offered has been adequately supported by the data (Pope & Mays 2006). In addition, a longitudinal approach was utilised in this study and such a prolonged engagement with the participants can establish excellent rapport and trusting relationships between the researcher and the research participants, resulting in richness and accuracy of information as a consequence. Accurate transcriptions, verbatim extracts and thick description all increase the trustworthiness of the final research findings.

Crosschecking of the design of, and analysed results from, this study by research assistants and supervisors was helpful in achieving internal validity in practice (Polit & Beck 2008). The primary coded interview was checked for its accuracy by supervisors. This was used as a guideline for further coding. The following coding and indexing were cross-checked for accuracy and consistency with my colleagues. The conversation with academic supervisors regarding data analysis and interpretation is another method to overcome researcher bias. Checking the accuracy of interpretation in relation to language by the field supervisors, who have bilingual (Thai-English) backgrounds, has been conducted repeatedly. It is an important process in order to diminish the chance of misinterpretation of data and data analysis.

### **3.4.2 Triangulation**

Triangulation enhances the construction of validity of a case study (Yin 2003). Triangulation involves the comparison of the results from either two or more different methods of data collection or two or more data sources (Pope & Mays 2006). This is generally accepted as a means of ensuring accuracy of data and the comprehensiveness of a set of findings (Bergen & While 2000). Triangulation relies on the assumption that any weakness in one method will be compensated by strength in another. Triangulation may be better seen as making a study more comprehensive than as a pure test of validity (Pope & Mays 2006). Two triangulation strategies have been adopted in this study, data triangulation and method triangulation.

#### **3.4.2.1 Data triangulation**

It is recognised that data triangulation is a central case study research strategy for enhancing construct validity (Yin 2003). Data triangulation refers to the use of multiple sources of data including patients, family caregivers, health care providers and written documents, with similar foci to obtain diverse views about the topic for validation of the findings. Data triangulation allowed me to compare the variety of data over time or to compare different types of data that may reflect different aspects of the project. The depth and breadth of evidence from multiple data sources can facilitate triangulation and offer findings that are likely to be much more convincing and accurate.

#### **3.4.2.2 Method triangulation**

The adoption of method triangulation is one of the major strengths of the case study. Method triangulation means the use of multiple data collection methods, including participant observation, semi-structure in-depth interviews and documentation analysis to capture information. The use of those methods can capture both internal (cognition) and external (interaction) features of participants.

### 3.4.2.3 Generalisability

Generalisability refers to the extent to which a finding from a study can be applied to a wider population or to different contexts. The logic of generalisability in a qualitative work is to provide a 'thick description' (Green & Thorogood 2009). The single case may have limitations for generalisation (Bergen 2000). Stake (1994) suggested the concept of generalisability of case study research related to the view that the purpose of case study is not to represent the world, but to represent the case. Moreover, Hamel et al. (1993) claimed that the single case could also be seen as representative, in its own right, provided that it offered sufficiently detailed descriptions of the research findings, since this would lead to a clearer understanding and hence to explanation of the topic researched.

Yin (1994) suggested generalisability in case study design can be created through analytical generalisation. Case study could provide generalisation at the level of theory, which then becomes a theoretical framework. The researchers expect their readers to comprehend their interpretation. The reader learns about the case to encapsulate the complex meaning into a finite report but the researcher/author should also present the case in sufficient descriptive narrative so that readers can experience these happenings vicariously and draw their own conclusions (Stake 1995). When the researcher's narrative provides the opportunity for a vicarious experience, readers extend their perception of happenings. The reader makes some natural generalisations entirely from personal or vicarious experience.

Case study encapsulates complex meaning into a finite report and describes the case with sufficient descriptive information that readers can experience and comprehend their interpretations, resulting in constructing their own conclusions (Danzin & Lincoln 2005). Based on the harmonious relationship between the reader's experiences and the case study itself, a 'naturalistic' generalisation will be generated (Stake 2005).

This six embedded cases study design described in detail above, attempts to provide a range of data covering a particular context, in order to reach an understanding of self-management of cancer pain and to broaden the basis of formal generalisation (Simons 1996). The rich information and meaningful interpretation of the findings, based on the case's context, allow

readers to understand the case in order to extend their experience, resulting in judging the generalisations coming from the study (Yin 2009).

## **Chapter IV**

### **Findings of context and individual cases**

#### **4.1 Introduction**

This chapter will provide the findings collected by observation and interviews from the patients, family caregivers and the patients' health care providers. The chapter begins with a brief description of the context of health care in Thailand, followed by a report of the situation during the information collecting process in the fieldwork. Details of the hospital context, ward circumstances, cancer care system, pain situation and pain management will be presented. The findings of each embedded case will be illustrated at the end of this chapter. Then the analysis across the embedded cases will be presented in the following chapter.

#### **4.2 The context of health care in Thailand**

There are many factors contributing to the health care behaviour of Thai people. Culture has been found to be a major factor influencing personal beliefs and behaviour (Garro 1990). In the Thai context, cultural beliefs are passed from one generation to another and further shaped by individual experiences. Thai people have strong beliefs in the Law of Karma and philosophy of life which influence their health behaviours (Petpichetchian 2001). Local culture influences people who live in each part of Thailand. Thai people, especially in the Northeast region, are likely to have a high tolerance to pain. Most patients never complain and/or ask for help unless the symptoms and pain are truly intolerable.

Patients' education, economy and community infrastructure also influence the way one makes a decision to deal with a problem (Wibulpolprasert 2008). In addition, patients tend to adopt a passive role; a

common characteristic of Thais, including cancer patients (Khounnikhom 2007; Wibulpolprasert 2008). These factors may affect their cancer pain control behaviour (Vatanasapt et al. 2008). Therefore, the particular context of this region should be carefully examined in order to gain more understanding of the patients' behaviours, especially for self-management of cancer pain.

Generally, in hospitals, a patient will be taken care of by a team of professionals. Once discharged from the hospital, a patient who needs to be cared for will be visited by a home healthcare team. Some patients may be referred to a community hospital, near the patients' home, and home visits will be organised by community nurses of that hospital.

A number of health professionals in a health care service depends on the service classification: whether it is a primary, secondary or tertiary health care service. The sufficient and appropriate number of health professionals is carefully managed by the Ministry of Public Health (MoPH); however, the evidence of insufficient and also unequally distributed manpower in the hospitals, especially in the rural areas, is still a crucial problem (MoPH 2011).

All Thai people hold a basic health insurance, for which patients make no payment while receiving standard care from the public health services. The patients who are admitted to a ward will receive their treatment, the hospital dress, and food and drink. Money will be spent for travelling to the hospital, extra food and beverage, and a daily living allowance for a caregiver who prefers to provide care for the patient in the hospital. Cost of treatment may be paid by the patient who requires off-standard treatment or specific uncommon strategies (MoPH 2011). Usually Thai people will choose a health care service from which they receive the standard care, without payment. However, lots of people prefer to buy drugs from a drug store as a primary solution or receive treatment from a physician at one of the many private clinics because such clinics are convenient, less time is spent waiting to be seen and patients express their satisfaction on the effectiveness of treatment received.

The family is likely to be the centre of care in Thai context: Traditionally, all family members have close relationships and are

responsible for taking care of any member who needs it (Methakanjanasak 2005). When an individual is admitted to hospital, one family member is generally identified to take on the role of caregiver. This caregiving role would normally be a close family member, such as spouse, child or parent (Methakanjanasak 2005). With the patient's admission, family can visit the patient in the ward following the time-table of family visiting. Additionally, there may be an occasion for one caregiver per family to stay in the ward to take care of the patient who needs physical or psychological support.

## **4.3 The data collecting in the field**

### **4.3.1 General information about the hospital**

The hospital where this research took place is a cancer centre that is part of the National Cancer Institute (NCI), the specific department of the Ministry of Public Health (MoPH), Thailand which takes responsibility for the provision of cancer care. It has been built specifically to serve cancer patients who live in the upper region of North-East Thailand.

The hospital organisation consists of three main groups: the administrative group, the academic group and the care service group. The administrative group plays a vital role on the hospital management and is led by the hospital director. The academic group is managed mainly by physicians who contribute to developing both theoretical and practical treatments. The care service group consists of the nursing education department, the out-patient department and the inpatient department, the main role of which is health care delivery.

Physicians are specialists in oncological surgery, radiation therapy and chemotherapy. This hospital has no gynaeco-oncologist. A gynaeco-oncologist in this region is a full-time worker in a tertiary care hospital. She works only once a week at the out-patient department of this hospital and provides occasional assistance on request.

Nurses in this hospital are all registered nurses, with some having oncological training certification and some holding Master's degrees. All

nurses have at least three years' experience in taking care of cancer patients and some nurses have over ten years' experience.

#### **4.3.2 The in-patients' care organisation**

A patient who is admitted to a ward is under the care of one consultant who acts as a case manager; this means that a physician takes responsibility for a patient in the whole course of treatment of that admission. The patient's status will have been identified by her doctor since admission, based on the optimal compatibility between symptoms and treatment. Most patients who have cervical cancer are allocated to a radiotherapist in the first instance, because the main treatment of these patients will be radiation. If the patient needs chemotherapy, the radiotherapist can also give the chemical. In case the patient has complex problems or needs more treatment from other specialists, co-management and consultation processes were typically practiced. The case manager can be changed after admission based on the patient's symptoms and the treatments needed. According to this system, questions about cooperative case management, and opinions of pain management in the hospital, were added to the interview with the first consultant and ward sister nurse, in order to gather information to understand the pain management context of this hospital.

In-patients are cared for by a nursing team under the supervision of a head nurse from the in-patient department. The staff complement for each ward consists of one charge nurse (ward sister) and eight nurses who rotate through three shifts in 24 hours, split into a morning, an afternoon and a night shift. A typical shift consists of one senior nurse, one nurse and a patient-aid taking care of all patients as a team. The charge nurse typically works the morning shift and is the ward manager. Nursing care includes disease specific nursing care, as well as basic care such as feeding, washing and assistance with daily activities for the patient who lives alone and/or who have high severity pain scores. The nominated family caregiver also assists with the basic caring for the patient, if that patient seems in good condition.

Visiting is allowed in the wards at three times: six to eight o'clock in the morning, twelve to one o'clock in the afternoon and four to eight o'clock in the evening. Additionally, it is customary for one caregiver per family to stay in the ward to take care of patients who need physical or psychological support. Some patients can visit home on weekends, leaving from the hospital on Friday evening and coming back on Sunday evening. Most patients who visit home at weekends are receiving only radiotherapy.

The family is likely to be the centre of care in this group of patients. The family caregivers were husbands, children and mother(s)?, respectively. These caregivers took care of the patients while admitted to hospital and at home.

Once a patient is discharged from hospital there is a home healthcare section, based in the hospital, that makes regular home visits to those with complex needs. Some patients may be referred to the community hospital near the patients' home, and home visits are organised by the community nurses from that hospital.

#### **4.3.3 Access into the wards and ward atmosphere**

Once the research was approved, by the ethic committee and also the hospital committee, for me to conduct the case study in the hospital, I had a discussion with a nurse who is the leader of the academic service department of the hospital. She agreed to be a gatekeeper for my research, in order to find the most appropriate way to promote my research project to all the staff. I met the gate keeper in her room in the morning and briefly described my project and overall plan to her again. I mentioned about the consent issue; basically that I needed the signatures from staff to permit observation. She gave me her opinion that it was quite unusual to ask the written consent for observation because this method has never been done in this hospital and it might induce unexpected consequence. She suggested that I should make a good rapport and communicate information about the project, as much and often as possible, to establish the sense of familiarity and trustworthiness. The project was distributed widely via the document system of the cancer centre and by announcements in the formal monthly

meeting. Then the 'gatekeeper nurse' introduced me to a key physician, who was a key person influencing the chance of my application being successful.

I was then introduced in the female wards 1 and 2 by the gatekeeper. At the first time I presented myself at the nurse station in ward 1, I was scared and worried about the nurses' thoughts. The formal introduction was made by the gatekeeper including my name and broad aim of my presentation. She also asked all staffs for co-operation to collect data. The staffs (charge-nurse, sub charge-nurse, and 2 nurses in the morning shift) expressed their perceptions. The staff might feel that the introduction was likely to push them to co-operate or that they might have questions about my project. I saw their eyes and felt they were in doubt and hesitated to join my research. I thought this was a normal reaction for a stranger who come and do something in the ward. But to decrease the barrier, I spent time to stay with them to bridge the gap. The reaction might have been due to the outfit I was wearing that day (blouse and black suit with a pair of ankle boots) that was very formal. Then the gate keeper let me to the ward 2, next door to the ward 1. I felt at the moment that the sense of friendliness was better than the previous ward. The sense of the familiar was met due to I used to teach my students here last two years. The gate keeper introduced me to the nurses, similar to the ward 1. I felt that some nurses seemed interest to join my project. This was helpful for me.

The gate keeper left me at the ward 2 so I started my job immediately. I introduced myself and my objective again. The details could not be provided at that moment because the nurse had to do their job of care delivery to the patients. I spent most time with the charge-nurse in order to answer her questions and also to distribute the 'participant information sheet for the health care provider'. The charge-nurse was very friendly during the conversation. She told me that she will distribute the information to her staff. She asked me about arrangements to stay in the ward and the clothes I will wear. I described my role, position and the uniform I will wear in the ward. She seemed satisfied with my answers. I stayed there around 1 hour and left from the wards with an appointment to come back tomorrow wearing the uniform. I went back to ward 1, talked to the charge-nurse there and answered her questions, made relationships with nurses individually, as well as distributed the 'PIS'. I remained there for

around 1 hour and then left from the ward and the hospital. I made an appointment to stay there whole day on the next day.

The second day, I arrived at the ward 1 at 07.55 am, wearing the uniform. There were two nurses on the night shift that I had not met yesterday; one who was a senior nurse was summarising the patients' documents in the nurse station and the other was clearing equipment in the treatment room, adjacent to the nurse station. I introduced myself to them. They smiled and nodded their head representing their acknowledgement. I thought that they might have received information about me from their colleagues. I joined in the turn-over and the morning routine round.

I made small-talk with the nurses. Some of them asked me about the project and broadly talked about the problem of pain and its management in the ward. A nurse began talking to me about the patients' information and their problems. That moment I felt more confidence and felt that I had a space to stand in the ward. It was not only they told me about an interesting case but the friendly atmosphere and talking about pain made me feel that the nurses might be interested and were aware that the project would be conducted in the ward.

I visited the patients who stayed at or in their beds, tried to build relationships, and had conversations with them in general issues. The patients looked at me with a bit of a question in their eyes but nobody said anything. Some patients just said hi, smiled and went quiet whereas some asked about me. These responses were not beyond my expectations. Generally, the atmosphere was pretty nice.

#### **4.3.4 The Female wards 1 and 2**

Each female ward takes approximately 30 patients and there are likely to be both mixed-diagnoses and varying stages. However, gynaecological cancer is the most common cancer on the female wards, making up around 50% of cases. The majority of women with gynaecological cancer have cervical cancer. Treatment of cervical cancer is typically by radiotherapy alone, or radiotherapy and chemotherapy in combination.

Each ward area is physically divided into three sections, ten beds per section, separated by low partitions. The nurses' station is located in the front of the middle section so that the nurse can see the whole ward. Each ward also has separate areas for drug preparation, for the setting up of treatment and dressing trolleys, for the disposal of waste and dirty linen, and patients' toilet facilities. A nurses' rest room is located behind the nurses' station. There is also a staff rest room close to the ward, which has an 'on-call' bed available for the duty doctor.

In general, most ward activities are conducted during the morning shift (0800-1600) including the doctor's round, nursing round, daily treatment with radiation and chemotherapy, and daily drug distribution from central drug store. The routine ward activities start with a meeting in the nurses' station for a handover of the shift, which is followed by the nursing round at the patients' bedside, which is conducted only in the morning shift. Then, all staff on the shift follow their assignments, as the leader or the member of that shift. The leader's main roles are to communicate with doctors and other health professionals (such as pharmacist, radiation officer and nutritionist), to distribute jobs to members and also to oversee all activities during the shift. The shift team members will be involved in delivering drugs for oral consumption and/or injection, giving chemo-medication and doing all procedures. Each specific activity is recorded by the nurse who has done that activity, whereas the patient's chart completion is the leader's responsibility.

#### **4.3.5 Cancer pain and cancer pain management**

Approximately 70% of patients experience mild to moderate pain due to cancer. The patients reported that the pain began generating at home and increase gradually during waiting for treatment in the cancer centre. The pain peaked around the time of admission and then declined after receiving cancer treatment during the next 2 weeks. Most cancer pain is controlled by medication, following guidelines set out in the WHO analgesic ladder document. There are around 10% of patients for whom the pain still remains; a level that may well increase to severe.

There is no pain specialist, no pain centre service and no core pain control regimen in the cancer centre. Therefore, patients who have pain have been controlled by their consultants with their own regimen. The consultant visits patients daily to assess pain and to adjust pain medication. The treatment is reviewed once a week.

In the cancer centre, pain is mainly controlled by following the analgesics ladder of the WHO. Morphine sustain release (MST) is the basic drug for dealing with cancer pain. Morphine (MO) injection is used in postoperative pain and breakthrough pain. Acetaminophen is used occasionally in non-persistent pain. Adjuvant including antidepressant is used in complicated pain. The physician's role is to prescribe a pain regimen that may require doses around the clock (such as every 6 hours and 12 hours) or as needed, whereas the nurse will deliver drugs for the patient following the prescription. If the pain increases, the nurse can provide drugs to the patient under the 'as needed' regimen. In case the patient needs drugs before the delivered-drug schedule, or the pain does not decline once the patient receives the 'as needed' analgesics, the nurse will consult the physician to deal with the problem.

The patient is assessed by a physician and ward nurses. However, the first communication about pain is mostly from the patient. It may be a complaint by the patient's self or by their family. When nurses receive pain information, they will assess the patient's pain by observation behaviour and ask about the location, severity, and any additional symptoms. Vital signs are assessed in the patient who seems in severe pain. A modified pain scale (0-10 numerical rating scale) is provided in ward, for pain assessment, which is explained to the patient before using it.

With the patients who participated in the study, their pain had occurred close to six o'clock both am and pm because of the reduction of blood analgesic concentration that they had taken every 12 hours. I therefore rearranged my times of observation occasionally, in order that I could observe how patients express pain, how they and their caregivers respond to and/or manage pain and how nurses deal with the pain. However, some patients had pain problems inconsistently, which meant I could not plan the precise time to observe the behaviour throughout the

day. Therefore, I stayed on the ward all day in order to observe any interesting behaviour which may occur.

Issues relating to pain problems were communicated among nurses in many ways, discussed in the nurse station during referral to the next shift and during routine morning rounds. The pain problem, including previous assessment and treatment, is recorded in the patient's cardex that contain a one-day assessment and treatment plan. This indicates that pain is a current problem. Nurse-sister has responsibility to contact the physician. She will inform about signs and symptoms during the routine daily doctor's round, and by telephone if necessary. Physician and nurse discuss the pain in a complicated case. All information from everybody has been shared. The goal of pain control of the case is agreed, and then the practice to reach the goal is followed.

In an interview a nurse, the leader of a pain management team, when asked about who takes responsibility for cancer pain management, informed the researcher that there was no pain control expert or pain clinic in the centre. A pain team was likely to be established but there was nobody qualified to take full responsibility, so pain management duties were distributed to the palliative care team or home care team. The pain team consists of a nurse-anaesthetist who acts as the leader of the team, and the members are a charge-nurse from each ward (accounting for 5 nurses), a nurse representing each ward (accounting for 5 nurses). A physician is invited to be the consultant of the team. This pain management team is established, aiming to generate a standard and effective cancer pain management for the hospital. They have monthly meeting to discuss topics around cancer pain, its management, and problems relating to pain management in practice. A pain control guideline, pain assessment record form and pain medication record form have been developed and distributed to each ward. Every three months all developed pain documents are evaluated and revised. I was not allowed to attend the meeting; however, the leader of the team explained some contents of the discussion and the revision of those documents, in brief. The leader also gave her opinion that this is the beginning step of cancer pain management in this hospital. The members of team are 'only' nurses but the optimal aim will be to include all

professionals related to cancer pain treatment into the team such as physicians, pharmacists, home care nurses and palliative nurses.

At present the pharmacists have responsibility to describe information about medicine that the patients received for the first time; this is the routine but if we request their help, they may provide it only occasionally because they have limited manpower in their department. The charge-nurse shared her opinion around the manpower problem that

*'actually the problem about manpower occurs everywhere that you can see in this ward; there are insufficient nurses to schedule all shifts. There are just 8 nurses in this ward, a charge nurse and a sub-charge nurse are working in the morning shift with 2 nurses, the afternoon and night shift is run by 2 nurses. The part-time nurses from other department such as OPD or OR (operation room) will be scheduled some shifts. But the solution is based on the hospital policy. So we have to be patient and do as much as we can...some nurses in this ward moved from other hospitals or other departments which may less experienced in caring for cancer patients, this may affect the covering of caring for the patient. However we are improving our job'.*

There is a close relationship between nurses and patients due to 24-hours working in the ward. Nurses perceive patients' pain by attending the handover and also the individual bedside assessment; therefore, they can follow the patients' symptoms and treatment. Nurses have a major role as care providers and they also are centres of communication among health care teams and between health care staff and patients. Patients and/or caregivers can express the pain and communicate their requests to the consultant via the nurses. However, from observation in the ward, there were some patients who seemed to prefer not to share their requests and needs to nurses. They would express their need when the nurses come to their bed in the routine assessment or they ask their caregiver to communicate their needs. This behaviour caught my interest in the need to clarify it, because this tendency might explain the efficacy of self-management in my case study.

### **4.3.6 Participants and sample size**

The current case study was constructed with 19 participants consisting of six patients, six family caregivers and seven health care providers. The patients who met the inclusion and exclusion criteria had been recruited to be participants. Purposive sampling had been conducted, based on the ability to provide valuable information about pain management for females with cervical cancer. The selected patients provided a range of data in relation to age, pain experience and number of family members. Such data should provide crucial and unique points of interest from these particular pain management contexts.

#### **4.3.6.1 The identified patients**

All six women, who were selected to be participants in the study, have been diagnosed with cervical cancer; they were in the advanced stage of disease. They experienced moderate to severe pain (identified by the pain assessment and pain medication history from the patient's document) and received at least one kind of analgesic during the period of recruitment. The patients experienced pain differently. Some patients experienced severe pain since their time of admission to hospital but others experienced pain at mild to moderate levels at home; the pain worsened after admission, while waiting to start the disease treatment. During the data collection period of this research, the pain levels varied over time. The prescription of pain relieving drugs, from analgesic to strong opioids, was adjusted based on the patient's symptoms. These dynamic changes of the behaviours in response to the pain could provide valuable information for the case study.

#### **4.3.6.2 The identified family caregiver**

There are six key family caregivers who provide close care for the patients in the project: four of those family caregivers were the spouse, one was the mother and one was the daughter. Most patients had a key family member who provided care for her both in the hospital and at home. One patient had three caregivers rotating to take care of her because none of them could provide continuous care during the period of hospital admission. The patient was asked to identify her key caregiver. Her selection was her husband because she would live with him when discharged from the

hospital. He had to take responsibility to care for his wife at home, therefore he was identified as the key caregiver.

#### **4.3.6.3 The identified health care providers**

The health care provider participants included four nurses, two senior nurses and one consultant, who were mostly involved in the care of six patients and liaising with the family caregivers above. All nurses had different backgrounds and experiences in taking care of cancer patients and pain. In addition, there were various job descriptions related to specific positions; for example three of them were in the hospital pain assessment group which took responsibility for all aspects of pain management in the hospital. One of the nurses specialised in palliative care and one was a psychiatric nurse.

There was an initial intention to recruit two consultants to be potential participants, who might provide valuable information about pain management from their own perspectives. Both consultants were radiation therapists with oncology backgrounds. One consultant had four patients, whereas the other took responsibility for two patients. There was a problem in recruiting the second consultant. In the middle of the study, he refused to participate in the interview for personal reasons, but he still agreed to be observed in his role. He would ask for clarification occasionally and allowed me to use his answers and information from the observation for analysis in the research. Although there was incomplete data relating to his perspective of cancer pain management, the given information about pain management activities would prove to be useful data supporting the research study.

In summary, there were two patients who, when approached by the researcher, declined to be participants in the project. Two patients withdrew, after one month, from the project after they had given consent. Moreover, a caregiver withdrew from the project because he felt uncomfortable about continuing to provide information. The selection process was continued until the sample size was reached and the resulting data was likely to be sufficient for the case study.

#### **4.4 Finding of individual case**

This section is a summary of each embedded case which yielded information from observations and interviews of patients, families and health care providers. Pseudonyms are used in order to keep the participants anonymous. In addition, the pseudonyms are the identifiers for each case, which includes the patients, families and health care providers.

## Case 1 : Malee

Malee was studied for five weeks in hospital (from May to June 2011) and for one home-visit after being discharging. The findings are introduced with Malee's family background and social circumstances, and then Malee's disease is summary is presented. Cancer pain and pain management from perspective of Malee, family and health care providers are described. Finally, the cancer pain management of Malee is concluded.

### 1.1 Malee's family background and social circumstance

Malee's family settled down in a village in the north-east of Thailand. Malee was the last child of three. The summary of Malee's family is shown in the family tree below.

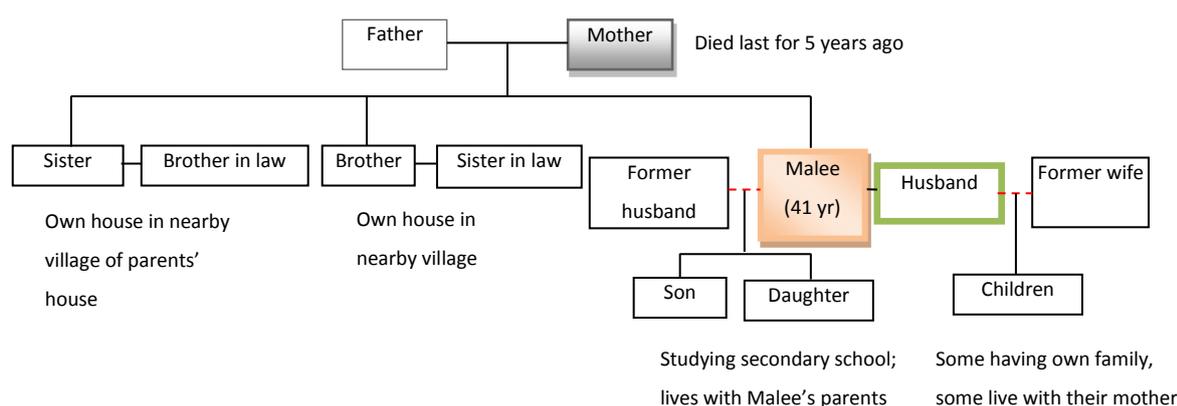


Figure 4.2 Malee's family tree

Malee had been married and then divorced for the last 10 years and had two children with her former husband. Two years ago she married her present husband and they had no children. Malee and her husband moved to the South for their careers. They would stay with Malee's father whenever they visited home.

Malee's father and some relatives worked in a salt-farm, located far away from the village, similar to their other neighbours. According to the geography of this area it is populated with thick beds of rock salt, hence the

majority of the local families' work was salt-farming. However, Malee and her husband declined to do salt-farming, due to the inconsistency of income, so they were employees in an industry in the South of Thailand.

Malee was educated at primary school as were the majority of residents in this village. This educational level would limit her chance to find job and therefore less income would be a consequence. The income was only to support daily living. Some spare money could be saved if possible. Therefore a problem with shortage of money was occasionally found. If Malee or another family member needed money urgently, she could loan the money with some interest from neighbours or a creditor in the village or in the city.

People who lived in this area seemed to hold a strong local belief in supernatural power such as the Nagas with a belief that the Nagas could protect them from danger and had magic powers for treatment.

## 1.2 Malee's disease summary

Malee's disease details were collected from the patient's chart under the approval of the hospital committee and from the patient's interviews. The summary is shown in the table below.

Table 4.1 Malee's disease summary

Time	Events
November 2009	During working in a province in the South of Thailand, Malee had severe vaginal bleeding. She was diagnosed with cervical cancer at a local hospital.
February 2010	Malee (and her husband) returned home in the North-East of Thailand in order to use her health insurance for treatment. She went to the general hospital and was investigated by cervical biopsy, cysto-proctoscopy, intra-ventricular pyelography for staging.
March 2010	The cervical cancer was confirmed that it was in the advanced stage. Malee was referred to the cancer centre and added into the waiting list of radiation therapy which would be done in the next two months. During the waiting time, Malee had been having worse dysmennorrhoea and back pain so she took analgesic bought from a drug store.

Time	Events
April 2010	Malee was treated by tele-radiation therapy (33 times of the fractionation schedule), chemotherapy (two cycles). The abnormal bleeding was stopped but the pain in the lower abdomen and the back became worse, so she was treated with two kinds of oral analgesic. She also had treatment of brachy-radiation therapy once a week for three weeks but it was delayed by four weeks because her perineum was burnt. This treatment was completed in July 2010 and she had a follow-up appointment in the next six weeks.
August 2010	Malee had the first follow-up with pain at lower abdomen and left groin. She took oral analgesics prescribed by the physician at home.
December 2010	Malee had the second follow-up. She was diagnosed with fibrosis in the lower abdomen but she did not have any treatment for it. She was given an appointed in the next six months. While waiting for the follow-up, Malee had pain irregularly. Malee took the analgesics prescribed by the physician before discharging. She also took traditional medicine provided by her father.
May 2011	Malee had worse pain in her hip and legs so she was re- admitted in a local hospital and received oral analgesic but the pain did not decrease. She was referred to the cancer centre and she was treated with oral morphine and morphine injection. However she still had severe pain so the physician increased the dose of morphine injection from twice a day to be three times a day and gave an anti-depressant additionally.
End of June 2011	One day in the last week of June, Malee had respiratory distress. The health care providers treated this problem and provided care closely. While the physician was readjusting pain control regimen, her family asked to take Malee home. She was discharged with an amount of oral morphine tablets two times a day and an amount of analgesics to take at home.

### 1.3 Cancer pain perspective and management

#### *1.3.1 Perspective and expression about cancer pain*

It was found that the most important of Malee's thoughts about her pain was related to the suffering and death. Malee said that the pain was terrible, it was suffering. She needed to get out from this feeling. The pain was much more than she expected. She could not bear the pain.

According to the observation, Malee moaned almost all the time while staying in the hospital, both at rest and having activities. She explained that the voice was not only to let other know about her pain, but it also let some help from others. Malee gave her reason for her moaning that sometime she felt 'Kreang Jai' (a feeling that patients do not need to disturb others) for asking for help directly, especially from the health care providers who seemed busy all the time. But the most important reason was that this was such a way to express herself in this situation, how she could tell everyone about the pain. Verbal communication, telling or asking for help from caregivers and nurses, was usually done but it seemed not enough. She claimed that she needed to communicate to nurses that she had pain and needed more attention.

Malee's pain expression of moaning resulted in a variety of reaction from people around her. The common response of her husband was asking about her symptoms and also her needs, talking to her in order to give her mental support or asking for help from the health care provider. The moans and cries were also responded to by health care providers, the nurse would come to her bed immediately in order to assess her pain and take action including informed knowledge about pain and strategy to relief pain, helping the patient to set a position and delivering pain medication.

However, it seemed that the reaction to the patient's voice was changeable. This behaviour would learn by both the patient, family caregiver and health care providers in interpreting the objective of the moaning and taking appropriate action based on this expression. Malee's husband seemed to take quicker and more suitable action, such as in helping the patient to change her position. Whereas in the nurse's reaction, perhaps due to the process of perceptual habituation, seemed less focused on the

patient's moaning. They would go to the patient's bed regularly instead of every time that the patient moaned. The nurses gave the reason for this was that it was not every time that the moaning indicated pain. Sometime the patient just made her voice to release her pain or to find help from her family. However, the nurses informed that they would teach the patient about pain assessment and how to express pain as moaning without disturbing other patients.

The reaction of other patients admitted in the same ward seemed, at first, to express interest in Malee's pain but the attention decreased, to be replaced by a feeling of dissatisfaction when the moaning continued. Finally they ignored this noise by closing their ears or turning away from Malee.

### ***1.3.2 Cancer pain management***

#### **1.3.2.1 Management by self**

By observation, it seemed that pain management was not to be dominated by Malee. She asked for help from her husband or her relatives in every activity. She gave the reason that it caused her severe pain resulting in she could not do anything by herself. In this situation, it was found that pain management was mostly led by her family.

#### **1.3.2.2 Caregiver**

Malee's family caregivers were a crucial factor for pain management including the caregivers' assignment of delivering care and home care. Malee's husband was the main caregiver both in hospital and at home. Malee's husband explained that it was the responsibility of the husband to take care of his wife, so he expected to provide most care for the patient. Moreover, he knew that the patient had pain. She could not do self-care properly. He needed to do everything that could help her better. His caring provided benefit not only for her general physical health but also for her emotion. He observed that if Malee had pain, she would be moody and her pain seemed to increase, stressful atmosphere in the family was generated as a result.

### **1.3.2.3 Decision maker**

Although Malee's husband was the main caregiver, he seemed to have had less authority to make decisions about her well-being than did Malee's father. Malee's husband gave his opinion that he had just married Malee and they then moved to another province. Therefore making a relationship between himself and his wife's family was difficult. Moreover, the new position in the family as son in law might affect the way he could or could not show his opinion and his authority.

### **1.3.2.4 Mental support**

Mental support was mentioned by the patient. All during the time of admission, Malee's husband always stayed with her. Malee explained that she had severe pain and she needed help to move or do any activities. However, when she rested she still needed to see her husband all the time, when she would ask for help or talk to him. This made her feel emotional warmth and help her refrained from feeling lonely.

### **1.3.2.5 Care at home**

Malee's family members asked to take Malee home. Malee gave her perspective that, at home, her relatives and her neighbours could visit her very often. There would be no restriction of visiting like in the hospital. She was happy due to the cares provided by her family. She still had pain but she preferred to control the pain at home.

When Malee was discharged from the hospital, she lived in her father's house due to more caregivers being available to care for her 24 hours a day. Malee's father's house was a detached house with small garden. The house was built from brick and cement on the ground floor and from wood on the first floor. The ground floor consisted of one spacious room in the front of the house, a kitchen and toilet in the back. The upstairs was to be bedrooms. The big room in the ground floor was a place for multi-purpose activities such as family's meetings, having dinner, or having a party with neighbours. The area of the house was fenced by barbed wire-fences on three sides, the lateral sides and the back. The front of the house has no fencing, which made it comfortable for neighbours to visit or to have

a chat. This house's structure is similar to those generally found in Thai villages.

There was a certain re-arrangement of home furniture in order to better care. Her bed was moved to the ground floor and located closed to a wall. A hand-rail was hung down from the ceiling in which Malee could hold and which could assist her to sit up by herself. Drugs, water and all necessary containers were put on a small table placed beside the bed, allowing the patient easily to access and take her medication. This design provided the patient with the ability do all activities on and from the bed. In addition, there was more space for the caregivers to take care of the patient and for the relatives or neighbours to visit the patient conveniently.

Malee provided her opinion on taking her home that this decision was not only to generate a feeling of warmth by receiving family care, but it could also provide benefit to the family in saving expenditure for travelling and daily living while she was admitted in the hospital.

#### **1.3.2.6 Traditional and alternative medicine**

Alternative and traditional strategies were presented in Malee's pain management before she was admitted. Malee's father found many kinds of traditional strategies in order to release her pain. According to the local belief of this area of the Naga, her father took some amulet from the Naga shrine in the expectation that the magic power would cure the cancer and relieve the pain. Her father also recommended her to drink the magic water, believing that it came from the Naga. Some relatives and some neighbours recommended to try many different herbs or alternative medicines. These strategies were not only to relieve pain but also to improve health in general. Malee said that she did not know whether these strategies could help her but it might be better than doing nothing.

#### **1.3.2.7 Conflict of care**

There was some inconsistency between the patient's needs and health care professionals' management in relation to the care. The patient listened to the advice but she did not seem satisfied. Regardless of the health care providers caring for Malee based on the principles of nursing but it seemed not meet the patient's and her family's needs. Malee claimed that

the nurses cannot give a help, or perhaps did not, they just came to ask about her situation, examine and give some advices, but did not give anything to relieve the pain. In contrast, the nurses argued that there was an obstacle in communication with the patient especially on pain assessment. The patient could not tell how much pain she had in which this would make it difficult to make a decision about the delivery of care or medication. This might be due to the pain situation being so severe that it prevented the patient from obtaining information from the nurse or from being able to appraise her pain precisely.

In addition, the need of patient and also family was to diminish the pain immediately but the nurses could not follow that requirement due to they have to follow the prescription. Therefore there seemed to be a certain amount of conflict in the provision of care due to non-corresponding needs.

#### 1.4 Summary of cancer pain management

From Malee's case, the key aspects related to cancer pain management can be summarised in term of the themes, as shown in the table below.

Table 4.2 Malee's cancer pain management themes

Themes	Sub-themes	Description / comment of themes / sub-themes
1. Perception	1.1 Symptom / Disease perception	The patient mentioned that death might be better than pain.
	1.2 Patient: Need assessment: caring/treatment	The patient claimed that at previous admission she could take care of herself with low pain but in this time of admission she needed helps from others because the pain was very severe.
	1.3 Family: Need assessment	A discharge plan was urgently required for Malee due to her family needed to go back home

Themes	Sub-themes	Description / comment of themes / sub-themes
		immediately after making their decision.
2. Taking action	2.1 Pain communication	Pain seemed to be the major problem in this patient that was communicated by her moaning almost all the time.
	2.2 Pain communication: non-verbal (implicit expression)	The patient's moaning was a way to communicate her pain and to show how much pain she had through the frequency and level of her voice. This expression seemed effective as the patient did not ask nurses, and also her caregiver, directly about her pain.
	2.3 Communication	There was no main receiver to get information process from the nurse so providing information was altered based on the current situation. From this, the effectiveness of the discharge plan was questioned.
	2.4 Pain: Medication	There were some conflicts within care for Malee. The main cause was to be the inconsistency of need between health care providers and the patients/family. (the standard care by nurse and outstanding care by PT)
	2.5 Pain: Alternative and traditional strategies	The most important strategy was related to the Nagas that was the local belief of residents in that area.
	2.6 Family support:	The most important caregiver was

Themes	Sub-themes	Description / comment of themes / sub-themes
	Caregiver	Malee's husband both in hospital and at home. However, in Malee's family, her father was the main decision maker.
	2.7 Family support: Mental support	Family empower the patient for receiving treatment and managing the pain.
	2.8 Home care planning: re-arrangement	This re-arrangement could provide benefits for both Malee to take care of herself and caregivers to provide care for her.
	2.9 Home care planning: care at home	This might provide the closed care by family members and generate an emotional warmth feeling for Malee.

## Case 2 : Junjira

Junjira was studied for six weeks (from May to June 2011) and had a home-visit which was arranged in mid-July 2011. She also had an interview arranged in August 2011. The findings are presented as follows: the background of Junjira's family, her disease summary and her cancer pain experience both in hospital and at home.

### 2.1 Junjira's background and social circumstance

Junjira has four siblings including two younger sisters and one younger brother. Junjira's sisters are married and live with their own families. Junjira's brother, who is single, moved to live with his mother in the mother's house when the father died 5 years ago. The summary of Junjira's family is illustrated in the family tree below.

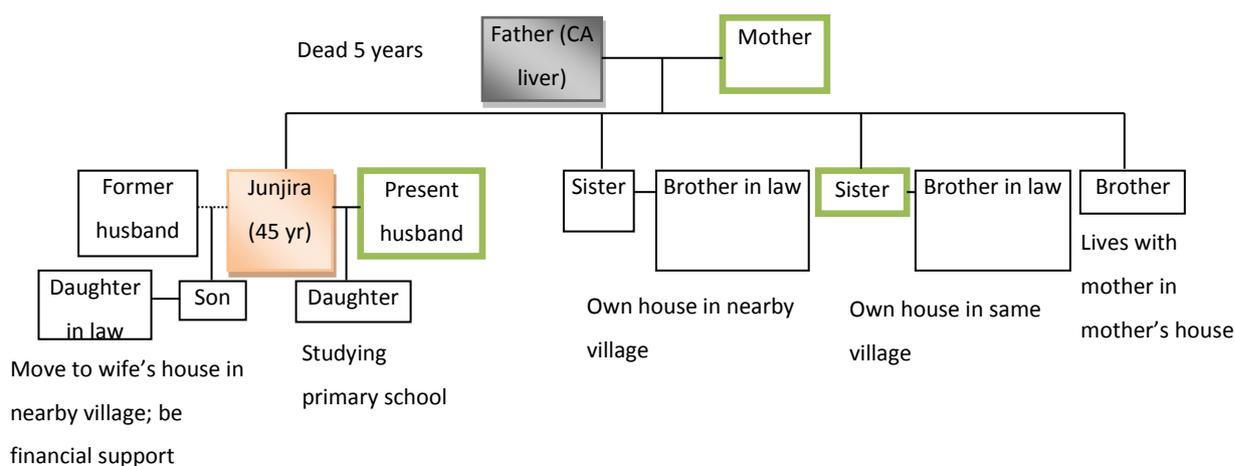


Figure 4.3 Junjira's family's tree

Junjira had been married to her former husband and was then divorced 15 years ago. They had one son who was 21 years old at the time of this study. Junjira's son was married and had moved to live with his wife in another village. Her son would visit her every month. He did his freelance job and provided some financial support to Junjira.

Junjira had been re-married and had a daughter. Her daughter was 12 years old and was studying in the village primary school. Junjira, her husband and her daughter owned their house in the nearby village. The house was approximately one and a half kilometres away from her mother's house. Junjira and her husband did various freelance jobs in which some of which they had to do in other provinces. The income was inconsistent. It just was only enough for daily expenditure, not for saving.

## 2.2 Junjira's disease summary

Junjira had signs of cervical cancer since November 2009. The summary of her disease is shown in the table below.

Table 4.3 Junjira's disease summary

Time	Events
November 2009	Junjira had back pain. She went to a variety of clinics, took anti-inflammatory drugs and some analgesics. Then she had an abnormal period. She went to her local hospital for a cervical biopsy.
December 2009	Junjira was diagnosed with cervical cancer. She was referred to the cancer centre and was added to the waiting list for treatment.
February 2010	Junjira was admitted to the cancer centre for six weeks for treatment including radiation therapy and chemotherapy. Junjira had mild to moderate pain. She took morphine tablets and paracetamol in hospital and continued taking those drugs at home. During this admission, Junjira did not have a caregiver to stay with her in the hospital.
April –August 2010	Junjira had two follow-up appointments. She still had mild pain and took morphine tablets and paracetamol prescribed by the hospital physician.
October 2010	Junjira missed her follow-up appointment due to personal reasons.
November 2010	Junjira had back and leg pain. She used many strategies to treat herself including taking the analgesics prescribed by the hospital physician, using herbs and alternative medicines, as well as performing rituals recommended by relatives and neighbours. She also went to the local hospital, took anti-inflammatory drugs and analgesics prescribed by the hospital physician.
December	Junjira had more back pain so she went to the general hospital. She had an X-ray to examine the waist and hip, and was diagnosed with bone metastasis.

Time	Events
2010	Then she was referred to the cancer centre but she did not go immediately due to money problems. She still had chest and back pain for which she simply took analgesics bought from a drug store.
January 2011	Junjira went to the local hospital when her pain increased. She had a chest X-ray that showed two masses in her left lung. She was referred to the cancer centre and found that the cancer was recurrent. She was added in the waiting list for radiation which she would receive within four months.
May 2011	Junjira was re-admitted to the cancer centre with severe pain at left side of her chest. She was treated with analgesics, an anti-depressant and an oral morphine, having additional morphine injections, and ten treatments of radiation therapy. During this admission, her husband was the caregiver in hospital.
June 2011	Junjira was discharged. She was booked for chemotherapy in the out-patient department once a week for three weeks. During this treatment, she had severe chest pain for which she received morphine injections. The physician also prescribed oral morphine for her to take at home.
July 2011	The second chemotherapy was postponed as Junjira was unwell.
August 2011	Junjira completed the chemotherapy but she still had mild pain. She continued taking oral morphine from the cancer centre to control the pain.

## 2.3 Cancer pain perspective and management

### 2.3.1 Perspective and expression about cancer pain

Junjira claimed that her pain at this time was more severe than the prior admission. At the beginning of the disease, her pain was mild to moderate. She could go to many clinics for investigation and finding treatment by public transport. The pain was controlled by a variety of analgesics prescribed by the physicians attached to those clinics. When Junjira was referred to the cancer centre for admission, she and her husband still travelled to the hospital by public transport.

When the admission process was completed her husband left Junjira alone in the hospital, so he could continue his job because it was appraised that Junjira could do most activities by herself.

### **2.3.2 Cancer pain management**

#### **2.3.2.1 Management by self**

Junjira would be patient with that pain, if the pain was mild, or around five to six out of ten, but if the pain increased she would ask for medication from the nurses. To deal with mild to moderate pain, Junjira used various ways such as deep breathing, rest and avoiding movement. Junjira changed her position carefully and found the best position for rest. It did not mean that same position used previously could make her feel comfortable this time. Junjira tried to sit up and walk by herself. Whether Junjira had pain, she would go outside and sit on a chair within the corridor area because she needed to change her environment rather than just rest on the bed.

Junjira tried to do everything by herself and asked for help as little as possible. She explained that a person should take care of oneself as much as possible. This would increase one's value and would be socially acceptable. She claimed that sometimes she needed to consult health care providers about her symptoms and to ask how to solve her problems, but she was quite reluctant to call. She gave, as her reasons for this, which she was afraid to get difficult or complex information in case she misunderstood the information due to her minimal education, as well as not knowing how to ask or raise her questions.

#### **2.3.2.2 Caregiver**

During that first, Junjira had mild to moderate pain in which the pain could be controlled by using an amount of analgesics and mild opioids. Junjira could care for herself quite well. She did not have any caregiver stayed with her in the hospital.

In this second admission, Junjira had recurrent cancer with severe pain. Junjira could not travel by any public transport because she would have had even worse pain. Junjira and her husband agreed to ask for help from Junjira's sister and her brother in law to take Junjira to the hospital because they had their own car. Junjira said that she felt 'Kreang Jai' to ask for this help as it would disrupt their works routine and they also spent money for various things on each journey. Junjira

needed her husband to stay with her in hospital to provide some caring for things that she could not do by herself. She would look for help from her husband rather than asking the staff for help. When she needed to go to the toilet, she would look around the ward in order to find her husband, regardless of whether a staff stood near her bed.

Junjira's husband informed that he provided daily living and general helps such as changing position, food serving at the patient's bedside, massage, providing care for the patient to do daily activities and doing things that the patient asked. He claimed that massaging could not help the patient; he just did it because it was better than doing nothing. He did not know what else to do that might help his wife.

#### **2.3.2.3 Decision maker**

Junjira's mother took action as a listener but her voice was quite important due to her position as mother and as centre of care for Junjira at home. Mother was the oldest person in the family in which everyone should, and was expected to, follow her advice. Junjira's sister and her husband seemed to be key persons in some decision making, especially in relation to travelling by their own car. The travelling was not only travelling to the cancer centre, but also was going to many places in relation to treatment such as the general hospital, as well as some temples and other places of worship. Their opinions about how to go and how much was the cost of travelling, were important to consider.

Junjira's husband seemed not to be a key person for making decisions. But there seemed to have been some conflict among family members, especially between Junjira's mother and Junjira's husband, the mother's son in law. Therefore, he tried to decrease this conflict by avoiding showing any dissenting opinions.

Decision making seemed to be led by one of the family members who had the best financial status. Because many activities in relation to care for the patient such as traveling, buying medication and daily living expenditure needed money support, so the person who provided money had to be the main decision maker.

#### **2.3.2.4 Mental support**

Junjira's mother and sister said that they observed Junjira's behaviour and might ask her need for help sometimes. They just provided food and drugs as

routine. They did not ask about her pain or about the drug too much because they did not want to lead Junjira to focus on her pain and worry as a result. Junjira informed that she knew that her activities were observed by the family. She tried to care for herself as much as possible and did not express her feelings openly, particularly about whether she had pain. She felt good with this behaviour because they did not focus too much on her symptoms, otherwise she might worry and feel less confident to do many things by herself. In the night time, Junjira's daughter and her husband took responsibility to care for her.

### **2.3.2.5 Care at home**

Junjira lived with her mother which differed from the first admission in that then she lived with her family after discharging from the hospital. Previously, Junjira could do daily activities closed to normal living and took analgesics if she had pain occasionally. But this time, she had worse pain. She had to take analgesics and opioids, as prescribed by the physician, at home regularly. Junjira needed help which she could receive in her mother's house where they were more caregivers available.

Junjira's mother's house, which has been built from brick and cement, had only one floor. The ground floor was a spacious room that was divided to be bedroom corner on the left, living room corner on the right, and multi-purpose activities area in the middle. A kitchen and a toilet were built as small cabins located in the back of the house separately. Both lateral sides and the back of the house were fenced by mixed barbed wire and hedge. There was no fencing in the front of the house, which made it comfortable for neighbours to visit or to chat. In the front of the house was a small hut, a place where one could sit and rest. There was no re-arrangement of furniture except for putting in a sofa bed for Junjira to rest in the daytime. This sofa bed made it easier for Junjira to stand and walk if she was ever alone.

Whether Junjira lived in her mother's house, because there were caregivers staying with her all day, nobody had the role of a key caregiver due to those members being available at different time. Family management for taking care of the patient at home involved caregiver assignments both in the day time and the night time. During the day the caregivers were mostly the patient's mother and

sister but if they could not provide the care, the husband had to stop his job and occasionally cared the patient, his wife. Actually, Junjira did not want to ask for help from her mother or her sister due to she felt 'Kreang Jai' if she would ask for the elderly or other people to leave from their job to help her.

Junjira's brother was one of the family's members in the mother's house. He was a cook who had a food store in a primary school. His support mainly took the form of providing his opinions during discussions and providing some financial support.

#### **2.3.2.6 Traditional and alternative medicine**

From the conversation in this visiting, Junjira told the researcher during the home visit that she used to 'SUK' on her body with pain, back and legs. 'SUK' is a local strategy of applying a needle on skin like tattoo without colour in order to relief pain. She claimed that she tried this strategy because it seemed not be drawbacks. Finally, she evaluated this strategy that it had some benefit in the short term and then the pain came back in a few days so she tried this only once. Moreover, many relatives and neighbours informed her of many ways to treat the disease and also relieve the pain. Using herbs, both eating and applying on the pain site, seemed the most popular suggestion. She chose some of those which sounded effective and worth for spent money. Praying and performing rituals in order to treat the disease and release pain was also done with the hope that these practices could help. Junjira claimed that these might result in nothing happening but it was better than doing nothing. These might be the ways that the patient used to maintain her mental health.

#### **2.3.2.7 Conflict of care**

Most ways that Junjira communicated about pain to nurses was answering their inquiries when the nurses came and asked. The reason why Junjira preferred not to ask for help from nurses was that she was afraid to receive bad responses from them. Therefore if the pain did not seem much more then she would be patient and she would not communicate anything to the nurses. However, Junjira said that she needed more attention from nurses and would have greatly appreciated it if the nurses would ask her about her symptoms more often.

Junjira said that she felt better when receiving explanation from the physician whether the physician did not tell everything to her. Actually Junjira needed more information, she claimed, but she felt 'Kreang Jai' to ask questions of the physician due to the physician looked busy. Nurses who provided care for Junjira argued that, in the later admission, it was more difficult to deal with the patient's and family's needs. This problem might have been caused by the progression of the disease, worry about the disease and symptoms, the experience of the patient in previous treatment and using analgesics and opioids.

Junjira wondered that why the second admission she was treated by radiation just ten times of the fractionation schedule. The positive result from the last radiation therapy led her to hope that radiation could help her again. She worried that how this short period of treatment could help her. Junjira claimed that she had experienced more pain severity than previously but the physician just gave her Paracetamol. Junjira stated that this drug could not relieve her current pain. The nurse informed Junjira that this was the start of new regimen; the revision was done afterward based on the patient's symptoms. However, the nurse observed that Junjira seemed dissatisfied with this treatment.

It seemed that psychological factors may have affected her ability to receive information. The nurse claimed that Junjira looked and really was so worried about her disease in this admission, as manifested by my observation that Junjira cannot pay attention when the nurse talked to her. This factor might influence the patient's ability to get the full information she need which, in turn, would decrease Junjira's ability to care for and manage her symptoms.

Junjira's husband informed that there were many worries, which included the patient's symptoms of pain, interference from doing work and a lack of money to support daily living. He tried to push the patient to do activities by herself in order improve her self-care ability in which he could return to his job and earn money.

Junjira and her family worried about how to self-care at home, in particular they were afraid that the pain would return. She was worried about issues: that the drugs could not stop pain continuously, how to deal with pain if the drugs could not stop the pain, and how the local health service could deal with this problem.

Although Junjira used the standard patient's health insurance, she spent money on additional traditional treatments, buying drugs, travelling, and living

costs. She encountered financial problems in which her relatives could not provide fully support. Her husband did various freelance jobs in which the wage was quite low and work was not available on a regular basis. Junjira was being in debt to some private financial creditors. She told me that this money problem affected her treatment, and that she did not know how to deal with this issue.

#### 2.4 Summary of cancer pain management

From those findings of Junjira, the vital aspects around cancer pain management could be summarised in term of the themes is shown in the table below.

Table 4.4 Junjira's cancer pain management themes

Themes	Sub-themes	Description / comment of themes / sub-themes
1. Problem solving	1.1 Self-solving 1.2 Find help	Junjira informed her plan to deal with pain that if the pain was mild, or around five to six from ten, she would be patient with that pain, but if the pain increased she would ask for medication from the nurses. Junjira tried to do everything by self and asked for help as little as possible.
2. Decision making	2.1 Factor related to treat/care: responsibility to self-care	The reasons were that a person had responsibility to take care of one-self, to increase one's value to get acceptable in society and to avoid looking down and looking to be different from others who live in the village.
	2.2 Factor relate to treat/care: better than do nothing	Junjira claimed that although nothing happen, it was be better than doing nothing.
	2.3 Factor related to treat: trustworthiness	Junjira got different diagnoses from the physicians. Therefore, she met many physicians in order to find more investigations to confirm her

Themes	Sub-themes	Description / comment of themes / sub-themes
		diagnosis.
	2.4 Decision maker	<p>For decision making for doing a thing with Junjira, it seemed that nobody acted as a decision maker precisely. A decision was usually made from discussion among family members, the most appropriate solution would be the final.</p> <p>Junjira's sister and her husband seemed to be key persons in some decision making, especially in relation to travelling. Junjira's sister was one of caregivers at home and her husband had a car to provide travelling for Junjira.</p>
	2.5 Factor related to communication	<p>Junjira needed more information, but she felt 'Kreang Jai' to ask questions to the physician. Most way that Junjira communicated about pain to nurses was by answering when the nurses came and asked. A reason offered by Junjira as to why she preferred not to ask for help from nurses was that she was afraid to receive bad responses from them.</p>
3. Taking action	3.1 Pain: Alternative strategies	<p>Junjira told that she looked for many strategies to treat cancer and diminish her pain including 'SUK', using herbs, praying and performing rituals.</p>
	3.2 Family support: Caregiver Home care planning	<p>Junjira lived in her mother's house because there were caregivers staying with her all days. However, she had nobody to be a key caregiver due to</p>

Themes	Sub-themes	Description / comment of themes / sub-themes
		those members having different available times. Family management for taking care of the patient at home were caregiver assignment in the day time and the night time.
	3.3 Family support: Travelling	Travelling choices depended on Junjira's health status. If her symptoms were not too bad, she could travel by public transport. Junjira's brother in law had a car to provide travelling for Junjira. He had his own small business, so Junjira had to book his time if she needed his help to travel.
	3.4 Family support Financial support	Junjira got financial problem in which her relatives could not provide fully support. Her husband did various freelance jobs for which the wage was quite low and inconsistent. Junjira was in debt to some private financial creditors. Junjira's brother and her sister provided some financial support occasionally. This financial problem was discussed in family meetings sometimes in order to find a solution but it had still no proper answer.
4. Perception	4.1 Symptom / Disease perception	Junjira mentioned about cancer pain that death might be better than pain due to her suffering.
	4.2 Impact of pain: Attention	She claimed that she could not pay attention to other, just the pain.
	4.3 Impact of pain: Emotional / social	She needed to live alone, to go away from society, did not need to see people (other people did not know

Themes	Sub-themes	Description / comment of themes / sub-themes
		what she was).
	4.4 Effectiveness: Medication	Junjira thought that oral drugs cannot help to control severe pain. The drugs just decreased her pain and maintained it at low level, but did not diminish her pain.
	4.5 Health care provider: Need assessment	<p>It was more difficult to deal with the patient's and family's needs. The patient needed an injection rather than oral medication due to thinking that this could stop pain.</p> <p>This problem might have been caused by the progression of the disease, being worried about the disease and symptoms, and the experience of the patient in previous treatment and using opioids.</p>
	4.6 Patient: Need assessment  Family: Need assessment	<p>Junjira needed her husband to be a caregiver in the hospital but her husband wished to go back home because he needed to do work and gain money. He said that he was quite bored due to less work to do here. Therefore when he appraised that Junjira was better he tried to push the patient to do activities by herself in order improve her self-care ability.</p>

### Case 3 : Sompon

Sompon was studied for eight weeks (from mid-May to July 2011) and had a home-visit which was arranged in mid-July 2011 after she was discharged from the cancer centre. She also had an interview that had been arranged for the end of July 2011. The findings are presented as follows: the background of Sompon's family, her disease summary and her cancer pain experience both in hospital and at home.

#### 3.1 Sompon's background and social circumstances

Sompon was the last of six children including three elder sisters and two elder brothers. Her father died 10 years ago. Her mother lived with an elder sister in the mother's home in north eastern Thailand. Sompon's family is illustrated in the family tree below.

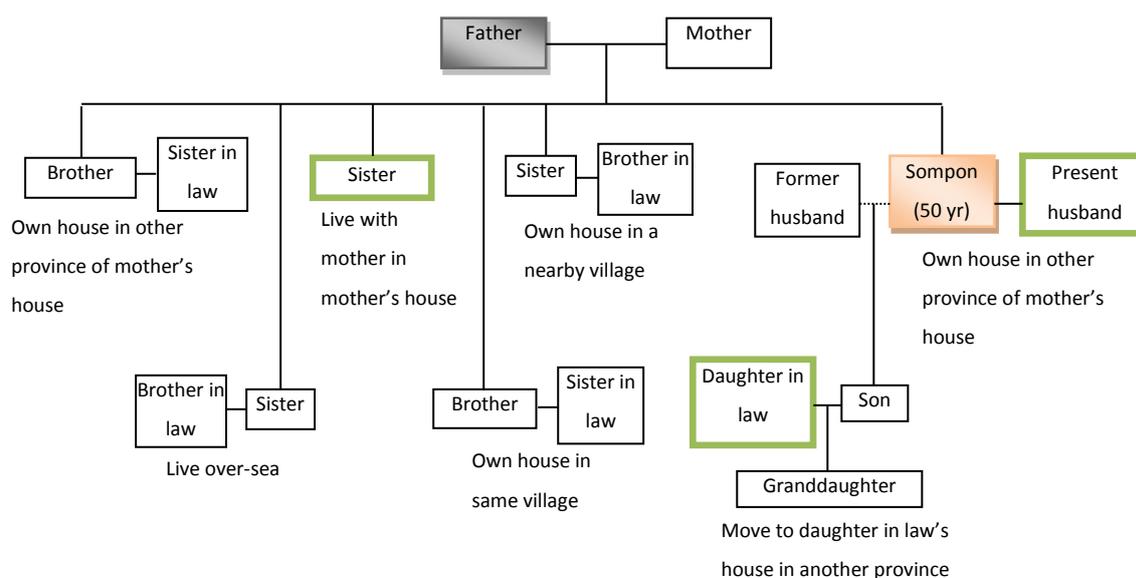


Figure 4.4 Sompon's family's tree

Sompon was married and then divorced ten years ago. She lived with her mother and her sister in the mother's house. Sompon worked as a masseuse for 20 years in many places. The income was fair but inconsistent, but it was enough for daily living. She also gave money to her mother irregularly. She had a small amount of money in the bank for emergency purposes.

Sompon had a son with her first husband. Sompom's son was a soldier who was working in the south of Thailand. He married and had a child. His wife and child lived with his mother in law in another province during the time he went away for working. During the period of time that Sompon was admitted in the hospital, her daughter in law was her caregivers.

In 2005, Sompon married her current husband who was a cook in a restaurant and she moved to live with him in another province, approximately 120 kilometres away from Sompon's mother's house. She did not have child with her current husband. One year later, Sompon and her husband moved to work in an island in the south of Thailand to earn more money. Then two years later they moved back to their home town due to Sompon's disease.

### 3.2 Sompon's disease summary

Sompon argued that she had signs of abnormality since 2003 when she had worked as a masseur for ten years. The signs and symptoms of cervical cancer were clearer in 2008. The summary of her disease is shown in the table below.

Table 4.5 Sompon's disease summary

Time	Events
Mid-2003	Sompon had back pain. She did self-massaging and took analgesics bought from drug stores in order to decrease pain but the pain still occurred repeatedly.
2005-2006	Sompon married her present husband and moved to another province to run their own restaurant. They then moved to work in an island in the southern region, Sompon as a masseuse and her husband as a cook. Sompon had back pain and fever. She went to the local hospital and was diagnosed with a kidney infection. She took antibiotics and analgesics prescribed by the physician at home
2007	Sompon had the kidney infection again. She was admitted to the local hospital for four days and continued taking the same drugs at home when she was discharged.
2008	Sompon visited home. She received the vaginal examination due to the community campaign. There was an abnormal finding so she had a cervical

Time	Events
	<p>biopsy, the result showing cervical cancer. The physician recommended to have a surgery but Sompon disagreed due to she did not trust the diagnosis. She went back to work.</p>
Mid-2010	<p>Sompon and her husband moved back home due to the natural disaster concern. They owned a small restaurant.</p>
September 2010	<p>Sompon visited her mother. She had severe period but the symptom stopped in a few days so she did not see a doctor at that time.</p>
January 2011	<p>Sompon had hypermenorrhea with clot but she still did not see the physician.</p>
February 2011	<p>Sompon had hypermenorrhea again and also had back and leg pain. She was admitted to a gynaecological ward of the general hospital. She underwent many tests (X-ray, blood test, procto-cysto scopy) and was diagnosed with cervical cancer. She was referred to the cancer centre and was added into the waiting list for radiation.</p> <p>During waiting for treatment, she lived in her mother's house due its location close to the cancer centre. She had pain and took analgesics and tried many ways to decrease the pain (massaging, exercising, supplementary medicine, herbs, traditional medicine recommended by relatives).</p>
April 2011	<p>Sompon was admitted to the cancer centre having severe vaginal bleeding. She received the treatment of fractionation schedule of radiation therapy (28 times) and chemotherapy (3 cycles) for 2 months.</p> <p>Sompon had low abdominal pain, back and legs pain in which the pain was controlled by an amount of analgesics. The pain was more severe so the regimen was changed to oral morphine and morphine injections. During admission in the hospital, Sompon mostly lived alone.</p>
Mid-June 2011	<p>Sompon was discharged and was appointed to receive the treatment with brachy-radiation therapy in the out-patient department (3 times). She lived with her mother during this period of treatment. Her husband took Sompon to the hospital for the treatment.</p>
August 2011	<p>Sompon moved back her home upon the completion of all treatment. She had a follow-up every 3 months. Sompon's husband would take her to to the centre every time. Sompon still had mild pain occasionally. The pain was</p>

Time	Events
	controlled by taking two kinds of oral analgesics.

### 3.3 Cancer pain perspective and management

#### 3.3.1 *Perspective and expression about cancer pain*

Sompon shared her experience about her disease, stating that at first she did not believe that she was diagnosed with cervical cancer. She told that in 2008 she got a vaginal examination with Pap Smear, without any symptoms. A nurse told her that the smear had an abnormal sign related to cervical cancer. The nurse suggested further investigation at the general hospital. A physician recommended having surgery but she did not agree because she did not believe the diagnosis. She did not have any abnormalities and she could not trust a physician who had so little confidence.

However Sompon found that there were signs of abnormality related to that disease. Next five months, September 2010, Sompon had massive period with some blood clots and had much period pain. But she did not go to see a physician due to financial problem. Finally, she had more severe bleeding and period pain to the extent that she could not rest, as well as pain in her legs, so she went to the hospital in February 2011.

Sompon was admitted at the gynaecological ward of the general hospital. The physician informed Sompon that she was diagnosed with cervical cancer. Sompon explained that she believed in the diagnosis and agreed to receive the treatment because there were signs and symptoms of cervical cancer. Moreover, her symptoms looked severe so she felt she needed a cure as soon as possible.

Sompon's opinion about the physician was that she believed in his treatment and preferred to follow all regimens; because the physician looked confidence on his professionals and he had long term experience on this area.

### **3.3.2 Cancer pain management**

#### **3.3.2.1 Management by self**

Sompon tried to relieve her pain by warm pack, self-massaging, doing exercise, correcting her position and supporting the pain area. If the pain increased she would take medicine bought from a drug store but the drugs might not diminish the pain, or just release the pain for a while. Then she tried taking anti-inflammatory drugs, which helped for a week but then the pain came back again.

In the hospital, Sompon used exercises and self-massaging to relieve mild pain. If the pain was more severe, she asked for taking analgesics from the nurses. The physician prescribed an amount of mild opioids and paracetamol to control the pain. The pain seemed to be controlled by those regimens but when the course of this regimen was finished Sompon had much pain again. Sompon shared that she did not want to take the drugs too much so she tried to relieve the pain by using those previous strategies; however, it seemed not to be effective. Finally, she told the physician about her pain and the physician revised his pain regimen for her. For this time the regimen consisted of a strong opioid and an analgesic.

Sompon appraised her ability to care for herself declined when the pain increased. She could not do many things as usual. But she tried to and trained herself to be a stronger by doing exercise. She tried to do many things as she did not want to be a burden for others. However, sometimes when she was in the hospital without a caregiver, for example when she got a blood transfusion, a caregiver of another patient beside her provided help for Sompon such as delivering a food dish or bed pan to her. Sompon claimed that she felt 'Kreang Jai' (a feeling of did not wanting to be a burden or to receive helps or things from others) but it was necessary to be a burden. So she tried to do something to help her as much as possible.

#### **3.3.2.2 Caregiver**

During admission, Sompon did not have caregiver because nobody in her family was available to care for her all the time at the centre. Sompon's husband took her to the hospital and he went back home to continue the restaurant to earn money. Her daughter in law lived with Sompon only in the first two weeks of admission, and then she leaved Sompon in the cancer centre in order to care for her baby at home. As a result, Sompon had to live alone intermittently. Her husband

visited her once a week if possible. He could not stay because he had to continue his business.

### **3.3.2.3 Care at home**

During waiting for the treatment, Sompon moved to live with her mother because the house was located close to the hospital and there were more family members who could provide care for her. Her husband still worked at his own home in another province. He visited Sompon in weekend. Sompon still had mild to moderate pain. She took analgesics prescribed by the physician from that hospital. She could do some daily activities but her mother and sister who lived in the mother's house asked her to rest.

### **3.3.2.4 Traditional and alternative medicine**

Sompon tried some alternative medicines made from many kinds of local herbs, some containing an alcohol substance. These could not help her to get well in general but these just served to release her pain for a while.

### **3.3.2.5 Conflict of care**

Sompon admitted that she was afraid to take the strong opioid. She said she did not want to depend on the drug so she raised her worry to the nurses. The nurses gave her about opioids information and described their side effects. They would discuss this concern with the physician and they also suggested that the patient should inform the physician directly.

Sompon claimed that she felt 'Kreang Jai' to ask nurses because she thought it was a small thing to do which she could do by herself. She would ask them if necessary. Sompon informed the researcher that she understood that the number of nurses was few and each nurses had much to do. So she would only ask them if she really needed help.

Sompon felt that the nurses could help her to talk with the physician because the doctor was quiet and did everything very quickly; she could not talk to him easily or clearly. If possible she needed someone to talk to the physician for her as a co-ordinator. Sompon argued that she had no opportunity and was not brave enough to talk to the physician. She was afraid to disturb him and perhaps cause disruption to his busy schedule. So if nurses could help her about this, it was very good.

### 3.4 Summary of cancer pain management

From those findings of Sompon, the vital aspects around cancer pain management could be summarised in term of the themes as shown in the table below.

Table 4.6 Sompon's cancer pain management theme

Themes	Sub-themes	Descriptions / Comments of theme / Sub-themes
1. Problem solving	1.1 Self-solving / Find help	Depends on the severity of the patient's symptoms. If the patient felt better the need of care from caregiver was less. However the patient still needed someone to stay near her so she could ask for help any time. Buy drug from drug stores; Refrained from heavy activities
2. Decision making	2.1 Factor relate to treat/care: Responsibility to self-care	Don't want to be a burden led the patient try to do activity by self 'Kreang Jai' referred to a feeling of not wanting to be a burden or receive helps or things from others was an important factor that led the patient to try to do self-care.
	2.2 Factor related to treat: Trustworthiness	Acceptance of the diagnosis was affected by trustworthiness of the physicians' personality that should show their knowledge and confidence in their professional. First impression about performing his/her characteristic as a professional affects trustworthiness and decision making to treat or to follow the recommendations or suggestions.
	2.3 Factor related to treat: Severity	The abnormality of the disease (signs and symptoms) was the vital evidences that led the patient to

Themes	Sub-themes	Descriptions / Comments of theme / Sub-themes
		<p>agree with the diagnosis.</p> <p>The decision making process would be affected by the severity of the symptoms and its disturbance as well as the financial status.</p> <p>Depends on the severity of the patient's symptoms.</p>
	2.4 Factor related to communication	<p>'Kreang jai' might be a barrier for communication about the pain to health care professionals.</p> <p>Factors affecting communication between the patient and health care provider included health care providers' personality as friendly or quiet, health care providers' behaviours / activities in each situation such as looking relaxed or looking hurried.</p> <p>Sompon said that she needed a nurse to act as a coordinator/ nominee to make contact with the physician.</p>
3. Taking action	3.1 Pain: Traditional medicine (massaging)	<p>The patient was a masseuse so she had knowledge and skill of massage so she used this strategy to relieve her pain. However, the effectiveness of this strategy was varied based on the severity of the pain.</p>
	3.2 Pain: Alternative medicine	<p>The patient tried many alternative medicines such as herbs, local medications and alcohol substance in order to treat the disease and decrease the pain.</p>
4. Perception	4.1 Symptom / Disease perception	<p>Sompon claimed that if the pain increased, it meant that the disease progressed.</p>

Themes	Sub-themes	Descriptions / Comments of theme / Sub-themes
	4.2 Effectiveness: Oral and injection	<p>Sompon wondered about the effectiveness of oral pain medication that had less effect than the injection.</p> <p>However, she was afraid to receive the injection too much because she was afraid to be drug dependent similar to an old woman that Sompon had heard about.</p>

## Case 4 : Narin

Narin was studied for 6 weeks (from June to July 2011) and had a home-visit which was arranged at the end of June 2011 when Narin was allowed a home visit during her admission in the cancer centre. The findings are presented in the following order: the background of Narin's family, her disease summary and her cancer pain experience both in hospital and at home.

### 4.1 Narin's background and social circumstance

Narin provided her background as she was 24 years old. She was the only daughter. Narin's mother divorced and moved to work freelance jobs in central Thailand since Narin was five years old, whereas Narin had to live with her grandmother and relatives in her hometown in the north east of Thailand. The summary of Narin's family is illustrated in the family tree below.

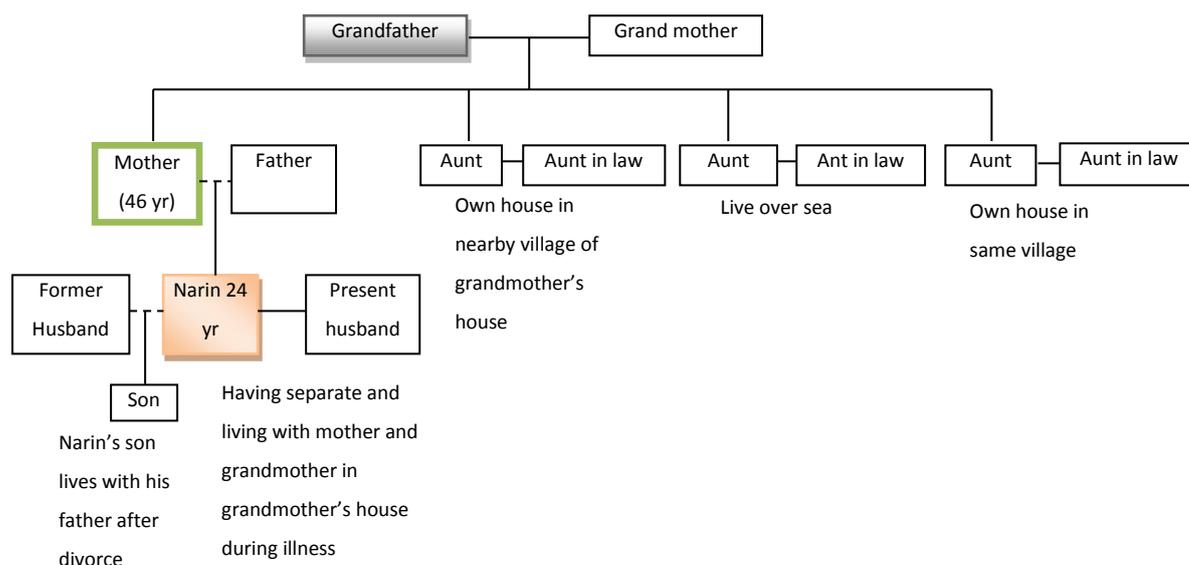


Figure 4.5 Narin's family's tree

Narin had one illegitimate son with her old boyfriend when she was twenty. The relationship between Narin and her old husband's family was bad so Narin separated from her husband in the next year, during which time her son lived with his father. Then Narin moved to live with her mother and did many freelance jobs. Last year Narin married her current husband. Three months later, she had problems

with vaginal bleeding. She blamed her husband that he was the cause of the disease. Narin needed to divorce but he did not agree. Narin returned to her home town and lived with her grandmother in order to ask for care and find treatments.

#### 4.2 Narin's disease summary

Signs and symptoms in relation to of Narin's cervical cancer are summarised and is presented in the table below.

Table 4.7 Narin's disease summary

Time	Events
2009	Narin worked in the central region of Thailand. She did not have her period for eight months due to the use of contraceptive injections for personal reasons.
May 2010	Narin married to her current husband. She stopped using contraceptive injection and then the period came irregularly. Three months later Narin had post coital bleeding. She took anti-inflammatory drugs and used the vaginal suppository bought from a pharmacist in a drug store but the symptom was not better.
June 2010	She had massive vaginal bleeding. She asked for her husband to take her to a hospital but her husband ignored her request.
August 2010	Narin returned her hometown and asked help from her grandmother for taking her to a hospital. She received a curettage procedure at the local hospital and was referred to the general hospital for having a procedure of cervical biopsy. She had an appointment to get the result in the next four weeks.
October 2010	Narin had herpermenorrhea but she did not look for treatment; she just observed the bleeding and rested at home.  Then she had severe dysmenorrhea. She was admitted to the general hospital. She received many dosages of analgesic injection. She was diagnosed with cervical cancer and was referred to the cancer centre.
November 2010	Narin still had massive vaginal bleeding and severe dysmenorrhea during the time she was admitted to the cancer centre. She was added in the waiting list for radiation therapy in which the treatment would be done in the next six weeks. Narin received an amount of coagulative drugs and analgesics prescribed by the physician to take at home.
December	Narin was admitted in the cancer centre. She received the treatment with 30

Time	Events
2010	fractionation schedule of radiation therapy (30 times) and chemotherapy (3 cycles). She also received the treatment with oral analgesics and oral morphine tablets to control the pain.
February-June 2011	When the treatment was completed, Narin was discharged and had an appointment to be treated with brachy-radiation in the out-patient department once a week for four weeks and then she had the follow-up the next month.
Mid-July 2011	<p>Narin had severe low back pain and an enlarged abdomen. She had an investigation with CT scan of the abdomen and chest in a private hospital. The finding showed the recurrence of cervical cancer with lung metastasis. She went to the cancer centre immediately for find treatment.</p> <p>During the second admission in the cancer centre, she had oedema of both legs due to the obstructive uropathy so she was referred to the general hospital to have ureterostomy and came back to continue admission in the cancer centre.</p>
End-July 2011	After Narin returned to the cancer centre, her ureterostomy leaked, causing the urine to irritated her skin. She had severe pain in her abdomen and back for which the physician prescribed her the oral analgesics and morphine syrup. Narin had difficulty taking oral medication because she had vomiting. So she received a morphine injection occasionally. Narin did not have the treatment for cancer due to poor kidney function and her general heath was not good.
Mid-August 2011	The physician had a plan for treatment with chemotherapy but Narin was not ready to have this treatment. Therefore, she asked to be discharged. The physician prescribed an amount of analgesics and oral morphine tablets for her to take at home.

### 4.3 Cancer pain perspective and management

#### 4.3.1 Perspective and expression about cancer pain

Narin informed the researcher that the first time she heard her diagnosis with cervical cancer from the physician of the local hospital she could not accept it. She claimed that she could not believe that she had the cancer because she was

young. She thought that cancer should occur in the old so she needed to confirm the diagnosis. During the time of preparing documentation for referral to the cancer centre, Narin went to a private clinic and a private hospital in order to have some investigations. The findings of those examinations from those hospitals showed the similar diagnosis. Therefore Narin had to accept that she had cervical cancer and started seriously to pursue information and treatment of cancer.

#### ***4.3.2 Cancer pain management***

##### **4.3.2.1 Management by self**

She explained that she tried to find the best position to rest but she could not stay in any one position for long time. For example, when she had rested in a position for thirty minutes, the pain would generate and she had to change to the new position.

The pain could be controlled by taking a kind of analgesic and oral morphine tablets. She could do many activities by herself such as walking, bathing and delivering food.

##### **4.3.2.2 Caregiver**

In the second admission, Narin had severe pain and had other complicated symptoms. Narin claimed that she had less ability to care for herself. She needed a caregiver to provide helps for her in some activities that she could not do by herself.

Narin's mother was the caregiver who stayed with her during the time of admission. She provided some help to Narin, such as massaging and buying some special food from the food shop outside the hospital. When the physician prescribed oral analgesics Narin could not take such drugs. She often vomited if she ate food or drank beverage. Her mother tried to find ways to help Narin in taking food and drugs.

##### **4.3.2.3 Mental support**

Narin's mother mostly took action as a mental supporter.

#### 4.3.2.4 Traditional and alternative medicine

Narin planned to try the treatment at a place that cared for patients with untreatable illnesses. The course of treatment of this place was the combination of modern medicine, traditional medicine and making religion merit. Narin felt that this would be better than doing nothing and this might help her to live longer. In addition, one of the purposes for trying this strategy was to improve her health status so she could return to receive the treatment from the cancer centre.

#### 4.3.2.5 Conflict of care

To control Narin's pain at moderate to severe level in the hospital, the physician prescribed an amount of oral analgesics and oral morphine tablets. Morphine syrup and also morphine injections were delivered if she had severe pain occasionally. She claimed that the oral analgesics could not provide benefit to decrease her pain. She just took them as the routine and sometime she did not bother to take those analgesics at all. This behaviour might affect the effectiveness of the pain regimen.

Narin argued that oral pain medicine was less effective compared to an injection. The oral analgesics could control the pain at low levels; however it could not diminish pain whereas an injection such as morphine could stop pain altogether. However Narin thought that she should learn to be patient with the pain and try not to receive morphine injections very often because she was afraid to become morphine dependent.

Narin remarked that she had less opportunity to talk to the physician for a long time. The physician would visit the patients at the ward every day but the time spent for each patient was short. The physician's conversation focused on the important problem but sometimes Narin needed to ask about her concerns in which the physician did not appear to have time to discuss.

Narin said that she felt conflict about the recent discussion that needed a decision to receive chemotherapy. The physician explained the plan to treat Narin with chemotherapy in a few days but Narin and her mother felt that the patient was not ready to receive that treatment. Narin gave her reason that she still had a problem with the kidney function and also had oedema on her abdomen and legs. If she received chemotherapy she had to drink water a lot in order to wash out the

chemical. Narin was afraid that the oedema would be worse due to drinking so much water, and the pain would increase as a result of that oedema. Another reason was that Narin was not ready to receive chemotherapy because she experienced the side effects of that therapy. She was scared to receive chemotherapy again if her health was not good.

Narin's mother argued that she worried about her daughter's symptoms in relation to how to live in the future. She also worried about the family's financial status in which she did not have any income and the spared money was being spent for daily living. She claimed that she did not want to borrow the money from her relatives if it was not necessary.

#### 4.4 Summary of cancer pain management

From those findings the vital aspects around Narin's cancer pain management could be summarised in terms of the themes as shown in the table below.

Table 4.8 Narin's cancer pain management themes

Themes	Sub-themes	Description / comment of themes / sub-themes
1. Problem solving	1.1 Self-solving	Buy drugs from drug stores sold by pharmacists.
2. Decision making	2.1 Factor related to care: Severity	Narin needed some care from her mother. The need was based on her severity of symptoms such as pain and her health status. Narin's mother claimed that she could not leave Narin for long time because she did not know when Narin would ask for help.
3. Forming PT/HCP partnership	3.1 Discussion / Agreement	Narin needed to discuss with the physician about her treatment. She needed more description and information about the plan for treatment before making a decision

Themes	Sub-themes	Description / comment of themes / sub-themes
4. Taking action	Pain: Non-medication	<p>Avoid doing heavy job</p> <p>Narin said that she tried to learn that she had to bear to the mild pain. It was a personal responsibility of patients to bear to pain as much as possible.</p> <p>Be careful during changing position or movement</p>
	3.2 Pain: Alternative strategies	<p>Narin planned to try the treatment at a place that cared for patients with untreatable illness. The course of treatment of this place was the combination of modern medicine, traditional medicine and making religion merit.</p> <p>Distraction technique to pay less attention on the pain</p>
	3.3 Family Support: Caregiver	<p>Narin's mother was a main caregiver both in hospital and at home. Based on her nuclear family that there were only two people in the family, the patient and her mother.</p> <p>Marital status would affect family management in taking care of the patient.</p>
4. Perception	4.1 Disease interpretation: Unbelievable / Inacceptable	<p>Narin did not believe in the diagnosis. She thought that cancer was far from her life as she was young.</p> <p>She needed confirmation of her diagnosis by having other investigations from many hospitals.</p>
	4.2 Symptom / Disease	Narin said that her pain caused

Themes	Sub-themes	Description / comment of themes / sub-themes
	perception	<p>suffering; she could not breathe when the pain peaked, it was likely to die.</p> <p>Cancer pain was a personal experience; it could not be explained clearly; nobody could know how much pain it was.</p>
	4.3 Effectiveness: Medication: Oral and injection	<p>Narin thought that oral pain medication was less effective than the injection. Sometime she denied taking oral analgesics due to thinking that they had no benefit.</p> <p>She was afraid to receive the injection too much because she was afraid to be drug dependent.</p> <p>Narin learned how to prescribe morphine when the pain was severe and the patient was likely to die the nurse would prescribe morphine.</p>

## Case 5 : Pranee

Pranee was studied for eight weeks (from mid-June to mid-August 2011) and had a home-visit in which was arranged in August 2011 when the patient was allowed visiting home on weekend. The finding would be presented the background of Pranee's family, her disease summary and her cancer pain experience both in hospital and at home.

### 5.1 Pranee's background and social circumstance

Pranee was 36 years old. She was a white, small woman. She was the last child of four including two elder sisters and one elder brother. When her father died, her mother lived with Pranee's brother in the mother's house located in the north east of Thailand. A sister lived with her husband in other province and a sister lives overseas. The summary of Pranee's family is illustrated in the family tree below.

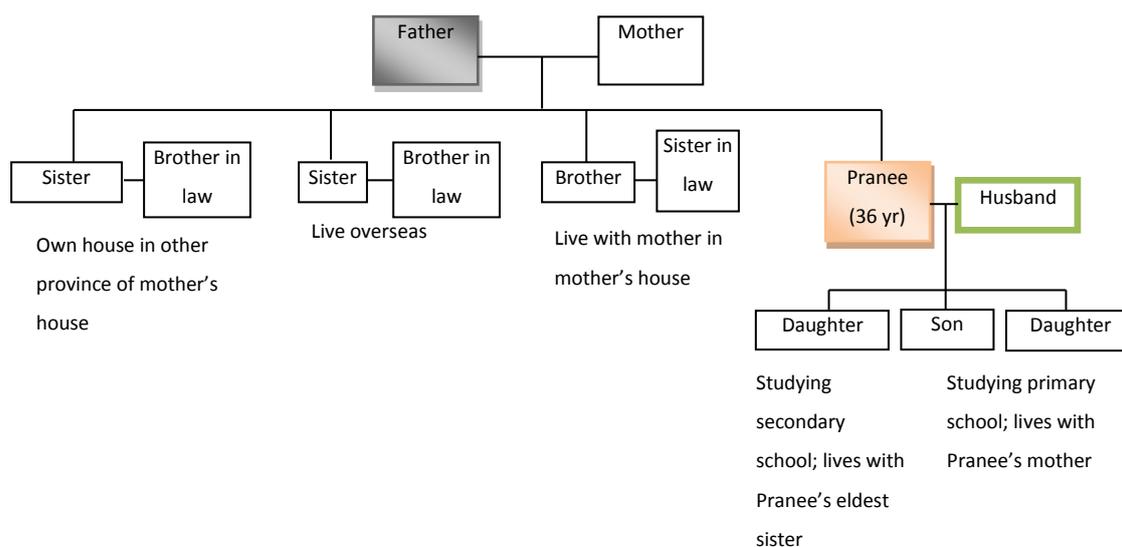


Figure 4.6 Pranee's family's tree

Pranee married when she was 18 years old. She has three children, two daughters and one son. Pranee's family own a house approximately one and a half kilometre away from Pranee's mother's house. Usually, Pranee and her husband work in a house-building company in which the work place often moves depending on where the company's work takes them. While they went away to do their jobs,

their children lived with Pranee's mother. Pranee, together with her husband, would visit home for a short time on special events such as New Year festival and Song-Kran festival.

## 5.2 Pranee's disease summary

From the interview, Pranee explained her disease's story that she had a sign of cervical cancer since 2005 which was an abnormal period. She did not pay attention to that sign because it was inconsistent and the bleeding was not severe. When the abnormal period seemed more severe and she also had more period pain in 2010, she started to find treatment for those abnormalities. The summary of her disease is shown in the table below.

Table 4.9 Pranee's disease summary

Time	Events
2005	Pranee worked in a province in the central region. She had an abnormal period and had post coital bleeding for which her husband advised her to see a physician but Pranee ignored him.
Mid-September 2010	Pranee had hypermenorrhea with many clots and severe dysmenorrhea. She took analgesics bought from a drug store that were able to stop pain for a while. Then she had severe pain. Her husband took her to a local hospital. She received pain treatment with analgesics both oral and injection. After discharging, she still had pain; she again took analgesics bought from a drug store.
March 2011	<p>The pain occurred repeatedly. Pranee did not have money to buy analgesics anymore so she returned home so she could use her standard health insurance. Pranee and her husband lived with her mother due to the availability of many caregivers.</p> <p>Pranee went to a gynaecological clinic and had a cervical biopsy for investigation. During waiting for the result, she had severe pain and severe vaginal bleeding so her husband took her to a hospital. The physician prescribed analgesics and a dosage of morphine injection in the hospital, and gave an amount of oral analgesics to take at home.</p>
Mid-April 2011	The biopsy result showed that Pranee was diagnosed with cervical cancer. The physician planned to refer to the cancer centre. During the planning, Pranee had worse pain so she was admitted in a local hospital and was referred to the

Time	Events
	general hospital to receive further investigations (X-ray, cysto-procto scopy) and then she was referred to the cancer centre.
May 2011	Pranee was added to a waiting list for radiation therapy in which the treatment would be done at the end of July. Pranee still had mild pain and she took analgesics prescribed by the physician of the cancer centre.
June 2011	During waiting for treatment, Pranee could not void. She went to the general hospital for having a procedure of ureterostomy.
Mid-July 2011	<p>Pranee still had mild to moderate pain. She took analgesics very often. She had severe pain two times in which she had be admitted to the local hospital and received morphine injections occasionally. The physician prescribed an amount of oral morphine to take at home.</p> <p>One week before the appointment Pranee had severe pain so she decided to see the physician at the cancer centre immediately. The physician admitted her for starting the treatment.</p>
End-July to August 2011	Pranee was admitted in the cancer centre. She had receiving the fractionation schedule of radiation therapy (30 times) and chemotherapy (3 cycles). She took a kind of oral analgesic and a kind of oral morphine to control the pain. Pranee had severe pain in the first week of admission and then pain declined. The pain was controlled at a mild pain level for which Pranee had to take the medicine regularly. Her husband was the caregiver in the hospital. The physician allowed her to visit home in a weekend when her symptom was stable.
Mid-September 2011	Pranee was discharged when the treatment was completed. She received an amount of oral analgesics to take at home. She had an appointment to follow-up her disease in the next month.

### 5.3 Cancer pain perspective and management

#### 5.3.1 Perspective and expression about cancer pain

Cancer was a very bad thing in her opinion; it was incurable disease. She believed that many people who had cancer would die. She was very worried and stressed. But when she was a patient with cancer and knew more information, she

thought 90% of cancers could be cured. The patient explained that in the past she lived in a small world. She did not know about cancer at all and had never had contact with patients who have cancer.

### **5.3.2 Cancer pain management**

#### **5.3.2.1 Management by self**

She tried to deal with the pain by taking analgesics bought from a drug store. She bought the drug from a drug store that has a pharmacist because it looked trustworthy. She could ask the pharmacist about the symptom and relevant drugs to deal with it. The drugs had some benefit to release mild pain but not to stop the pain totally. The pain came back repeatedly. The patient noted that the drug was quite expensive but she still bought those drugs to deal with the pain. She did not want to leave her job to see a physician.

Pranee did not wish to find any examination or treatment as long as her symptom was not severe and she had little pain. If the symptom did not turn to severe, she would just observe and took analgesics. But the drugs bought from the drug store could not stop pain so she needed stronger drugs to deal with the problem. She was ready to follow every treatment because she trusted the physician.

During the weeks she was waiting for the appointment, Pranee still had moderate to severe pain. She took analgesics prescribed by the physician of the cancer centre quite often. She took two tablets of the drug every four to five hours. Pranee was admitted in the local hospital two times due to severe pain. The physician treated her pain with morphine injection in the hospital and prescribed oral morphine tablets to take at home.

Pranee stated quite firmly that she did not want to take drugs too much. She used to tell herself that today she had mild pain; she should not take the drug. She tried to think that she took a lot of drugs in this week, she should take it less. It was impossible to depend on drug, she thought. From this thinking, it seemed keep her away from pain, or at least the pain seemed to have decreased. The other ways the patient used to reduce pain were by listening to the radio and watching television. These distractions helped her to feel relaxed. A light exercise such as walking in the house was a way that Pranee did in helping to improve her health and to direct her attention away from the issue pain.

Pranee read many boards and brochures about cervical cancer in order to find more information. She compared her symptoms with that information and this made her more certain that she had cervical cancer.

#### **5.3.2.2 Caregiver**

Her husband was aware of this sign and told Pranee to see a physician for investigation but Pranee did not pay attention to his suggestion.

#### **5.3.2.3 Mental support**

Pranee revealed that she was very worried about her disease and symptoms resulting in her becoming nervous and depressed. This made her feel less healthy, unable to eat and sleepless, for which she had to take some sleeping pills. In addition she claimed that her character changed from a funny and friendly woman to being quiet and seeming quite antisocial. Her family helped her a lot with these situations. Her mother and relatives provided care and empowered her a lot. Her husband encouraged and stayed with her all the time. These gestures of support made her felt better and more powerful. She thought that she could live with these encouragements of them.

#### **5.3.2.4 Care at home**

While waiting for the result, Pranee lived in her mother's house because there were many caregivers. Her husband also lived with her. The patient's mother's house ad two levels, the ground floor was constructed with brick and cement, and the first floor was constructed with wooden boards. The rear of the house was additionally constructed to be a general purpose room and a kitchen. The distance from the front door to the back door including the additional room, was approximately 20 meters. The patient said that it was very long house in which she could walk backwards and forwards in the house for exercise during the time she was ill.

#### **5.3.2.5 Traditional and alternative medicine**

When asking her opinion about other ways, such as alternative strategies to treat the disease or relieve the pain, Pranee replied that she had never gone to obtain treatment with other ways but only with the physician in the hospital. The reason for this was the patient and her husband believed in the physician, believed in the treatment with modern medicine rather than traditional medicine. The patient told the researcher that some older people in her village suggested some traditional treatment for her such as herbs or performing rituals or trying to access the cult

power of the super nature. She just listened to these suggestions but did not follow them up. She said she did not believe in the thing that she could not see. She trusted and specified the modern treatment so she waited for treatment in the cancer centre.

#### **5.3.2.6 Conflict of care**

On one day Pranee had more severe bleeding per vagina and severe pain, so her husband took her to a local hospital nearby the family home. The physician gave her some analgesics but the pain did not release, therefore the doctor gave her a morphine injection. The physician said that morphine is a strong drug. She did not know how strong of the drug was, but it was effective and the pain diminished with the result that she was able to sleep. However, three days after the first injection, the pain came back and was bad enough for her to receive the second morphine injection. Before the physician would give Pranee the drug, she asked her to assess the pain level, as it did not easy to receive morphine.

Pranee thought that, for injection, the physician would prescribe only in the hospital the patient was admitted to. In addition, she learnt that she would be given the morphine injection if she had severe pain. When she was better, the physician discharged her and gave her an amount of oral analgesics to take at home.

Pranee claimed that the environment between the general hospital and the cancer centre was different. When she was admitted to the general hospital, she had to live with other patients who had different problems such as accident or other diseases. She felt that she differed from others in term of the diagnosis itself, the type of treatment and the long period of treatment. These made her so worried because she was not the same as the others. She felt worse and worse, could not sleep, could not eat and felt unhealthy as a result. Moreover Pranee claimed that other patients who knew of her disease looked at her strangely. They saw her with 'insulting eyes' which made her feel sad. On the other hand, when Pranee was admitted to the cancer centre, she felt better. There were lots of patients with cancer here. There was the same disease here and the patients would encourage each other. Some groups of patients had the same symptoms, some had different. The patients gave their smile to each other. Pranee argued that the pain might be affected by both mind and environment. When she lived in the cancer centre with this supportive environment, talking to other patients, she felt good. She could eat

more and could smile. Pranee said that although she had severe pain, she felt the pain was less compared to the pain when admitted to the general hospital.

#### 5.4 Summary of cancer pain management

From those findings of Pranee, the vital aspects around cancer pain experience and pain management could be summarised in term of the themes as shown in the table below.

Table 4.10 Pranee's cancer pain management themes

Themes	Sub-themes	Description / comment of themes / sub-themes
1. Decision making	1.1 Factor related to treat: Trustworthiness	Pranee claimed that she trusted the modern treatment. She was ready to be treated without questions or complaints because she trusted the physician.
	1.2 Factor related to treat: Severity and Current symptom	An important factor that led the patient to find treatment was the severity of the symptom and the current symptom.
	1.3 Factor related to treat: Financial concern	This factor might relate to financial status in which the patient seemed reluctant to find treatment because she did not want to stop doing job which meant that stopping earning money.
	1.4 Factor related to care: Responsibility to self-care / not to be burden	Pranee tried to do self-care because she needed to make sure her family was happy / was not worrying about her.
2. Information finding and utilisation	2.1 Finding information	Pranee started to find information about cancer after she was diagnosed with cervical cancer.  She argued that the information gained after she was admitted to the

Themes	Sub-themes	Description / comment of themes / sub-themes
		cancer centre would change her opinion about cancer and its treatment.
3. Taking action	3.1 Pain: Medication	<p>Pranee usually dealt with her pain by taking drugs bought from a drug store / pharmacists. Other strategies were giving less attention to the pain, using distraction techniques such as watching television, listened to the radio or other activities.</p> <p>Learning how the nurses delivered morphine injections; learned about the criteria for delivering drugs that morphine could be prescribed only in hospital and when the pain was severe.</p> <p>Pranee claimed that she only received the treatment provided by the health care providers. She never used alternative medicine or alternative strategies to deal with her disease or her pain.</p>
	3.2 Non-medication	Be patient with the pain
	3.3 Pain: Alternative strategy	Using self-empowering
	3.4 Family support: Caregiver	Pranee's husband was the main caregiver both in hospital and at home. He provided caring, taking the patient to the hospital, helping with all daily living activities and mental supporting.
	3.5 Family support: Encouragement and	All family members, but especially her mother and her husband, were the

Themes	Sub-themes	Description / comment of themes / sub-themes
	Empowerment	main source of encouragement and empowerment in which the patient felt warm and continued the treatment
4. Perception	4.1 Symptom / Disease perception	Pranee claimed that if the pain increased, it meant that the disease progressed.  She claimed that her pain was making her suffering.
	4.2 Effectiveness: Oral and injection	Pranee thought that both oral and injected pain medication had their own effectiveness. Oral medication was effective to relieve pain at low level whereas an injection could stop pain suddenly.
	4.3 Symptom / Disease perception: Alienation	Admission in the general hospital, Pranee felt a sense of being a stranger, a feeling of alienation whereas, after admission to the cancer centre, she felt better. There were lots of patients with cancer here. The patients had the same disease and they encouraged each other. Pranee claimed that her pain was less when she was admitted to the cancer centre.

## Case 6 : Duangjai

Duangjai was studied from June to July 2011, for 6 weeks including a home-visit in which was arranged in mid-July 2011 when the physician allowed Daungjai a weekend home visit. The findings are presented as follows: the background of Duangjai's family, her disease summary and her cancer pain experience both in hospital and at home.

### 6.1 Duangjai's history

Daungjai was 58 years old. She had four children including three sons and one daughter. Her sons married and lived with their wives and their children in other provinces. Daungjai's daughter married and has 2 sons, 5 and 1 year old respectively. Her daughter's family lived in their house nearby Duangjai's house and would visit her occasionally. Duangjai's family is illustrated in the family tree below.

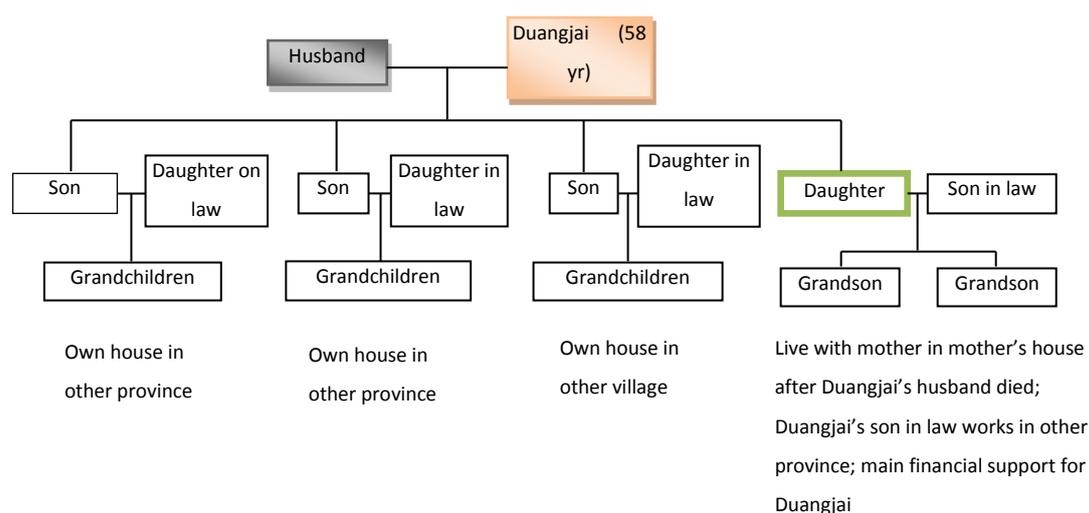


Figure 4.7 Duangjai's family tree

Usually, there were only Duangjai and her husband lived in their own house. When Duangjai's husband died, last for 3 years ago, her daughter's family moved to live with Duangjai in the Duangjai's house. Duangjai's daughter and her husband took responsibility to provide support and care for Duangjai in any issues.

Duangjai's son in law did his job in a company in a central region of Thailand. Duangjai's daughter was a housewife but occasionally she would do a freelance job occasionally. If healthy, Duangjai earned money by doing a freelance job in order to earn additional family income.

## 6.2 Duangjai's disease summary

Duangjai's symptom began with pain at her lower abdomen since 2009. She went to various health care services in order to investigate her abnormality and received many treatments. The summary of her disease was shown in the table below.

Table 4.11 Duangjai's disease summary

Time	Events
2009-2010	Duangjai had lower abdominal pain repeatedly for which she took some analgesics bought from a drug store occasionally. Then the pain increased in November 2009 so that taking old analgesics could not stop the pain, as a result she went to see physicians in many health care services including private clinics and a local hospital. She was diagnosed with gastritis or peptic ulcer and those physicians prescribed an amount of medicine for her to take at home.
November 2010	Duangjai had severe pain in which the pain referred to her legs. The pain disturbed her ability to walk. She went to find the cause of pain from many health care services. She received a procedure of vaginal examination in the general hospital and was diagnosed with myoma uteri. Duangjai distrusted the diagnosis so she disagreed be treated by surgery. She just took some analgesic prescribed by the physician from the general hospital.
January 2011	Duangjai had worse pain and also experienced vaginal discharge. This was the abnormal sign because Duangjai went through the menopause for 10 years ago. Duangjai went to see a physician in the general hospital and received the procedure of cervical biopsy. The physician prescribed her some analgesics to take at home during waiting for the biopsy result.
February 2011	Duangjai had severe pain; she was admitted in the general hospital. She received two dosages of analgesic injections and received an amount of oral analgesics to take at home.
End-February 2011	The biopsy result showed that Duangjai was diagnosed with cervical cancer. She was referred to the cancer centre and was added into the waiting list of the treatment of the radiation therapy. She also received other kind of analgesic and an amount of mild opioid from the cancer centre to take at home. Her pain was controlled to remain at a low level.
March	Duangjai was admitted to the cancer centre. She received the treatment with fractionation schedule of the radiation therapy (30 times) and chemotherapy (5

Time	Events
2011	cycles). During this treatment, Duangjai had severe pain that was controlled by oral analgesic, oral morphine and morphine injection in combination. She was allowed to visit home on weekend during the period of treatment because her pain was mild. She took the analgesics prescribed by the physician at home.
May 2011	When the treatment with radiation and chemical was completed, Duangjai was discharged and was booked for further treatment with brachy-radiation in the out-patient department (2 times). After completion of all treatment, Duangjai had an appointment to follow-up. She still took some analgesics at home.
June 2011	Duangjai had worse pain intermittently. Her daughter took Duangjai to the cancer centre. The physician assessed and prescribed another kind of analgesic and some oral morphine tablets to take at home. Duangjai still had severe pain, ate less and became fatigued.
End-July 2011	Duangjai died from respiratory failure at home.

### 6.3 Cancer pain perspective and management

#### 6.3.1 Perspective and expression about cancer pain

Actually Duangjai did not believe that she had problem related to her gastrointestinal system because her pain was in the lower abdomen. She claimed that the pain area was not correlated to the diagnosis. However, she still took drugs prescribed by the physician of those hospitals. She explained that it was not other thing better than tried this treatment and waiting for evaluation of the treatment. If this was ineffective she would try another way.

Some of her relatives recommended Duangjai to see a physician in the cancer centre but she disagreed to follow that recommendation because she thought that her symptom did not relate to cancer. She did not have any signs that corresponded to the cancer. Until she had discharge from vagina and dysmenorrhea, she went to the general hospital. A physician of that hospital suspected that she had cervical cancer so Duangjai received a procedure of cervical biopsy in order to confirm the hypothesis.

### **6.3.2 Cancer pain management**

#### **6.3.2.1 Management by self**

Duangjai claimed that she tried to do most activities by herself based on her health status and pain level. She informed that mostly she had pain at low level. She would bear to the pain and rest if the pain increased because she did not want to take medicine. Sometime she massaged her legs in order to relieve her leg pain as this could help her. If she could not be tolerant of the severe pain she would take the drugs prescribed by the physician of the hospital. Duangjai told of her experience when the pain peaked so that, regardless of whether she took some analgesics but the pain was still severe. She thought that the oral analgesics she had taken gave no benefit. Therefore her daughter took her to a local hospital in which a physician gave her an injection of a drug, and then the pain decreased. Duangjai claimed that the injection had more benefit than the oral medicine.

#### **6.3.2.2 Caregiver**

Her daughter was the main caregiver both in the hospital and at home. Mostly Duangjai tried to do various activities by herself; she would ask her daughter for help in some activities that were too heavy for her. Her daughter's care in relation to pain included assessing her pain, delivering pain medication and taking her to the hospital or the cancer centre if the pain could not be controlled at home.

Duangjai's daughter gave her opinion that she felt that her mother's symptom was severe but she did not know how to deal with it. She did the best thing for her mother in providing care and took her to the hospital. She and other members even thought about her death sometime and she thought that her mother might also have this thought but her mother did not discuss the topic with anyone.

#### **6.3.2.3 Care at home**

At home, Duangjai lived with her daughter in her own house. The family members in the house were Duangjai, her daughter and two grandchildren. Her son in law went away to do his job in the other province and would come home once a month. He was the main financial support of the family's daily living expenses and also for Duangjai's treatment.

The physician allowed Duangjai to visit her home for four days (the official holiday) with an amount of oral analgesics. During the home visit, Duangjai felt happy due to the care from her relatives. Her neighbours also visited her at home, asked about her symptoms and gave her a wish for good health. The pain seemed to decrease some days when Duangjai might not have taken the drug.

### 6.3.2.4 Traditional and alternative medicine

Duangjai tried some alternative strategies to treat her disease and also relieve her pain including 'Suk' on her legs and prayers by a faith healer. These strategies were recommended by her relatives and neighbours. They said that the faith healer could make many patients be better so this might not have disadvantage if Duangjai would like to try. However, Duangjai informed that she tried 'Suk' only one time because she felt that this could not help her, in contrast it actually gave her more pain.

### 6.3.2.5 Conflict of care

Duangjai gave her opinion that the injection was very effective to diminish her pain. There were no other ways to stop her pain except the injection. The oral analgesics would help her if the pain was low.

Duangjai asked for help from nurses quite rarely. She stated that she hesitated to interrupt nurses' activities, as they seemed busy all the time. She just informed the nurses of her symptoms and needs during the routine nursing round of each shift. Daungjai claimed that sometimes she needed to know more information about her disease, her symptoms and also treatments from the nurses and the physician but she did not know how to describe her symptoms clearly. However, she thought that this was not a problem; following the physician's treatment might be enough.

## 6.4 Summary of cancer pain management

From those findings from Duangjai, the vital aspects around her cancer pain management could be summarised in term of the themes as shown in the table below.

Table 4.12 Duangjai's cancer pain management themes

Themes	Sub-themes	Description / comment of themes / sub-themes
1. Decision making	1.1 Factor related to treat: Trustworthiness	Duangjai did not believe in the diagnosis due to a lack of correlation between the pain area and the diagnosis. She needed confirmation of her diagnosis by having other investigations from many clinics and

Themes	Sub-themes	Description / comment of themes / sub-themes
		hospitals.
	1.2 Factor related to treat: Severity and current symptom	The decision making to receive the treatment was based on the severity of the symptom and the evidence of that symptom that the patient could see.
	1.3 Factor related to treat: Better than do nothing	She claimed that 'SUK' might not produce positive results but it was better than doing nothing. These would help her to improve mental health.
	1.4 Factor related to care: Responsibility to self-care	Duangjai preferred to do everything by herself if she could do such as daily living activities and housekeeping. This was her personality as an active person.
	1.5 Factor related to care: Severity	Providing care depended on the severity of the patient's symptom. Mostly Duangjai preferred to do everything by herself if she could do. However the patient still needed someone to stay near her so she could ask for help at any time.
	1.6 Factor related to communication	<p>'Kreang jai' might be a barrier for communicating the pain level to health care professionals.</p> <p>Duangjai claimed that she hesitated to talk with health care providers because she did not know how to ask / describe what she wanted to tell. (hierarchy)</p> <p>She felt that nurses seemed not to have told everything to her, especially about the drugs. She needed more details about her disease, pain and all</p>

Themes	Sub-themes	Description / comment of themes / sub-themes
		treatments.
2. Taking action	2.1 Pain: Medication	Taking drugs which needed careful reading of the regimen, she had to ask for her daughter in order to prevent mistakes.
	2.2 Pain: Non-medication	She tried to bear to pain as much as possible.
	2.3 Pain: Alternative strategies	Duangjai had even tried some alternative strategies in order to diminish her pain, there were 'SUK', and prayers by a faith healer and performing rituals.  She took rest and massaged to relieve the pain.
	2.4 Family support: Caregiver	Duangjai's daughter was the main caregiver because she lived with her mother all the time.
3. Perception	3.1 Effectiveness: Oral and injection	Duangjai thought that oral pain medication was less effective than the injection. When the pain peaked, she needed an injection rather than oral medication.
	3.2 Home environment	When the patient visited home, it seemed that she felt better. She could eat, sleep and smile because she got empowerment from her relatives who visited her at home regularly.



## Chapter V

### Finding of all embedded cases

#### 5.1 Introduction

This chapter present the findings emerging from all six cases by using cross-case analysis. There are five interesting areas of the case study that will be presented: the cancer pain perspective, perspective about effectiveness of medication, self-management, family management and finally health care providers & patient interaction.

#### 5.2 cross-case analysis

Summary of cancer pain management of each case (in Chapter ) provided by a table; data grouped into corresponding themes and sub-themes. Information in the 'Description/comment of themes/sub-themes' was reviewed and the 'Revised-themes' segment was developed in a new column. A new matrix (theme-based finding) was applied to interviews and observation allowing comparison of the data across six cases. This stage of the analysis could lead to develop the empirical conclusion and a descriptive model of the phenomena being studied.

Table 5.1 Cross-case analysis

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
Problem solving	Self-solving Find help	Junjira informed her plan to deal with pain that if the pain was mild, or around five to six from ten, she would be patient with that pain, but if the pain increased she would ask for medication from the nurses.	Try to do everything by self. Decision making: ask for help if severe  Try to do everything

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>Junjira tried to do everything by self and asked for help as little as possible.</p> <p>Depends on the severity of the patient's symptoms. If the patient felt better the need of care from caregiver was less. However the patient still needed someone to stay near her so she could ask for help any time.</p> <p>Buy drug from drug stores; refrained from heavy activities</p> <p>Buy drugs from drug stores sold by pharmacists.</p>	<p>by self</p> <p>Ask for help if severe : Decision making, Buy drug from drug stores</p> <p>Non-medication</p> <p>Buy drug from drug stores</p>
Decision making	Factor related to treat/care: Responsibility to self-care	<p>The reasons were that a person had responsibility to take care of one-self, to increase one's value to be acceptable in society and to avoid being looking down on and looking to be different from others who live in the village.</p> <p>Don't want to be a burden led the patient try to do activity by self</p> <p>'Kreang Jai' referred to a feeling of not wanting to be a burden or receive helps or things from others was an important factor that led the patient to try to do self-care.</p> <p>Duangjai preferred to do everything by herself if she could do, such as daily living activities and housekeeping. This was her personality as an active person.</p>	<p>Try to do everything by oneself: Better than do nothing</p> <p>Try to do everything by oneself: Better than do nothing</p> <p>Alternative strategy: 'SUK'</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
	Factor relate to treat/care: better than do nothing	<p>Junjira claimed that although nothing happen, it was be better than doing nothing.</p> <p>She claimed that 'SUK' might not produce positive results but it was better than doing nothing. These would help her to improve mental health.</p>	<p>Try to do everything by oneself: Better than do nothing</p> <p>Try to do everything by oneself: Better than do nothing</p> <p>Alternative strategy: 'SUK'</p>
	Factor related to treatment: trustworthiness	<p>Acceptance of the diagnosis was affected by trustworthiness of the physicians' personality that should show their knowledge and confidence in their professional.</p> <p>First impression about performing his/her characteristic as a professional affects trustworthiness and decision making to treat or to follow the recommendations or suggestions.</p> <p>Pranee claimed that she trusted the modern treatment. She was ready to be treated without questions or complaints because she trusted the physician.</p> <p>Duangjai did not believe in the diagnosis due to a lack of correlation between the pain area and the diagnosis. She needed confirmation of her diagnosis by having other investigations from many clinics and hospitals.</p>	<p>Decision making: Trustworthiness</p> <p>Decision making: Trustworthiness</p> <p>Decision making: Trustworthiness</p> <p>Modern treatment</p> <p>Decision making: Trustworthiness</p>
	Factor related to treat: Severity	The abnormality of the disease (signs and symptoms) was the vital evidences that led the patient to	Decision making: Symptom/Severity

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>agree with the diagnosis. The decision making process would be affected by the severity of the symptoms and its disturbance as well as the financial status.</p> <p>Depends on the severity of the patient's symptoms. Narin needed some cares from her mother. The need was based on her severity of symptoms such as pain and her health status. Narin's mother claimed that she could not leave Narin for long periods because she did not know when Narin would ask for help.</p> <p>An important factor that led the patient to find treatment was the severity of the symptom and the current symptom.</p> <p>The decision making to receive the treatment was based on the severity of the symptom and the evidence of that symptom that the patient could see.</p> <p>Providing care depended on the severity of the patient's symptom. Mostly Duangjai preferred to do everything by herself if she could do. However the patient still needed someone to stay near her so she could ask for help at any time.</p>	<p>Decision making: Symptom/Severity</p> <p>Decision making: Symptom/Severity</p> <p>Decision making: Symptom/Severity</p> <p>Try to do everything by self</p>
	Factor related to treat: Financial concern	This factor might relate to financial status in which the patient seemed reluctant to find treatment because she did not want to stop doing job	Decision making: Finance

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		which meant that stopping earning money.	
	Factor related to communication	<p>Junjira needed more information, but she felt 'Kreang Jai' to ask the physician questions.</p> <p>Most ways that Junjira communicated about pain to nurses was by answering when the nurses came and asked. A reason offered by Junjira as to why she preferred not to ask for help from nurses was that she was afraid to receive bad responses from them.</p> <p>'Kreang jai' might be a barrier for communication about the pain to health care professionals.</p> <p>Factors affecting communication between the patient and health care provider included health care providers' personality as friendly or quiet, health care providers' behaviours / activities in each situation such as looking relaxed or looking hurried.</p> <p>Sompon said that she needed a nurse to act as a coordinator/ nominee to make contact with the physician.</p> <p>'Kreang jai' might be a barrier for communicating the pain level to health care professionals.</p> <p>Duangjai claimed that she hesitated to talk with health care providers because she did not know how to ask / describe what</p>	<p>Communication: 'Kreang Jai'</p> <p>Communication</p> <p>Communication: 'Kreang Jai'</p> <p>Communication: Personality</p> <p>Communication</p> <p>Communication: 'Kreang Jai'</p> <p>Communication: Communication skill, Hierarchy</p> <p>Communication Information need</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>she wanted to tell. (hierarchy)</p> <p>She felt that nurses seemed not to have told everything to her, especially about the drugs. She needed more details about her disease, pain and all treatments.</p>	
	Decision maker	<p>For decision making for doing a thing with Junjira, it seemed that nobody acted as a decision maker precisely. A decision was usually made from discussion among family members, the most appropriate solution would be the final one.</p> <p>Junjira's sister and her husband seemed to be key persons in some decision making, especially in relation to travelling. Junjira's sister was one of caregivers at home and her husband had a car to provide travelling for Junjira.</p> <p>Malee's family, her father was the main decision maker.</p>	<p>Decision maker</p> <p>Decision maker</p>
Information finding and utilisation	Finding information	<p>Pranee started to find information about cancer after she was diagnosed with cervical cancer. She argued that the information gained after she was admitted to the cancer centre would change her opinion about cancer and its treatment.</p>	<p>Information need</p> <p>Finding information</p>
Forming PT/HCP partnership	Discussion / Agreement	<p>Narin needed to discuss with the physician about her treatment. She needed more description and information about the plan for treatment before making a decision</p>	<p>Hierarchy in talking to physicians/nurses</p> <p>Information need</p>
Taking	Pain	<p>Pain seemed to be the major</p>	<p>Communication:</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
action	communication: non-verbal (implicit expression)	<p>problem in this patient that was communicated by her moaning almost all the time. The patient's moaning was a way to communicate her pain and to show how much pain she had through the frequency and level of her voice. This expression seemed effective as the patient did not ask nurses, and also her caregiver, directly about her pain.</p> <p>There was no main receiver to get information from the nurse so providing information was altered, based on the current situation. From this, the effectiveness of the discharge plan was questioned. There were some conflicts within care for Malee.</p> <p>The main cause was to be the inconsistency of need between health care providers and the patients/family. (the standard care by nurse and outstanding care by PT)</p>	<p>Expression</p> <p>Communication</p> <p>Conflicts in the interaction</p>
	Pain: Medication	<p>Pranee usually dealt with her pain by taking drugs bought from a drug store / pharmacists. Other strategies were giving less attention to the pain, using distraction techniques such as watching television, listened to the radio or other activities.</p> <p>Learning how the nurses delivered morphine injections; learned about the criteria for delivering drugs</p>	<p>Modern strategies</p> <p>Buy drugs from drug store</p> <p>Rest / Distraction</p> <p>Learning to prescribe the medication</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>that morphine could be prescribed only in hospital and when the pain was severe.</p> <p>Pranee claimed that she only received the treatment provided by the health care providers. She never used alternative medicine or alternative strategies to deal with her disease or her pain.</p> <p>Taking drugs which needed careful reading of the regimen, she had to ask for her daughter in order to prevent mistakes.</p>	<p>Modern strategies</p> <p>Taking drugs</p>
	Pain: Non-medication, Bear to pain	<p>Avoid doing heavy job, Narin said that she tried to learn that she had to bear to the mild pain. It was a personal responsibility of patients to bear to pain as much as possible.</p> <p>Be careful during changing position or movement</p> <p>Be patient with the pain, Using self-empowering</p> <p>She tried to bear to pain as much as possible.</p>	<p>Non-medication</p> <p>Try to do everything by oneself</p> <p>Bear the pain &amp; be patient</p> <p>Non-medication</p> <p>Bear the pain &amp; be patient</p> <p>Bear the pain &amp; be patient</p>
	Pain: Alternative and traditional strategies	<p>The most important strategy was related to the Nagas that was the local belief of residents in that area.</p> <p>Junjira told that she looked for</p>	<p>Traditional/alternative strategies</p> <p>'Suk' with/without prayed by healer</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>many strategies to treat cancer and diminish her pain including 'SUK', using herbs, praying and performing rituals.</p> <p>The patient was a masseuse so she had knowledge and skill of massage so she used this strategy to relieve her pain. However, the effectiveness of this strategy was varied, based on the severity of the pain.</p> <p>The patient tried many alternative medicines such as herbs, local medications and alcohol substance in order to treat the disease and decrease the pain.</p> <p>Narin planned to try the treatment at a place that cared for patients with untreatable illness. The course of treatment of this place was the combination of modern medicine, traditional medicine and making religion merit. Distraction technique to pay less attention on the pain</p> <p>Duangjai had even tried some alternative strategies in order to diminish her pain, there were 'SUK', and prayers by a faith healer and performing rituals. She took rest and massage to relieve the pain.</p>	<p>Traditional medicine: herbs</p> <p>Traditional/alternative strategies</p> <p>Traditional medicine: herbs</p> <p>Modern medicine and Distraction / Prayer</p> <p>Self-empowering</p> <p>'Suk'</p> <p>Traditional/alternative strategies</p>
	Family support: Caregiver	The most important caregiver was Malee's husband both in hospital and at home.	<p>Caregiver assignment</p> <p>Caregiver assignment</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>Junjira lived in her mother's house because there were caregivers staying with her 24/7. However, she had nobody to be a key caregiver due to those members having different available times. Family management for taking care of the patient at home were caregiver assignments in the day time and the night time.</p> <p>Narin's mother was a main caregiver both in hospital and at home. Based on her nuclear family that there were only two people in the family, the patient and her mother. Marital status would affect family management in taking care of the patient.</p> <p>Pranee's husband was the main caregiver both in hospital and at home. He provided caring, taking the patient to the hospital, helping with all daily living activities and mental supporting.</p> <p>Duangjai's daughter was the main caregiver because she lived with her mother all the time.</p>	<p>Caregiver assignment</p> <p>Caregiver assignment</p> <p>Caregiver assignment, Providing care</p>
	Family support: Travelling	<p>Travelling choices depended on Junjira's health status. If her symptoms were not too bad, she could travel by public transport. Junjira's brother in law had a car to provide travelling for Junjira. He had his own small business, so Junjira had to book his time if she needed his help to travel.</p>	Travelling

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
	Family support Financial support	Junjira got financial problem in which her relatives could not provide fully support. Her husband did various freelance jobs for which the wage was quite low and inconsistent. Junjira was in debt to some private financial creditors. Junjira's brother and her sister provided some financial support occasionally. This financial problem was discussed in family meetings sometimes in order to find a solution but it had still no proper answer.	Financial support
	Family support: Mental support / Encouragement / Empowerment	Family empowers the patient for receiving treatment and managing the pain.  All family members, but especially her mother and her husband, were the main source of encouragement and empowerment in which the patient felt warm and continued the treatment	Mental support  Palliative care
	Home care planning	This re-arrangement could provide benefits for both Malee to take care of herself and caregivers to provide care for her.	Managing the home environment
	Home care planning: care at home	This might provide the closed care by family members and generate an emotional warmth feeling for Malee.	Mental support
Perception	Symptom / Disease perception	The patient mentioned that death might be better than pain.  Junjira mentioned about cancer pain that death might be better than pain due to her suffering.	Death  Death  Progression /

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>Sompon claimed that if the pain increased, it meant that the disease progressed.</p> <p>Narin said that her pain caused suffering; she could not breathe when the pain peaked, it was likely to die. Cancer pain was a personal experience; it could not be explained clearly; nobody could know how much pain it was.</p> <p>Pranee claimed that if the pain increased, it meant that the disease progressed. She claimed that her pain was making her suffering. Admission in the general hospital, Pranee felt a sense of being a stranger, a feeling of alienation whereas, after admission to the cancer centre, she felt better. There were lots of patients with cancer here. The patients had the same disease and they encouraged each other. Pranee claimed that her pain was less when she was admitted to the cancer centre.</p>	<p>Incurable</p> <p>Death</p> <p>Personal experience</p> <p>Progression /</p> <p>Incurable</p> <p>Suffering /</p> <p>Uncontrollable</p> <p>Feel of stranger /</p> <p>Alienation,</p> <p>Environment</p>
	<p>Disease interpretation:</p> <p>Unbelievable /</p> <p>inacceptable</p>	<p>Narin did not believe in the diagnosis. She thought that cancer was far from her life as she was young.</p> <p>She needed confirmation of her diagnosis by having other investigations from many hospitals.</p>	<p>Unbelievable /</p> <p>Inacceptable</p>
	<p>Impact of pain:</p> <p>Attention/</p>	<p>She claimed that she could not pay attention to others, just the pain.</p>	<p>Patients' perspectives</p> <p>Patients' need</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
	Emotional / social	She needed to live alone, to go away from society, did not need to see people (other people did not know what she was).	
	Patient: Need assessment: caring/treatment	<p>The patient claimed that at previous admission she could take care of herself with low pain but at this time of admission she needed help from others because the pain was very severe.</p> <p>Junjira needed her husband to be a caregiver in the hospital but her husband wished to go back home because he needed to do work and gain money.</p>	<p>Need of the treatment</p> <p>Need of the treatment</p>
	Family: Need assessment	<p>A discharge plan was urgently required for Malee due to her family needing to go back home immediately after making their decision.</p> <p>Junjira's husband said that he was quite bored due to less work to do here. Therefore when he appraised that Junjira was better he tried to push the patient to do activities by herself in order improve her self-care ability.</p>	<p>Urgent need of the treatment</p> <p>Information need</p> <p>Need of the treatment (family)</p>
	Effectiveness: Medication: Injection better than oral Morphine better than others	<p>Junjira thought that oral drugs cannot help to control severe pain. The drugs just decreased her pain and maintained it at low level, but did not diminish her pain.</p> <p>Sompon wondered about the effectiveness of oral pain medication that had less effect than the injection. However, she</p>	<p>Oral and injection</p> <p>Effectiveness of medication</p> <p>Drug-dependent</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		<p>was afraid to receive the injection too much because she was afraid to be drug dependent, similar to an old woman that Sompon had heard about.</p> <p>Narin thought that oral pain medication was less effective than the injection. Sometime she denied taking oral analgesics due to thinking that they had no benefit. She was afraid to receive the injection too much because she was afraid to be drug dependent.</p> <p>Narin learned how to prescribe morphine when the pain was severe and the patient was likely to die the nurse would prescribe morphine.</p> <p>Pranee thought that both oral and injected pain medication had their own effectiveness. Oral medication was effective to relieve pain at low level whereas an injection could stop pain suddenly.</p> <p>Duangjai thought that oral pain medication was less effective than the injection. When the pain peaked, she needed an injection rather than oral medication.</p>	<p>Oral and injection, Effectiveness of medication</p> <p>Learning to prescribe the medication</p> <p>Oral and injection , Learning to prescribe the medication</p> <p>Oral and injection , Effectiveness of medication</p>
	Home environment	<p>When the patient visited home, it seemed that she felt better. She could eat, sleep and smile because she got empowerment from her relatives who visited her at home</p>	<p>General care / daily activities, Palliative care / Mental support, Environment</p>

Themes	Sub-themes	Description / comment of themes / sub-themes	Revised themes
		regularly.	
	Health care provider: Need assessment	It was more difficult to deal with the patient's and family's needs. The patient needed an injection rather than oral medication due to thinking that this could stop pain. This problem might have been caused by the progression of the disease, being worried about the disease and symptoms, and the experience of the patient with previous treatment and using opioids.	Conflicts in the interaction / communication, Urgent need of the treatment

The revised theme was reconsidered and re-organised based on the 'match linkage' of the pattern across all cases. The final group of themes is provided below in summary and the discussion of them is followed.

### **Cancer pain perspective**

- Death and the Incurable/Uncontrollable Nature of the Disease
- Personal experience
- Factors affecting the patients' perspectives
  - Knowledge of cancer pain
  - Environment: general hospital & cancer centre

### **Perspective about the effectiveness of medication**

- Oral and injection
- Learning to prescribe the medication

### **Self-management**

- Concept of self-management
  - Bear the pain & be patient
  - Try to do everything by oneself
- Finding more information
- Decision making
  - Personal belief
  - Current symptom & severity

- Decision maker
- Use of strategies
  - Modern strategies
  - Traditional/alternative strategies
  - Self-empowering

### **Family management**

- Degree of the management by the family
  - Patient's severity
  - Family's knowledge
- Caregiver assignment
- Providing care
  - General care / daily activities / travelling
  - Pain management
  - Financial support
  - Palliative care

### **Health care providers & patient interaction**

- Conflicts in the interaction / communication
  - Hierarchy in talking to physicians/nurses
  - Kreang Jai
- Inconsistency of the need between patient (outstanding care) and health care provider (standard care)
  - Urgent need of the treatment
  - Information need

## **5.3 Cancer pain perspective**

It is recognised that human behaviour involves the influences of cognitive appraisal, psychological aspects and physical conditions (Bandura 2002). These factors affect pain perception, in consequence shaping and directing the person's behaviour relating to their pain management (Chatwin et al. 2009). In the case study, the patients' perceptions in relation to cancer pain can be considered, because they may be the key or determining factors influencing the patients' responses. To manage the cancer pain of these patients, their behaviour would be affected by their thoughts about cancer pain, examples of which are provided.

### **5.3.1 Death and the Incurable/Uncontrollable Nature of the Disease**

Some patients claimed that their pain caused them to experience very great suffering. It emerged continuously that there was nothing which could relieve the pain. In addition, some patients argued that death would be better than living with the pain. These perspectives might generate a variety of the patients' responses in relation to pain, including ignoring or trying to ignore the pain due to thinking that the patient could not deal with the pain. On the other hand, some of those expressing concerns might be active patients trying to find ways to treat or relieve the pain, particularly if they thought that it was the first priority to deal with and they did not have a feeling that they were going to die.

### **5.2.2 Personal experience**

Pain is a personal experience in which it was difficult to explain to others, for them to know what the pain was like or the quality of the pain. Others who have no direct experience of cancer pain cannot absolutely perceive or understand. From this perspective, this might lead the patient to think that nobody could understand what the patient felt and therefore nobody could help. Some patients had to deal with the pain on their own, without family supporters or carers being with them. However, this status depended on family relationships; in the warmth of the family atmosphere, the patient would perceive the help and support provided by the family both physical and mental.

### **5.2.3 Factors affecting the patients' perspectives**

There were two main factors that influenced how the patient's thought about the cancer pain; the knowledge of cancer pain and the environment.

#### **5.2.3.1 Knowledge of cancer pain**

An important factor affecting the patient's thoughts was knowledge of cancer pain. Some patients thought that the pain indicated the disease's progression. Some of them wondered about their pain, especially if it was inconsistent in its severity. Sometimes the pain peaked so they could not rest, but sometimes the pain declined regardless of whether they did, or did not, take any medicine. Some of them claimed that the cause of cancer pain was their past sins, so the way to deal with the pain might relate to performing rituals in order to decrease that effect. These situations

showed a variety of patients' cancer pain knowledge, which might relate to their levels of education. The unclear knowledge about cancer pain might lead the patients to try to find more information and find the best way to treat their disease and pain.

### **5.2.3.2 Environment: general hospital & cancer centre**

A patient claimed that there was a different atmosphere between the two hospitals, the general hospital and the cancer centre. She explained that in the general hospital there were mixed-diagnostic patients but the most fatal disease was cancer. People generally perceived that cancer was dangerous, serious and incurable. Patients who were diagnosed with cancer usually were treated by special treatments and died sooner than other patients. This led the patient to feel that she was in the worst situation, a feeling of alienation.

Whereas in the cancer centre, where all patients were diagnosed with cancer; they were treated by the same strategies. This situation led the patient to think that she was similar to others. A feeling of unity was generated. The patient explained that patients helped each other in terms of encouraging and empowering during their time together in the cancer centre.

## **5.3 Perspective about the effectiveness of medication**

### **5.3.1 Oral and injection**

Most patients argued that oral medication was less effective than the injection. A dose of oral medication could relieve and maintain the pain at a low level, whereas an injection could stop the pain completely. This might lead the patient to ignore taking the oral medicine. Some patients reported that they still took the medicine delivered by the nurse; they said that they just took those medicines without perceiving their benefit.

### **5.3.2 Learning to prescribe the medication**

The patients claimed that the nurses would prescribe morphine injections if the pain was severe. The nurses would assess the patient's pain by asking how much pain the patient had and sometimes they would check around the pain site. At first the nurses did not provide morphine, they would check what the regimen of the patient was and prescribe the medicine based on that regimen. However, most times

the pain would emerge before the medication schedule so the nurses would inform the patients and teach them ways to relieve the pain such as rest, adjusting physical position, breathing and massaging. The nurses would re-assess and deal with the pain based on its severity. If the pain was still severe, the nurses would report to the physician to deal with the pain in some way, such as adding other medication or revising the pain control regimen.

The patients claimed that morphine injections would be prescribed only in the hospital. They said that before receiving morphine the patient and/or the caregivers would be informed by a pharmacist and nurses about morphine. The nurses also explained about possible side effects of morphine and abnormal symptoms so that patients and caregivers could observe and tell the nurses if the patient suddenly had a problem. Most patients perceived that morphine had various adverse effects but they still needed the drug, due to its effectiveness to stop the pain. They claimed that their pain caused their suffering; they could not deal with the pain. They needed a way to stop the pain rather than thinking of that adverse result. If they had severe pain at home and felt that the pain could not be controlled by oral medicine, they would go to hospital with the intention to receive the injection.

A patient remarked that she would count the time for delivery of her pain control medication. She recalled that once she asked a nurse for the drugs, but the nurse told her that the drugs could not be prescribed in this time; the drugs would be delivered following a schedule, so the patient had to wait for the time. Even if or when the nurse taught other ways to relieve the pain, the patient seemed think that those strategies had no benefit. She looked at the clock very often and anticipated when the time of delivery would come.

Some patients learned that being paid attention from caregivers and also health care providers was related to the pain level. A patient moaned in order to represent her pain. She moaned almost all the time in order to get more attention from her caregivers and from the nurses, as well as asking them about her symptoms and also her needs. The patient explained that the voice was not only to let others know about her pain, but it also elicited some help from others. Her pain expression as moaning resulted in a variety of responses. The basic response of her husband was asking about her symptoms and also her needs, talking to her as a form of mental support or asking for help from health care providers. Her voice was also responded to by health care providers in that the nurses would come to her bed immediately in order to assess her pain and take action in some way, such as

offering knowledge about pain and strategies to relieve pain, helping the patient to set a position, or deliver pain medication. However, the family caregiver and health care providers also learned what the objective of the moaning was and how to respond to this explicit expression of pain, performed by the patient appropriately.

## **5.4 Self-management**

### **5.4.1 Concept of self-management**

There were two main concepts that the patients used to self-manage themselves, to patiently bear the pain and try to do everything by oneself. Patients may think about their own ability and the possibility of success when trying to control their pain. Patients, who believed in their ability to, or the possibility to, control pain tended to find or undertake behaviour which assisted them to deal with their pain. Whereas bearing pain was often the choice expressed by patients who perceived analgesic or other pain control strategies to be not particularly effective.

#### **5.4.1.1 Bear the pain & be patient**

All patients mentioned this way to deal with the pain for various reasons. Some patients had mild pain and they did not want to take the medicine so they would talk to themselves to be patient and used other ways to relieve the pain. In contrast, the patients who had severe pain claimed that they had to bear the pain because they did not know how to decrease it. The medication could not help them to diminish the pain, or it was not the time to receive the medicine, so they had to wait for the actual time.

#### **5.4.1.2 Try to do everything by oneself**

Some patient claimed that it was the responsibility of a person to do self-care. Some patients thought that the ability to do activities by oneself referred to their recovering their health status. Therefore, the patients tried to do everything by themselves first and would only ask for help from others if they could not do that job.

A patient argued that she tried to do many activities as much as possible, because she did not want to differ from others in the community. A patient who had severe symptoms became a focus of interest. She did not want to receive too much attention from neighbours and she was also afraid to be looked down upon by

others, due to her diminishing abilities. Therefore, regardless whether the pain would increase from doing some activity, she still tried to do it.

Patients balanced their ability to deal with pain by themselves, against the appraisal of the need for help. The main factor that influenced how patients appraised themselves was health status, including severity of pain and symptoms. Relatively healthy patients may need less help than those whose health was poor. However, a hidden reason that patients may ask for help was a need for psychosocial support.

These two concepts were used, based on a simple code of conduct of people in Thai society known as 'Kreang Jai'. 'Kreang Jai' referred to a feeling that people did not want to disturb others or to be a burden. All patients said that they had an intention not to be a burden on family members; not to make others get involved in extra activities to help them. This feeling might lead the patient to try to do such activities by herself. Another reason supporting the self-management concept was a feeling of hierarchy. The patients might have a feeling that they were of a lower status than health care providers, due to less education, financial status and position in society. This might lead the patients to fear to contact the health care providers in terms of the difficulty to communicate their problems and to ask for help. These issues were the underpinning reason for the behaviour of the patients' self-management.

There is an interesting factor which may influence the decision to deal with pain, the belief in the principle of Buddha as Karma. Karma leads to the belief that any current situation is affected by past sins. People who have a strong belief in this principle may consider a particular situation, such as cancer, to be uncontrollable; therefore, some patients may do nothing to deal with their disease, or just bear the pain because of their belief in Karma. This applies especially to patients who are in a bad condition.

A co-factor, influencing the patients' perception of their ability to deal with pain, was pain severity. Patients who have mild pain, or begin to have pain, are likely to solve the problem by themselves. This is correlated with the patients' appraisal that they have the ability to deal with pain and/or daily living. The patients ask themselves basic questions, such as how much pain do they have, can they deal with their pain, and do they need help from other people?

Another important factor relating to the source of help, in terms of its availability and effectiveness, also influenced the patients' choice of how to deal

with their pain. Comparisons between benefit and drawback of each support or help, were carefully considered in order to choose the most appropriate solution.

Two main sources of help were from the health care providers and the patient's family. Patients asked for help from health professionals mainly concerning their disease and treatment, whereas the family is requested to provide physical and emotional care and support. Patients perceive that a health care provider can offer help in many ways. Some patients, who question their diagnosis, seek clarification from health care providers by asking for explanations or requesting investigations about their disease and/or symptoms. Most patients find help from health care providers, especially relating to the issue of pain medication. Asking for drugs is a common request from patients who have severe pain. Families can help the patients in relation to the provision of a variety of support, regarding such issues as daily living, travelling and finance. Families can also provide alternative treatment for the patients.

#### **5.4.2 Finding more information**

One of actions that the patients did in relation to self-management of their disease and symptoms was finding information. This behaviour was based on two main reasons; wondering about the diagnosis and the need for information related to their disease and treatment. Some patients did not believe that they were correctly diagnosed with cervical cancer, which led them to try more investigations from many health care services and also to find more information from various sources, such as health care providers, relatives and leaflets about cervical cancer, in order to compare their symptoms and to confirm the diagnosis. Some patients read books and/or handouts related to the disease in order to increase their knowledge of cervical cancer and find the best way to cure the disease. In addition, if they wondered or were unclear about the information, they would ask the physician to clarify the facts.

Sources of information that the patients found were different based on the patients' education and family financial status. The main source of information was human, including health care providers, family members and/or neighbours. In the human resource category, it seemed that family members were the primary informants for everything, whereas health care providers were the final choice. This situation might be informed by the patient's education and/or the personal confidence to contact the health care providers.

Most patients graduated from primary school and left the school to find a job in order to earn money to support their family. Financial status led the patients to focus on finding work rather than paying attention to improve their knowledge. In addition, the money was expended on necessary things for daily living; they had no spare money for unnecessary infrastructures or computer. These might be examples of barriers preventing the patients from finding knowledge from useful sources. Moreover, lower education might lead the patient to feel less confident to communicate their problems to health care providers. The feeling of 'Kreang Jai' and hierarchy also seemed to be additional factors that limited the successful finding out of information from health professionals.

### **5.4.3 Decision making**

Decision making covered the issues around how to go to find the investigations and treatments in terms of the places that provide the services and the people who provided them. There were three main factors influencing how the patients made a decision: personal belief, current symptoms & their severity and the decision maker.

#### **5.4.3.1 Personal belief**

It was the fact that personal action would be influenced by what was thought of that issue. In terms of making a decision, the patients had their own perspective that led them to take an action as a result. From this finding, the patients' belief could be divided into three areas: belief in the diagnosis, belief in the health care providers and belief in the treatment strategies.

##### ***Belief in the diagnosis***

Most patients did not believe, in the first instance, that they were correctly diagnosed with cervical cancer. The patients raised their opinions about the diagnosis - that it was unacceptable and unbelievable. There were big differences between these two words. Some patients said that they could not believe that they had this disease. It did not mean that they did not know their diagnosis but they could not accept it. Actually, the patients might well know about cancer but it was difficult for them to agree with or accept such a diagnosis. On the other hand, unbelievable, the patients might also know about the diagnosis but they still had some questions. These might be if the patient was young or there were no symptoms related to the diagnosis. These issues led to the patients being reluctant

to believe their diagnosis or to follow the recommendations provided by the health care providers. They would do many things in order to confirm the diagnosis, including finding information from various sources and going to many other health services, both private and public, to do more investigations. However, it was found that even when some patients did not fully believe their diagnosis they received the treatment without the question. This might be due to thinking that it would be too late to start the treatment if they still waited for the hundred percent agreement on the diagnosis.

### ***Belief in the health care providers***

This issue referred to how health care providers could present their professional performance to the patients. The health care professionals were respected by the patients who provided care for them as smart and trustworthy people. It was expected that they could save the patient's life. If there were some behaviour of the health care providers which deviated from the patients' expectations, the patients would not believe everything they said and would not follow the treatment and/or the recommendations as a result.

### ***Belief in the treatment strategies***

There were two main pain management strategies that the patients chose to deal with, modern and traditional. However, in Thai society this is not a simple dichotomy, it is not possible to fully separate the choices of treatments as modern or traditional, for the patients to choose. All patients in the study received modern strategies for treatment of their cancer. However all of them still had some belief in the traditional strategies at various levels.

#### **5.4.3.2 Current symptom & severity**

The current symptom was an important factor for the patient's belief in the diagnosis. Most patients would not believe that they were diagnosed with cancer if there was no visible symptom. The visible symptom also affected the urgency to make a decision to treat. Some patients thought that if there was no any symptom, it meant that the disease might not progress or it would not affect their life. These perspectives led to decision making based on the principle that if there was no symptom currently, the patients would ignore or postpone the time to find an investigation and/or the treatment.

The severity was also the vital factor for making the decision to see a physician, especially the severity of pain. Some patients argued that if the pain was

low and could be controlled by analgesics they would prefer not to go to a hospital. They did not need to leave from their job, which would involve the loss of money. This decision might relate to the financial status of the patients. Some patients did freelance jobs, and some had no job, so their incomes were unstable and any spare money was limited. Hence the patients preferred earning money for daily living, rather than finding a treatment if the symptom was not severe.

#### **5.4.3.3 Decision maker**

There were differences between the patients in terms of who would be the decision maker. This decision maker was not only for dealing with the patient but also general issues in daily living. It seemed that family members had an influence on the decision making process.

In general, each member could make a decision about their own concerns. However, dealing with the patient who had a serious problem would affect the effectiveness of decision making. A reason for this situation might be that the ability for self-care by the patient might have decreased. Another reason, possibly more important than the prior reason, was the need of family members to offer care for the patient and to be a part of the process in dealing with the fatal disease.

To what degree the family would join the decision process depended on how good the relationship among family members was. Generally in Thai society, the main decision maker was the one who was the oldest and/or one who was the major financial supporter. The oldest person was usually a father or mother who was respected by their children. Even if the youngsters raised opinions in the family discussion, they were taught to show respect and good manners to the elders. Therefore, in dealing with the patients' problems, there was discussion among family members and the oldest person would make the decision.

The patient's husband was the main caregiver and was usually the main decision maker due to his role as the leader of the family. However, this situation could not be generalised to every family. The relationship between the patient's husband and his wife's family was a major factor influencing how much he could take action to provide care for his wife. In some families the husband claimed that he was less important in the discussion because he had only recently married the patient and lived far away from his wife's family. When the patient's disease became more severe, she lived with her old family because there were lots of caregivers available to care for her. In this situation, he had to show respect to the house's owner by following their recommendations.

#### **5.4.4 Use of strategies**

There were various strategies that the patient used to deal with their pain problems. The strategies could be divided into two main groups: modern and traditional. The choices of strategies and decisions were influenced by the patients' own knowledge, experience and belief, their family's belief, as well as social circumstances.

##### **5.4.4.1 Modern strategies**

All patients received modern treatments in various ways, including using medication on their own and receiving treatments from health care services.

###### ***Buy drugs from drug store***

The primary problem solving strategy that the patients used to deal with their pain was buying drugs from a drug store, both with and without the suggestion from a pharmacist. Most patients used this way to deal with their pain, based on their knowledge learned from their personal experience, their family and advertising. If this way was effective they would continue using it, but if the drugs could not solve the pain problem they would find better ways.

###### ***Go to hospital/clinics***

The patients would see a physician whenever they perceived that their own strategies could not provide benefit. All patients went to a hospital based on their health insurance, whereas some patients might explore more investigations and treatment from private clinics. Using the latter choice depended on financial status and the expectation that those clinics would provide more advantages. However, finally all patients received treatment from the cancer centre based on the belief and hope that this treatment could cure the disease.

##### **5.4.4.2 Traditional/alternative strategies**

These strategies were favourite choices of Thai people in dealing with health problems. Most patients and their families believed that traditional strategies might provide some help, not only for the pain but also the general health status. Some patients claimed that even if they did not have complete belief in some traditional Thai strategies, trying them would be better than doing nothing.

### ***Traditional medicine: herbs***

Thailand has many kinds of herb regimens used by both healthy and ill people. For the patients, they would try many herbs recommended by their family members. The patients thought that if the herbs had no adverse effects, it would be good to take those traditional medicines.

### ***Rest / Distraction / Prayer***

All patients revealed that the strategy they usually used when the pain increased, was to rest. Some of them also used distraction techniques and tried to ignore the pain by paying more attention to other activities or the environment, rather than the pain. Some patients prayed following the Buddhist principle. These initiatives could help them to forget their pain for a while.

### ***'Suk' with/without prayed by healer***

Two patients reported that they used to have a local procedure known as 'Suk' in order to relieve the pain. 'Suk' refers to a local strategy of applying a needle on skin like tattoo without colour in order to relief pain. The patients said that they had heard of the advantages of this procedure for many illnesses and their families agreed with this treatment so they thought it might be helpful strategy for relief of their cancer pain. They just tried this way only one time because the strategies did not diminish their pain completely.

### ***Spirit/magic healer and super natural power***

Some patients took some magical beverage, performed rituals and prayed for spirit or super natural power. These were the local beliefs of Thai communities in some areas. This might not directly affect improvements in physical health but this might improve the patients' mental health.

People who lived in some area seemed to hold a strong local belief in supernatural power such as the Nagas. Nagas, in the form of a great cobra-like snake, are represented in Buddhist temples as architectural elements and also figured in some stories of Thai folklore. The Nagas of Buddhist tradition are notable as the servants and the protectors of the Buddha so the Nagas are a strong and sacred belief held by Buddhist people. Local residents in this area believed that the Nagas could protect them from danger and had magic powers for treatment. Therefore, performing ritual for the Nagas was held by locals and worship was

usually done in order to ask for help on many difficulties, specifically for problems with uncured disease.

#### **5.4.4.3 Self-empowering**

The patients improved their own mental health by empowering themselves. Trying to do activities by themselves, without help, was one behaviour that led the patients to think they could be better, could do self-care and need not be a burden to others. Another way to empower themselves was via positive thinking about their own symptom, by comparing it with others who were worse off than themselves.

## **5.5 Family management**

Family was the vital factor in relation to managing the patients' problems. It was not only the need of patients to ask for a caregiver but the family also needed to be a part of caring for the patients. In Thai society, it could be seen that the family would play a vital role in dealing with every issue relating to its members; especially when dealing with the crucial problem of the member with cancer pain, the family would take on every aspect of caring.

Some interesting issues in relation to family management emerged from the analysis; for example the degree of management that was provided by the family, caregiver assignments and the care provided by family members.

### **5.5.1 Degree of the management by the family**

There was a variety of factors influencing how much the family would provide care. These factors are as follows.

#### **5.5.1.1 Patient's severity**

The family caregiver would provide care depending on the severity of the patient's illness and the ability to take care of herself. Usually the help was asked for by the patient so that the family could provide the care appropriately. In addition, the family might observe the patient's expression and behaviour and provided care without any request, if they appraised that the patient needed some help.

### **5.5.1.2 Family's knowledge**

Some caregivers revealed that sometimes they did not know how to relieve the pain, or how to help the patients to get better. They said that their knowledge about cancer and also the pain was minimal. Whether they received information from nurses, physicians and pharmacists, they were still not sure about their ability to provide care, especially on delivering medication. They just did the things that the patients requested. Some family caregivers had knowledge about traditional medicine that might benefit the patient's symptom so they recommended the patient try that strategy.

### **5.5.2 Caregiver assignment**

The caregiver role was assigned, based on the relationship between the patient and the caregiver and on availability of the family member. Generally the patient's caregiver was her husband because he was the closest person who lived with the patient all the time. The husband was expected to be the family member who provided most care for the patient, due to his position and his responsibility to take care of his wife.

However, the position of husband might not take action as the main caregiver in some situations. There were some families where the husband had to pursue his career in order to earn money to support the family and in some families there was no husband living with the patient due to their marital problems. From these situations, one of the other members, such as mother, sister or daughter, who was available at that time, was assigned to be the caregiver.

### **5.5.3 Providing care**

Families would provide caring for the patients in many ways. Such caring could be divided into four topics as follows.

#### **5.5.3.1 General care / daily activities / travelling**

Most care provided by the family caregivers was general care for daily activities including eating, bathing, exercising and sleeping. The degree of care provision depended on the patient's ability to do activities by herself. Whether or not the patient seemed better and did not ask for help, the caregiver still lived with the

patient in order to observe any abnormality and could provide help suddenly if the patient needed it.

For travelling, it was the main duty of the caregiver to take the patient to various places for treatment. Mostly the husband would be that person, taking the patient to hospital; however there were some difficulties affected the travelling. There was the severity of the patient's illness to consider and the availability and affordability of a vehicle for transportation. If the patient's symptom was less severe, the patient and her husband would travel by public transport if they did not have their own car. But if the patient's pain was worse and/or she had worse symptoms, means of transportation would be discussed among family members in order to find a solution for travelling. Mostly the solution seemed to be that the family member who had their own car would take responsibility to take the patient and also some family member to the hospital. From the solution, it meant that the car owner might have to take a time-out from his career to provide the transportation, as a consequence of which his income might be affected.

#### **5.5.3.2 Pain management**

The family would provide a variety of care in relation to the relief of pain which could be divided into two main aspects; as providing relief directly to the patient and managing the home environment to facilitate the caring.

##### ***Providing care directly to the patient***

The main caregiver and other family members relieved the patients' pain by massaging, delivering drugs and finding traditional medicine for the patient. The massage was not precisely based on any specific principle; the caregivers just did it based on their own knowledge and experience about massaging so it may or may not be effective to decrease the pain. However the patient claimed that the massage could help her to relax and gave her the feeling of warmth; a psychological massage.

Delivery of medication prescribed by the physician in the hospital seemed to be the main way that could relieve the patient's pain. Traditional medicine would be an additional treatment that the caregivers offered to the patient. This strategy might not fully focus on the pain; it would perhaps provide general improvement of the patient's health.

### ***Managing the home environment***

Each family would manage the home environment, for the care of the patient, differently. Some families undertook a major home re-arrangement of furniture and facilities in order to provide care more conveniently. Most families just looked after the house by cleaning and preparing more space in order to decrease the opportunity of accident. There was at least one caregiver who lived with the patient always, so a major home re-arrangement was unnecessary.

#### **5.5.3.3 Financial support**

Mostly the patient and her husband would take full responsibility for any expenditure in relation to the cancer treatment. However, there were times when they might have a problem due to a lack of money, because the husband might have to leave his career to provide care for the patient, so reducing their income. Some patients had small amounts of money that had been saved to fund an emergency but it might be drained by the expenditure. The financial problem was discussed in family meetings, sometimes in order to find a solution. A simple solution was a member who had a stable income, who had spare money and who would provide the financial support. However this way could not solve the problem in all instances. Sometimes the patient or her husband was obliged to borrow money from the private creditor in the village, with some amount of interest needing to be repaid, over and above the principal.

#### **5.5.3.4 Palliative care**

Palliative care at home was one of the needs that family member mentioned to provide for the patient. A family commented that if the treatment in the hospital was not providing any benefit to the patient they needed to bring the patient home. A husband and family member gave their opinions that this would be better than staying in the hospital. The patient should receive the palliative care from the family at home before passing away.

## **5.6 Health care providers & patient interaction**

The interaction between health care providers, the patients and the family was generated all the time when managing the disease and symptoms. The emerging aspects from both patients' perspectives and health care providers' views are shown below.

## **5.6.1 Conflicts in the interaction / communication**

During the many interactions between patients and health care providers, some conflicts were reported, which might have negatively influenced the effectiveness of communications and the success of the disease management as a result.

### **5.6.1.1 Hierarchy in talking to physicians/nurses**

This feeling was raised by the patients who said they felt it extremely difficult to describe their needs because they did not know how to communicate their thoughts precisely. They were reluctant to talk to the physician because they did not know that word would be polite for them. Some patients claimed that they felt the physician was quite busy and looked to be in a hurry all the time; therefore they were afraid to interrupt his/her activities to ask some questions and also worried they may receive bad responses from him/her. Therefore, they chose to keep silent, listening to information provided from the physicians or nurses and then just following the treatment.

### **5.6.1.2 Kreang Jai**

'Kreang Jai' referred to a feeling of people not wanting to be a burden or receive helps or things from others, if not necessary. This was transferred from the old generation to the new generation, especially in the family, in the belief that such an attitude was good manners. Therefore this feeling seemed to be a symbol of manners for Thai people. This might be an important factor leading the patient to try to do self-care because they did not want to be a burden to others. However, this behaviour might also be an obstacle to managing the pain because the patient did not raise or communicate their needs or their actual problems, so the proper solution was difficult, perhaps impossible, to provide.

## **5.6.2 Inconsistency of the need between patient (outstanding care) and health care provider (standard care)**

There was some inconsistency between the patient's needs and health care providers' management, in relation to the care provided, as summarised below.

### 5.6.2.1 Urgent need of the treatment

The patients needed to diminish their disease problem as soon as possible, whereas the health care professionals provided care based on the principle of treatment. This might lead the patient to feel that it seemed too long to see the effectiveness of that treatment.

A patient claimed that the treatment provided by the health care provider could not and did not help. The responsibility of the nurses was to visit, to ask, examine and give some advice, but not to give anything to relieve the pain. This situation might affect the trust of the patient towards the health care providers.

In contrast, the nurses argued that there was an obstacle in communication with the patient, especially on pain assessment. The patient might have some difficulty to score herself how much pain she had, resulting in difficulty when making a decision to deliver care or medication. This inability of the patient to estimate pain levels might be affected by the severity of her pain, so the patient might devote less attention to getting information from the nurse and to appraise her pain precisely.

Another inconsistency was the patients' need to diminish the pain immediately but the health care providers could not follow that requirement, due to the principle of regimen and the pathology of the disease. Therefore this seemed to result in some conflict about the quality of care which might be an important success factor of pain management.

### 5.6.2.2 Information need

The physician informed the patients about the progression of the disease and treatment but this seemed insufficient for the patients. The patients argued that it would be better if they received more explanation from the physician. However by asking the physician, the patients said that they felt 'Kreang Jai'. One patient said she preferred to communicate her needs to nurses, rather than the physician, due to the conversation being a lot more relaxed; she could tell her problem precisely; the nurse would then act as a nominee to transfer the patient's problem to the physician. This way might be one solution to decreasing the amount of missing information or overcoming the hierarchy of fear.



# **Chapter VI**

## **The case study's self-management model development**

### **6.1 Introduction**

This chapter presents a developed model of self-management for pain control for the patients involved in this six embedded case study. Significant aspects that emerged in chapter five are used to generate the model and their relationships are discussed in order to generate an understanding of self-management of pain control in patients who have cervical cancer. Criticism of this model, against the former self-management model, is further provided.

### **6.2 Developing a self-management model for pain control in patients who have cervical cancer**

According to information from all the cases, that be summarised in the final theme as shown in previous chapter, the broad view of the self-management model pertaining to this case study can be considered that it can be consist of two main concepts, thinking and behaving. The concept of thinking is the internal process of cognition whereby the patients think about pain: including their perception and interpretation about cancer pain, how they solve their pain problem, how they decide to use a strategy to deal with pain based on what reasons supported that solution. The concept of behaving relates to the way that patients express and communicate about their pain or what they do to solve their pain, as well as establishing whether the patients relieve their pain by themselves or ask for help from others. The behaviour would be the consequence of the process of thinking. However, the behaviour was changeable due to various factors in the real situation.

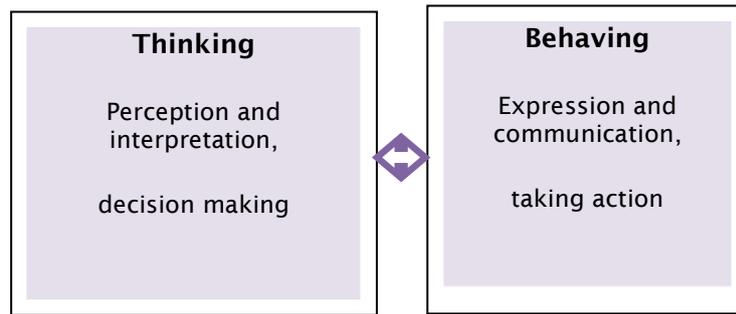


Figure 6.1 The self-management model: concept of 'Thinking & Behaving'

In this thesis, the revised-themes from previous chapter were grouped and mapped in order to find relationships between themes, and then the self-management for this case study was developed. The developed self-management model was illustrated below.

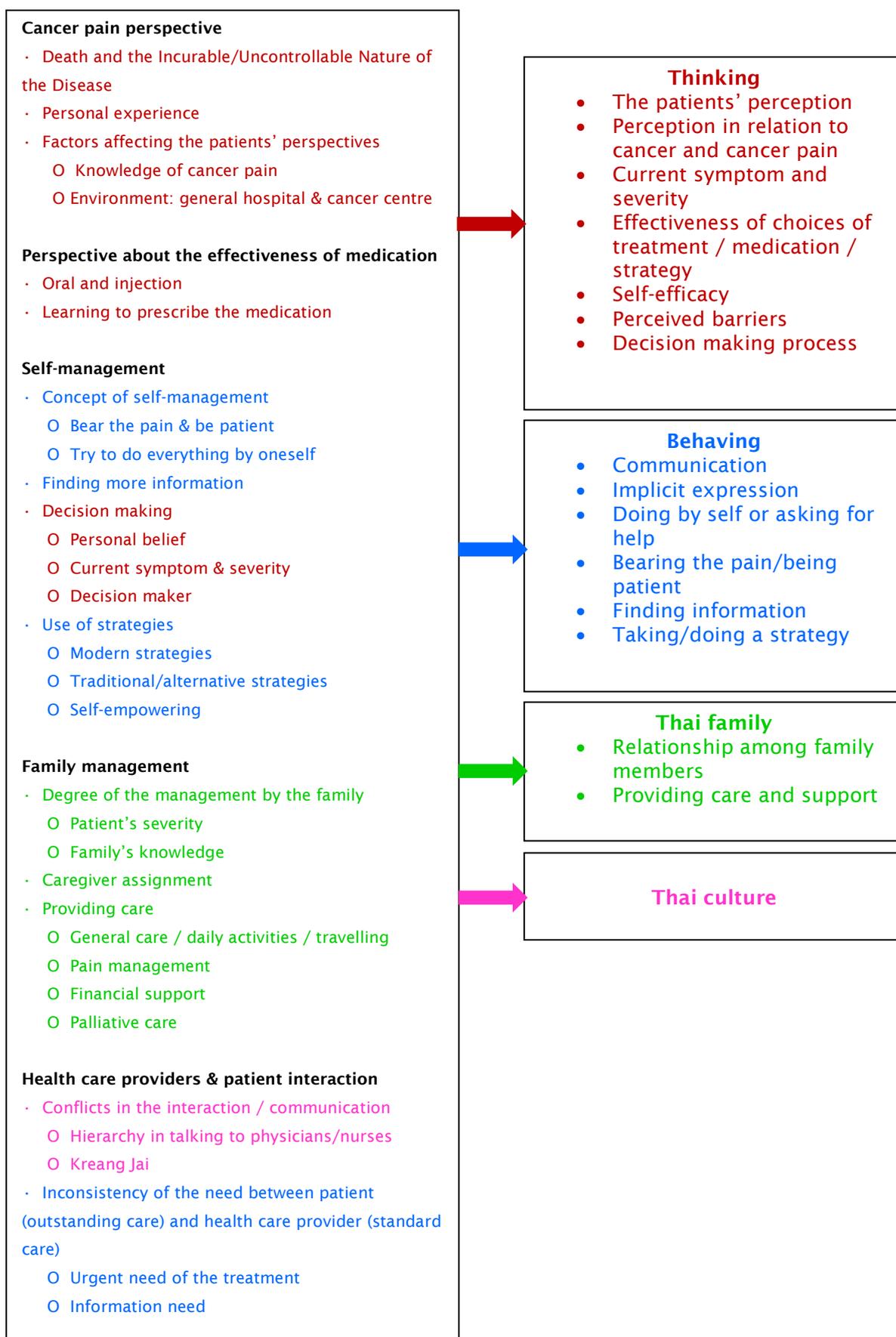
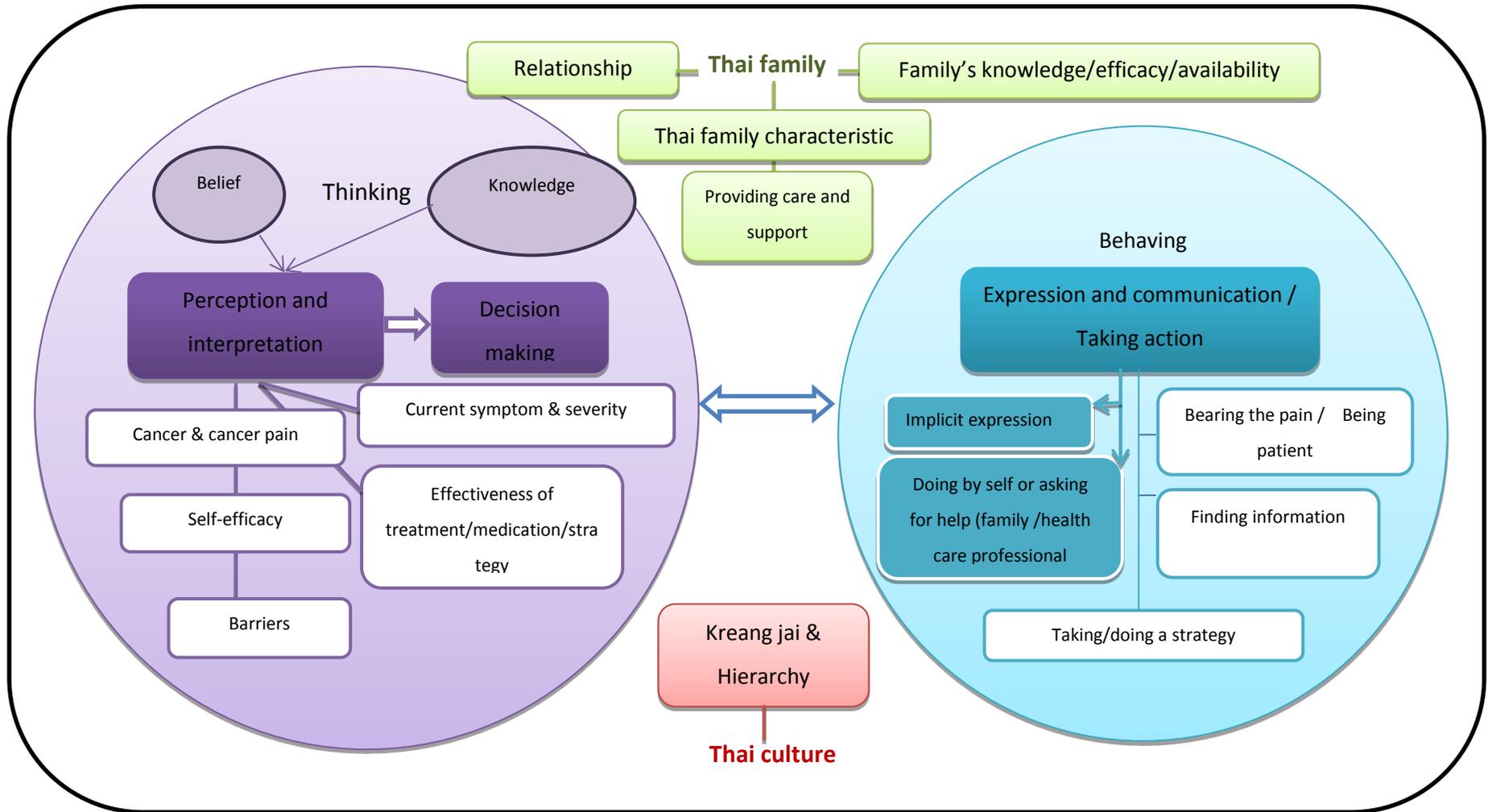


Figure 6.2 The developed self-management model

Human behaviour in relation to self-management is based on the actor's personal reasons and is influenced by their individual backgrounds. It was found that self-management behaviour of the case study participants was uniquely influenced by the family and Thai culture. Therefore the model would include the aspects of family and Thai culture which influenced both concepts of thinking and behaving, in order to make the model more appropriate for Thai patients. The model of self-management for pain control in this case study is illustrated in the figure below.



## 6.3 The self-management model for pain control in the case study

From the model, there are three main aspects involved in the case study. Firstly is the concept of thinking that refers to the cognitive process of how the patients think and decide to manage their pain, what are the reasons underpinning those decisions. Second is the concept of behaving, including direction of action, as implicit expression and decision making whether to do by self or ask for help, and actual behaviour that the patients exhibit. The last two-part component of the model consists of the Thai family and Thai culture, which together generate a unique context and are important factors that influence both the process of thinking and behaving.

### 6.3.1 Thinking

This process refers to the patients' perception and interpretation about cancer and cancer pain, what factors influence this process and how the patients make a decision to carry out such behaviour in order to deal with the pain.

#### 6.3.1.1 The patients' perception

There are five concepts in relation to the patient's perception which affect how the patients think about cancer and cancer pain and how to deal with the pain. The explanation of each concept is provided as follows.

##### *Perception in relation to cancer and cancer pain*

Individuals vary greatly in terms of their perceived vulnerability or their perception of imminent risk. One dimension of the HBM as 'perceived susceptibility', has been reformulated to include acceptance of the diagnosis (Henshaw et al. 2009). This aspect of accepting the diagnosis as cervical cancer and its consequence as a pain source, emerged in the case study as affecting the patients' behaviour for dealing with that diagnosis. Some patients did not believe that they were diagnosed with cervical cancer and ignored the recommended treatment as a result. The most important factors influencing the belief in the diagnosis of the case were the visible signs and trust in the health professionals who informed the patient of the diagnosis.

The main factors affecting how the patients perceived cancer pain are the patients' knowledge and personal belief. Education about health, particularly health literacy, refers to a person's capacity to obtain, process, and communicate information about health. It affects health behaviour in various ways including the ability to understand clinical and health-related information, as well as the ability to communicate and seek help from other (Glanz et al. 2009). Low levels of health literacy may restrict the patient's ability to be an active participant in medical consultations, because there was a limitation of familiarity with health-related terms. In addition, people who have less education may feel embarrassment and reluctance to interact with health professionals, due to this limited understanding. These factors might greatly affect the ability of individuals to access and benefit from health care.

Levels of education might influence self-management ability in terms of assertive communication, ability to find information, and level of belief about the diagnosis and choices of treatment. It seems that patients who have a strong belief in traditional or local culture will have less education. This would affect the patients' thinking about, and dealing with, cancer pain in various ways including thinking about the cause of cancer pain, ability to find information and the use of some strategies to relieve the pain.

In addition, the patients' literacy and beliefs may relate to the patients' preference for clinician and patient roles in care. Less educated patients are more likely to prefer paternalistic decision-making models, whereas more educated patients desire more active and collaborative roles (Glanz et al. 2009). Evidence was found in this case study that a patient who had less education would prefer not to follow all treatment provided by the physician, whereas another patient who has a higher level of education would ask more questions about her treatment and alternative pain relief strategies from the health care providers. However, the preference for physician and patient roles in the encounter may change from visit to visit, or even over the course of the health care service. Patients' preferences can moderate the function of communication between patients and health care providers and can affect the effectiveness of health care behaviour to achieve better outcomes.

The illness experience, medical treatment, a diagnosis of illness, and fear of developing an illness can all generate stress. Stress does not affect all people equally. It is considered to be a transactional phenomenon dependent on the

meaning of the stimulus or stimuli to perceivers. The central concept is that a given event or situation is perceived in different ways by different people. In addition, reactions to stressors can promote or inhibit healthful practices, and influence motivation to practice habits that promote health (Glanz et al. 2009).

When a person faces an event, judgement about the event occurs automatically. The appraisal of the event may be that it is stressful, positive, controllable, challenging or irrelevant. The appraisal can prompt efforts to cope with the stressors, as in addressing or seeking support, and also can prompt escape-avoidance behaviour. This unique personal judgement is influenced by self-efficacy appraisal (Glanz et al. 2009). To manage the pain, the patients would address what they can do about the situation, including their perceived ability to deal with the situation and expectations about the effectiveness of the solution strategies.

In the case study, the patient might determine their cancer pain based on their individual background and experience, which might affect judgement of their abilities to deal with pain. In addition, the cancer pain stressor may change over time; outcomes may occur in differing timeframes. Therefore, the patient's adaptation to the pain, following an appraisal of the situation, resources, self-efficacy and coping efforts, consequently changes.

Cultural differences, as well as an individual's personal experience, are likely to shape a patient's perception of treatment. Diverse religious oriented beliefs as a spiritual cause of illness have been associated with preference for treatment from a religious leader, rather than health professionals (Henshaw et al. 2009). Some Thais still believe that spirits are responsible for illness, so they would find a spirit healer to perform divining rites in order to remove the afflicting ailment. However, people are generally unanimous that spirit healers were unable to cure advanced stages of fatal diseases, such as cancer (Lyttleton 1996). Occasionally, official physicians will recommend patients with chronic illness to see a spirit healer if they feel that the illness is psychosomatic in origin. It has been found that such rites have a beneficial influence in providing psychological reassurance (Lyttleton 1996).

Local belief systems do not always credit the official physicians with exclusive understanding of the cause of illness. In particular, because some physicians practicing Western medicine neither take the time to explain causes of sickness nor offer prognoses for improvement, a vacuum is created into which traditional practitioners provide crucial contextualisation of the illness experience.

The patients also look for alternative explanations. In this context, Buddhist ideology remains a powerful underpinning of attitudes to sickness and healing. Concepts of merit and karmic attribution to explain afflictions are constant components of understanding illness rather than prediction (Lyttleton 1996).

### ***Current symptom and severity***

A co-factor, influencing the patients' perception of cancer pain which affects decision making to deal with pain, was the pain's severity. Perceived severity refers to propose the consequences of contracting a health problem or leaving it untreated. The patients judged how serious was their problem, and their urgency to receive treatment, by the severity of their symptoms, especially the pain.

In the case study, pain level was determined as positively correlated to the progression of the disease in all patients. This interpretation prompted the patients, and also their family members, to make a decision in order to deal with this serious problem. Patients who have mild pain or begin to have pain are likely to solve the problem by themselves. This is correlated with the patients' appraisal that they have the ability to deal with pain or daily living. The patients ask themselves basic questions, such as how much pain do they have, can they deal with their pain, and do they need help from other people?

### ***Effectiveness of choices of treatment / medication / strategy***

Performing a certain behaviour depends on how beneficial the individual believes the various alternatives will be (Davidhizar 1983). An action is not likely to occur unless individuals believe that their efforts will be efficacious. This perception refers to a belief in effectiveness of a variety of pain therapeutic strategies, employing both modern and traditional means. The clients are unlikely to seek treatment if they do not believe they will benefit from the chosen and involved professional services. When individuals are made aware of how treatment could improve their daily functioning, they may be more motivated to overcome the perceived barriers to their treatment (Henshaw et al. 2009).

In the case study, the preference of the patients to receive treatment varied. A preference for a combination of modern treatment from the cancer centre and Thai traditional medicines or strategies was found in all patients. It was also found that the patients were satisfied to control pain by an injection, rather than via oral medication. Evidence can be generally found in Thai villagers that injections are a

highly valued means of taking pharmaceutical drugs, because of their supposed efficacy in curing illness (Lyttleton 1996).

### ***Self-efficacy***

Self-efficacy is an individual's belief in their capabilities to organise and execute a course of action (Bandura 2002). It is suggested to be the key to the successful achievement of self-management.

Pain induces patients to appraise themselves about their ability to deal with pain. Ability appraisal depends on the perception of the severity of pain and its impact. This is an important factor upon which to base further decisions about choosing ways to deal with pain. If the patients seem confident about their ability to deal with the pain, they will try to solve the problem by themselves. But if the patients considered that the problem seemed complicated and they might not solve the problem on their own, asking for help would be undertaken. Some patients judge themselves to be a burden for their family, which may induce a responsibility to begin self-care.

Supernatural power and ghosts, as the cause of cancer and pain, were identified in some patients. Moreover, the previous behaviour from the past sin, leads to having pain in a patient. These beliefs might lead the patients do nothing because they perceive that they appraised themselves that they will not be able to control the pain. Some patients might find an alternative strategy, based on their supernatural belief, to deal with their problem.

### ***Perceived barriers***

Perceived barriers or negative aspects of particular actions may act as impediments to undertaking recommended treatments or behaviour. In the case study it seemed that financial problems related to their family's financial status was the most important barrier to taking action. This affected the way a decision would be made to follow recommended strategies for better health and travelling to receive treatment in the hospital.

The fear of addiction and worry about unmanageable side effects caused the patients to be reluctant to take pain medication, resulting in poor adherence to the prescribed pain regimen. Regardless of whether the patients were provided with information about drugs from health professionals, their own perceptions about opioids, and their potentially adverse effects, still influenced the patients' feelings.

### 6.3.1.2 Decision making process

A good medical decision is one that the physician and patient mutually agree on, where all parties are satisfied with their level of involvement in the process, the decision aligns with the patient's values as well as the best available clinical evidence, and the decision is feasible to implement. A physician's understanding and accommodation of a patient's preferences for involvement are important, because patients who believe their actual level of involvement in the consultation is congruent with their preferred level are more satisfied with care and with the decision (Glanz et al. 2009).

Three types of decision making: paternalistic (physician makes decision), shared (physician and patient decide together), and informed (patient decides after considering physician's input) are relevant to this study. Each proceeds through three stages as follows: exchanging information, deliberating, and deciding treatment. Many patients want to be actively involved in exchanging information about treatment possibilities and in deliberating the pros, cons, and deciding treatment options. Yet these same patients may prefer not to assume responsibility for the decision making process (Glanz et al. 2009).

Lower quality in decision making due to patients' values and preferences may not be discussed (Glanz et al. 2009). Some patients may not have an opportunity to clarify conflicting goals and needs, whilst other patients are not being adequately involved in the decision making process, due to minimal discussion between the patients and their physician. The physician may not discover patients' beliefs about health and treatment, which may be inconsistent with scientific evidence.

Different experts may give conflicting recommendations, forcing patients to choose among different sources of authority. Physicians and patients have different analytical interpretations about the risk of evidence. They may not achieve a shared understanding of the risk and benefits associated with different treatment possibilities, a lower-quality decision may occur, the patient's choice for treatment may not be fully informed, and the patient's commitment to treatment may be decrease (Glanz et al. 2009).

Physicians can help patients to diminish patient's ambivalence by providing alternative options to achieve the same goal, and giving patients time to consider choices rather than forcing a premature decision. The purpose of this is to bolster

the patients' sense of self-efficacy and motivate the patients to take control of their symptoms.

### **6.3.2 Behaving**

Direction for behaving consists of the way that Thai patients prefer to communicate as 'implicit expression' and making a decision to 'do by self or ask for help' from family or health care provider.

#### **6.3.2.1 Communication**

The model of communication is based on the degree of control between patients and HCP. The level of patient involvement in the communication may vary on a continuum from totally passive to extremely active.

Clinician-patient communication can affect health directly, or can affect it indirectly through the mediating effect of proximal outcome (such as greater mutual understanding, trust, patient satisfaction, and patient involvement in decision making) and intermediate outcomes (such as change in patient health behaviour, self-care skills, adherence to treatment, and better medical decisions) (Glanz et al. 2009).

Factors that influence communication exchange include volume of information provided by clinicians, the emotional salience of some types of information, discrepancies between physician and patient's understandings of disease and treatment, literacy and communication skills (Glanz et al. 2009).

#### ***Implicit expression***

Patients think about how to communicate or express their need or their pain, as well as how to behave or deal with that pain. Most patients preferred to use implicit expression rather than explicit behaviour. This seemed to be a common behaviour in Thai people due to education or values transferred from the older generation. The caregiver needs to be aware of this implicit dimension since, in such a situation, the patient wishes for help to be provided without having to ask for it.

Patients may not complain of pain because they want to be a 'good patient' or they are reluctant to distract the physician from treating the primary disease, leading to a lack of communication about pain to the patients' health care

providers. Another aspect affected the way that the patients would communicate to health care providers is social distance. Social distance refers to the number and importance of dissimilarities between physicians and patients (Glanz et al. 2009). Factors contributing to this social distance are clinician-patient differences in beliefs about health, use of language, and health-related values; all of which have the potential to create the risk of misunderstanding or bias.

Social distance can make it more difficult to establish strong physician-patient relationships. Patients appreciate clinicians who can understand and empathise with their life circumstances. Physician communication, intended to enhance the patient - doctor relationship, may not be as effective in building a therapeutic alliance if the patient does not perceive the communication as sincere or believes the doctor is not capable of empathic understanding. Ways of reducing social distance includes showing attentiveness, avoiding interrupting, asking about the patient's beliefs and values, and giving clinical information in a way the patient understands; the physician communicates commitment, respect, and an interest in the patient as a person (Glanz et al. 2009).

#### **6.3.2.2 Doing by self or asking for help**

Cancer pain is an on-going condition which patients face, together with its problems and concerns, on a day to day basis. They need to manage their persistent pain and related problems in everyday life (Lorig 2003; Kralik 2004). Patients who face pain have two major choices when it comes to the solution of that pain: 'do by self' and 'ask for help'. 'Do by self' refers to the process when the patient tries to solve problems by herself. 'Ask for help' refers to when the patients consider that the problem is so complicated that they cannot solve the problem on their own.

Patients balanced their ability to deal with pain by themselves, against the appraisal of the need for help. The main factor that influenced how patients appraised themselves was health status. Relatively healthy patients may need help less than those whose health was poor. However, a hidden reason that patients may ask for help was a need for psychosocial support.

Two main sources of help are from the health care provider and the patient's family. Patients ask for help from health professionals mainly concerning their disease and treatment whereas the family is requested to provide physical and emotional care and support. Patients perceive that a health care provider can offer

help in many ways. Some patients, who question their diagnosis, seek clarification from health care providers by asking for explanations or requesting investigations about their disease and/or symptoms. Most patients find help from health care providers, especially relating to the issue of pain medication. Asking for drugs is a common request from patients who have severe pain. Families can help the patients in relation to the provision of a variety of support, regarding such issues as daily living, travelling and finance. Families can also provide alternative treatments for the patients.

#### **6.3.2.3 Bearing the pain/being patient**

Patients may think about their own ability and the possibility of success when trying to control their pain. Patients who believed in their ability to, or the possibility to, control pain tended to find or undertake behaviour which assisted them to deal with the pain. Whereas bearing the pain was often the choice expressed in patients who perceived the use of analgesics or other pain control strategies to be less effective in pain control.

There is an interesting factor which may influence the decision to deal with pain, the belief in the principle of Buddha as Karma. Karma leads to the belief that any current situation is affected by past sins. People who have a strong belief in this principle may consider a particular situation, such as cancer, to be uncontrollable; therefore, some patients may do nothing to deal with their disease, or just bear the pain because of their belief in Karma. This applies especially to patient who are in a bad condition.

#### **6.3.2.4 Finding information**

Information seeking is a frequently used coping response. Although there is substantial evidence that information seeking can lead to reduced distress and adaptive health behaviour, there is also evidence that individuals differ in the extent to which they seek information in the face of a health threat (Glanz et al. 2009).

#### **6.3.2.5 Taking/doing a strategy**

The patients' reaction to a situation consists of two main strategies: engaging and disengaging coping strategies. Engaging coping strategies such as active coping, planning problem solving, information seeking and the use of social support is more likely to be employed by a person who has favourable beliefs about self-efficacy. Disengaging coping strategies include distracting, cognitive avoidance (not to think about stressor), behaviour avoidance (not going for a follow-up), and

denial. These strategies may be of benefit to release stressful feeling but these may also lead to intrusive thoughts that can generate increased distress over time and keep people from developing healthier coping strategies (Glanz et al. 2009).

The Thai villagers have several choices of treatments. The most favourite strategy for the patients in controlling their pain is simply to buy drugs from drugstores. In Thailand, self-medication remains widespread. Many drugstores readily sell most types of pharmaceuticals across the country (Lyttleton 1996).

### **6.3.3 Thai family and Thai culture**

#### **6.3.3.1 Thai family**

In Thai culture, family members take responsibility to care for the patients, especially ones who have chronic disease (Lundberg and Rattanasuwan 2007). However, the effectiveness of care provided by family was influenced by many factors.

##### ***Relationship among family members***

The way to comprehend Thai social values is to focus on its basic unit, the family. The father is generally regarded as the leader, but the mother also plays a significant role, particularly in the family finances.

In relationships between the younger and the senior generations, Thai society is hierarchical. The juniors must pay respect to the seniors, while the latter must be generous to the former in return (Siriwan 2000). A distinction is applied not only to the relationship between parents and children but also to those siblings of different ages. This same delineation of role also applies to the wider world outside the family and will remain deeply ingrained throughout life, thus explaining the reluctance of younger Thais to oppose or otherwise confront a senior during their subsequent careers in business and government (National Identity Office of the Prime Minister 1991).

##### ***Providing care and support***

Family members play the prime role in offering care and comfort in order to maximise the quality of pain control for the cancer patients (Given and Given 1994; Duhamel and Dupuis 2003). They can assist the patients in many ways including in deciding how and when to give the pain medication, monitoring and recording the

patient's symptoms and communicating with health professionals. In addition, they also remind and encourage the patient to follow the prescriptions and find alternative ways to help patients in relieving pain.

Family is the primary source of support and assistance to people with cancer and collaboration between family and health care providers may improve patient outcomes (Kahana et al. 1994). Patients who are in poor condition cannot perform self-management; for this situation, social support provided by family members and health care providers may be the main factor to improve the patient's self-management and their health status.

Family and friends can either reinforce or undermine the decisions reached by physicians and patients and thus affect the treatment adherence and health outcomes. Providing transport to medical appointments and assisting in the patient's self-care can enhance the emotional support and self-care help.

#### **6.3.3.2 Thai culture**

Thai society is characterised by a hierarchical tradition in which people occupy differently ranked social positions (Choowattanapakorn 1999). Children are taught early to respect older people and people of higher status. Older Thais are usually given high status that demands care, respect and obedience from children, and can expect to be valued and honoured by their children.

Individually, Thais perceived that caring for parents or supporting them financially, and doing good acts for other people in general, is believed to bring merit. Villagers hope such merit will mean a better life in future (Choowattanapakorn 1999).

The feeling of 'hierarchy', as well as the custom that young people should show respect to the old, inform the way that Thai people behave. 'Kreang Jai', a common Thai expression, refers to a feeling that people do not need to disturb others or to be a burden. People should prioritise doing everything by self-help, if possible, before asking others for help.

Thais believe that social harmony is best maintained by avoiding any unnecessary friction in their contacts with others. From this has grown the strong Thai feeling of 'Kreang Jai'. In general, people will do their utmost to avoid personal conflict.

## Chapter VII

# Revision of the self-management

### 7.1 Introduction

This chapter illustrates a revision of perspective of self-management in the Thai context. The self-management skills applied to increase self-management abilities in various studies might not be suitable to the unique circumstance related to Thai culture. A careful critique of the original self-management, and the developed self-management for Thais, is provided.

### 7.2 The original self-management *versus* the developed self-management for Thais

There are many aspects similar and also different between the original self-management model provided by Lorig and Holman (2003) and the developed self-management model for Thai patients featured in this study. Discussion on those similarities and differences is provided as follows.

Self-management refers to an ability to manage oneself by using various necessary skills. It is a dynamic-active process of learning, trailing and overcoming the boundaries (Kralik D, 2004). There are two main concepts considered as the foreground issues for developing a self-management programme: concept of chronic illness and concept of self-management itself.

Chronic patients are the experts to deal with their own condition in everyday life. The researchers also suggest that health providers can facilitate people toward self-agency by embracing new understandings of self-management in long-term illness.

Self-management is the problem base; in other words the problems and concern of patients have to be considered along with applying the self-management

approach. The important consideration in self-management should be focused on an individual needs assessment for each new topic (Lorig and Holman, 2003).

From these two main aspects, Lorig and Holman (2003) proposed the five, core, self-management skills to be the base skills in many self-management programmes for chronic patients. The five core skills are as follows.

1. Problem solving: patients are taught basic problem solving skills including problem definition, generation of possible solution, solution implementation and evaluation of results.

2. Decision making: this skill is part of problem solving. Patients must make day-to-day decision in response to change in the condition of their disease. They need enough and appropriate information.

3. Resource finding and utilisation: patients have to learn how to seek and utilise resources from many sources identified or provided by health providers.

4. Forming of a patient/health care provider partnership: patients must be able to communicate their condition and their need via an accurate report. Moreover, they should make informed choices about treatment and discuss these with the health providers.

5. Taking action: patients have to learn how to change behaviour by using a short-term action plan and pursue their task to reach the goal. This skill depends on patients' confidence (self-efficacy). There is a tendency to succeed, based on a high level of self- efficacy, On the other hand, the individual needs to do some problem solving to make the plan more realistic and to avoid failure in the case of low confidence.

The key component of self-management is self-tailoring, in other word using self-management skills and knowledge and applying them to and for oneself, as appropriate. The best means of self-tailoring is done by patients, based on learning the principles for changing behaviours and self-management (Lorig and Holman, 2003).

It is found that all skills involved in the former self-management model are also found in the developed self-management model of this case study but the presentation and emphasis are different.

The developed self-management model seems not focus on problem solving skills, which was the first skill of the former model. However, when considering the definition of this skill, many processes of problem solving are also described in the thinking concept of the developed model. The developed model illustrates the details of factors influencing the thinking process that affects how the patients perceived problems, considering the possibility and effectiveness of the choices of solutions. This aspect is unique due to the cultural influence, which is the vital factor affecting the way Thai patients interpret their problem, and then make a decision to solve that problem as a result.

With decision making skills, the detail is quite different between the former and the developed self-management model. In the developed model decision the making process seems more complicated because it is not only the individual making a decision but, in Thai society, the whole extended family plays a vital role in the decision making process. Close relationships among family members, knowledge and availability of members, together with the role of main support provided by the family, all need to be considered in the decision making process.

The last three skills of resource finding and utilisation, forming of a patient/health care provider partnership and taking action, are illustrated under the behaving concept of the developed model, but receive less emphasis than the other component skills. All three of the skills in the developed model need to improve in the patients, but there are three important factors which affect the way that the patients' behave in Thai culture. Implicit expression is the general expression for most Thais, which health care providers have to consider while having a communication exchange with the patients. Forming a partnership between patient and health care provider is mostly affected by the concept of 'hierarchy' and 'Kreang jai'. These two aspects seem to be the obstacles for improving the patient - HCP relationship and information exchange. However, understanding these Thai characteristic will help health care providers in developing an appropriate approach to the patients. Taking action by the patients in the developed self-management model is based on their knowledge, their own experience, and confidence to behave or solve the problem by themselves. Health literacy and local context are important factors influencing how the patient engages in self-management activities and how she will use the health care service.

## **7.3 Specific considerations for developing a self-management programme for Thais**

### **7.3.1 Self-efficacy, the key to success of self-management, is not enough for Thais**

Focusing on previous self-management programmes, many such programmes centre on problem solving, decision making and confidence building, based on increasing self-efficacy (Coster and Norman 2008). Therefore self-efficacy is the key achievement of self-management (Bandura 1997).

It can be seen that the developed self-management programme is based on the original perspective of self-management, with its focus on individual efficacy. A number of studies have demonstrated the positive outcome of self-management programmes on increasing personal knowledge of symptom management resulting in improving health status. However, the effectiveness of self-management was uncertain. Other systematic reviews argued that self-management programmes had only a small to moderate benefit in chronic patients and the effectiveness was only in some chronic diseases (Warsi et al. 2004; Newman et al. 2004). Researchers argued that self-management programmes should be developed specifically for the particular subgroups based on the individuals' needs and capabilities (Warsi et al. 2004). A study by Newman et al. (2004) claimed that a single theory of self-management may not be suitable for all patients. To improve the individual aspect of management, there may be the need to use more than one means, depending on patients' conditions as well as their efficacy.

For Thais, self-efficacy might not be the sole factor of success. According to the self-management model of the case study, it can be seen that performing self-management behaviour was influenced by various factors. The theoretical basis of self-management is the principle of behaviour change (Lorig and Homan 2003) which, in turn, is influenced by personal thought and belief (Bandura 2002). Thus, knowledge of the personal beliefs and perspectives related to cancer pain were essential to generate an understanding of self-management behaviour of Thai patients.

The optimal purpose of the original perspective of self-management was to develop self-care agency of individuals. Human agency refers to a power to originate actions for given purposes. The key factor of human agency relates to a belief of

personal efficacy; perceiving self-efficacy to be based on a belief in one's capabilities to organise and execute the course of action required to produce given attainments. However, human agency still operates within an interdependent causal structure involving personal factors, behaviour and external environment. This view of human behaviour and action is based on the social cognitive theory premise that people do not live their lives in isolation, and people share beliefs in their capabilities to produce effects collectively. Both social circumstance and collective beliefs in society influence human's ability to adapt and change. From these perspectives, it might be possible to more precisely explain self-management of Thais.

### **7.3.2 Cultural influence on self-management**

There is a correlation between social support and different culture which may enhance self-efficacy and self-management. The cultural diversity should be considered along with the process of self-management.

In Asian cultures, including Thailand's, people may believe that one should not have to ask for support because people should anticipate other's need for support and provide it before support is explicitly sought (Kim et al. 2008). There is also a strong belief that any personal problem should be solved independently, people should be responsible for their own problem. There may be more concern about the potentially negative relational consequences of support seeking, rather than about the problem itself.

The way to express social support is based on cultural diversity. Explicit social support is a result of people's specific recruitment and use of their social networks in response to a specific stressful event that involves the elicitation of advice, instrumental aid, or emotional support. Implicit social support may well refer to the emotional comfort one can obtain from social networks, without disclosing or discussing personal problems related to specific stressful events. By using implicit social support, the recipient, especially for Asians, can enjoy the benefits of social support without potential concerns about the relational implications (such as losing face or worrying others).

### 7.3.3 Family: a crucial factor for self-management

In Thai culture, family member takes responsibility to care for members who have illness in the family. Family members play the prime role in offering care and comfort in order to maximise the quality of pain control for the cancer patients (Given and Given 1994; Duhamel and Dupuis 2003). They would engage in every process of caring including informing choices of treatment, decision making for treatment, and providing care and comfort. The degree of involving care for the patients depended on the family structure and the relationship among family members. However, there was shared behaviour in the process of providing care for the patients in the family, respect for the family leader and members of the older generation.

Social support is defined as the resources provided by other persons. Social support may affect symptom reporting by altering physical states as well as psychological states. Kinds of support depend on its appropriateness for the situation and individual.

There are some studies that have reported a high correlation between social support and the effectiveness of self-management. Cohen and Syme (1985) reported that feelings of belonging elevated self-esteem and security, increments that were engendered by social support. However, the consideration to use social support is informed by its appropriateness for the situation and person. The effectiveness of the support depends on matching the type of support and the type of problem encountered (Cohen & Syme 1985).

The Thai family should be carefully considered as a vital influence of self-management for pain control for Thai patients, because of their close relationship among family members. According to the findings of the case study, it can be seen that all patients would seek help from their family. The patients' requests were not only for physical help, but for all aspects related to care and treatment such as providing care, travelling, and finance. Moreover, family support was important for the patients in term of improved psychological status.

Patients receive social support from health providers and family in many ways. In Thailand, family is important to patients as a source of psychological, financial and material support. Therefore, family has a central role in any serious problem. Because of the intimate relationship among family members, all will sense their responsibility to everyone who has problems (Lundberg & Rattanasuwan 2007).

By understanding the differences in social support use, it should be possible to consider more indirect and contextual cues to propose support for an individual to deal with her or his problem.

Considering the broad view of the former self-management model, it is found that the model focuses on individuals' potential abilities to manage and construct environments to suit purposes they devise for themselves. The programmes developed to improve self-management ability contain individually targeted strategies; there is no emphasis on how social circumstance, especially families, take part in the behaviour. In focusing on individuals' health-related perceptions, the former model does not explicitly address important social, interpersonal, and contextual issues. This consideration illustrates the missing of important factors that could play central roles in shaping health behaviour, especially in Thai communities in which the patients' self-management is greatly influenced by family and culture.

## 7.4 Implementation

According to the finding of this case study, patients have their own self-management potential, founded on a variety of abilities; they can undertake their self-management, based on their individual factors or context. This study recognises that individual has a variety of self-management capacity; people have their own belief and experience to manage their lives, particularly. This aspect should be considered in providing information, education, training and nursing care to the patients in nursing practice.

However, there is a variety of the effectiveness of self-management for pain control which might be affected individuals by various factors. Major factor influence self-management behaviour of Thai patients is cultural circumstance. The way that people behave, including making decisions, interacting between people and taking action, was shaped by Thai culture. People would perform the most suitable behaviour in a situation which was also acceptable behaviour by society. From this, it could provide the understanding of self-management for Thais.

Culture influences people to communicate and behave in Thai context. It is an important factor affects not only how Thai patient communicate and interact but families' and health care professionals' behaviour are also affected by Thai culture. A major finding of my thesis is that the cultural belief of Kreang-Jai is a major factor

influencing pain communication and behaviour between patients, family and health care professionals. It affects how patients talk about their pain and the way how health care providers communicate with patients.

Kreang-Jai is the key answer of behaviour in relation to pain control in Thai context. Patients may not ask or communicate their pain due to Kreang-Jai or they may change their decision to ask for pain medication if they felt Kreang-Jai. This led the patients may deal with the pain by do nothing, just bear to the pain, or find ways to relief the pain by their own but it is found that the patients were still suffer from the pain. It should be better if the pain can be assessed and manage suitably and immediately before the problem was getting worse.

It seem difficult to know what patients needs because they do not tell you, you might not know the answer. Patients might not ask for help from their family and/or health care provider if they considered that the asking might bother them. In addition, nurses might interpret that the patients had no problem because the patients did not request their needs and the nurses might not assess the patient's need very often due to afraid that the assessment might disturb the patients. Even when health care professionals do ask patients, the patients reluctant to say they have pain. These example behaviours were observed in the study which presents the influence of Kreang-Jai on Thai people in relation to pain communication and pain management. Therefore, key factor in improving pain control is to understand Kreang-Jai influence pain communication. It is important to help health care provider understanding and beginning to behave differently to achieve good pain management.

It was not the work of this thesis to discover better ways of pain management training. However, some suggestions would be provided. Communication skill training for health care professional with different techniques is needed, for example, experiential communication skills training, building courses or curricular need to take into account value of Thai culture, not just the communication training base on Western models education.

There is quite difficult to communication over the feeling of Kreang-Jai because Thai people were taught and grew up with this tradition. In addition, the respectful thinking and behaving between Thais is affected by education, position in society and might related to financial status. These made the Thai patients would pay respect and have strong feeling of Kreag-Jai to health care professionals.

Therefore, health care professionals need to take into account about Thai culture and the influence of Kreang-Jai in communication about pain management.

In addition, Kreang-Jai also underpins self-management of pain and we know how to support self-management for pain control based on Kreang-Jai. We need to help patients to find way to respectfully communicating their pain to their family and health care provider. In self-management, there are need to be about explaining with patients how they will express their pain and to help family to know how to respond to a person's pain.

For health care professionals, we need to consider different ways of using pain management tools, for example pictural tools or tools designed for non-verbal expression of pain. The findings demonstrate that patients may express their needs by trying to attract a health care provider help by looking at them or sighing, so counting the frequency that the patients of looking at nurses might be cues to start the assessment and respond to them.

However, although nurses' knowledge about pain is good they tend to focus on routine tasks and not individual experience. It may be that routine is being need as some of protection for nurse so that they are not exposed to patients' pain and suffering. Of this is the case this will be complicated to address but can start with student nurses to equip them manage suffering in a more open way and effective way

For students, they need to take into account that verbal communication is insufficient in communication about pain. They need different techniques in order to more effective to find the patients' needs in relation to pain control. An Education on communication of pain management needs a bit broader and emphasis in implicit expression rather than ordinary verbal communication. I consider that it is imperative to allow students time to consider the experience of the culture and attitude about communication and pain management, on the way the nurse, on the experience of the patient.

As a result of my work, we have discovered that ordinary communication training for health care professionals in Thai health care service is not necessary adequate, but we have to take into account that Thai people have very strong manner of Kreang-Jai which means Thai patients might not express their pain or their needs directly. Therefore, Thai health care professionals who work with Thai patients need to understand and need different way to communicate to them

individually. They need to think carefully what the meaning of the patients' expression rather than what health care professionals observe the patients' behaviour.

In consequence, I have to express this to practice in order to emphasis health care professions to take into account more about Kreang-Jai. And, as the educator, I will take into account when I teach my student about communication of pain management and how Thai culture, as Kreang-Jai, influence communication and pain management behaviour. It needs in to account that the patients would not say that they are in pain in which health care professionals have to concern this expression carefully.

This study conducted by discussion a descriptive model of self-management for pain control in particular group of Thai patient who have cervical cancer in a regional cancer centre. To increase base of knowledge in this area, a study of cancer pain experience and self-management for pain control in various diagnosed-patient with cancer is recommended.



## **Appendix**



## Appendix II Participant Information Sheet

UNIVERSITY OF  
**Southampton**  
School of Health Sciences

### Participant Information Sheet\_For patient

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics number:** EC 190/2010

*Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.*

#### **What is the research about?**

This research is a study about pain; an important problem of patients with cancer. This research aims to understand pain experience, pain management and self-management in controlling pain in women with cervical cancer. Data will be collected from patients, family caregivers and health professionals. The findings will be used to inform the development of self-management programme to control pain related cancer in Thailand.

#### **Why have I been chosen?**

You have been invited to take part in this study because you have experience about cancer pain and pain management. This information will be useful to improve pain management and self-management of cancer pain in clinic and community environments.

#### **What will happen to me if I take part?**

If you take part, the interactions between you, your family caregiver and health care provider will be observed in relation to pain by the researcher during the period of study. Moreover, you will be interviewed one or two times about your experience about pain management by the researcher. After you are discharged, you will be visited at home at once and asked about managing your pain at home. The home visit will be done the research team which may include a hospital nurse up to the need for support. An appointment will be made with you in advance. In summary, you may take part in this study approximately three months.

Before taking part in this research project, you will be asked to sign a consent form. You will be given an information sheet which provides detail of this study and you will be offered a further opportunity to ask questions or seek clarification on any matter. The details of consent form cover your voluntary participation in the study and allow the researcher to observe and interview you, your permission for audio-recording and note taking and your permission for using all material including your medical records in the any process of the research and in publications. You will be asked to sign the consent form again when you have been interviewed to confirm that you are still willing to be a participant and allow the researcher team to use your given information in all process of study.

**Are there any benefits in my taking part?**

There may not be benefit to you directly but your information may help to improve the understanding about pain experience and pain management in patients with cancer and may be useful in a further study to develop a programme to increase self-management capability of people with cancer pain.

**Will my participation be confidential?**

Yes. Your identification during the process of research will be kept strictly confidential. We will follow the ethical and legal practice. Information from the hospital about your name and address will be deleted. False names or codes will be used to protect your identify. All hard copies will be kept in the locked cabinet. All electronic records and transcripts will be kept on a password protected computer. Only the research team will be able to access your data. We will keep your information secure for ten years in the University data protection system. Then all recordings will be destroyed.

You should be aware that the absolute confidentiality may be not kept if the researcher has concerns about some aspects will become a risk to you or others. The researcher will firstly discuss with you in order to help you to manage that concerns and seek appropriate support. In the extreme case, the risk will be referred to appropriate professionals to deal with that risk.

**What happens if I change my mind?**

You have the right to withdraw from the study at any time without having to give any reason. This withdrawal will not affect your routine treatment and health service. If you withdraw from this study, we will destroy all data that identifies you. Information collected may still to be used up to your withdrawal.

**Are there any risks involved?**

There is acknowledging the risk of this research as low. However, we understand that you may feel uncomfortable during the period of the study from the observation by the

researcher or talking about the painful issues. We are aware that the safety of the participants is the first priority. We intend to support and prevent any uncomfortable by providing information and encouraging you through individually discussion about the thing you feel unhappy. In the event that have any sign of harm during the study, you will be taken care of immediately by the research team and health professionals. You may be referred with your agreement to appropriate clinics. We will make sure that support is available to you afterwards.

### **What will happen to the result of the research study?**

The results of the study will be disseminated in several ways, including a PhD thesis, presentations at local, national and international conferences; writing papers for publication. You will be asked at the end of the study if you wish to receive a summary of the findings.

### **How can I do if I have any concern?**

If you have any concern about any aspect of this study, you can ask for question and seek clarification from the researcher who will provide the best information of this study.

#### *The researcher's contact details:*

*Miss Thitiwan Yothathai  
Boromarajonani College of Nursing Udonthani  
88 Moo 1, Tambon Nongpai, Amphor Muang, Udonthani 41330;  
Tel: +66 (0)42 295 406 or +66 (0)80 812 0618  
Email: ty2e08@soton.ac.uk*

If you are still unhappy and wish to complain formally, you can contact the ethic committees of the National Cancer Institute, Ministry of Public Health who approving this research project.

#### *Contact details:*

*Research ethic committee  
National Cancer Institute  
268/1 Rama 6 Road, Rachadevi  
Bangkok 10400  
Tel. +66 (0)2 354 7025 or +66 (0)2 354 7028-35*

Or you can contact Susan Rogers, Head of Research & Enterprise Services, at the Faculty of Health Sciences, who can provide you with details of the University of Southampton Complaints Procedure.

*Contact details:**Susan Rogers**Building 67, Faculty of Health Sciences,**University of Southampton, Highfield, Southampton,**SO17 1BJ United Kingdom**Tel: +44 (0)23 8059 7942**Email: S.J.S.Rogers@soton.ac.uk***Thank you for considering taking part in the study**

## **Participant Information Sheet\_For family**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics number:** EC 190/2010

*Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.*

### **What is the research about?**

This research is a study about pain; an important problem of patients with cancer. This research aims to understand pain experience, pain management and self-management in controlling pain in women with cervical cancer. Data will be collected from patients, caregivers and health professionals. The findings will be used to inform the development of self-management programme to control pain related cancer in Thailand.

### **Why have I been chosen?**

You have been invited to take part in this study because the patient who take part in this study identify you are her closest carer that you have experience to take care of the patient. This information from you will be useful to improve pain management and self-management of cancer pain in clinic and community environments.

### **What will happen to me if I take part?**

If you take part, the interaction between you, the patient and health care provider will be observed by researcher during the period of the study. Moreover, you will be interviewed once about your experience to care for the patient who has pain by the researcher. You will be visited at home once and asked about managing the patient's pain at home. The home visit will be done the research team which may include a hospital nurse up to the need for support. An appointment will be made with you in advance. In summary, you may take part in this study approximately three months.

Before taking part in this research project, you will be asked for sign a consent form, you will be given an information sheet which provides detail of this study and you will be offered a further opportunity to ask questions or seek clarification on any matter.

The details of consent form cover your voluntary participation in the study and allow the researcher to observe and interview you, your permission for audio-recording and note taking and your permission for using all material in the any process of the research including in publications. You will be asked to sign the consent form again when you have been interviewed to confirm that you are still willing to be a participant and allow the researcher team to use your given information in all process of study.

**Are there any benefits in my taking part?**

There may not be benefit to you directly but your information may help to improve understanding about pain experience and pain management in patients with cancer and may be useful in a further study to develop a programme to increase the self-management capability of people with cancer pain.

**Will my participation be confidential?**

Yes. Your identification during the process of research will be kept strictly confidential. We will follow the ethical and legal practice. Information about your name and address will be deleted. False names or codes will be used to protect your identify. All hard copies will be kept in the locked cabinet. All electronic records and transcripts will be kept on a password protected computer. Only the research team will be able to access your data. We will keep your information secure for ten years in the University data protection system. Then all recordings will be destroyed.

You should be aware that the absolute confidentiality may be not kept if the researcher has concerns about some aspects will become a risk to you or others. The researcher will firstly discuss with you in order to help you to manage that concerns and seek appropriate support. In the extreme case, the risk will be referred to appropriate professionals to deal with that risk.

**What happens if I change my mind?**

You have the right to withdraw from the study at any time without having to give any reason which without penalty. If you withdraw from this study, we will destroy all data that identifies you. Information collected may still to be used up to your withdrawal.

**Are there any risks involved?**

There is acknowledging the risk of this research as low. However, we understand that you may feel uncomfortable during the period of the study from the observation by the researcher or talking about the painful issues. We are aware that the safety of the participants is the first priority. We intend to support and prevent any uncomfortable by providing information and encouraging you through individually discussion about the thing you feel unhappy. In the event that have any sign of harm during the study, you will be taken care of immediately by the research team and health professionals.

You may be referred with your agreement to appropriate clinics. We will make sure that support is available to you afterwards.

### **What will happen to the result of the research study?**

The results of the study will be disseminated in several ways, including a PhD thesis, presentations at local, national and international conferences; writing papers for publication. You will be asked at the end of the study if you wish to receive a summary of the findings.

### **How can I do if I have any concern?**

If you have any concern about any aspect of this study, you can ask for question and seek clarification from the researcher who will provide the best information of this study.

*The researcher's contact details:*

*Miss Thitiwan Yothathai  
Boromarajonani College of Nursing Udonthani  
88 Moo 1, Tambon Nongpai, Amphor Muang, Udonthani 41330;  
Tel: +66 (0)42 295 406 or +66 (0)80 812 0618  
Email: ty2e08@soton.ac.uk*

If you are still unhappy and wish to complain formally, you can contact the ethic committees of the National Cancer Institute, Ministry of Public Health who approving this research project.

*Contact details:*

*Research ethic committee  
National Cancer Institute  
268/1 Rama 6 Road, Rachadevi  
Bangkok 10400  
Tel. +66 (0)2 354 7025 or +66 (0)2 354 7028-35*

Or you can contact Susan Rogers, Head of Research & Enterprise Services, at the Faculty of Health Sciences, who can provide you with details of the University of Southampton Complaints Procedure.

*Contact details:*

*Susan Rogers  
Building 67, Faculty of Health Sciences,  
University of Southampton, Highfield, Southampton,  
SO17 1BJ United Kingdom  
Tel: +44 (0)23 8059 7942  
Email: S.J.S.Rogers@soton.ac.uk*

**Thank you for considering taking part in the study**

## **Participant Information Sheet\_For health care provider**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics number:** EC 190/2010

*Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.*

### **What is the research about?**

This research is a study about pain; an important problem of patients with cancer. This research aims to understand pain experience, pain management and self-management in controlling pain in women with cervical cancer. Data will be collected from patients, caregivers and health professionals. The findings will be used to inform the development of self-management programme to control pain related cancer in Thailand.

### **Why have I been chosen?**

You have been invited to take part in this study because you are closely caring for the patient who participates in this study. You have an experience to take care of and to provide health support the patient who has cancer pain. This information will be useful to improve pain management and self-management of cancer pain in clinic and community environments.

### **What will happen to me if I take part?**

If you take part, the interaction between you and other health care providers, the patients and family caregivers will be observed during the period of the study. The researcher may listen to the conversation particularly during the physician's round and the nursing round. The researcher will also follow you to see how you deliver care for the patients. The researcher may ask questions about what you are doing and why. Moreover, you will be interviewed once about pain experience, pain management and self-management by the researcher. You will also be observed the activities during a home visit. In summary, you may take part in this study approximately three months.

Before taking part in this research project, you will be asked to sign a consent form, you will be given an information sheet which provides detail of this study and you will be offered a further opportunity to ask questions or seek clarification on any matter. The details of consent form cover your voluntary participation in the study and allow the researcher to observe and interview you, your permission for audio-recording and note taking and your permission for using all material in the any process of the research including in publications. You will be asked to sign the consent form again when you have been interviewed to confirm that you are still willing to be a participant and allow the researcher team to use your given information in all process of study

**Are there any benefits in my taking part?**

There may not be benefit to you directly but your information may help to improve the understanding about pain experience in patients with cancer and may be useful in a further study to develop a programme to increase self-management capability of people with cancer pain.

**Will my participation be confidential?**

Yes. Your identification during the process of research will be kept strictly confidential. We will follow the ethical and legal practice. Information about your name and address will be deleted. False names or codes will be used to protect your identify. All hard copies will be kept in the locked cabinet. All electronic records and transcripts will be kept on a password protected computer. Only the research team will be able to access your data. We will keep your information secure for ten years in the University data protection system. Then all recordings will be destroyed.

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**What happens if I change my mind?**

You have the right to withdraw from the study at any time without having to give any reason which without penalty. If you withdraw from this study, we will destroy all data that identifies you. Information collected may still to be used up to your withdrawal.

**Are there any risks involved?**

There is acknowledging the risk of this research as low. However, we understand that you may feel uncomfortable during the period of the study from the observation by the researcher or talking about the painful issues. We are aware that the safety of the participants is the first priority. We intend to support and prevent any uncomfortable

by providing information and encouraging you through individually discussion about the thing you feel unhappy. In the event that have any sign of harm during the study, you will be taken care of immediately by the research team and health professionals. You may be referred with your agreement to appropriate clinics. We will make sure that support is available to you afterwards.

### **What will happen to the result of the research study?**

The results of the study will be disseminated in several ways, including a PhD thesis, presentations at local, national and international conferences; writing papers for publication. You will be asked at the end of the study if you wish to receive a summary of the findings.

### **How can I do if I have any concern?**

If you have any concern about any aspect of this study, you can ask for question and seek clarification from the researcher who will provide the best information of this study.

#### *The researcher's contact details:*

*Miss Thitiwan Yothathai  
Boromarajonani College of Nursing Udonthani  
88 Moo 1, Tambon Nongpai, Amphor Muang, Udonthani 41330;  
Tel: +66 (0)42 295 406 or +66 (0)80 812 0618  
Email: ty2e08@soton.ac.uk*

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Or you can contact Susan Rogers, Head of Research & Enterprise Services, at the School of Health Sciences, who can provide you with details of the University of Southampton Complaints Procedure.

*Contact details:*

*Susan Rogers*

*Building 67, Faculty of Health Sciences,*

*University of Southampton, Highfield, Southampton,*

*SO17 1BJ United Kingdom*

*Tel: +44 (0)23 8059 7942*

*Email: S.J.S.Rogers@soton.ac.uk*

**Thank you for considering taking part in the study**

## Appendix III Consent Forms



### The observation consent form\_for patient

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [redacted] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics reference:** EC 190/2010

I, ..... consent to participate in the above research study. All information of this study include purpose, nature, benefit, risk and risk management has been explained to me by Thitiwan Yothathai.

I agree for the collecting data to be observing with field note taking. I also agree for my data to be used for the purpose of this study. I give permission for anonymous quotes of thing I informed in this study to be use in dissemination activities related to this study.

I agree that my identification will be kept confidential. However, if the researcher has perceived a risk to me or others, my information may be referred to an appropriate professional to deal with that risk.

I understand that my participation in this study is voluntary and that I can withdraw from it at any time without giving a reason. I also understand that if I decide to withdraw from the study, I will continue to receive the best conventional treatment that is available and without jeopardy to my future care.

If I have any further questions or need clarification regarding the study at any time, I should contact Thitiwan Yothathai on tel 080 812 0618

Signature of participant .....

Print name of participant ..... Date .....

Signature of researcher .....

Print name of researcher ..... Date.....

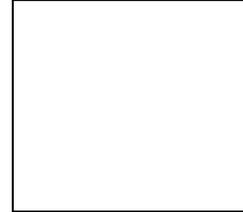
***If the participant is illiterate***

Signature of witness .....

Print name .....Date.....

Signature of witness .....

Print name .....Date.....



The thump print of the participant

**The observation consent form\_for family caregiver**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics reference:** EC 190/2010

I, ..... consent to participate in the above research study. All information of this study include purpose, nature, benefit, risk and risk management has been explained to me by Thitiwan Yothathai.

I agree for the collecting data to be observing with field note taking. I also agree for my data to be used for the purpose of this study. I give permission for anonymous quotes of thing I informed in this study to be use in dissemination activities related to this study.

I agree that my identification will be kept confidential. However, if the researcher has perceived a risk to me or others, my information may be referred to an appropriate professional to deal with that risk.

I understand that my participation in this study is voluntary and that I can withdraw from it at any time without giving a reason. I also understand that if I decide to withdraw from the study, I will continue to receive the best conventional treatment that is available and without jeopardy to my future care.

If I have any further questions or need clarification regarding the study at any time, I should contact Thitiwan Yothathai on tel 080 812 0618

Signature of participant .....

Print name of participant ..... Date .....

Signature of researcher .....

Print name of researcher .....Date.....

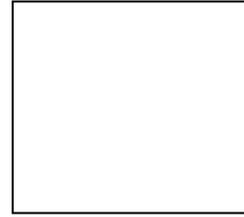
***If the participant is illiterate***

Signature of witness .....

Print name .....Date.....

Signature of witness .....

Print name .....Date.....



The thump print of the participant

**The observation consent form\_for health professional**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics reference:** EC 190/2010

I, ..... consent to participate in the above research study. All information of this study include purpose, nature, benefit, risk and risk management has been explained to me by Thitiwan Yothathai.

I agree for the collecting data to be observing with field note taking. I also agree for my data to be used for the purpose of this study. I give permission for anonymous quotes of thing I informed in this study to be use in dissemination activities related to this study.

I agree that my identification will be kept confidential. However, if the researcher has perceived a risk to me or others, my information may be referred to an appropriate professional to deal with that risk.

I understand that my participation in this study is voluntary and that I can withdraw from it at any time without giving a reason. I also understand that if I decide to withdraw from the study, I will continue to receive the best conventional treatment that is available and without jeopardy to my future care.

If I have any further questions or need clarification regarding the study at any time, I should contact Thitiwan Yothathai on tel 080 812 0618

Signature of participant .....

Print name of participant ..... Date .....

Signature of researcher .....

Print name of researcher .....Date.....

**The interview consent form\_for patient**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics reference:** EC 190/2010

I, ..... consent to participate in the above research study. All information of this study include purpose, nature, benefit, risk and risk management has been explained to me by Thitiwan Yothathai.

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If I have any further questions or need clarification regarding the study at any time, I should contact Thitiwan Yothathai on tel 080 812 0618

Signature of participant .....

Print name of participant ..... Date .....

Signature of researcher .....

Print name of researcher .....Date.....

***Serial consent after interview***

I, ..... declare that the interview has now been conducted and I consent for it to be used as described above.

Signature of participant .....Date .....

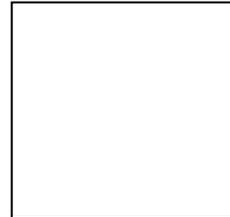
***If the participant is illiterate***

Signature of witness .....

Print name .....Date.....

Signature of witness .....

Print name .....Date.....



The thump print of the participant

**The interview consent form\_for family caregiver**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [redacted] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics reference:** EC 190/2010

I, ..... consent to participate in the above research study. All information of this study include purpose, nature, benefit, risk and risk management has been explained to me by Thitiwan Yothathai.

I agree for the collecting data to be interview with audio-recording and field note taking. I also agree for my data to be used for the purpose of this study. I give permission for anonymous quotes of thing I informed in this study to be use in dissemination activities related to this study.

I agree that my identification will be kept confidential. However, if the researcher has perceived a risk to me or others, my information may be referred to an appropriate professional to deal with that risk.

I understand that my participation in this study is voluntary and that I can withdraw from it at any time without giving a reason. I also understand that if I decide to withdraw from the study, I will continue to receive the best conventional treatment that is available and without jeopardy to my future care.

If I have any further questions or need clarification regarding the study at any time, I should contact Thitiwan Yothathai on tel 080 812 0618

Signature of participant .....

Print name of participant ..... Date .....

Signature of researcher .....

Print name of researcher .....Date.....

***Serial consent after interview***

I, ..... declare that the interview has now been conducted and I consent for it to be used as described above.

Signature of participant .....Date .....

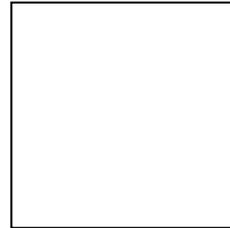
***If the participant is illiterate***

Signature of witness .....

Print name .....Date.....

Signature of witness .....

Print name .....Date.....



The thump print of the participant

**The interview consent form\_for health professional**

**Study title:** Self-management for pain control in Thai patients who have cervical cancer of the [REDACTED] Cancer Centre

**Researcher:** Miss Thitiwan Yothathai

**Ethics reference:** EC 190/2010

I, ..... consent to participate in the above research study. All information of this study include purpose, nature, benefit, risk and risk management has been explained to me by Thitiwan Yothathai.

I agree for the collecting data to be interview with audio-recording and field note taking. I also agree for my data to be used for the purpose of this study. I give permission for anonymous quotes of thing I informed in this study to be use in dissemination activities related to this study.

I agree that my identification will be kept confidential. However, if the researcher has perceived a risk to me or others, my information may be referred to an appropriate professional to deal with that risk.

I understand that my participation in this study is voluntary and that I can withdraw from it at any time without giving a reason. I also understand that if I decide to withdraw from the study, I will continue to receive the best conventional treatment that is available and without jeopardy to my future care.

If I have any further questions or need clarification regarding the study at any time, I should contact Thitiwan Yothathai on tel 080 812 0618

Signature of participant .....

Print name of participant ..... Date .....

Signature of researcher .....

Print name of researcher .....Date.....

## Appendix IV Patients' demographic data

<p><i>For researcher</i></p> <p>Participant's number.....</p>
---



### Patients' demographic data

#### General data

Participant's name (Mr/Ms/Mrs) .....

Age ..... years

Educational level

Primary school

High school

Graduate of technical college

Graduate degree of .....

Master degree of .....

Specific certificated degree of .....

Occupation

Official

Company employee

Private business owner

Other .....

#### Medical data

Hospital number ..... Admission number .....

Consultant's Name.....

Name of diagnosis ..... Date of diagnosis .....

Staging .....

Present illness

.....

.....

.....

.....

.....

Pain assessment (by the hospital's tool)

Location .....

Pain intensity .....

Treatments related to cancer

- Surgery .....
- .....
- Chemotherapy .....
- .....
- Radiotherapy .....
- .....
- Medication .....
- .....
- Others .....
- .....

Treatments related to pain

- Medication .....
- .....
- Others .....
- .....
- .....

Family tree (family members and relationship)

## Appendix V Data Collecting Guidelines

### 5.1 Observation guideline



#### Observation guides

##### *Stage 1: Descriptive observation*

Purpose : to describe how pain management is organised, what priority it is given in the work of nurses and other health care providers, how patients and family caregivers direct attention of health care professionals to pain in Thai cared context

Schedule : What does nurses / physicians take care of the patient?  
 How does s/he assess pain?  
 How does s/he manage pain?  
 What does s/he communicate or say about pain?  
 What things does s/he record about pain?

##### *Stage 2 : Focused Observation*

Purpose : to explore how patients manage their pain including how patient, family caregiver and health care providers interact in order to manage pain, to draw a picture of six individual cases and to explore whether there are specific issues which need further clarification in stage 3

Schedule : The patients' pain

- How do the patients perceive and address their cancer pain?
- How do they decide to manage pain?
- What action do they take to manage their pain?
- What resources do they use to manage their pain and how do they utilise these resources?

Is there collaboration between the patients, family caregivers and health care providers to deal with pain?

What is the collaboration? Who is in-charge in dealing with pain?

What action do family caregivers and health care providers do in order to deal with the patients' pain?

In what ways do family caregivers and health care providers encourage and support or hinder self-management of cancer related pain?

**Stage 3 : Selective Observation**

Purpose : to clarify interesting activities emerging around pain management

Schedule :

What do specific things emerge on pain management by the patients, family caregivers and health care providers?

**Home visit observation guide**

Purpose : to gain information around pain management in home context and to describe interaction between patient and family caregiver and interaction between patients, family caregiver and a nurse if that visit including a nurse

**Schedule for a visit by the research team**

How do women with cervical cancer conceptualise and perceive their pain?

When pain is perceived to be a problem what process do patients undertake to solve this problem?

What decisions do they make to manage their pain and how do they make their decision?

What resources do they use to manage their pain and how do they utilise these resources?

What action do they take to manage their cancer pain?

Is there collaboration between the patients and family caregivers to deal with pain? What is the collaboration? Who is in-charge in dealing with pain?

In what ways do family members support or hinder self-management of cancer related pain?

## 5.2 Semi structure interview guideline



### Semi structure interview guides\_For patient

The interview will be divided into two parts. The questions in Part 1 is to explore the experience and impact of cancer pain. The questions in Part 2 will focus on pain management and support for managing pain. The interview will be last for approximately 1 hour.

#### ***Interview part 1 The experience and impact of cancer pain***

In this part, I want to ask you about your experience of cancer pain. I want to know about what factors affect your pain and how pain affects you and your family.

Main question 1.1 : *Tell me about your pain, what is it like?*

Probes                      What is the first thing comes to your mind when you've got pain?  
                                   What are you feeling about that pain?

Main question 1.2 : *What does the pain signify for you?*

Probes                      Do you think that pain related to your disease?  
                                   What factors make pain worse?  
                                   What factors make pain better?

Main question 1.3 : *How does the pain affect you?*

Probes                      How does pain affect your daily living?  
                                   Activity, Household working, Paid work, Sleep pattern, Emotion  
                                   How does the pain affect your ability?  
                                   Do you think that your ability is less than before you've  
                                   pain?  
                                   How do you know? Could you give some examples?

Main question 1.4 : *How does the pain affect your family?*

Probes                      How do your family think about your pain?  
                                   How do you know what your family think?  
                                   Could you give some examples?  
                                   How does pain affect your family relationship?  
                                   How does pain affect your role in your family?

#### ***Interview part 2 Pain management, Self-management and social support for managing cancer pain***

In this part, I want to ask you what you do about your pain and how you manage it.

Main question 2.1 : *When you've got cancer pain, what do you do?*

Probes                      Who do you tell when you've got pain? (your family, nurse,

- doctor, other)
- Main question 2.2 : *How do you deal with your pain?*
- Probes
- What do you do when you have mild pain / when pain increase / when you have no pain?
  - Do you take pain medicine when you got pain?
  - What do you think about pain medicine?
  - Do you think are there other way can relief pain rather than taking pain medicine?
  - What are there? How is it helpful?
  - What made you decide to use that method?
  - What else might you do?
- Main question 2.3 : *Who is helpful when you've got pain? (your family, nurse, doctor, other)*
- Probes
- What is helpful from others to do?
- Main question 2.4 : *How do you ask for help from others?*
- Probes
- How do you ask for help from nurse?
  - What things she can do for you? What is the result?
  - What do you feel about that help?
  - How do you ask for help from family?
  - What thins they can do for you? What is the result?
  - What do you feel about that help?
- Main question 2.5 : *Is there collaboration in dealing with pain between you, your family and health care provider?*
- What is the collaboration? Who is in-charge to deal with pain?
- Main question 2.6 : *What different between pain management at hospital and at home?*
- Probes
- Which one do you think that pain can be controlled better?
  - What are things that make it better?
- Main question 2.7 : *'Patient who has persistent pain can learn from one's day-to-day experience to deal with pain and is the best person to manage one's pain.'*
- What do you think about this statement?
- Main question 2.8 : *How do you think about your ability to deal with your own pain?*
- Probes
- Do you think that you can deal with pain by yourself?
  - What is thing that makes you think like that?
  - What things can help you to deal with pain by yourself?
  - How is your feeling if you can deal with your own pain?

### **Semi structure interview guideline\_For family**

The interview will be divided into two parts. The questions in Part 1 is to explore the experience and impact of cancer pain. The questions in Part 2 will focus on pain management and support for managing pain. The interview will be last for approximately 1 hour.

#### ***Interview part 1 The experience and impact of cancer pain***

In this part, I want to ask you about your experience of cancer pain. I want to know about how pain affects you and the patient.

Main question 1.1 : *Tell me your thinking about cancer pain, what is it like?*

Probes                      What is the first thing comes to your mind, when the patient's got pain?  
                                    What are you feeling about that pain?

Main question 1.2 : *What does the pain signify for you?*

Probes                      Is that pain related to the patient's disease?  
                                    What factors make pain worse?  
                                    What factors make pain better?

Main question 1.3 : *How does the pain affect the patient?*

Probes                      How does pain affect her daily living?  
                                    Activity, Household working, Paid work, Sleep pattern, Emotion  
                                    How does the pain affect her ability?  
                                    Do you think that her ability is less than before she's got pain?  
                                    How do you know? Could you give some examples?

Main question 1.4 : *How does the pain affect you and your family?*

Probes                      What do you and your family think about patients' pain?  
                                    How does pain affect your family relationship?  
                                    How does pain affect your role in your family?

#### ***Interview part 2 Pain management, Self-management and social support in managing cancer pain***

In this part, I want to ask you what you do about the patient's pain, how the patient manages her pain, how you interact with the patient in order to manage her pain.

Main question 2.1 : *What does the patient do when she's got pain?*

Probes                      Who does she tell when she's got pain? (you and your family,

- nurse, other)
- If the patient doesn't tell anyone about her pain, how do you know?
- Main question 2.2 : *How does the patient deal with her pain?*
- Probes  
What does she do when she has mild pain / when pain increase / when she has no pain?
- Main question 2.3 : *How does the patient ask for help from others?*
- Probes  
How does she ask for help from nurse?  
What does the nurse do?  
How does she ask for help from you and your family?  
What do you and your family do?  
What do you feel about that asking?  
Do you give pain medicine when the patient's got pain?  
How do you think about pain medicine?  
Do you think are there other way can relief pain rather than taking pain medicine?  
What are there? How is it helpful?  
What made you decide to use that method?  
What else might you do?
- Main question 2.4 : *Is there collaboration in dealing with pain between you, your family and health care provider?*
- What is the collaboration? Who is in-charge to deal with pain?
- Main question 2.5 : *How is your ability to help the patient when she's got pain?*
- Probes  
What do you want to improve your ability to help her?
- Main question 2.6 : *What different between pain management at hospital and at home?*
- Probes  
Which one do you think that pain can be controlled better?  
What are things that make it better?
- Main question 2.7 : *'Patient who has persistent pain can learn from one's day-to-day Experience to deal with pain and is the best person to manage one's pain.'*
- What do you think about this statement?
- Main question 2.8 : *How do you think about patient's ability to manage her own pain?*
- Probes  
Do you think that the patient can manage pain by herself?  
What thing makes you think like that?  
What things can help the patient to manage pain by herself?  
How is your feeling if the patient can manage her own pain?



- Main question 2.3 : *How does the patient ask for help from others?*
- Probes
- How does she ask for help from her family?
  - What does her family do?
  - How does she ask for help from you?
  - What do you do?
  - What do you feel about that asking?
  - Do you give pain medicine when the patient's got pain?
    - How do you think about pain medicine?
  - Do you think are there other way can relief pain rather than taking pain medicine?
    - What are there? How is it helpful?
    - What made you decide to use that method?
  - What else might you do?
  - Do you communicate/refer the patient's pain to your team/among health professionals?
    - What does the reason for that?
    - How to do that?
- Main question 2.4 : *Is there collaboration in dealing with pain between you, your family and health care provider?*
- What is the collaboration? Who is in-charge to deal with pain?
- Main question 2.5 : *What different between pain management at hospital and at home?*
- Probes
- Which one do you think that pain can be controlled better?
  - What are things that make it better?
- Main question 2.6 : *'Patient who has persistent pain can learn from one's day-to-day experience to deal with pain and is the best person to manage one's pain.'*
- What do you think about this statement?
- Main question 2.7 : *How do you think about patient's ability to manage her own pain?*
- Probes
- Do you think that the patient can manage pain by herself?
  - What thing makes you think like that?
  - What things can help the patient to manage pain by herself?
- How is your feeling if the patient can manage her own pain

## Appendix VI\_An individual embedded case finding

Table A-1 The patient’s transcript including the coding, the coding index and description of the coding index

Line		Details	Coding	Coding index	Description
1	Int	Could you please tell me about your illness since it started?			
2		Yes. I was a masseuse for 20 years. I worked in many places, a			
3	Pt3	massage unit of a primary care unit and in the .....			
4		Hospital (the tertiary care hospital of ..... province). I had			
5		my own massage shop and had delivery service as well. I had	Pain caused by work	PT-6.5.4.1	SM-perception_cause of
6		pain problem since 2003, I thought it caused by my work. It had	Use more power, position		pain_position/ movement
7		to use more power and had to make many postures during I	(PT3_Int1:L7-11)		
8		massaged customers for many years which it might be the cause	Massaging self	PT-5.2.2.2.2	SM-TA_pain_non-
9		of my pain. I relieved my pain by massaging myself and took	Taking analgesic	PT-5.2.1.1	medication_massaging
10		analgesics that I bought from a drug store. I made me better.	Buy analgesic from drug	PT-1.2.1	SM-TA_pain_medication
11		And I always used these to cure myself when I had got it.	store (PT3_Int1:L11-14)		SM-PS_drug finding (drug
12		In 2006, my friend persuaded me to work at ..... Island (a			store)
13		famous island in the south of Thailand) for massaging travellers.	Back pain and fever		
14		I worked at there for 5 months and I had back pain and fever. I	(PT3_Int1:L17-18)	PT-6.1.1.1	SM-perception_pain
15		went to see doctor at a hospital. He said I had kidney infection.	Go to hospital		characteristic_site
16		He gave me some drugs to take at home. 2 weeks later the	(PT3_Int1:L18-19)	PT-1.1.1	SM-PS-find help_from HCP
17		illness was cured.			
18		In 2007 the same problem with kidney occurred again. I went	Go to hospital /Admission		
19		back to the hospital and was admitted for 4 days and discharged	(PT3_Int1:L22-23)	PT-1.1.1	SM-PS-find help_from HCP
20		to take medicines at home. 2 weeks later my illness was better			
21		and I continued my work suddenly because I wanted to earn	Work whether unhealthy due		
22		money. A week after that my pain and fever were still happening	to earn money	PT-2.2.1	SM-DM_factor to
23		and they didn’t completely go away. My friend suggested that I	(PT3_Int:L24-25)		treat_financial concern
24		should go back to my home town and treated with herbs (local	Following friend’s suggestion		
25		traditional medicine). I came back to ..... and	(PT3_Int1:L27-30)	PT-5.2.2.2.1	SM-TA_pain_non-
					medication_traditional

Line	Details	Coding	Coding index	Description
<p>26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 ... ...</p>	<p>followed by the suggestion. 1 month later my symptoms were better and I went to ..... Island again. In 2008 I went to ..... for visiting parents. Before I went back to ..... Island, my cousin persuaded me to examine cervix with Pap Smear at a primary care unit. A nurse told me that it had an abnormal sign which it might be cervical cancer. She suggested further investigation at the ..... Hospital. I went to the hospital with the intention for only vaginal checking but a doctor admitted me and cut my cervix which I thought he cut it so wide. I used my finger to self-exam my cervix and found that it looked as a hole. At that time he didn't tell me what it was. He appointed me to get the result 1 month later. Then he told me that I had cervical cancer and recommended to have surgery. I thought that I had no cervical cancer because I didn't trust his diagnosis. Because when he saw my result he asked other staff to read it and asked them that 'it was cervical cancer, wasn't it?' How could I trust him when he didn't have confidence? Moreover he recommended having surgery. I said I could not believe his suggestion and I thought I had no any abnormalities .....</p>	<p>Following cousin's persuasion, Having cervical examination in primary care unit (PT3_Int1:L33-34) Having further vaginal examination in hospital Dislike doctor's investigation (PT3_Int1:L37-42)  Distrust the diagnosis due to perceive doctor's confidence (less), (PT3_Int1:L44-50)</p>	<p>PT-1.1.3  PT-1.1.3  PT-1.1.1  PT-2.1.1 PT-6.2.3.1 PT-2.2.3.2</p>	<p>medicine SM-PS_getting help from friend  SM-PS_getting help_by persuasion  SM-PS_finding help_from HCP SM-DM_place of treatment_general hospital SM-perception_ effectiveness of caring_by HCP SM-DM-factor to treat_ trustworthiness_HCP's confidence</p>

## Appendix VII An example of the thematic framework chart with the patients’ codes and reference

Table A-2 An example of the thematic framework chart with the patients’ codes and reference

	Theme 1			Theme 2					Theme 3			Theme 4	Theme 5	Theme 6	
Main theme	1 Pain management by self			2. Management in the family					3. Decision making (to treat)			4. Effectiveness of pain regimen	5. Perspective about care environment	6. Interaction between the patient and health care providers	
Sub theme	1.1 Try to do everything by self	1.2 Alternative strategies	1.3 Massaging	2.1 Caregiver management (Assignment)	2.2 Provide care by family Travelling management Financial management Home re-decoration The palliative care at home	2.3 Encouragement and Empowerment Mental support from family	2.4 Decision making in the family	2.5 Conflict in the family (Non-corresponded need)	3.1 Agree with the diagnosis Confirmation the diagnosis Trustworthiness on the health care provider (confident)	3.2 Agree to treat: based on severity and current symptom	3.3 Trustworthiness in modern treatment (affect making a decision)	Oral and injection	5.1 Compare between hospitals 5.2 Home environment	6.1 The standard care and outstanding care	6.2 Conflict in a discussion about treatment 6.3 Communication 6.4 Difficulty in discharging

Case1 Malee		The most important strategy was related to the Nagas that was the local belief of residents in that area.		The most important caregiver was Malee's husband both in hospital and at home.	This arrangement could provide benefit for both Malee to take care of herself and caregivers to provide care for her.  This might provide the closed care by family members and generate the warmth feeling for Malee.	This might not related to improve self-management but to empower for receiving treatment and managing the pain.	Malee's father was the main decision maker.							There were some conflicts within care for Malee. The main cause was to be the non-corresponding needs between health care providers and the patients/family.	Discharge plan was urgently applied for Malee due to her family needed to go back home immediately after made their decision.
Case 2 Junjira	Junjira tried to do everything	Junjira told that she looked		Junjira lived in her mother's	Travelling choices was		It seemed that nobody	Junjira needed her husband							Junjira needed more information



<p>Case 3 Somp on</p>	<p>Don't want to be burdened the patient try to do activity by self 'Kreang Jai' referred to a feeling of did not want to be a burden or receive helps or things from others was an important factor led the patient tried to do self care.</p>	<p>The patient tried many alternative medicines such as herbs, local medications and alcohol substance in order to treat the disease and decrease the pain.</p>	<p>The patient was a masseuse so she had knowledge and skill of massage so she used this strategy to relieve her pain however, the effectiveness of this strategy was varied based on the severity of the pain.</p>		<p>Depend on the severity of the patient's symptom. If the patient felt better the need of care from caregiver was less. However the patient still need someone stayed near her in which she could ask for help all time.</p>				<p>Acceptance the diagnosis was affected by trustworthiness to the physicians personality that should show their knowledge and confidence on their professional. <b>(performing his/her characteristic as professional)</b>  The abnormality of the disease (signs and symptoms) would be vital evidences that led the</p>	<p>The decision making process would be affected by the severity of the symptom and its disturbance as well as the financial status.</p>				<p>'Kreang jai' might be a barrier for communication the pain to health care professionals. Factors affected communication between the patient and health care provider included health care providers' personalities as friendly or quiet, health care providers' behaviours / activities in each situation</p>
-------------------------------	---	---	---	--	---	--	--	--	--	--	--	--	--	--

									patient agreed with the diagnosis.						such as they look relax or look hurry.
Case 4 Narin		Narin plan to try the treatment at a place that service for patients with untreatable illness. The course of treatment of this place was the combination of modern medicine, traditional medicine and making		Narin's mother was a main caregiver both in hospital and at home. Based on her nuclear family that there were only two people in the family, the patient and her mother. Marital status would affect family management in taking care for	Narin needed some cares from her mother. The need based on her severity of symptom such as pain and her health status. Narin's mother claimed that she could not leave Narin for long time because she did not				Narin did not believe in the diagnosis. She needed confirmation on her diagnosis by having other investigations from many hospitals.			Narin thought that oral pain medication was less effective than the injection. However, she was afraid to receive the injection too much because she was afraid to be drug dependent.			Narin needed to discuss with the physician about her treatment. She needed more description and information about the plan for treatment before making a decision

		religion merit. This was an additional strategy that might help her get well and could receive the modern treatment.		the patient. Narin still had problem about her marriage.	know when Narin would ask for help.										
Case 5 Pranee	Pranee usually dealt with her pain by taking drugs bought from a drug store. Other strategies were less attention on the pain, used			Pranee's husband was the main caregiver both in hospital and at home. He provided caring, taking the patient to the hospital, helping all daily living activities		All family members, especially her mother and her husband, were main source of encouragement and empowerment in which				An important factor led the patient to find treatment were the severity of the symptom and the current symptom. This factor might relate to financial status in	Pranee claimed that she trust in the modern treatment. She only received the treatment provided by the health care providers She claimed that she		Admission in the general hospital, Pranee felt a sense of stranger, felt different from others whereas admission in the cancer centre, she felt better.		

	distracti on techniq ue such as watche d televisio n, listened to the radio or did other activitie s.			and mental supportin g.		the patient felt warm and continu ed the treatme nt				which the patient seemed reluctant to find treatment because she did not want to stop doing job which meant that stop earning money.	never used alternativ e medicine or alternativ e strategies to deal with her disease or her pain.		There were lots of patients with cancer here. The patients were the same disease and they encourage each other. Pranee claimed that her pain was lesser when she was admitted in the cancer centre.		
Case 6 Duang jai	Duangja i preferre d to do everythi ng by self if she could do such as daily			Duangjai' s daughter was the main caregiver because she lived with her mother all the					Duangjai did not believe in the diagnosis due to it did not correlate d between pain area and the	The decision making to receive the treatment was based on the severity of the symptom		Duangjai thought that oral pain medicatio n was less effective than the injection. When the pain peak,	When the patient visit home, it seemed that the patient felt better, she could eat, sleep		

	<p>living activities and housekeeping. This was her personality as the active person. However, for taking drug which need careful reading the regimen, she had to ask for her daughter in order to prevent mistake n.</p>			<p>time. Providing care depended on the severity of the patient's symptom. Mostly Duangjai preferred to do everything by self if she could do. However the patient still need someone stayed near her in which she could ask for help all time.</p>					<p>diagnosis. She needed confirmati on her diagnosis by having other investigations from many clinics and hospitals.</p>	<p>and the evidence of that symptom the patient could see.</p>		<p>she needed an injection rather than try oral medication.</p>	<p>and smile because she got empowering from her relatives who visited her at home regularly.</p>		
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## Appendix VIII The numerical system of the indexing reference

Table A-3 The numerical system of the indexing reference

**Description :** PT = Patient      FM = Family caregiver      HCP = Health care provider  
 Red colour = Most frequency      Blue colour = The second frequency      Green colour = Interesting point

1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	
1. Problem solving	1. Find help / Giving help	1. HCP			
		2. FM			
		3. Others			
	2. Self-solving / Providing help	1. Drug finding (Buying drug)			
		2. Prevention			
		3. Avoiding			
		4. Caring / Suggestion / Persuasion			
2. Decision making	1. Place of treatment	1. Hospital (Local /emergency / Health register)			
		2. Private hospital / Clinic (Guarantee to meet doctor)			
	2. Factor related to treat / to care	1. Financial concern			
		2. Health status/ Ability / Severity			
		3. Credible / Trustworthiness	1. Specialist / Famous		
			2. HCP's confidence / Credibility		
			3. Investigation		
			4. Current symptom		
			5. Compatibility of information		
		4. Past experience / Comparison			
		5. Benefit / Effectiveness			
		6. Better than do nothing / No disadvantage			
		7. Proudness / Show ability			
8. Responsibility to self-care (Not to be burden, Social expectation)					
9. Knowledge / Understanding / Acceptance					
10. Unity / Similarity					

1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>
		11. Opinion / Feeling about HCP (Hierarchy / Fear of bad response / Afraid to disturb)		
		12. Fear		
	3. Factor to communicate	1. Opinion / Feeling about HCP (Hierarchy / Fear of bad response / Afraid to disturb /Afraid to be burden, KREANG JAI)		
		2. PT's communication skill		
4. Decision maker	1. Patient			
	2. Family			
3. Information finding and utilisation	1. Source	1. HCP		
		2. Family		
		3. Other / Friend / Neighbour	Board, Brochure, Publish	
2. Utilisation	1. Comparison / Confirmation			
4. Forming PT/HCP partnership	1. Share information			
	2. Discussion / Agreement			
5. Taking action	1. Communication	1. Verbal	1. Disease and treatment	
			2. Pain / symptom and treatment	
		3. Cooperation		
		4. Prohibiting / Warning / Reasoning		
	2. Non-verbal	Pain / Emotion expression / Posture		
		3. No communication / Quiet		
		2. Pain	1. Medication	1. Modern medicine
	2. Traditional medicine / Herbs			
2. Non-medication	2. Alternative / Traditional strategies	1. Bear to pain / Be patient		
			1. Rest	
			2. Massaging, Pressure, Warm-cold press	
			3. Exercise / Movement / Position	
			4. Cognition / Distraction /Acceptance / Empowering / Encouraging / Consolation	

1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	
			3. Praying supernatural power / doing ritual		
			4. Pain expression (moaning / crying)		
			3. Do everything / Do many things 4. Do nothing / Deny / Reject / Ignorance		
	3. Disease		Treatment		
	4. Other symptom		1. Rest		
			2. Movement		
			3. Care / Treatment / Adjustment / Prevention		
			4. Ignorance / Do nothing		
	5. Assessing / Investigation / Analysis / Referring /				
	6. Financial support / Facility support / Traveling				
7. Home care planning		1. Place			
		2. Caregiver / caregiver identification			
8. Moral support		1. Visiting / Asking			
		2. With PT / Together / Always			
		3. Acceptance / Understanding			
9. Life management		1. Emotional management			
		2. Balancing / home management			
6. Perception	1. Symptom / Disease	1. Perception of pain / symptom characteristic	1. Kind / site		
			2. Severity		
			3. Pattern / character		
		2. Perception of pain and disease interpretation	1. Pain interpretation	1. Death / Disappear 2. Suffering	
				3. Individual	
				4. Unbearable	
				5. Uncontrollable / Incurable / Severity	
				6. Inevitable / In the body	
				7. Be better if cut organ	
8. Most importance / First priority					

1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>
			2. Disease interpretation	1. Unbelievable / Inacceptable / Frustration 2. Fear / Flight / scare 3. Incurable / Severity 4. Progression / Recurrence 5. Be aversion / Stranger / Differentiation 6. Most importance / First priority
	2. Effectiveness / complication	1. Medication	1. Oral	Less help / Release
			2. Injection	Stop
			3. Learning to prescribe	
		2. Treatment		
		3. Caring	1. By HCP	Consistency / Regularly / Disturbance
	2. By family / relative		Inattention, remiss / Warm, Sympathy, Certainty	
	3. By other / friend / neighbour			
	4. Exercise / Massage			
	3. Information	1. Validity / Compatibility	Frustration	
		2. Completion		
	4. Self / Family	1. Feeling appraisal	1. Questioning / Frustration (Why me)	
			2. No choice / Necessary / Hopeless	
			3. Fight or Flight	
			4. Compassion / Pity	
			5. Blaming / Guilty / Be burden	
	2. Characteristic / Personality appraisal	Self-centre		
		3. Health status / Ability appraisal	1. Ability to bear to pain	
			2. Ability to do / work	
		4. Knowledge appraisal		
		5. Need assessment	1. Medication	1. Start / continue / increase / drug dependence 2. Stop / decrease
			2. Caring / treatment	1. By HCP 2. By family / relative 3. By other / friend / neighbour
	3. Information			
		4. Cooperation		

1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	
	5. Factor / Cause	6. Family relationship appraisal			
		1. Disease	1. Interpreted by site 2. Interpreted by the result of treatment 3. Interpreted by own knowledge / experience		
		2. Sin / Fate			
		3. Supernatural power / Ghost			
		4. Physical factor	1. Position / Movement 2. Fever 3. Temperature of environment 4. Intercourse / marriage		
		5. Cognitive factor	Attention		
		6. Cannot define			
		6. Impact	1. Physical impact	1. Daily activity / Daily living 2. Feature / Appearance	
			2. Personality impact (change)		
			3. Emotional impact	1. Sad / Sorrow / Hopeless / Worry / Stress / Depress / Hopeless 2. Lonely / Be leaved / Be ignored 3. Angry 4. Boring / Burn out	
			4. Cognitive / Attention impact		
			5. Social & Relationship	1. Social activity 2. Relationship	1. Family 2. Marriage
	6. Career impact				

## References

- Appleton JV and Cowley S (1997) Analysing clinical practice guidelines: A method of documentary analysis. *Journal of Advanced Nursing* 25:1008-1017
- Attasara P (2007) *Hospital-based cancer registry 2006* Bangkok:National Cancer Institute, Department of Medical Service, Ministry of Public Health
- Bandura A (1997) *Self efficacy: the exercise of control* New York:W.H. Freeman and Company
- Bandura A (2002) Social cognitive theory in cultural context. *Applied Psychology: An International Review* 51(2):269-290
- Barlow J, Wright C, Sheasby J, Turner A and Hainsworth J (2002) Self-management approaches for people with chronic conditions: a review. *Patient Education Counseling* 48:177-187
- Beck SL and Falkson G (2001) Prevalence and management of cancer pain in South Africa. *Pain*, 94:75-84
- Bendalow GA (1993) Pain perception, emotional and gender *Sociology of Health & Illness*, 15:273-294
- Bennett MI (2012) in Tracey I (editor) *Pain 2012: refresher courses : 14th World Congress on Pain*. Seattle, IASP
- Bennett MI, Bagnall A and Closs SJ (2009) How effective are patient-based education interventions in the management of cancer pain? Systematic review and meta-analysis. *Pain* 143:192-199
- Bergen A and While A (2000) A case for case studies: exploring the use of case study design in community nursing research. *Journal of Advanced Nursing* 31:926-934
- Berry PH (2007) The pain of residents with terminal cancer in USA nursing homes: family members' perspectives. *International Journal of Palliative Nursing* 13(1): 20-27
- Blyth FM, March LM, Nicholas MK and Cousins MJ (2005) Self-management of chronic pain: a population-based study. *Pain* 113:285-292
- Boagy P and Glasper A (2012) *Sourcing the Best Evidence IN: Glasper A and Rees C (eds) How to Write Your Nursing Dissertation*. West Sussex: Wiley-Blackwell, 55-76
- Boontasaeng P (2008) *The development of care model for family caregiver with cancer pain management in advanced stage of cervical cancer*, Unpublished MS thesis, KhonKaen University
- Broadhead WE and Kaplan BH (1991) Social support and the cancer patient. *Cancer* 67:794-799

- Buathongjan J (2005) *The effect of self-management program on dyspnea in patients with chronic obstructive pulmonary disease, lower southern region*, Unpublished MS thesis, Chulalongkorn University
- Buraraungrote S (2006) *Experience and self-management for fatigue in breast cancer patients receiving chemotherapy*, Unpublished MS thesis, Mahidol University
- Chang VT, Sorger B, Rosenfeld KE, Lorenz KA, Bailey AF, Bui T, Weinberger L and Montagnini M (2007) Pain and palliative medicine. *Journal of Rehabilitation Research & Development* 44(2):279-294
- Chatwin J, Closs J and Bennett M (2009) Pain in older people with cancer: attitudes and self-management strategies. *European Journal of Cancer Care* 18:124-130
- Closs SJ, Staples V, Reid I, Bennett MI and Briggs M (2007) Managing the symptoms of neuropathic pain: an exploration of patient's experiences. *Journal of Pain and Symptom Management* 34(4):422-433
- Coster S and Norman I (2008) Cochrane reviews of educational and self-management interventions to guide nursing practice: A review. *International Journal of Nursing Studies* Available from:DOI: 10.1016/j.ijnurstu.2008.09.009 [Accessed 10 April 2010]
- Davis BD (2000) *Caring for people in pain* London:Routledge
- Deandrea S, Montanari M, Moja L and Apolone G (2008) Prevalence of undertreatment in cancer pain. A review of publish literature. *Annls of Oncology* 19:1985-1991
- Deeseang W (2006) *Effects of self-management program on hemoglobin A1c and LDL-cholesterol level of type 2 diabetic patients* Unpublished MS Thesis, Chulalongkorn University
- Denzin NK and Lincoln YS (2005) *The sage handbook of qualitative research* London:Sage
- Drever E (1995) *Using Semi-Structured Interviews in Small Scale Research: a teacher's guide* Edinburgh:SCRE Publication 129
- Duangklai P (2003) *Effectiveness of self-management program in the elderly with osteoarthritis of the knee* Unpublished MS Thesis, Burapha University
- Duangpaeng S (2002) *Chronic dyspnoea self-management of Thai adults with COPD* Unpublished PhD Thesis, Mahidol University
- Duhamel F and Dupuis F (2003) Families in palliative care: exploring family and health-care professionals' belief. *International Journal of Palliative Nursing* 9: 113-119.
- Fenlon D and Foster C (2009) *Self-management support: a review of the evidence* Southampton:University of Southampton
- Ferrell BR and Grace D (1995) The Meaning of Cancer Pain. *Seminars in Oncology Nursing* 11(1):17-22

- Filligim RB, King CD, Ribeiro-Dasilva MC, Rahim-Williams B, Riley JL, 3rd. Sex, gender, and pain: a review of recent clinical and experimental findings. *J Pain* 2009;10:447-485.
- Fitzpatrick J (2007) Finding the search for evidence-based practice: Part one- The development of EBP. *Nursing times* (1887)103(17): 32-33.
- Foley KM. Advances in cancer pain. *Arch Neurol* 1999;56:413-417.
- Garro LA (1990) Culture, pain and cancer. *Journal of Palliative care* 6:34-44
- Given BA, Given CW and Kozachik S (2001) Family support in advanced cancer. *CA: A Cancer Journal for Clinicians* 51(4):213-231
- Given CW and Given BA (1994) The home care of a patient with cancer IN: Kahana E, Beigel DE and Wykle ML (eds) *Family caregiving across the lifespan* London:Sage
- Glanz K, Rimer B, Lewis F, Jossey-Bass S. Health behavior and health education: Theory, research, and practice. *Education for Health* 2004;17:399-402.
- Green J and Thorogood N (2009) *Qualitative Methods for Health Research* London:Sage
- Gubrium JF and Holstein JA (2001) *Handbook of Interview Research: context & method* California:Thousand Oaks and Sage
- Hansen EC (2006) *Successful quality health research: a practical introduction* London:Open University Press
- Health Information Unit (2008) *Number of Deaths and Rates per 100,000 Population by Leading Cause of Death and Sex* Bangkok:Health Information Unit, Bureau of Health Policy and Strategy, Ministry of Public Health
- Holloway I and Wheeler S (1996) *Qualitative research for nurses* Oxford:Blackwell Science Ltd
- International Association for the Study of Pain (IASP) (2008) *Global year against cancer pain*. Available from: [http://www.iasp-pain.org/AM/Template.cfm?Section=Fact\\_Sheets1 &Template=/CM/HTMLDisplay.cfm&ContentID =7198](http://www.iasp-pain.org/AM/Template.cfm?Section=Fact_Sheets1 &Template=/CM/HTMLDisplay.cfm&ContentID =7198) [Accessed 15 July 2009]
- Jacobsen R, Møldrup C, Christrup L and Sjøgren P (2008) Patient-related barriers to cancer pain management: a systematic exploratory review. *Scandinavian Journal of Caring Sciences* 23:190-208
- Johnjumrut C (2007) *Individualized empowerment approach to dietary self-management to improve metabolic control in patients with type 2 diabetes* Unpublished MS Thesis, MahidolUniversity
- Kahana E, Biegel DE and Wykle ML (1994) *Family caregiving across the lifespan*, California:Thousand Oak and Sage
- Kangchai W (2002) Efficacy of self-management promotion program for elderly women with urinary incontinence. *Thai Journal of Nursing Research* 6(3):101-114
- Keeratiyutawong P et al. (2006) Effectiveness of a self-management program

- for Thais with type 2 diabetes *Thai Journal of Nursing Research* 10(2):85-97
- Khounnikhom S (2007) *Evaluation of cancer pain management in Srinagarind Hospital*, Unpublished MS thesis, KhonKaen University
- Khuhaprema T, Srivatanakul P, Sriplung H, Wiangnon S, Sumitsawan Y and Attasara P (2008) *Cancer in Thailand Vol.IV* Available from: [http://www.nci.go.th/cancer\\_record/cancer\\_rec1.html](http://www.nci.go.th/cancer_record/cancer_rec1.html) [Accessed 12 November 2008]
- Kim HS, Sherman DK and Taylor SE (2008) Culture and social support. *American Psychologist* 63(6):518-526
- Kralik D (2004) Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing* 13:259-267
- Kongsakul S (2009) *The effects of a self-management skill training program on self-management behaviours regarding glycemic control and blood sugar level among persons with type 2 diabetes mellitus* Unpublished MS Thesis, Thammasat University
- Konyai J (2007) *Patient's perception of diabetes mellitus, foot complications and self-management of the condition in diabetic type 2 patients* Unpublished MS Thesis, Khon Kean University
- Kumpanut J (2007) *Effects of self-management promotion program on self-management practice, dyspnea, pulmonary function and anxiety in the elderly with chronic obstructive pulmonary disease*, Unpublished MS thesis, Burapa University
- Lee SC (2007) Management of cancer pain in Korea. *European Journal of Pain Supplements* 1:6-9
- Lewandowski W, Morris R, Draucker CB and Risko J (2007) Chronic pain and the family: theory-driven treatment approaches. *Issues Mental Health Nursing* 28:1019-1044
- Lohasarn W (2007) *The effect of a self-management education program on knowledge and self-management skills in patients with asthma* Unpublished MS Thesis, Khon Kaen University
- Lorig KR and Holman HR (2003) Self-management education: History, definition, outcome and mechanisms. *Annals of Behaviour Medicine* 26(1):1-7
- Lukkahatai N (2004) *The Thai cancer pain experience: relationships among spiritual beliefs, pain beliefs, pain appraisal, pain coping, and pain perception and outcomes*, Unpublished PhD thesis, University of North Carolina at Chapel Hill
- Lundberg PC and Rattanasuwan O (2007) Experiences of fatigue and self-management of Thai Buddhist cancer patients undergoing radiation therapy. *Cancer Nursing* 30(2):146-155
- May T (1997) *Social research: Issues, methods and process* Philadelphia:Open

University Press

- Methakanjanasak N (2005) *Self-management of end-stage renal disease patients receiving haemodialysis*, Unpublished PhD thesis, Chiang Mai University
- Okuyama T, Wang XS, Akechi T, Mendoza TR, Hosaka T, Cleeland CS and Uchitomi Y (2004) Adequacy of cancer pain management in a Japanese Cancer Hospital. *Japanese Journal of Clinical Oncology* 34(1):37-42
- Parahoo K (2006) *Nursing Research: Principle, Process and Issues*. (2<sup>nd</sup> edition) New York: Palgrave Macmillan
- Peng WL, Wu GJ, Sun WZ, Chen JC and Huang AT (2006) Multidisciplinary management of cancer pain: A longitudinal retrospective study on a cohort of end-stage cancer patients. *Journal of Pain and Symptom Management* 32(5):444-452
- Petal S, Anthony H and Dickenson (2012) in Tracey I (editor) *Pain 2012: refresher courses : 14<sup>th</sup> World Congress on Pain*. Seattle, IASP
- Petpichetchian W (2001) *The cancer pain experience in Thai patients: meanings of cancer pain, control over pain, pain coping, and pain outcomes*, Unpublished PhD thesis, Wayne State University
- Pisanbowornsri N (2007) *Development of the model for promoting competency in chronic dyspnea self-management for patients with chronic obstructive pulmonary disease* Unpublished MS thesis, Burapa University
- Pole CJ and Lampard R (2002) *Practical social investigation: qualitative and quantitative method in social research* Essex: Pearson Education Limited
- Polit DF and Beck CT (2008) *Nursing research: generating and assessing evidence for nursing practice* Philadelphia: Lippincott Williams & Wilkins,
- Wolters Kluwer Polomano RCF and John T (2006) Pain and Neuropathy in Cancer Survivors. *American Journal of Nursing* 106(3):39-47
- Pope C and Mays N (2006) *Qualitative research in health care* (3<sup>rd</sup> Edition) Oxford: Blackwell Publishing Ltd
- Pradujkanchana N (2006) *Prevalence, type, severity, self-management and consequence of urinary incontinence in late adult and elderly* Unpublished MS Thesis, Mahidol University
- Prombutr R (2007) *The effect of self-management program on reducing acute exacerbations in persons with chronic obstructive pulmonary disease* Unpublished PhD thesis, Chulalongkorn University
- Rattanasukhon P (2001) *Experiences of pain and pain management in patients with cancer of female reproductive system*, Unpublished PhD thesis, Prince of Songkla University
- Ritchie J and Lewis J (2003) *Qualitative Research Practice: A guide for Social Science Students and Researchers* London: Sage
- Rustøen T, Fosså SD, Sci M, Skarstien J and Moum T (2003) The impact of demographic and disease-specific variables on pain in cancer patients.

*Journal of Pain Symptom and Management* 26:696-704

- Sae-Tae N (2008) *Effect of discharge planning program on self-management ability of asthmatic patients attending emergency unit in unrest area of southern Thailand* Unpublished MS Thesis, Prince of Songkla University
- Sanjaithum K (2006) *Factor influencing nutritional self-management among older adults with diabetes mellitus* Unpublished MS Thesis, Mahidol University
- Santayopas P (2001) *Related factors and self-management methods of urinary incontinence in Thai female elderly* Unpublished PhD Thesis, Mahidol University
- Scottish Intercollegiate Guidelines Network (SIGN) (2008) *Control of pain in adults with cancer: A national clinical guideline* Available from: <http://www.sign.ac.uk/pdf/SIGN106.pdf> [Accessed 16 January 2009]
- Simons H (2009) *Case study research in practice* London:Sage
- Somrarnyart M (2006) *Effectiveness of self-management training program among Thai cancer patients with pain*, Unpublished PhD thesis, Chiang Mai University
- Spradley JP (1980) *Participant observation* New York:Holt, Rinehart & Winston
- Stake RE (2006) *Multiple case study analysis* New York:The Guilford Press
- Summers S (2000) Evidence-Based Practice Part 1: Pain Definitions, Pathophysiologic Mechanisms and Theories. *Journal of PeriAnesthesia Nursing* 15:357-365
- Suttharattanakun S (2006) *Factors influence self-management of type 2 diabetic patients* Unpublished MS Thesis, Khon Kaen University
- Tangwichitsakun S (2007) *Effects of self-management program on quality of life among heart failure patients* Unpublished MS Thesis, Mahidol University
- Tsigaropoulos T, Mazaris E, Chatzidarellis E, Skolarikos A, Varkarakis I and Deliveliotis C (2009) Problems faced by relatives caring for cancer patients at home. *International Journal of Nursing Practice* 15:1-6
- Tookaew R (2007) *Effects of self-management promotion program on self-management practice and haemoglobin a1c level among the elderly patients with type 2 diabetes mellitus*, Unpublished MS thesis, Burapa University
- Tudtheang S (2004) *The experience of heart disease illness : self, meaning and self-management* Unpublished PhD Thesis, Mahodol University
- Unchit P (2005) *The effectiveness of promoting competency in a chronic dyspnea self-management program on self-management outcomes in people with chronic obstructive pulmonary disease* Unpublished MS thesis, Burapa University
- van den Beuken-van Everdingen MHJ, de Rijke JM, Kessels AG, Schouten HC, van Kleef M and Patijn J (2007) Prevalence of Pain in patients with

- cancer: a systemic review of the past 40 years. *Annals of Oncology* 18(9):1437-1449
- Verchuren P (2003) Case study as a research strategy: some ambiguities and opportunities. *International Journal of Social Research Methodology* 6:121-139
- Voorde C and Leonard C (2007) Search for Evidence and Critical Appraisal: Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre
- Warsi A, Wang PS, LaValley MP, Avorn J and Solomon DH (2004) Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. *Archives of Internal Medicine* 164:1641-1649
- Wattana C, Srisuphan W, Pothiban L and Upchurch SL (2007) Effects of a diabetes self-management program on glycaemic control, coronary heart disease risk, and quality of life among Thai patients with type 2 diabetes. *Nursing and Health Sciences* 9:135-141
- Weihs K, Fisher L and Baird M (2002) Families, health and behaviour: a section of the commissioned report by the committee on health and behaviour: research practice and policy, Division of Neuroscience and Behavioural Health and Division of Health Promotion and Disease Prevention Institute of Medicine, National Academy of Sciences. *Families Systems & Health* 20(1):7-46
- Wibulpolprasert S (ed) (2008) *Thailand Health Profile 2005-2007* Bangkok: The War Veterans Organization of Thailand Press
- WHO (1996) *Cancer pain relief: with a guide to opioid availability* Switzerland:WHO Press
- WHO (2008) *World Health Statistics 2008* Switzerland:WHO Press
- Wongputtakham S (2007) *Effects of self-management on health behaviours and blood pressure among hypertensive patients* Unpublished MS Thesis, Mahidol University
- Yin RK (2009) *Case study research: design and methods* California:Sage