Family caregivers' experiences of caring for elderly women undergoing treatment for breast cancer in Thailand

by

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Statement of Original Authorship

'I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.'

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Date

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Dedication

This dissertation is dedicated to my parents. My beloved father who diagnosed with lung cancer for over a year and my beloved mother who is more than willing to take a 'Family caregiving role' to provide cancer care for her love one.

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Summary

Background: Breast cancer and its subsequent treatments affect elderly women's physical and psychological health. After undergoing treatment, those diagnosed with breast cancer encounter significant side effects and also increase emotional distress. Elderly patients with breast cancer often have multimorbidity and are less likely to survive due to old age. They require appropriate care to manage various needs, often from family caregivers who play an important role in the transition from hospital to home setting. Family caregivers need to fulfil both caregiver roles and their normal family roles. This may place additional burdens and greatly affect the mental and physical health of the family caregivers. Currently, there appears to be little evidence in the literature regarding Thai family caregivers of elderly women with breast cancer. This study aims to explore the lived experience of family caregivers providing care for elderly patients with breast cancer in Thailand.

Methodology: This research uses phenomenology to reveal the experiences of caregivers. Ethical approval was given prior to collecting data in Chiang Mai, Thailand. Data collection was conducted using digitally recorded audio with semi-structured interviews through the open-ended and closed-ended questions. The 22 family caregivers were recruited from Thai healthcare services.

Findings: This research provides a deep understanding of family caregivers' experiences and the meaning of caregiving in the context of providing care for the elderly with breast cancer. The stage of disease (initial or advanced phase of caregiving) contributes to caregiver burden. The findings of this study are divided into four themes: family caregivers' relationships, acceptance, care management, and burden of care.

Conclusions: The importance of current findings on nursing practice, nursing education and health policy are presented. Results may help health professionals to understand family caregivers' views and inform future nursing practices. This would help the health professional regarding managing family concerns to advocate and take action to prepare family caregivers in coping and enhancing their role performance. Understanding caregiver perspectives may also inform policy makers' decisions to support family caregivers and promote caregiver roles in communities. Welfare system is required to provide sufficient support for family caregivers during assisting the elderly in Thai society.

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CHAPTER 1 INTRODUCTION

Background

This research programme will describe the experiences of family caregivers in their provision of care to elderly patients undergoing treatment for breast cancer. The context of the phenomenon of the care situation is the family caregivers' perceptions and responses to the experience of caregiving. Currently, family caregiving is increasing worldwide, and they play an essential role in the lives of patients with chronic diseases (Baider & Surbone, 2014; Barello, Savarese, & Graffigna, 2015). Chronic diseases, in particular cancer, often occur among older people and can be associated with poor health status and low immune functioning (American Cancer Society, 2014). In regard to breast cancer globally, there are a number of elderly women patients, and the incidence is increasing among this population (Agarwal, Pradeep, Aggarwal, Yip, & Cheung, 2007; American Cancer Society, 2006).

Issues for elderly women with breast cancer are related to the cancer stage, side effects from treatment, and the impact of comorbidity (Albrand & Terret, 2008). After patients are discharged from hospital, family caregivers are expected to assist patients, for example, supporting daily activities due to culture, attitude and also limited budget for healthcare. That is, the family caregiver role begins with routine tasks and commences in the home environment (Beaver & Witham, 2007). In the long-term care situation, family caregivers may encounter physical, psychological, economic, and social challenges. Most reviews report that approximately 80% of all caregiving tasks that involve physical, emotional, social, and financial support are provided by family caregivers (Kaplan & Berkman, 2016; LeSeure & Chongkham-ang, 2015). Studies suggest that there are positive and negative impacts on family caregivers. On the one hand, some studies note that family caregivers report a high level of satisfaction related to providing care (Jayani & Hurria, 2012; Khanjari, Langius-Eklöf, Oskouie, & Sundberg, 2014; Kitrungrote, Wonghongkul, Chanprasit, Suttharangsee, & Cohen, 2008; Youngmee & Given, 2008). On the other hand, the effects of cancer and its treatment can cause a high level of family caregiver burden including physical, mental, financial, and social consequences, as well as impacting on the relationship among family caregivers and patients (Haley, 2003; LeSeure &

Chongkham-ang, 2015; Meecharoen, Northouse, Sirapo-ngam, & Monkong, 2013).

Cancer can be difficult to treat and care for. Cancer care provides the patient with a high-emotion service to deal better with an atmosphere of suffering, and addresses patients' intense emotions because they are facing a life-changing situation (Barbara, Charles, & Paula, 2012; LeSeure & Chongkham-ang, 2015). This is different to other illnesses; for example, the process of long-term cancer care is complicated and also needs to be closely monitored and treated appropriately throughout the entire cancer journey. Moreover, family caregivers need to cope with the caregiving burden of the daily routine. It was challenging for family caregivers to find that they often had less time for themselves, which diminished their quality of life as well as the quality of the patient care. As such, long-term cancer care is complicated and is never really complete in relation to the caregiving tasks for their loved one. Family caregivers are required to provide care for several years until the patient recovers or loses their life (LeSeure & Chongkham-ang, 2015). The lived experiences of cancer patients and their family caregivers in Western, Africa, Latino/Hispanic and Middle East countries have been studied intensively (Adams, Boulton, & Watson, 2009; Angélique, Hardouin, Leger, Dravet, & Sebille, 2012; Baider & Surbone, 2014; Bevans & Sternberg, 2012; Consuelo & Arevalo-Flechas, 2008; Githaiga, 2015). Their literature has been focused on caregiving as having both positive and negative effects exemplified by physical, psychological, social, information and financial burdens. Existing evidence has provided a range of views of the care experience. However, little is known at a deeper level of understanding of the meaning of individuals' experiences as reflected by Asian family caregivers. The circumstances and perceptions of caregiving may vary based on culture and background. Traditional norms may respond differently about caregiving experience from one population to another. Traditional cultures of Asian family values demand that people should take care of their parents when they are getting old and have health problems. However, culture and caregiving experience have rarely been addressed in the Asian context of elderly patients during breast cancer treatment. Therefore, the study to be reported explores the experiences of family caregivers providing care for elderly women with breast cancer.

This chapter presents an overview of the thesis, including aim, objectives and research questions. Breast cancer incidence, prevalence, and its treatment will be described. The importance of family caregivers in breast cancer management for elderly patients is then discussed, followed by an introduction to the theoretical framework that is to be used. Finally, a brief description of the content of the remaining chapters is provided.

Aim, Objectives, and Research Questions

This study aims to explore the experiences of care from the perspective of family caregivers providing care for elderly women with breast cancer. Further research questions concerning the phenomenon of family caregiving with elderly patients during breast cancer treatment will also be addressed. In order to develop a deep understanding of the meaning of providing care by family caregivers, the objectives of this study are:

1. To explore the experiences of family caregivers in providing care to elderly women with breast cancer during treatment;
2. To discover the lived experience of family caregivers while older women received treatment using a phenomenological theory;
3. To identify family caregivers' perceived burdens and enablers associated with caring for older women with breast cancer undergoing treatment.

In summary, this study undertakes qualitative research using phenomenological theory to gain a better understanding of the meaning and nature of the phenomenon being examined. Thus, the research question is: What are family caregivers' experiences of caring for elderly women undergoing treatment for breast cancer in Thailand?

Breast Cancer

Breast cancer causes both physical and psychological impact, as well as financial, social and relationship impacts (Bastiaannet et al., 2010; Crivellarl, Lombardi, Scalone, & Veronesi, 2005; Jarin, Panita, Kosin, & Sawanyawisuth, 2014; Jemal et al., 2011). In 2013, breast cancer was the most common disease among women worldwide and has been the leading cause of death among females in 161 countries (Global Burden of Disease Cancer Collaboration, 2015; U.S. Cancer Statistics Working Group, 2015). Statistical reports show that breast cancer was a principal cause of death and disability amongst women in 46% of developed and 8% of developing countries in 2013 (Global

Burden of Disease Cancer Collaboration, 2015; Shulman, Walter, Amy, & Felicia, 2010). In the USA, while the incidence rate of breast cancer has grown continuously, the mortality rate has nonetheless declined since 2000 (Global Burden of Disease Cancer Collaboration, 2015; Houlihan & Nancy, 2015). In the USA and Europe, breast cancer has been increasing in those aged 75 and older (Traa, Meijs, de Jongh, van der Borst, & Roukema, 2011). Approximately 10% of American women aged over 65 have advanced breast cancer (Yoo, Levine, Aviv, Ewing, & Au, 2010). One in eight of Australian women will be diagnosed with breast cancer before the age of 85, with 16,045 new cases diagnosed every year in Australia (Australian Institute of Health and Welfare & Cancer Australia, 2012).

Asian countries such as India, Malaysia and Hong Kong have lower rates of breast cancer than Western countries (Agarwal et al., 2007). In Mexico, women aged 30 to 54 are most commonly diagnosed with breast cancer tumours (Shulman et al., 2010). The incidence of breast cancer is age-related, with women over 30 most at risk (Youlden et al., 2012), and one third of women aged over 70 diagnosed with breast cancer (Tesarova, 2013). This information exposes the fact that age is one of the risk factors for developing breast cancer. Similarly, a report by Locatelli et al. (2010) notes that ageing (particularly 65 years and over) is the critical factor preceding tumour growth and metastases. Malignant cells leading to metastases and new tumours are consistently associated with older age. However, due to immune related ageing, combinations of treatments in cancer therapy may not be considered in older women because of risk factors such as age, multiple comorbidities, and weakness.

Incidence and prevalence

Breast cancer is the most common cause of cancer death among females (Breast cancer organisation, 2013). Since 2008, approximately 1.4 million women have been diagnosed with breast cancer (Youlden et al., 2012). In 2007-2011, as reported by the National Cancer Institute, new breast cancer cases accounted for 24.6 per 100,000 females in the USA. Likewise, as stated in the National Centre for Health Statistics, since 2009 there is a greater proportion of the US female population living with breast cancer. Four years later (2013), over half a million women with breast cancer had died (Siegel, Naishadham, & Jemal, 2013). In Asian countries such as Japan, China, India, Taiwan, Singapore and Philippines, the highest rates of breast cancer are in women aged between 45 and 50 years. In India and China, the number of new breast cancer cases annually are reported to be 83,000 and 126,000, respectively. Although the incidence rate of breast cancer in Asian countries is considerably lower than in Western countries, it remains the most commonly diagnosed cancer and leading cause of death among women (Curado, 2011).

Treatments and complications

Cancer treatment can lead to improved survival rates as cancer cells are destroyed and tumours shrink (Traa et al., 2011). However, treatment in elderly women is concerning due to the high mortality rates related to the side effects of treatment. Some studies report that breast cancer in women aged 70 years and older are undertreated and underdiagnosed because therapy would decrease the survival rate of these patients (Markopoulos & van de Water, 2012; Tesarova, 2013; Wang, Singh, Luce, & Go, 2011). The adverse complications of therapy are particularly harmful to elderly patients undergoing prolonged treatments (Giacalone et al., 2009; Walker, 2013). Comorbidities and age lead to both poor survival and poor prognosis (Sterba et al., 2014). Therefore, treatment for elderly patients is limited, and they are often excluded from clinical studies, even though the number of these patients grows continuously (Blair, Robles, Weiss, Ward, & Unkart, 2016; Rosenkranz et al., 2006). Treatment for elderly patients is very complicated due to a lack of proper options for this patient group (Blair et al., 2016). In general, treatments of breast cancer are classified as chemotherapy, hormonal treatment, surgery, and radiation therapy (Audisio, 2011; Hurria et al., 2007; Joerger et al., 2013; Khuhaprema, Attasara, Sriplung, Wiangnon, & Sangrajrang, 2009). Each is described below.

Chemotherapy

Chemotherapy is generally provided in both oral and injection cycles in an initial period and a recovery period after six months (Audisio, 2011). The chemotherapy is usually received as an outpatient. Chemotherapy is associated with various side effects due to the number of doses required. Most side effects are related to infection arising from lower blood cell counts and blood clots because chemotherapy drugs can decrease the white blood cell count (American Cancer Society, 2013). Therefore, some patients can have bruises or bleeding and are easily fatigued due to lowered resistance. Other side effects include mouth ulcers, diarrhoea, vomiting, hair loss, and loss of appetite. However, these effects disappear when patients finish their treatment cycles (American Cancer Society, 2013; Khuhaprema et al., 2009). Chemotherapy significantly improves the survival of elderly women with cancer, but trials are inadequate to resolve for this age group (Brouwers et al., 2016; Extermann et al., 2017; Harder, Ballinger, Langridge, Ring, & Fallowfield, 2013; Jayani & Hurria, 2012; Kalsi et al., 2015). There is evidence of successful use of chemotherapy in the younger group; however, there is insufficient evidence to prove the usage amongst aging women aged over 70 years (McGuire, Brown, Malone, McLaughlin, & Kerin, 2015). Although adjuvant chemotherapy may be suitable for elderly patients, the risk for negative outcomes is unacceptably high (Brouwers et al., 2016). In addition, the incidence of experiencing adverse effects from chemotherapy is significantly high, which could lead to worse outcomes in relation to comorbidities (Kalsi et al., 2015).

Hormonal treatment

Hormone treatment can block estrogen receptors in order to prohibit cancer cells spreading through the bloodstream. Tamoxifen in particular can prevent new cancer cells metastasizing in both premenopausal and postmenopausal women (Audisio, 2011; Gluck, von Minckwitz, & Untch, 2013). However, hormonal treatment may not control reproductive breast cancer cells in women aged over 70 years (Audisio, 2011). Most studies suggest that hormone treatment is only slightly effective when used alone, but more effective when used in combination with other treatments such as chemotherapy (Albrand & Terret, 2008; Gluck et al., 2013; Joerger et al., 2013; Metin Seker et al., 2014). The side effects of hormone treatment are similar to the symptoms of menopause, including nausea, vaginal dryness, cataracts, joint or muscle pain, and hot flashes. Other hormone therapy drugs, termed aromatase inhibitors, include exemestane, letrozole, and anastrozole, which can protect from the recurrence of cell cancers after surgery. These drugs work by blocking the important enzyme aromatase, instead of stopping the estrogen hormone (American Cancer Society, 2013; Gluck et al., 2013). This therapy reduces the estrogen receptors related to the growth of breast cancer in the endocrine system. It is suitable for older women who are menopausal, or younger females whose ovaries have been removed (American Cancer Society, 2013; Gluck et al., 2013;

Petrakis & Paraskakis, 2010).

Surgery

Studies show that surgical treatment is effective when combined with other therapies (Crivellarl et al., 2005; Cutuli et al., 2009). Surgery such as mastectomy, conservative breast cancer, biopsy, anaesthesia, and reconstruction can increase the survival rates of both older and younger women (Audisio, 2011; Crivellarl et al., 2005; Cutuli et al., 2009). Surgery includes the use of anaesthesia, pain management, wound care, and has implications for quality of life and social support. These details need to be explained with good quality information both before and after treatments for family caregivers who may not have been provided with requisite knowledge and older patients who are under-recognised at risk because of their age (Audisio, 2011; Biganzoli et al., 2012; Cutuli et al., 2009; Tesarova, 2013; Wildiers et al., 2007).

Radiotherapy

Approximately 11% of women aged over 70 years receiving a mastectomy are likely to experience a recurrence of cancer every five years depending on other risk factors (National Cancer Institute, 2010; Petrakis & Paraskakis, 2010). Radiation is an alternative treatment for breast cancer. In the case of older women, they are often given a one-dosage radiotherapy per day after chemotherapy or hormonal therapy (Audisio, 2011). Older patients encounter side effects from radiation comprising exhaustion and skin problems (burning, redness, dryness, tight and itching) after finishing the radiation course (Audisio, 2011; Crivellarl et al., 2005; Cutuli et al., 2009).

Importance of Family Caregivers in Breast Cancer Management for Elderly Patients

Cancer treatment involves in-outpatient services in the transition from hospital to home care (Bevans & Sternberg, 2012). In other words, during and after cancer treatment, elderly patients need appropriate care from family caregivers who are key to the patient's care, especially when patients are frail. Family caregivers provide care management for elderly patients with breast cancer in tasks such as medication administration, transportation, personal tasks, physical and mental support, as well as supporting patients in handling the complications of cancer treatment. Many elderly patients are considered terminal and prefer dying at home with support from family caregivers. The number of people opting for in-home care for late-stage cancer has been growing continuously worldwide (Foreman, Hunt, Luke, & Roder, 2006; Gomes, Calanzani, Gysels, Hall, & Higginson, 2013; Grunfeld et al., 2004). A large scale survey reported 58% of respondents prefer to die at home (Foreman et al., 2006). A systematic review found that 75% of studies revealed that most cancer patients prefer to spend their last days at home and subsequently died at home rather than in a hospital or hospice (Gomes et al., 2013). Also, they wished to have family caregivers involved in caring duties at home. However, some patients make a decision to die in a particular health care setting, such as a hospital or a nursing home. Previous studies reported that 43%- 46% of patients expressed a preference to die in hospital (Bell, Somogyi-Zalud, & Masaki, 2010; Gomes et al., 2013). There are factors associated with the patient's preference of place of death such as social support, environmental, individual, and illness concerns (Bell et al., 2010). For example, one study conducted in Japan found that elderly people aged over 65 years indicated home as their preferred location of death because of concerns about staying in the hospital or long-term care facility (Ohmachi et al., 2015). Breast cancer requires long-term treatment and causes many complications in physical and psychological health leading to long-term disability among the elderly group. Elderly patients have been treated by health professionals through special care in hospital, and after discharge home, family caregivers play a vital role in their long-term care (Barello et al., 2015; Clark et al., 2014; Grunfeld et al., 2004; Houlihan & Nancy, 2015). Caregiving is an essential physical and psychological support provided by family caregivers. However, in some cases, this role could be a major responsibility. One study indicated that approximately 80% of cancer care occurs at home, and is mainly provided by family members (Kaplan & Berkman, 2016).

The majority of elderly breast cancer patients cope with intensive cancer treatment causing emotional and physical side effects disrupting their routine life (Baider & Surbone, 2014; Jayani & Hurria, 2012; Surbone et al., 2010). Family caregivers can reduce psychological distress and maintain daily household tasks allowing patients to cope with cancer (Belcher et al., 2011). Furthermore, elderly patients need supportive care from a principal family caregiver rather than friends or neighbours. Perhaps, relatives or friends may not offer care as good as the main family caregiver because of their special intimate relationship (Belcher et al., 2011; Borstelmann et al., 2015; Duggleby, Doell, Cooper, Thomas, & Ghosh, 2014; Fergus & Gray, 2009). It explains family caregivers playing a vital role in the long-term care of elderly patients requiring physical and psychological support. They might pay more attention to providing care than others who have limited care abilities through a wide range of activities and spending time interacting with patients. It is a common assumption that patients would have better care from a family caregiver, but this depends on the culture, education level, and socioeconomic status of the family caregiver. Therefore, care provided by a family caregiver is an essential component of supportive care that can reduce the emotional burden of those with breast cancer (Belcher et al., 2011). Some studies note that patients with breast cancer have unique physical and psychological problems and that social support and caregiving varied in breast cancer cases of different age groups (Sawin, 2012; Sterba et al., 2014; Susan, Barbara, & Nirvana, 2008). There are some explanations why breast cancer patients' needs are unique. Firstly, these needs are not limited only to the diagnosis of the patient, but also to the individual care in relation to what causes cancer, how it is treated, what the long term consequences are, and how to provide care by family caregivers who face similar stressors. Secondly, breast cancer patients feel uncertain and hopeless in terms of how to adjust their life during a life-threatening situation. Thirdly, many studies have been limited to reporting physical and psychological distress after the patient has been diagnosed with breast cancer. Lastly, in some of the previous research, the care needs of breast cancer patients have long-lasting effects on their quality of life as well as their psychological and physical health. Therefore, these are important factors in the patients' ability to cope with their diagnosis, and in the coping strategies of the family caregiver during the caregiving period (Kauffmann et al., 2016; Kramer & Thompson Jr, 2001; Turner et al., 2013). Family caregivers and patients report a higher level of burden in dealing with diagnosis and treatment than those reported by people across a range of groups experiencing emotional distress (Fergus & Gray, 2009). Family caregivers may be unfamiliar with breast cancer and its treatment. They also need to cope with health problems that they themselves may face, such as poor physical and mental health, occupational and economic impacts associated with caregiving, and adjustment (Grunfeld et al., 2004; Susan et al., 2008). A variety of adjustments required of family caregivers include coping strategies, communication, relationship, roles and responsibilities, economy, health professionals, and patients' demands (Ekstedt, Stenberg, Olsson, & Ruland, 2014; Grunfeld et al., 2004; Houlihan

& Nancy, 2015; Junda, 2004; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Smither-Williams, 2008; Sterba et al., 2014). Caregiving may interrupt the daily lives of family caregivers (Belcher et al., 2011).

In summary, it is important for family caregivers to maintain a personal relationship with the patient while dealing with adjustment to the cancer context. Family caregivers are confronted with various breast cancer experiences that may impact on their personal feelings, thoughts, and actions. Some studies suggest that family caregivers use positive thinking, religiousness and spirituality when patients face the post-treatment period of breast cancer (Smither-Williams, 2008; Sterba et al., 2014). Other research indicates that there are adverse impacts of caregiving such as family caregivers concentrating on their role rather than attending to their own physical and psychological health (Bachner, Karus, & Raveis, 2009; Borstelmann et al., 2015; Glajchen, 2012; Grunfeld et al., 2004; Siefert, Williams, Dowd, Chappel-Aiken, & McCorkle, 2008). Family caregivers' experiences of caregiving may have a unique cultural aspect that dictates positive or negative reactions towards the individual's experience (Surbone et al., 2010). In order to address the cultural diversity of the carer experience, the current research has focussed on the cultural diversity and norms within the Thai caregiver experience.

Research Method: Phenomenological Approach

This study focuses on hermeneutic phenomenology as presented by van Manen (1990). Based on an epistemological and phenomenological (or transcendental) framework, this program discloses patterns of an interpretative phenomenological analysis arising from hermeneutic philosophy. Phenomenology seeks to make explicit the lifeworld in understanding the meaning of an individual's rationales reflecting the phenomenon of interest (Balls, 2009; Behnke, 2011). In addition to hermeneutics, its manner investigates the meaning of lived experiences as an interpretive methodology (Guimond-Plourde, 2009). Personal storytelling is a methods used to help the researcher to understand the discovery of the meaning of the phenomenon, which is the purpose of hermeneutic phenomenology (van Manen, 1990, 2007). Underlying meanings of experience arise from pre-reflective awareness. The pre-reflective phenomenon reveals a dimension of each personal lifeworld (Laverty, 2003; van Manen, 1990). Individuals' pre-reflective awareness from their statement can uncover meanings of individual experience (Bench, 2014). The viewpoint of lived experience provides a way of communicating that encourages unexplored phenomena in a somewhat misunderstood situation (Guimond-Plourde, 2009). Hermeneutic phenomenology is concerned with how people understand and share their experiences and how their experiences are interpreted by the researchers with their professional background and knowledge In this explication, the researcher examines the ways in which participants describe sharing their experiences, for example by talking about shared family concerns, and family meaning situated in day-to-day life such as the day-to-day family caregiver in the long-term experience of providing care. Thus, phenomenological and hermeneutic approaches are both descriptive and interpretative to assign the meaning that lives within experience to individuals' accounts.

Overview of Thesis

This thesis consists of eight chapters. The contents of each is briefly provided below by way of orientation to the research and the thesis.

Chapter 2: literature review

Chapter 2 presents a review of cancer epidemiology in the elderly population. Relevant definitions are also provided. Then, the current understanding of the lived experiences of family caregivers providing care for elderly patients with breast cancer is described.

Chapter 3: methodology and method

Chapter 3 includes a description of both the methodology and the method used in this research. A phenomenological framework based on van Manen is presented as a methodology. The method section of the chapter presents each of the practical considerations required in completing this research, such as ethics approval, recruitment, and data collection. The details of interviews and participants (family caregivers) are also described. In summary, 1) data collection and setting where the research was conducted, 2) data and characteristics of the participants, and 3) steps of van Manen's approach used for the analysis of the data are presented in this chapter.

Chapter 4: field notes: living arrangements

Chapter 4 describes statements from field notes of 22 participants who are family caregivers sharing their backgrounds based on their beliefs, relationships, cultures and daily life during caregiving experience. Backgrounds and narratives of elderly women with breast cancer are also presented by family caregivers. Each case was written immediately after interviews and provides additional insight into the perspectives on the phenomenon.

Chapters 5 through 8: presentation of thematic findings

Each chapter presents the findings associated with one of the major themes identified in this research. Chapter 5 presents the theme of **family caregivers' relationships**, which describes the sense of relationship felt by family caregivers in their role with patients, other family members, professional staff, and the healthcare system. Chapter 6 discusses the theme of **acceptance**. Different levels of acceptance at different stages of the disease, reflecting caregiving based on changing experiences, knowledge, attitudes, beliefs, and backgrounds, are described. Chapter 7 presents the **care management** of family caregivers, which reveals how family caregivers manage the care of patients after diagnosis and treatments. Chapter 8 discusses the **burden of care**. It describes the physical, mental, financial, and work burden experienced by family caregivers in situations of long-term caregiving.

Chapter 9: discussion

The final chapter presents an overall discussion of the research program, focusing on the findings, and presents recommendations and implications that follow from these findings. The strengths and limitations of the research are also described. Issues relevant to future research are also presented.

Chapter Summary

This chapter provides the background and significance of the research program and has set out the aim and objectives as well as the research question to be addressed. Breast cancer, its incidence and treatments are described, with particular reference to elderly women. The research approach, methodology and method, are briefly described, which are equipped to address the issue of family caregivers’ experiences in caring for this patient group. In the next chapter, a full literature review is presented regarding what is known about family caregivers’ experiences.

CHAPTER 2 LITERATURE REVIEW

This chapter presents a literature review of family caregivers' experiences, across the globe, in providing care for elderly cancer patients. The chapter addresses family caregivers' physical, psychological, financial, work, and relationship experiences, in addition to their information and communication needs and actions, and the cultural context in which these actors are bound. The gaps in the existing research, which inform the current study, will be presented. Finally, the broad Thai cultural context and its influence on the caregiving experience will be discussed towards the end of the chapter.

Experiences of Family Caregivers in Providing Care for Patients with Cancer: A Global Literature Review

There are various descriptions of 'family caregivers' that are used interchangeably, including the terms primary caregiver, principal caregiver, typical caregiver, informal caregiver, unpaid care provider, carer, and care provider (Grunfeld et al., 2004; Honea et al., 2008; LeSeure & Chongkham-ang, 2015; National Cancer Institute, 2010). Family caregivers can be family members, friends, or neighbors involved in assisting elderly patients with many errands that patients are unable to manage themselves (LeSeure & Chongkham-ang, 2015; National Cancer Institute, 2010; Senden et al., 2015). Being a family caregiver refers to having an unpaid role providing informal (e.g., non-medical) care for elderly patients during their treatment (Bevans & Sternberg, 2012; Clark et al., 2014; Jarin et al., 2014). A cancer diagnosis and subsequent stages of the disease and its treatment can produce side effects that place intense pressure on both patients and family caregivers (Sherwood, Given, Given, & Von Eye, 2005). Most elderly cancer patients require supportive care from family caregivers, which is often provided in the home (National Cancer Institute, 2010; Senden et al., 2015). Elderly cancer patients need assistance to organise a variety of activities in coping with daily routines including cooking, toileting, bathing, dressing, and preparing medications (Consuelo & Arevalo-Flechas, 2008). Family caregivers are required to help elderly patients with these activities of everyday life during cancer diagnosis, before treatment, and in the post-treatment phase (Woźniak & Iżycki, 2014; Yoo et al., 2010). They are required to provide support with both mental and physical wellbeing and also to assist with practical household tasks (Woźniak & Iżycki, 2014). Consequently, these caregiving duties have a significant impact on family caregivers' physical and psychological health (Meecharoen, Northouse, et al., 2013; Segrin et al., 2005). Family caregivers are likely to encounter concurrent stressful events which affect their levels of distress, and this overload can place a great burden on family caregivers which can increase their risk of declining wellbeing, including physical, psychological, financial, social, and spiritual problems (Hughes, 2008; Juth, Silver, & Sender, 2015; Woźniak & Iżycki, 2014).

Physical and Psychological Experience

Family caregivers may suffer gradually from physical strain as a result of the physical activities that overload their bodies (National Cancer Institute, 2010). There are three physical burdens that family caregivers encounter, including physical activities specific to caregiving tasks, physical problems related to helping patients through the particular management of their symptoms, and physical problems related to stress that can affect family caregiver's physical symptoms (McMillan et al., 2006). For these reasons, physical activities can cause health problems because family caregivers are unaware of, and often dismiss, their health concerns when providing supportive care to the patient as a result of assisting them with their daily care tasks (e.g., toileting, bathing, cleaning, cooking, shopping, and preparing meals and medications) (Grunfeld et al., 2004; Stenberg, Ruland, & Miaskowski, 2010). Furthermore, physical problems can arise as the result of physical caregiving tasks; for example, low immune system function can occur because the carer might dedicate caregiving time for their loved one rather than focusing on their own health (Glajchen, 2012). Additionally, stress levels can cause physical symptoms among family caregivers. One study reported that family caregivers can experience equal, or even more, stress than elderly cancer patients when providing care. Such caregiving stress can result in physical symptoms, including sleep impairment, fatigue, pain, weight loss, muscle strain, and a decrease in appetite (Stenberg et al., 2010). Some serious conditions that can develop include heart disease, hypertension, prolonged fatigue, and back pain (Glajchen, 2012; Sherwood, Given, & Given, 2012). A number of studies have found that husband caregivers, in particular, reported high levels of physical problems such as poor sleep, fatigue, and pain (Bevans & Sternberg, 2012; Goldzweig, Merims, Ganon, Peretz, & Baider, 2012; Stenberg et al., 2010; Swore, Dodd, Schumacher, & Miaskowski, 2008).

High levels of physical demand involved in the complex tasks related to the family caregivers' burden when providing care for a cancer patient. Caregiving tasks affected by the deterioration in the patient’s health lead to an increased risk in the decline of a family caregiver's physical health (Glajchen, 2012; Willette-Murphy et al., 2009). Moreover, the impact of patient deterioration, including recurrence or metastatic disease which cannot usually be cured, increased the caregiver burden in performing the multiple roles of the family caregiver. Also, the caregiving burden negatively affects quality of life and requires creative strategies for coping with stress among family caregivers (Glajchen, 2012; Terry Altilio & Otis-Green, 2011). Previous studies have indicated that family caregivers have worse physical health due to their caregiving responsibilities. For example, nearly half (47%) of family caregivers had sleep problems related to high anxiety as a result of providing care for a patient with severe pain during the night (Gibbins et al., 2009). The long-term effects of caregiving for cancer patients often cause physical health problems such as heart disease, hypertension, and arthritis, which were found in family caregivers who had been providing care for 3.5 years after the cancer diagnosis (Fletcher et al., 2008).

In addition to the physical burden, poor psychological wellbeing among family caregivers, such as high levels of tension, stress, anxiety, depression, exhaustion, low self-esteem, and other mental health problems, has been reported in many studies (Butow et al., 2014; National Cancer Institute, 2010; Woźniak & Iżycki, 2014). Some researchers have noted that family caregivers face high levels of depression if they develop health problems while continuing their care duties (Grunfeld et al., 2004; Kershaw et al., 2004; Sherwood et al., 2012). The caregiving burden can also result in role overload, strain, and stress that can cause depression and affect the caregiver’s adjustment, their coping strategies and social problem-solving abilities, and their life satisfaction (Bambara et al., 2009; Jayani & Hurria, 2012). Researchers have found that 64% of family caregivers struggle with depression and try to cope through various strategies (Lkhoyaali et al., 2015; Papastavrou, Charalambous, & Tsangari, 2009). Other research has demonstrated that family caregivers used avoidant techniques when they were emotionally distressed to maintain their own mental health (Goldzweig et al., 2012; Kershaw et al., 2004). Emotional distress, including depression and anxiety, dramatically increases when the elderly cancer patient is approaching the terminal stage of the disease (Bernard & Guarnaccia, 2003; Francis, Bowman, Kypriotakis, & Rose, 2011; Germain et al., 2017; Govina et al., 2015; Grunfeld et al., 2004; Longacre, Ridge, Burtness, Galloway, & Fang, 2012; Stafford & Judd, 2010). However, previous research has found that the emotional distress of family caregiving begins much earlier in the role with initial stress following diagnosis and loss of control of the situation (Laudenslager, 2014). The study reported that six months after a cancer diagnosis is a critical period of stress for family caregivers as they commence their caring role (Longacre et al., 2012). Such reactions might be due to perceived uncertainty about their future and the journey of the patient under their care (Sherwood et al., 2012; Woźniak & Iżycki, 2014). Nevertheless, after 18 months of caregiving, the research has found that emotional stress and negative perceptions reduced (Fredman et al., 2004; Houlihan & Nancy, 2015; Longacre et al., 2012; Maly, Umezawa, Leake, & Siliman, 2005).

Many studies have developed a holistic view of the perceived burden on family caregivers in relation to their cultural context. In the Turkish context, for example, family caregivers reported a higher level of stress such as shock, depression, fear, anxiety, and sleep disorders (Baider & Surbone, 2014; Hacialioglu, Ozer, Yilmaz Karabulutlu, Erdem, & Erci, 2010; Houlihan & Nancy, 2015), compared to the French context in which family caregivers reported a low burden of physical and emotional distress during caregiving (Hacialioglu, Ozer, et al., 2010; Houlihan & Nancy, 2015). Asian-American caregivers provide more caregiving duties than do African-American, Hispanic, and white caregivers. However, Asian-American caregivers have also reported the highest levels of emotional distress, including depression and anxiety compared to other groups of family caregivers (Baider & Surbone, 2014). In Asian countries, the previous research has demonstrated that family caregivers experienced physical and psychological distress associated with caregiving in cohorts with different beliefs and cultural contexts (Kitrungrote et al., 2008; Meecharoen, Northouse, et al., 2013).

The recent research has reported that psychological problems can exacerbate physical well-being (Germain et al., 2017; Khanjari et al., 2014; Northouse, Katapodi, Schafenacker, & Weiss, 2012). These emotional burdens such as depression and anxiety can affect family caregivers' health, subsequently reducing their ability to provide care (Lobchuk, Degner, Chateau, & Hewitt, 2006; Mortimer & Blair, 2006). Several studies revealed that family caregivers encounter a sense of distress with depression, anxiety, and stressful feelings related to caregiving, including fear, uncertainty, hopelessness, and powerlessness (Dumont et al., 2006; Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2007; Youngmee, Frank, & Rachel, 2007). Conversely, some studies have found that family caregivers reported low psychological impacts in providing care for elderly cancer patients (Khanjari et al., 2014; Meecharoen, Northouse, et al., 2013). Such research reported a positive emotional experience in which caregivers describe the strong relationship between them and the care recipient, because they spent more time together every day after commencing this role (Meecharoen, Northouse, et al., 2013; Youngmee, Frank, et al., 2007). This may be because they spent a substantial amount of time together during care activities, rather than actually a strong bond at the time they reported having a positive relationship. Family caregivers expressed that caring for someone is challenging, but creates meaningful experiences, purposeful activities, satisfaction, and an increase in self-worth (Youngmee, Schulz, & Carver, 2007).

Much of the research has focused on the experience of family caregivers in relation to the quality of life. The trajectory of cancer and its care might impact on the quality of life of family caregivers in many ways. In other words, the quality of life of family caregivers can be affected differently by varying stages of care, such as the acute stage (1-2 years of diagnosis and treatment), the mid-term stage (2 years post-diagnosis), and the long-term stage (recurrence, palliative, end-of-life) (Bloom, 2002; Bowman, Rose, & Deimling, 2005; Youngmee & Given, 2008). The quality of life of family caregivers affects the quality of the care they provide (Youngmee & Given, 2008). Previous studies have concluded that their caregiving experience often negatively influenced the quality of life for family caregivers (Angélique et al., 2012; Rha, Park, Song, Lee, & Lee, 2015). Due to the physical and psychological burden, family caregivers who experience poor quality of life were likely to provide a low quality of care (Hyejin & Myungsun, 2015; Northouse et al., 2012; Rha et al., 2015). Existing studies illustrated that family caregivers reported unmet needs (physical and psychological health, social and financial support as well as information need) and stress in providing care, which are fundamentally linked between the physical and psychological health that significantly impact people's quality of life (Butow et al., 2014; Hyejin & Myungsun, 2015; O'Hara et al., 2010; Obaidi & Al-Atiyyat, 2013). Some research showed that when coping strategies are limited, the quality of life and mental health of the family caregiver worsened (Kershaw et al., 2004; Youngmee, Frank, et al., 2007; Youngmee & Given, 2008). Further studies have investigated quality of life in male spouses, indicating that males had a higher quality of life, higher levels of hope, and lower levels of depression than female spouses, because providing care among couples revealed a positive linear relationship and fewer negative outcomes that can reduce depression and anxiety symptoms related to caregiving (Deng, Weber, Sood, & Kemper, 2010; Duggleby et al., 2014; Y. Kim et al., 2008; Li & Loke, 2014). Other studies noted that hope, self-efficacy, and gratitude of family caregivers correlated with a high quality of life, as they used their feelings of hope for miracles and their faith in God to encourage them in dealing with the situation (Hacialioglu, Özer, Yilmaz, Erdem, & Erci, 2010; Papastavrou, Charalambous, & Tsangari, 2012).

Financial and Occupational Experience

The negative impacts on financial status have been frequently reported for both family caregivers and elderly cancer patients. The literature demonstrates that family caregivers might be unprepared for the financial challenges caused by a caring role. This involves the enormous cost of cancer treatment and care, including medication, transport to medical appointments and other extra living expenses (Butow et al., 2014; Haley, 2003; Jayani & Hurria, 2012; Wagner, Bigatti, & Storniolo, 2006). Some studies noted that family caregivers who have low levels of income can only provide limited financial support to the patient, which has a negative impact on their confidence in covering the treatment and their living costs (Borstelmann et al., 2015; Glajchen, 2012; Grunfeld et al., 2004; Siefert et al., 2008). There are some economic burdens that family caregivers experience that are caused by the cost of caregiving. The research has found that 79% of family caregivers had used their savings early in the piece due to caregiving expenses including credit-card debt, the sale of properties, and requesting help from their networks to cover expenditures (Lkhoyaali et al., 2015). Caregiving may also experience hidden costs such as travelling, prescription drugs without extended health coverage, and food to support an elderly patient with cancer (Grunfeld et al., 2004; Lkhoyaali et al., 2015). Lkhoyaali et al. (2015) reported that 87.3% of elderly patients indicated that they did not have health insurance to cover medical costs. A family caregiver inevitably encountered this situation; therefore, financial support during caregiving could help patients and their caregivers to cope with the financial burden. More than half (62.7%) of family caregivers reported that they had an income of less than $200 per month, or for some, no monthly income to support the patient.

A majority of family caregivers experience the adverse impacts of the patient's cancer diagnosis related to the employment of family caregivers during the caregiving period and the early stages of cancer. Taking on the caregiver role on top of regular work after a cancer diagnosis causes significant stress related to limitations on paid work or reducing work to assume more caregiving responsibilities (Adler & Page, 2008; Given & Paula, 2006; Plotti et al., 2014). For example, one study found that 5% of family caregivers quit their job, stopped going for job promotions, declined extra work hours, and used their annual leave early to fulfil their obligations to undertake care (Grunfeld et al., 2004). As a result, there are many financial situations associated with poor work experience among family caregivers. For instance, 30% of family caregivers had limitations on their work due to the time-consuming nature of caregiving, while 69% of family caregivers had high levels of absenteeism due to providing care (Lkhoyaali et al., 2015; Meecharoen, Sirapo-ngam, Monkong, Oratai, & Northouse, 2013; Park et al., 2010). Approximately 50% of family caregivers are unemployed, and one in three caregivers report experiencing a major setback in their career because of their caregiving role (Sherwood et al., 2008). During the late stages of cancer, caregiving for elderly cancer patients has been reported to have a significantly negative impact on the employment of family caregivers (Grunfeld et al., 2004). This is due to the caregiving obligations that family caregivers choosing to leave their job to provide full-time care for elderly cancer patients. The research found that 76% of family caregivers take care of patients during the terminal phase of cancer (Grunfeld et al., 2004). As well, 54% of family caregiver cases reported that they had obstacles in their work, while 53% decided to quit their job during the palliative care phase. In addition, two family caregivers were fired because of a repeated absence from work (Lkhoyaali et al., 2015). Other studies supported that some family caregivers had to quit their jobs to take care of patients in their final stages of cancer (Meecharoen, Northouse, et al., 2013; Plotti et al., 2014).

Relationship Experience

There are both positive and negative elements to relationships between elderly cancer patients and family caregivers. Family caregivers undertake more intensive tasks than non-family caregivers (Koopmanschap, Van Exel, Van den Bos, van den Berg, & Brouwer, 2004; Parveen, Morrison, & Robinson, 2011; Pinquart & Sörensen, 2003). Also, they can potentially provide better support for cancer patients in relation to the activities of day-to-day living, emotional support, and companionship. Considering the cultural norms that exist in relation to support and comfort, non-family caregivers are expected to provide only a low level of care compared to family caregivers (Parveen et al., 2011). Care provided by family caregivers is uniquely based on the specific contexts and circumstances that can be categorised according to culture, religion, language, socio-economic background, and the relationship between the patient and the family caregiver (Parveen et al., 2011; van Groenou, de Boer, & Iedema, 2013).

In relation to the closeness of relationships, there were positive relationships between family caregivers and their patients; therefore, family caregivers reported significantly less burden in caring for their patients (Giacalone et al., 2008; Kitrungrote et al., 2008; Locatelli et al., 2010). Some studies found that elderly cancer patients and their partners had strong bonds which appeared to grow despite the impacts of the illness (Duggleby et al., 2014; Fergus & Gray, 2009). Indeed, caregiving is often expected to be provided by a family caregiver instead of by health professionals, due to the personal relationships between family caregivers and patients (Papastavrou et al., 2009, 2012). Family caregivers who have good relationships with patients exhibited fewer depressive moods and sustained positive relationships by placing the patient at the centre of care (Belcher et al., 2011; Duggleby et al., 2014; Francis et al., 2011; Senden et al., 2015). Nevertheless, some family caregivers are negatively impacted by mental health issues, which can lead to relationship conflict between family caregivers and their patients.

The relationships between family caregivers and health professionals, and between patients and health professionals, play a crucial role in the mental health of both the family caregiver and the patient. A positive relationship between the caregiving dyad and healthcare staff can help with reducing the patient and caregiver's depression or anxiety, particularly during the late stages of cancer (Francis et al., 2011; Youngmee & Given, 2008). In addition, family caregivers who help elderly cancer patients with daily care and mental support play a key role in maintaining the patient-physician relationship (Kissane et al., 2003; Locatelli et al., 2010). One study found that family caregivers who have maintained good relationships with other family members and health professionals reported lower emotional concerns, such as depression and anxiety, than family caregivers who demonstrated poor relationships (Francis et al., 2011). This suggests that relationships between health professionals and family caregivers can be positive, and that forming good relationships helps to reduce the negative aspects of caregiving. On the other hand, family caregivers reported that they were often misunderstood when communicating with health professionals, which caused emotional strain and high levels of uncertainty due to the challenges of caregiving and the lack of knowledge about cancer. Some family caregivers found it uncomfortable or difficult to seek advice from health professionals to help them to understand how to provide cancer care in order to assist patients to undertake self-management (Senden et al., 2015). The previous study noted that a lack of knowledge of cancer self-management was found amongst the majority of cancer patients, while family caregivers were concerned about physical and psychological problems as well as financial and social supports to manage cancer care for the patient (McCorkle et al., 2011).

Culture, attitudes, and beliefs about cancer and treatment can influence the relationships between the parties involved in cancer care, including family caregivers, patients, and health professionals, and indeed, perspectives tend to vary according to these social and cultural differences (Baider & Surbone, 2014). Close relationships within the family help the patient to adjust their life to cope with the illness, such as the relationship between the parents and the child. Female caregivers are expected to be the principal family caregivers based on cultural norms, as it is perceived that providing care is a female duty and responsibility within most families (Fauth et al., 2012). Female caregivers, particularly daughters and wives, tend to be more considerate and generous than male caregivers. Nevertheless, husbands who are caregivers reported experiencing positive feelings when providing care for their spouse (Fergus & Gray, 2009; Galanti, 2003; Pinquart & Sörensen, 2003). Family caregivers have both positive and negative experiences of providing care, based on their long-term relationships, and the commitment among the couple (Fauth et al., 2012; Fergus & Gray, 2009).

Information and Communication

The understanding of the patient’s cancer status and the treatment process is a vital part of providing care. There is a need for adequate consultation time to allow family caregivers to enquire about cancer and treatment to help them deal with the effects of cancer (Hudson, Aranda, & Kristjanson, 2004; Kitrungrote & Cohen, 2006). Many studies have revealed that family caregivers feel unprepared in the role because of inadequate information (Giacalone, Blandino, Spazzapan, & Tirelli, 2005; Giacalone et al., 2008, 2009; Locatelli et al., 2010). Family caregivers have identified that there is limited information available regarding diagnosis, treatment, treatment decision-making, and care options to increase their knowledge and understanding of essential information and advice from doctors (Beaver & Witham, 2007; Chapman & Rushy, 2003; Giacalone et al., 2005; Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2004). They were dissatisfied with this lack of information, and also experienced the same levels of stress and depression as the elderly cancer patients themselves (Adams et al., 2009). Giacalone et al. (2009) found that 52% of family caregivers misunderstood the needs of their patients and required additional information about the cancer diagnosis and future care options to prepare themselves for their role. Many studies on breast cancer have noted that there were further details that families needed to be informed of, including treatment options, the probability of cure, the stage of the disease, the impact on daily life, all-cause mortality and risk factors, as well as the survival chances for breast cancer (Beaver & Witham, 2007; Fitch & Abramson, 2007; Forrest, Plumb, Ziebland, & Stein, 2006; Kristjanson, Chalmers, & Woodgate, 2004; Lindholm, Mäkelä, Rantanen-Siljamäki, & Nieminen, 2007). Some studies have shown that family caregivers expressed some reluctance in relation to care due to insufficient skills/knowledge of cancer care, especially among young family caregivers who have less experience in coping with caregiving situations (Adams et al., 2009; Angélique et al., 2012).

Many studies have supported the notion that information resources, health education, and healthcare services should be available and accessible for family caregivers to improve their knowledge and skills in cancer care management, which will increase their confidence in providing care (Beaver & Witham, 2007; Chapman & Rushy, 2003; Giacalone et al., 2008). Health professionals are key actors in providing information and education to family caregivers, and can potentially influence how they solve problems and make decisions (Meeker, Finnell, & Othman, 2011; Papastavrou et al., 2009). Nevertheless, sociocultural issues may be an inevitable barrier between health professionals and family caregivers, particularly the issue of unclear communication. Several studies have shown that family caregivers concealed sensitive matters during consultations with healthcare staff due to limited knowledge of cancer and lack of confidences in relation to communication with health care provider (Adler & Page, 2008; Baider & Surbone, 2014; Giacalone et al., 2005; Giacalone et al., 2008; Locatelli et al., 2010; McPherson, Wilson, & Murray, 2007; Yun et al., 2010). Another significant issue was limited consultation time with health professionals which can negatively impact on the effectiveness of communication between health professionals and family caregivers them, especially when there is a language barrier (Epstein & Street, 2007; Sherman, McGuire, Free, & Cheon, 2013). One study noted that 90% of family caregivers did not discuss cancer treatment options with doctors during the end of life phase due to feelings of anxiety and discomfort (Yun et al., 2010). Some family caregivers reported carrying the burden of communication with health professionals because of unfamiliar medical terminology, which can lead to misunderstandings and missing essential details (Glajchen, 2012).

Effective communication skills are the key to helping both family caregivers and elderly cancer patients to cope with lifestyle changes, and to have better quality of life after cancer treatment. A study by Hotta et al. (2010) noted that patients had agreed with communication about cancer care how to decide on cancer treatment and how to cope with the beginning of each phase of breast cancer. Sharing stories about their life and the adjustments they have had to make has been identified as positive ways of coping with such situations (Giacalone et al., 2005). In western societies, such as the USA and northern Europe, elderly patients with cancer are openly provided with information about cancer and acknowledge better communication than occurs in southern Europe and South America (Mack et al., 2007; Yun et al., 2010). Some physicians may assume that elderly patients are in denial about their condition, and consequently, do not know how to cope with their situation; as a result, they fail to recognise their role in self-care management and decision-making (Hotta et al., 2010). Some family caregivers also prefer to conceal information about a cancer diagnosis from the patient, which can affect the exchange of information (Giacalone et al., 2005).

Cultural Context

Cultural context in relation to cancer care management varies across countries, ethnic groups, and communities (Baider & Surbone, 2014; Juarez & Ferrell, 2003). There are a range of factors associated with such variation among diverse communities, including traditional beliefs, attitudes, culture, religion, and socio-economic elements (Smither-Williams, 2008). Elderly cancer patients in many communities or ethnic groups rely heavily on care from family caregivers, rather than from health professionals (Ruiz, 2007). In western countries, the autonomy of the individual, full disclosure, and open conversation are the key to the culture of caring. However, the aspects of one's personality of western culture can be concealed due to the decision-making processes and social relationships related to differing familial circumstances (Baider & Surbone, 2014). The elderly population in western society has an upward trend in relation to the autonomy of the individual, and also, elderly patients with cancer are likely to be a burden on their family and community. Conversely, in other cultures, such as in the Middle East and Asia, elderly patients are fully supported by their families and relatives (Surbone et al., 2010). In the Middle East, family caregivers take on the role due to religious beliefs and fate, rather than because of human rights or the condition of the cancer (Baider & Surbone, 2014; Searight & Gafford, 2005). Family caregivers provide care based on holy scripture and fate, rather than on healthcare guidelines (Baider & Surbone, 2014). There are several reasons that family caregivers believe in fate in these cultures (Baider & Surbone, 2014; Becker et al., 2007; Benzein, Norberg, & Saveman, 2001; Surbone & Baider, 2013). With a belief in fate, the elderly patients and family caregivers recognise that fate is preordained, outside of personal influence, and can improve their psychological, emotional, and spiritual wellbeing during illness. Belief in fate influences the awareness of body, mind, psyche, soul, and spirit which are an alternative explanation based on the traditional religious and cultural forms. Therefore, fate leads to improved hope and optimism, and can compensate for problems or dissatisfaction. Lastly, fate is always uncertain, but many traditional families prefer to live with, and believe that, fate can create a miracle. On the other hand, they perform care duties and make decisions based on individual rights and communication (Baider & Surbone, 2014). Furthermore, differences in culture can cause isolation characterised by a lack of social and emotional support (Baider & Surbone, 2014; Hacialioglu, Özer, et al., 2010; Haynes-Maslow, Allicock, & Johnson, 2015; Siefert et al., 2008; Smither-Williams, 2008).

Asian society shares a similar social structure to the Middle Eastern society; however, the culture is quite different. For example, Asian culture emphasises religious and spiritual beliefs (Bedi & Devins, 2016). The research found that Buddhist family caregivers conduct their caregiving tasks and make lifestyle adjustments based on the principles of their religion more so than do other religions (Meecharoen, Sirapo-ngam, et al., 2013). The Buddhist perspective helps develop insight into caregiving because family caregivers can experience being physically strong when facing problems (Meecharoen, Sirapo-ngam, et al., 2013). The aspects of traditional customs, and seniors and family systems, are based in part on the social norms of filial obligation to perform valued tasks and roles in relation to a health-illness viewpoint (Baider & Surbone, 2014; Surbone et al., 2010). Cultural relationships between patients, families, and physicians shared the same perspective of the caregiving role through their understanding of an individual's perception of social normative beliefs (Bedi & Devins, 2016). Studies on caring for elderly patients have shown the importance of social and cultural attitudes for family caregivers and their patients. In traditional norms, seniors are highly valued as a source of knowledge and experience (Surbone et al., 2010). Perceptions of, and attitudes about, caregiving for the elderly reflect a positive or meaningful view of religion, beliefs, tradition, and family hierarchies that shape caregiving responses as being polite in manner.

Thai context

The majority of Thai people share several common beliefs, but there are some different cultural traditions and beliefs in the various geographic regions, including Central, North, South, West, East, and North-Eastern Thailand (Kuasirikun & Sherer, 2004). Thai society also comprises a variety of religious beliefs, including Buddhism, Islam, Christianity, Hinduism, Sikhism, and some minor religions (Byrne, 1995). In the Thai context, a family caregiver refers to a patient’s blood relatives, such as the patient’s parents, children, siblings, nephews, or nieces, and commonly refers to a person who lives under the same roof as the patient, or close to their home (Chunharas, 2007). Generally, Thai families include the extended family where more than one nuclear family lives together and family members can support each other in providing care and assisting with daily tasks for an ill family member (Junda, 2004). Support from friends and neighbours is another common aspect of Thai culture. Thai families prefer to seek help from their relatives rather than from healthcare services. Although family caregivers are willing to take care of elderly cancer patients, they are concerned about providing appropriate care for seniors with chronic diseases, particularly for those with cancer (Kamnerdsupaphon, Sumitsawan, Lorvidhaya, Sukthomya, & Srisukho, 2009; Knodel, Bussarawan Teerawichitchainan, Prachuabmoh, & Pothisiri, 2015; Kotepui & Chupeerach, 2013).

In the Thai context, it is not surprising for Thai family caregivers to adopt religious and spiritual aspects into their daily life. Religion provides a positive mindset for the family caregiver in dealing with difficult situations, and an optimistic viewpoint provides meaning in cancer caregiving for the patient and the family caregiver (Blum & Sherman, 2010; Meecharoen, Northouse, et al., 2013; Prechavittayakul, 2006). Positive thoughts and religion are related to an optimistic nature, showing empathy for others, enthusiasm, and one's potential to overcome problems, despite the strain of caregiving which may increase every day (Blum & Sherman, 2010). In Iran, religion is deeply involved in the people's lives, and is used as the spiritual centre during hardships or crises in life. Many Iranians also believe that religion can lead them to be optimistic and satisfied with life (Khanjari et al., 2014). In African-American culture, family caregivers maintain a positive attitude and trust their religion to help them to provide care for elderly patients with breast cancer (Sterba et al., 2014). In brief, for some people, belief in religion can motivate them to deal with crises or stressful times.

Patients are prompted to seek out the experiences of other cancer survivors, suggesting that they might experience emotional distress and lack of confidence because of their cancer diagnosis and treatment. Thus, family caregivers living with breast cancer patients need to be thorough with their coping strategies. Previous research has reported that a lack of confidence and emotional distress were caused by the disease in patients with breast cancer, and that family caregivers received little information as to how to support their elderly cancer patients. Family caregivers also described the same situation, but they place additional importance on the positive side of accepting their caregiving role (Zahlis & Lewis, 2010). During the course of treatment, patients were encouraged to be optimistic in fighting cancer and were supported to have the autonomy to increase their sense of control (Northouse et al., 2012). It has been noted that even in the face of challenges, caregivers show more positive attitudes, even though this can be quite harmful to physical and psychological wellbeing, as well as having their lifestyle disrupted. The perceived positive aspects of the role can be rewarded through coping techniques that appear to develop more positive than negative emotions. A strong relationship between the patient and the family caregiver is important for perceived positive outcomes in the caregiving role (Northouse et al., 2012).

The Current Study

This literature review has presented a substantial body of evidence about the experience of family caregivers in relation to cancer care. Nevertheless, there are a number of gaps in the research that require further investigation in the area of family caregivers caring for elderly women with breast cancer. First, previous studies have explored the experience of family caregivers in all age groups, but the specific experiences of caring for elderly patients with breast cancer are very limited. This is a serious issue because the risk of breast cancer increases with age through menopause. The risk for breast cancer has been shown to increase in the older age groups as a result of menopause. This remains an under-represented issue in the literature. The risk in the older age groups, as compared to the younger groups, is associated with complexities in relation to psychological and physical health problems, as well as lifestyle factors (Kilpela, Becker, Wesley, & Stewart, 2015; Mortimer & Blair, 2006; Muss, 2011). Even though 75% of breast cancers are found in women aged over 60, treatment for breast cancer has been primarily focused on younger women (Mortimer & Blair, 2006). Previous studies have found that there is a large-scale crisis of physical health problems in the aging population. As the aging population grows, the number of elderly breast cancer patients has rapidly increased. There is a limited discussion on the synthesis of qualitative and quantitative research to recommend treatment option for a standard treatment or “standard of care for the elderly patients with breast cancer. In addition, the data suggest that specific guidelines regarding cancer care and care processes for individualised decision-making in elderly patients with breast cancer are insufficient (Louwman et al., 2007; Mortimer & Blair, 2006; Muss, 2011). As a result, elderly women with breast cancer have double the risk of death, with mortality rates tending to be excessively high over time, in particular for those aged 80 years or older (Mortimer & Blair, 2006). Additionally, breast cancer has a negative impact on the daily life of elderly patients, causing them to suffer from physical and emotional symptoms, along with a sense of being a burden to others, and a sense of worthlessness that causes them to desire a hastened death (Nilmanat et al., 2010; Obaidi & Al-Atiyyat, 2013). These impacts are also experienced by family caregivers who provide more than half of the typical care needed to alleviate the suffering of elderly patients. As these studies indicate, family caregivers who play a major role can support the physical and mental wellbeing of elderly patients to help them cope with the effects of breast cancer. However, family caregivers appear to be less prepared to maintain the health and care needs of the elderly due to facing special challenges that vary in their care experience. The differential impact of the burden needs to be assessed on an individual basis.

Second, many studies have focused on spouse caregiver experiences in caring for breast cancer patients, whereas only limited studies have extended the inclusion criteria to other family caregivers rather than just the spouse, such as daughters, sons, and grandchildren. Third, the theoretical approach and conceptual framework have been found to be quite different in taking many varied approaches based on the purpose of the study. Finally, the family caregiver experience in a range of countries is constructed through different social, cultural, and religious contexts (Siefert et al., 2008). Unfortunately, the impacts on both family caregivers in relation to caregiving and elderly patients suffering from cancer diagnosis and treatment have not been previously studied in an Asian context. Asian caregivers undertake more tasks and more caregiving hours, but show lower levels of unmet supportive care needs than in other cultures, such as by African-Americans, Whites, Hispanics, and others. Asian studies have focused on the quality of life of the family of elderly cancer patients and the different problems and feelings of burden as a result of the caregiving experience (Park et al., 2010; Rajasekaran et al., 2016; Rha et al., 2015; Yu et al., 2017). For example, the financial burden of family caregivers has mostly been studied through quantitative research mainly in Western and Middle Eastern countries. Therefore, it is necessary to undertake qualitative research to further explore and understand these issues.

Additionally, previous Asian studies may not be generalisable to the unique social and cultural context of Thailand. The research in Thailand has not yet explored the phenomenon of the caregiving experience in elderly patients with breast cancer, nor the meaning of the caregiving situation through phenomenology. Recent Thai studies exploring the experiences of cancer patients and caregivers in relation to breast cancer care, have used various research methods, particularly interviews and focus groups. Therefore, this phenomenon might vary significantly based on varying degrees of burden of care (Junda, 2004; Meecharoen, Sirapo-ngam, et al., 2013; Piamjariyakul et al., 2010; Wongsawang, Lagampan, & Lapvongwattana, 2013). These studies do not reveal the in-depth individual experience or the entire caregiving situation that can be attained through qualitative methods. Even though existing quantitative and qualitative Thai cancer studies have explored the experiences of breast cancer patients (Junda, 2004; Kershaw et al., 2004), it is a different matter when attempting to gain an insight into the experiences of the care experience among the elderly population. Thailand is unique in its culture and the elderly community in Thailand is somewhat under-investigated. Likewise, cancer among elderly patients is more complicated in terms of providing care (Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth, & Pimporm, 2013), and there is limited research into Thai family caregiving for the very elderly with chronic diseases such as cancer (Jarin et al., 2014). Therefore, little is known about the care experience of Thai family caregivers for elderly patients with breast cancer. There appears to be no evidence in the literature to date in relation to the Thai context; therefore, this context needs to be examined more closely.

Nevertheless, breast cancer is a very common problem in comparison to other diseases. Statistics reveal that breast cancer has increased in elderly women who are fragile and require more supportive care. Currently, the number of elderly patients with breast cancer in Thailand has significantly increased over the last decade. Breast cancer in the elderly is now the leading cause of cancer-related deaths among women aged 50 years and older (Suwankhong & Liamputtong, 2016; Thai Breast Disease Society, 2011; Thai Society of Therapeutic Radiology and Oncology, 2011). Moreover, the treatment for breast cancer has a negative impact on physical and psychological health, can lead to a lack of social support, and can reduce quality of life (Suwankhong & Liamputtong, 2016). Thai family caregivers have always taken care of their loved ones, but experience in relation to breast cancer care are limited. Some family caregivers are not be able to deal with changes in daily life caused by the patient’s diagnosis and the burden of caregiving. They are more likely to have negative responses, such as increased stress and feelings of isolation.

Consequently, unpaid caregiving is increasing, but also significantly affects the family caregiver (Khuhaprema et al., 2009; McDonald, Hertz, & Susan, 2008; Mollica & Newman, 2014; Siegel et al., 2013). This study, therefore, aims to explore the experiences of family caregivers who are providing care for elderly women in Thailand who have undergone various forms of treatment. To the best knowledge of the researcher, there has been no previous research that has addressed the experiences of the family caregiver in relation to providing care for women with breast cancer. The purpose of this study is to develop a deep understanding of the meaning of providing care by family caregivers.

Chapter Summary

Providing ongoing care for elderly patients with cancer causes significant distress. Family caregivers are likely to experience physical, emotional, social, and financial distress that contribute to the burden they experience. Different cultural contexts will also have varied impacts on family caregivers' perspectives.

The following chapter describes the qualitative research approach of the current study, outlining the phenomenological approach used in the study, and which methods have been used to explore the lived experiences of cancer care provided by family caregivers.

CHAPTER 3 METHODOLOGY AND METHODS

This chapter presents both the methodology and methods used in this research. First, the methodology is described, which includes the general principles of qualitative methodology, phenomenology, and hermeneutic phenomenology. The methods of the study are then presented, including the study setting, participant recruitment, sample selection, interview design, and ethics considerations. The last section explains the data analysis and interpretation in which themes and sub-themes are described.

Methodology: Phenomenology and Hermeneutic Phenomenology

Recently, qualitative research methodologies have been deployed in many areas of academic research. Many qualitative approaches are widely used such as phenomenology, ethnology, grounded theory, and hermeneutic phenomenology. Generally, qualitative methodologies provide explanations of how an individual experiences a phenomenon (Langdridge, 2007; Nouria, 2007). These approaches address questions that seek to develop an understanding of meaning based on human experience (Brown, 1996). Phenomenology seeks the understanding of how humans experience particular phenomena and phenomenologists draw the frame where the meaning reflects an aspect of personal engagement with their assumptions in response to phenomena (Matua & Van Der Wal, 2015; van Manen, 2007).

Phenomenological tasks in relation to the phenomenological method include subjective, inductive, and dynamic practice which is interactive between researchers and participants. In seeking to understand human experience, the meaning of human experiences is being focused on rather than describing the phenomenon being studied. To discover the meaning of human experiences, participants were asked to reflect on their narratives that expressed the actual situation of a certain experience (Laverty, 2003; Reiners, 2012). Phenomenology is a traditional qualitative research philosophy that emerged in the 20th century. Phenomenology was established by Edmund Husserl (descriptive) and Martin Heidegger (interpretive) (Reiners, 2012). Originally, Husserl (2012) has been presented as coming from a transcendental approach in which he assumes that people can separate their personal knowledge from their life experiences. His phenomenology is referred to as ‘descriptive phenomenology’, which is the opposite of an interpretive approach (Cammarata, 2013). Descriptive phenomenology takes account of the researcher’s assumptions by using bracketing when exploring empirical events and human accounts. Husserl's approach used this bracketing to describe the meaning of common-sense beliefs. This is used to ensure that the phenomenologist is not presupposing human beliefs and experience. Bracketing allows the researcher to acknowledge their prejudices and how such perspectives might influence their interpretation. Accounting for such biases improves the rigour of the research (Spiegelberg, 2012).

On the other hand, Heidegger described human life as ‘being in the world’ (Dasein), concentrating on the reality of humans existing in the world or people experiencing their everyday occurrences instead of ‘knowing the world’ (Heidegger, 1996). He developed hermeneutics (interpretive) through an approach based on interpretation (Reiners, 2012). This approach aims to describe meaning instead of bracketing prior assumptions and expectations of the study of the meaning of experiences of the world as they are lived (Merleau-Ponty & Smith, 1996; Sloan & Bowe, 2014; Wilcke, 2002). This can be moved beyond the description in the consciousness (an epistemological approach) to interpret the meanings that are embedded in people's experiences (Matua & Van Der Wal, 2015; Merleau-Ponty & Smith, 1996; Sloan & Bowe, 2014; Wilcke, 2002). The current study draws on both the descriptive and the interpretive approach to identify meaning.

Hermeneutic phenomenology and phenomenology has been adopted as a study method of gaining knowledge on research methodologies to explore experiences in the human sciences. Researchers need to defend the value of the human sciences that study the philosophical, biological, social, and cultural aspects of human life while placing a strong emphasis on the research phenomenon (Cammarata, 2013; Kakkori, 2009). In relation to psychology, phenomenology is described as a way of understanding how consciousness works in a social context to create meaning that can support the understanding of the biological, psychological, and social aspects of human life, in which the parts and the whole of the experience are considered (Owen, 2008). Hermeneutic phenomenology seeks an understanding of how humans describe their experiences of particular phenomena. Its discipline describes how one interprets a deeper understanding of text or language in human inquiry (Sloan & Bowe, 2014; van Manen, 1982). Interpretation informs the hermeneutical approach to make sense of particular circumstances in order to conduct the phenomenological task that allows texts to speak again (Smith, 2007; van Manen, 1997).

Hermeneutic work includes the dynamic movement between some matters in the parts and in the whole of certain texts or research which claims to have followed the hermeneutic cycle. The hermeneutic cycle implies that the parts and the whole of the texts are interpreted. The cycle of part and whole is always movement within the text that we learn (Burhans & Alligood, 2010; Motahari, 2008). This cycle is focused on the understanding and interpretation of human activity in lived experience that cultivates the narrative and which constructs human thinking (Kakkori, 2009). Hermeneutics is used in which themes are interpreted from the texts to discover the exact meaning of the experience (Doyle, 2007).

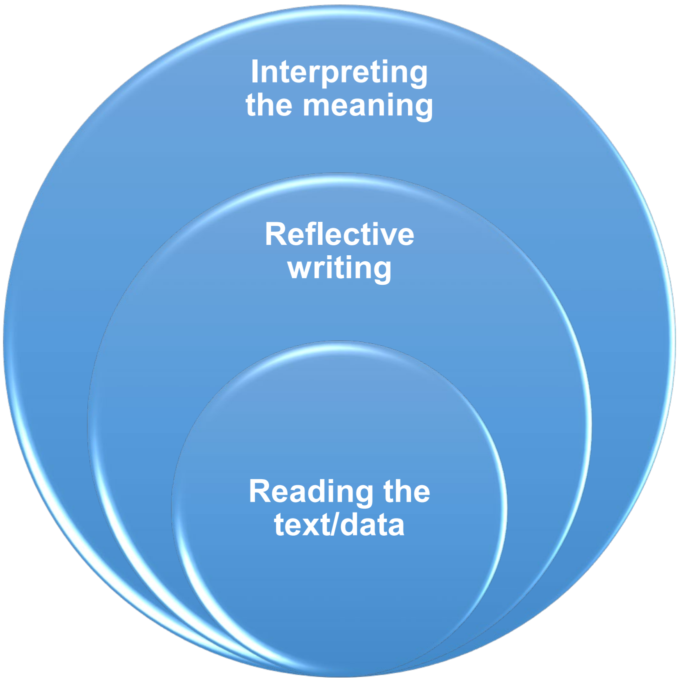
The idea of rigour in qualitative research is the legitimacy of knowledge associated with a critique to achieve validity and reliability within qualitative research (Golafshani, 2003). The researcher adopts the research method in both a qualitative methodology and in a detailed scientific method, including its purpose, theory, framework, method, and methodology to ensure the accuracy of the data and to enhance trustworthiness (Golafshani, 2003; Shenton, 2004). Trustworthiness encompasses credibility, transferability, dependability, and conformability (Graneheim & Lundman, 2004). Trustworthiness is established by using digitally-recorded audio, audited transcripts, and field notes to ensure the accuracy of the data and to enhance the credibility of the research (Cope, 2014). Field notes are written immediately after each interview and include a detailed account of the elements of the participant’s experience of the phenomena that resonated with the researcher according to the theoretical framework (Burhans & Alligood, 2010). This study uses van Manen’s method to carry out an audit of the overall process. Participant narratives, including their background, beliefs, and feelings are interpreted to assign the meaning of the lived experience. A reflective process is used in data analysis to create the themes providing a definition, categories, theories, explanation, interpretation, and exploration. In this work, the participants’ experiences and lived meanings were included followed by the participants’ voices.

Max van Manen’s Hermeneutic Phenomenological Approach

A well-known Canadian phenomenologist, Max van Manen, explicated hermeneutic phenomenological philosophy and developed a hermeneutic phenomenological approach to the human science context for research and practice with written texts (Ehrich, 2005; van Manen, 2016). As van Manen (1990) stated, “human science research is a form of writing. Creating a phenomenological text is the object of the research process” (van Manen, 1990, p. 111). In addition, the language in terms of phenomenological philosophy includes literature, documentaries, novels, poetry, biographies, stories, and diaries in order to explicate the phenomena through the writing process (van Manen, 1990). Writing tasks come from Husserl’s concept of seeking meaning within individuals’ consciousness. van Manen applied Heidegger’s phenomenological concepts to discuss interpretation and responses to the new knowledge of phenomenology (Dowling, 2007). Heidegger’s approach adopted the descriptive phenomenology of Husserl. The bracketing in Husserl’s approach is about acknowledging assumptions to set aside for the event or directly questioned, and removing them is part of the researcher’s reflection and self-consciousness which helps them to interpret the person’s experience (van Manen, 1991). Additionally, both Husserl’s descriptive phenomenology and Heidegger’s hermeneutic phenomenology are described by van Manen (1997; p.25) as, “it is possible to make a distinction in human science research between phenomenology (as pure description of lived experience) and hermeneutics (as interpretation of experience via some ‘text’ or via some symbolic form)”. Therefore, van Manen’s phenomenology adopted descriptive and interpretive, or in other words, a hermeneutic approach through his phenomenological concept (Dowling, 2007).

The phenomenological method does not contain guidelines for collecting and analysing data (van Manen, 1991). In relation to data collection where the researcher can choose a wide variety of data sources to understand the phenomena at hand, this includes personal experience from an etymological viewpoint, written statements and descriptions from interviews and observations, and texts from narratives, art, stories, poetry, and diaries. van Manen described the interview process “as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon” in which the interview process is designed to answer the research question (van Manen, 1990; p. 66). All types of data sources are effective ways of supporting the researcher in understanding the phenomenon in question (van Manen, 1990). Regarding data analysis, van Manen (1990) outlined thematic analysis as “experiential structures of experience” which assist with the identification of the elements of the phenomenon according to relevant themes (van Manen, 1990; p.79). There are three main holistic approaches that van Manen recommended to isolate themes, capturing (reading) the essence of the text/data source, the writing process (reflecting) that reveals the data source, and then interpreting the actual meaning (Figure 1) (Ehrich, 2005). In addition, van Manen outlined a process for the phenomenological researcher, the hermeneutic circle, in which the parts and the whole are moved around the texts to interpret as it is the circle of phenomenology (Langdridge, 2007; Sloan & Bowe, 2014). Thus, van Manen’s work provides experiential structures to guide the researcher in identifying themes by using the hermeneutic cycle.

Figure 1: Hermeneutic Cycle



The rationale for using the phenomenological approach and van Manen’s framework

Phenomenology is the most appropriate methodology through which to present the human meaning of the family caregiver’s care experience. This study has used the phenomenological framework of Max van Manen as the methodological approach because the concept and its application are holistic, sensitive, and reflective in interpreting the participants' contributions. This approach will provide an insight into the natural attitudes and the human condition. The phenomenological approach is difficult to describe in human science research, but Max van Manen formulated his approach to clarify the practical concerns of phenomenology, to test the assumptions behind the outcomes of phenomenological tasks. Other hermeneutic phenomenological approaches do not provide a step-by-step approach to assist with data collection and analysis. van Manen (1990) provides guidelines for the researcher to follow. These guidelines benefit the researcher by introducing the hermeneutic circle which allows the researcher to interpret the data under the hermeneutic discipline. His framework helps the researcher address the research question by examining the lived experience. The experiences of family caregivers in this study provides unique data due to differences in the experiences within particular contexts to illustrate how people make sense of, and describe, their subjective accounts. Therefore, van Manen's framework helps the researcher to uncover particular experiences such as the caregiving experiences of the family caregiver, and his approach draws upon both descriptive and hermeneutic phenomenology to interpret the meaning of the lived experience. The written process can help the researcher to interpret and discuss the data through insights into the lived meaning within the subject matter. This study is informed by Max van Manen's phenomenological framework to guide data collection, analysis, and interpretation in relation to the aims of the study, which are described in the following section.

Phenomenological Framework of Max van Manen

van Manen developed the six steps of the phenomenological approach: 1) Turning to the nature of lived experience; 2) Investigating experience as we live it; 3) Hermeneutic phenomenological reflection; 4) Hermeneutic phenomenological writing; 5) Maintaining a strong and oriented relation; and 6) Balancing the research context by considering the parts and the whole (van Manen, 1990, 2002). This study uses steps 1, 2, and 3 for the data collection, and steps 4 to 6 for the data analysis and interpretation.

Step 1: Turning to the nature of lived experience

Orienting to the phenomenon

The objective and subjective data are grasped to meet the meaning and to discover the essence of personal experience in particular contexts (van Manen, 1990). The researcher's assumptions about the participants' thoughts should be avoided so that there is no pre-understanding of the participants based on a lifeworld perspective. The term 'presupposition' as prejudice or preconscious of understanding that is starting points to describe the things surrounding human in ordinary life (van Manen, 1990, 2002). The objective and subjective data for this study were explored through the family caregivers' lived experience. The phenomena including prior knowledge and pre-understanding of participants were reflected. Then, it seeks to formulate questions to return the purpose of study, underlying assumptions, focusing on presupposition which is unreflective to expose perform the appropriate ways to explore the phenomenon.

1. Formulating the Phenomenological Question

The research questions simplify the meaning of human phenomena related to the sense of being in exploring lived experience. van Manen's question asks "what is the nature of the phenomena as meaningfully experienced?" (van Manen, 1944; p.7). The phenomenological research in this study investigates how the participants describe their experiences of the phenomenon of caregiving. Additionally, the research aims to identify the family caregiver experience in providing care for elderly patients with breast cancer. The research question is 'what are the care experiences of family caregivers providing care for elderly women undergoing treatment for breast cancer in Thailand?'

2. Explicating Assumptions and Pre-understandings

Pre-understandings, presuppositions, and assumptions are interpreted through the phenomena. Max van Manen stated that "it is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories … not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself …" (van Manen, 1990; p. 47). In this study, the assumptions and pre-understandings of the researcher are outlined based on personal background, knowledge, and attitudes that might influence the interpretation. For example, the researcher has knowledge and skills in nursing, teaching, and conducting qualitative phenomenological research. This study also involved providing care for woman patients with breast cancer in a surgical ward, and support information including diagnosis and caregiving for family caregivers. This can help the researcher to frame the impacts of caregiving in a natural situation.

Step 2: Investigating experience as we live it

This step means "the nature of data" when the researcher begins exploring the person's experience and obtains descriptions that people had lived in the lifeworld (van Manen, 1990; p. 53). The researchers lived in "the fullness of life" growing into people's situations. The researcher must understand the possible event and often involves an investigation of the meaning of the text (van Manen, 1990; p. 32). In other words, the researchers have been interested in investigating the presence to discover the meaning of an experience. van Manen creates an appropriate methodology for human science as the tools of the phenomenological method, which is "all recollections of experiences, reflections on experiences, descriptions of experiences, taped interviews about experiences, or transcribed conversations about experiences are already transformations of those experiences" (van Manen, 1997; p. 54). This section presents five steps for collect data and exploring the lived experience of family caregivers: *1) using personal experience as a starting point; 2) tracing etymological sources; 3) obtaining experiential descriptions from others; 4) protocol writing (lived-experience descriptions); and 5) interviewing (the personal life story).* The tools for gathering the data include digitally audio-recorded, semi-structured in-depth interviews and field notes, which are used to investigate the participants' experiences during the interview process.

Step 3: Hermeneutic phenomenological reflection

A phenomenon (a lived experience) is not fulfilled in a reflective grasp of the essence of experience and formulated a thematic understanding. Therefore, this step demonstrates the method of reflection used prior to identifying the themes, including conducting the thematic analysis, isolating thematic statements, composing linguistic transformations, and using lifeworld existential approaches as guides to reflection.

Conducting the Thematic Analysis

Conducting the thematic analysis is a way of manage the meanings within written work developed from the data analysis. The data analysis presents a guide to conducting a thematic analysis including analysed, disclosed, discussed and interpreted form (van Manen, 1990). In this study, the family caregivers' accounts were analysed through the creation of themes which then allowed the researcher to answer the research question that can be open to draw the meaning. The actual meanings that arise from the thematic analysis are used to isolate specific themes in the text.

Isolating Thematic Statements

van Manen asked the question, “what does this sentence or sentence cluster reveal about the phenomena or experience being described?” (van Manen, 1990; p. 92-93). To isolate the thematic statements, the statements of the family caregivers were considered by reading the entire sentence and then marking, underlining, highlighting, or adding some comments and notes (van Manen, 1990). In this study, listening to the digitally-recorded audio, reviewing and reading the transcriptions, and writing notes were all important steps. Each paragraph was read and marked in parts and by considering the overall content. The texts were focused, and the statements or sentences were repeated several times until the meaning of the messages were clear. Consequently, the themes emerged according to the text, word, or part of the narrative.

Composing Linguistic Transformations

In describing this step, van Manen stated that “composing linguistic transformations is not a mechanical procedure … it is a creative, hermeneutic process” (van Manen, 1990; p. 96). In this study, each transcript or statement is read for linguistic descriptions, uncovering phenomenological themes, and transforming the meaning units or thematic development.

Lifeworld Existential as Guides to Reflection

van Manen used a reflective lifeworld approach to reflect the findings after the analysis process and the establishment of emerging themes. The reflective tasks comprise “spatiality, corporeality, temporality, and relationality” (van Manen, 1990; p. 102). Lifeworld themes draw upon an understanding of how people make sense of the world. Family caregivers’ experiences of caregiving demonstrated these life-world existentialist themes. The lived space connects with the location in which people have lived or have experienced with someone; for example, when the family caregiver provides care for the patient at home. The lived body reflects existentialist themes of how the family caregiver discusses their experience of how caregiving affects their physical and emotional wellbeing. Lived time reflects the time spent in their caregiving situation which can be explained in terms of slowing down or speeding up, and can be associated with being busy or less busy. Lived human relations or relationality demonstrates the family caregiver feeling positively or negatively about the relationship they have with their networks, including friends, neighbours, and health professionals. These four existent lifeworlds are described in the following section.

1. Lived space (spatiality)

Lived space (spatiality) means the felt space in which people are located, and that space affects people (van Manen, 1990). A small and narrow space, such as 2m x 3m or 3m x 3m full of furniture might give people a feeling of being crowded, while a large room the size of a building can demonstrate a feeling of freedom, feeling comfortable, or feeling small (van Manen, 1990). Lived space refers to a human being that people 'felt space' in the location in which people are located or have lived in, including their workplace, home, or somewhere else. When people were questioned about their world, one would think "the nature of the lived space" (van Manen, 1990; p. 103). Lived space in this study grounds the family caregiver in providing care at home that demonstrates the sharing of the everyday care experience and caregiving activities between the patient and the family. Positive and negative emotions related to caregiving in the home are also demonstrated.

2. Lived body (corporeality)

Lived body (corporeality) refers to "we are always bodily in the world" which is the idea of embodiment (van Manen, 1990; p. 103). When we see someone in his or her reality, then we find individual appearance through his or her body. We might show or conceal something such as our body language consciously and unconsciously. In this study, the researcher met the participants in the comfort of a familiar space or in their home. The lived body represents the body language of both the researcher and the family caregiver when communicating together. They (the researcher and the family caregiver) might have expressed a number of issues, but were also concealing something. Physical appearance, non-verbals, facial expressions, and manner were observed.

3. Lived time (temporality)

Lived time refers to a period in which time seems to go quickly when people feel happy. Lived time is a subjective time which is not the same as clock time. Lived time can appear to slow down when people feel unhappy during a stressful situation. This temporarily shows the past, present, and future of people living in the world (van Manen, 1990). The life cycle is explained in relation to attitude, knowledge, and the time of the caring situation linked to the lived meaning of caregiving through the family caregiver's life. The past, for instance, can reduce uncomfortable feelings about high pressure circumstances and look forward towards a current event (van Manen, 1990). The family caregiver might stay temporarily to provide for their loved one in relation to their moods, emotions, or feelings of their lifeworld which varied according to past, present, and future circumstances.

4. **Lived others (relationality)**

Lived others implies a relationship in which we keep and share our story with each other. van Manen (1990) stated that “the lived relation we maintain with others in the interpersonal space that we share with them. As we meet the other, we approach the other in a corporeal way” (van Manen, 1990; p. 104). In this study, when the researcher met the family caregiver in the first place, the researcher expected the participant to have various feelings, including feelings of being welcome/unwelcome to the researcher. The researcher starts by working to build a relationship, providing a good impression to the participants before conducting the interviews.

Step 4: hermeneutic phenomenological writing

Hermeneutic phenomenological writing included attending to the speaking of language, writing and rewriting through a cycle of writing. Attending to the speaking of language refers to speaking when the participants tell their story and describes the true meaning of the experience when the researcher is listening (van Manen, 1990). The sound and tone of the voice imply a sense of language as a whole context. The writing process includes writing, rewriting, revising or editing, and reflecting. This process is “to approach again and again … re-thinking, reflecting, re-cognizing and rewriting (van Manen, 1990; p. 131). The writing task for this study was part of the phenomenology. The writing and re-writing process was conducted and reflected upon. Revising and refining of reflectivity was deliberated throughout the writing process.

Step 5: maintaining a strong and oriented relation

Our Text Needs to be Oriented

The text needs to be clear along with the “content and form, speaking and acting, text and textuality” (van Manen, 1990; p. 151). The text of the interview transcripts in this study need to be oriented and always needed to be considered and comprehended. The research question would answer how the researcher needs to focus, observe, and listen to a certain context.

Our Text Needs to be Strong

The text identifies significant meaning in the phenomena under consideration and elucidates their experiences including intention, knowledge, practice, and interpretation (van Manen, 1990). In this study, a certain process including reading, writing, and revising of texts needed to be clarified and needed to be strong, especially in the case of the interpretations, understandings, and formulations.

Our Text Needs to be Rich

The rich statements gained from the phenomena under study guide the researcher's interpretations of the participants' story (van Manen, 1990). The meanings of the lived experience were useful for instant experience. In this study, life experience needed to be explored to provide rich statements and rich descriptions of certain stories. The terms of the textual dialogue need to be clear in a whole phenomenological picture.

Our Text Needs to be Deep

The researcher clarifies the writing work as "oriented, strong, rich, and deep" to interpret the lived experience of phenomena (van Manen, 1990; p. 152). To apply this step, transcription and analysis were undertaken, and the narratives were interpreted through immersion. Journals and articles were used to reflect on whether the research question needed to be reconsidered. The researcher often had to discuss the project tasks with her academic supervisors to assist the reflection to ensure that all the research tasks were deeply considered.

Step 6: balancing the research context by considering the parts and the whole

The writing activity, including 'working the text', provided the regulation to guide the way of interpreting the participants' description. The themes reflected the main idea of the participants' stories (van Manen, 1990). This 'working the text' included re-considering the parts and the whole of the documents that embodied the actual lived experience.

Methods

Setting, participants, and sample selection

Data were collected between August and October 2015 in the Chiang Mai province of Thailand. The eligible participants were recruited by Thai health professionals. The researcher provided the purpose of, and information about, the study through the Head of Health Services, while information flyers (see Appendix VI) were posted on the noticeboard of the District Health Promotion and Prevention Centres, Chiang Mai, Thailand. Potentially eligible participants expressed their interest to participate in the study by contacting the researcher via the health professionals. The health professionals then provided an information sheet and the letter of introduction (see Appendix III) to eligible participants and informed the researcher to contact the participants before conducting the interviews. The project was discussed, and questions fielded about the process, via telephone. Before commencing the interviews, a consent form was provided and the participants were given an explanation of the purpose of the study, and the benefits and risks of the project to them. Each participant signed a consent form prior to the interview process. All interviews took place within the participants' homes where they indicated that they felt comfortable in sharing their care experience. The participants were contacted by telephone before and after the visit, and a time was arranged to conduct the interview. In total, there were 22 participants recruited who met the eligible criteria. The participant selection criteria were:

1. 20 years or older
2. Lived in the area of Chiang Mai, Thailand (at the time of the interview)
3. Family caregivers who were mainly providing care for Thai elderly women with breast cancer in the family home, either males or females, were identified by elderly women in performing the caregiver role.
4. Elderly female Thai participants had to be aged 60 years or older (as defined by the Thai Population Censuses of 1960-1990) (Knodel & Chayovan, 2008), and who had been given a diagnosis of breast cancer by physicians after/during cancer treatment.

Phenomenological studies generally require small numbers of participants, but very in-depth interviews. van Manen did not mention a specific sample size for his method. Munhall (2012) recommended that a sample size of 10-20 participants or less was suitable for qualitative research.

Typically, guidelines for sample sizes in qualitative research suggest a range of 5 to 25 for phenomenological research (Mason, 2010). The interviews were completed when the data was saturated, meaning that no new knowledge or information emerged from the interviews after saturation had been reached.

Ethical Considerations

Ethics approval was provided by the Social and Behavioural Research Ethics Committee (SBREC), Flinders University. The approval number was 6762 (Appendix II). An ethics approval form was provided before recruiting any participants for this research. The participants were provided with a plain language information sheet, and the researcher's contact details were included to provide the participants with the opportunity for making enquiries after an interview. All participants were fully informed about the purposes, benefits, and potential risks of the study. During the interview process, the consent form, including explanations of the interview process, the potential risks, and the assurance of anonymity and confidentiality, were included. The participants' personal information was kept confidential.

The study in Thailand was conducted in 20 health centres (Appendix IV). The ethics committees of each of these Thai health centres required a letter of introduction (see Appendix III), an information sheet (see Appendix III), and a flyer (see Appendix VI) from Flinders University. The health centres allowed the researcher to collect the data after the ethics application in Thailand had been approved. Following this, all the participants were given the information sheet and consent form before being interviewed. The consent form did acknowledge that there was a possible risk that the participants might experience distress and discomfort as a result of the interviews. Therefore, they were assured that they could withdraw from the project at any time. The health professionals and the researcher would contact a psychiatric consultant to help the participants in relation to the impact of the interview if needed.

Data management

All data, including the individual participant data, the interview data (audio-recorded through a digital voice recorder), and the consent documents will be kept in safe secure storage at all times, with all the information to be destroyed after five years, as per Flinders University policy. The data have been stored in the researcher's station in the postgraduate room in the College of Medicine and Public Health, Flinders University, where it will be held in the repository on a password-protected laptop computer, including a password-protected flash drive, and then locked in the cabinet in the researcher's office, which only the researcher can access.

Participant descriptions

A total of 25 participants, who were approached to participate between August and October 2015, were confirmed to be eligible. However, two were excluded from participating as one refused to participate while the other was too busy. Also, one interview was discarded as the voice-recording failed. Therefore, this study builds on narrative interviews with a total of 22 family caregivers who expressed their willingness to participate. The characteristics of the participants, including their age, marital status, current health status, employment status, occupation, duration of care, education level, and relationships are shown in Tables 3.1 and 3.2. The participants who were principal family caregivers comprised both females (14) and males (8). Their ages ranged between 34 and 72 years. The majority (21) of participants were married. Half of the participants (11) had been living with their patient. Eleven participants were employed and seven were doing non-paid work. Nine participants (6 daughters, 3 sons) were adult children who were taking care of their mother with breast cancer. Other participants were spouses (5), siblings (4), and relatives (4). More than half of the participants had completed primary school (14), with three having completed high school, two finishing a diploma degree, and three completing a bachelor degree. In terms of duration of care, six-month care experience was the minimum with a maximum of 16 years of care experience. Current health status was self-rated by the participants as poor (1), fair (13), good (1), and very good (7). Half of the participants (11) identified themselves as having a health problem including hypertension, diabetes, dermatitis, heart disease, leiomyoma, anaemia, a breast cyst, raised cholesterol, and osteoarthritis. Eleven participants reported that they had no serious health problems during caregiving. In addition, pseudonyms were created for all the participants to avoid the possibility of their identity being revealed, and to confirm that their data was confidential.

Table 3.1 Characteristics* of female participants

Females	Characteristics
Ampai	47, married, good health status, full-time, employee, 11yrs of caring, primary school, caring for grandmother
Aumara	60, married, poor health status, none, housewife, 2yrs of caring, primary school, caring for older sister
Ann	50, married, fair health status, full-time, a personal business, 3yrs of caring, high school, caring for mother
Boonta	64, married, fair health status, none, housewife, 3yrs of caring, primary school, caring for older sister
Daow	43, married, very good health status, employee, civil servant,15yrs of caring, bachelor, caring for mother
Lapa	36, married, very good health status, none, housewife, 1yr of caring, diploma, caring for mother-in-law
Pimon	65, married, fair health status, none, housewife, 6yrs of caring, primary school, caring for mother
Pisut	57, married, fair health status, full-time, merchant, primary school, 13yrs of caring, caring for aunt
Pim	45, single, very good health status, full-time, a personal business, 6 mths of caring, bachelor, caring for mother
Siri	37, widowed, fair health status, full-time, merchant, 10yrs of caring, high school, caring for mother
Siriluk	52, separate, fair health status, full-time, merchant, 8mths of caring, primary school, caring for mother
Sirimas	55, married, fair health status, full-time, a personal business, 8yrs of caring, high school, caring for older sister
Suchada	70, single, fair health status, full-time, a personal business, 6mths of caring, primary school, caring for younger sister
Wanna	38, married, very good health status, none, housewife, 1yr of caring, diploma, caring for mother-in-law

* Pseudonym, age, marital status, current health status, employment status, occupation, duration of care, education, loved one in care

Table 3.2 Characteristics* of male participants

Males	Characteristics
Arthorn	34, married, very good health status, full-time, public officer, 6yrs of caring, bachelor, caring for mother
Aunucha	36, single, fair health status, none, none, 10yrs of caring, diploma, caring for mother
Aom	49, separated, fair health status, full-time, hotel worker, 2yrs of caring, primary school, caring for mother
Decha	72, married, fair health status, none, none, farmer, 1yr of caring, primary school, caring for wife
Prakit	61, married, poor health status, full-time, farmer, 9yrs of caring, primary school, caring for wife
Srichai	64, married, fair health status, full-time, constructer, 1yr of caring, primary school, caring for wife
Supod	72, married, fair health status, full-time, farmer, 11yrs of caring, primary school, caring for wife
Suratin	61, married, very good health status, full-time, merchant, 1yr of caring, primary school, caring for wife

* Pseudonym, age, marital status, current health status, employment status, occupation, duration of care, education, loved one in care

The age of the patients ranged from 60 to 86 years. The majority of the patients were mothers (9), followed by wives (5), older sisters (3), mothers-in-law (2), a younger sister (1), an aunt (1) and a grandmother (1). Nine patients were married, while another nine were widowed, and the rest were single (4). The majority of the patients (14) had good self-rated health status, while seven patients had fair health. The remaining patients had poor health because of late-stage breast cancer. Most patients had been diagnosed with breast cancer from between 2 and 5 years ago (8), while the rest of the patients (10) had been diagnosed from between 5 and 10 years ago.

There were various stages of breast cancer, from stages 1 through 4, reported by the family caregivers. However, five patients were unsure of their stage of breast cancer. Five were reported to be in the final stage and had breast cancer metastasis to other organs such as the lungs and bones. However, one patient, who was in the final stage of breast cancer, had not found metastasis.

Four treatments were common among the patients: surgery (mastectomy) (22), chemotherapy (15), radiotherapy (16), and hormone treatment (22). The side-effects of the treatment of the breast cancer that the patients had undergone varied, including hair loss, wound infection, lost weight, skin problems, gastro, fatigue, and emotional distress, particularly as a result of chemotherapy. For example, patients experienced complications during chemotherapy such as fatigue, hair loss, nausea, vomiting, loss of appetite, mouth and throat sores, skin problems, weight loss, and emotional changes. Wound infection was reported in two patients after having radiotherapy and surgery. Radiotherapy-related side-effects caused radiation skin problems such as dry, burnt, sensitive, and darker skin, as noted by four patients (see Table 3.3). Hormonotherapy did not have any side-effects for this patient group. In addition, follow-up healthcare for these patients consisted of checks every 3 months, 6 months, and then annually. The majority of patients (13) also experienced other health conditions including hypertension, diabetes mellitus, heart disease, chronic obstructive pulmonary disease (COPD), gout, osteoarthritis, high cholesterol, and cataracts.

Table 3.3 Demographics of all patients

Characteristics	**Number of patients**
Age	
60-70	15
71-80	6
> 80	1
Marital Status	
Single	4
Married	9
Widowed	9
Relationship	
Mother	9
Wife	5
Older sister	3
Mother-in-law	2
Younger sister	1
Aunt	1
Grandmother	1
Stage of cancer	
1	5
2	5
3	4
4	5
Unsure	5
Treatments	
Surgery	22
Chemotherapy	15
Radiotherapy	16
Hormonal therapy	22
Duration of treatment	
≤ 1 year	4
2-5 years	8
5-10 years	5
>10 years	5
Side effects	
Hair loss	11
Wound infection	2
Weight loss	2
Skin problem	18
Gastro	22
Fatigue	16
Emotional disorder	9
Other	4
Current health	
Good	14
Fair	7
Poor	1

Interview design

Semi-structured and open-ended interviews were used for data collection to allow the informants to express their views in their own terms. This process was used to ask questions exploring definitions of care experiences and to get the respondents to share their memories (Guimond-Plourde, 2009). In this study, the participants were interviewed using a semi-structured interview (Appendix V). The semi-structured interview schedule was developed by the researcher to explore the experiences of the participants. The schedule was also assessed through peer-checking by academic researchers. The semi-structured interviews were designed to gather information on the relevance of the family caregiver's context in relation to their background, experiences, problems, and issues. During the phenomenological interviews, the main purpose was to obtain a deeper understanding of the meanings that underlie the caregiving experiences of family caregivers. A digital audio-recorder was used during the interviews, and field notes were written after each interview was completed.

Data collection

Data was collected using face-to-face and in-depth interviews. They were recorded using a recording device during an interview and immediately taking written notes after an interview (Appendix V). All the participants were asked for their permission to allow the use of a digital audio-recorder. The interviews were conducted privately and confidentially with eligible participants who agreed to participate. The participants were asked about the essence of their experience of their caregiving role. This involved the phenomenological process of seeking to disclose the lived experience of family caregivers in providing care. This was complemented by reflective field notes. The data collection process included:

1. The semi-structured interview schedule was used by the researcher to guide the conversation, based on the research questions, between the participants and the researcher.

2. Each interview was recorded to obtain a true account, and later transcribed for the data analysis phase.

3. Field notes were written after each interview in relation to the statements given by the participants about their background and their caregiving experiences.

4. All the interview recordings were transcribed by the researcher in the Thai version. The interview transcripts were translated by qualified translators for the English version. All data were entered into a Microsoft Word file.

Interview questions

All the participants were asked to respond in their own words about their caregiving experience following the initial questions which included, ‘Could you tell me about your previous and current occupation?’, ‘What is your experience when you are a family caregiver?’, and ‘Could you please describe your feelings during the caregiving role for the patient undergoing treatment for breast cancer?’. The next questions were associated with health condition and wellbeing; for example, ‘How is your health currently?’, and ‘Did you have any health conditions after caring?’ Subsequent questions focused on the impact of the caregiving situation; for instance, ‘Tell me about how the caregiving situation has impacted on your life?’. The main research questions guiding the study were as follows: ‘What is it like to be a family caregiver for your loved one?’, ‘Could you tell me the feelings you experienced during the family caregiver role?’. The interviews lasted between 60 and 90 minutes, averaging 75 minutes per participant.

Data analysis and interpretation

The process of analysis followed van Manen’s six steps of hermeneutic phenomenology (van Manen, 1990). First, turning to the nature of lived experience meant turning to the things themselves that we explored through the phenomena of lived experience and which were connected to the world of the family caregivers. The researcher explored the lived meaning of family caregivers and the nature of their caregiving experiences. The second and third analysis process described the experience as the researcher live it into participants’ experience and reflecting on the hermeneutic phenomenological phenomenon. The researcher lived the experience of the family caregivers and reflected the themes developed from the interviews. Fourth, through hermeneutic phenomenological writing, the researcher reflected on the themes through the written form and interpreted the work written in the texts. Maintaining a strong and oriented relation is the fifth point which was to be oriented within the caregiving experience texts in which the researcher has to maintain a strong, rich, and deep connection between theory and the real lives of experience. Sixth, is the balancing of the research context by considering the parts and the whole through which this study explored the lived meaning of family caregivers' contexts of caregiving. Transcriptions of the interviews were created for later coding and making notes, after which they were read and re-read several times, and going through a process of thinking and rethinking, and immersion in the data to identify the themes and categories. The data was imported into NVivo software through which several of the coding frames were illustrated, including particular caregiving experiences, personal values, certain statements, and emotions. The transcripts were coded into categories to illustrate the data. This process was used to develop the key themes and tested whether the data were consistent with the pre-assumptions and the theory. If other codes emerged during the analysis, the coding frame was added/changed. Also, all the transcripts were re-read and the digital audio recording was replayed to identify additional coding. The codes were grouped into themes/categories or sub-theme/sub-categories which were then clearly described. Narrative field notes were written up after each interview to reveal the different voices of the participants.

Themes and Sub-Themes

Themes and sub-themes of caregiving experience were discovered in the voices of the participants. There were 4 major themes and 15 sub-themes that emerged from the data. Theme 1: family caregivers' relationships were demonstrated by comments such as 'some sorts of a strong bond', 'a close personal relationship', 'avoiding argument', 'having argument', 'helped each other', and 'believed in family caregivers'. Theme 2: acceptance was interpreted in statements such as 'feeling shock', 'were worried', 'were unaccepting', 'had to accept', 'let it be', and 'acceptance of responsibility'. Theme 3: care management of family caregivers was interpreted through comments such as 'back to normal mode', 'be arms and legs for her (patient)', 'routine changed', and 'being positive'. Theme 4: burden of care revealed the physical and psychological burden, care management, and employment being affected by the caregiving experience. These were interpreted through phrases such as 'heavy-duty', 'the duty on the shoulders', 'insufficient money', and 'often taking a day off work'. These themes are shown in Table 3.4 and are described in detail in Chapters 5 to 8.

Table 3.4 Summary of themes and sub-themes

Themes	Sub-themes
Theme 1 Family caregivers' relationships	1.1: Elderly women with breast cancer 1.2: Other family members 1.3: Professional staff 1.4: Healthcare systems
Theme 2 Acceptance	2.1: Unprepared for being a family caregiver 2.2: Being together 2.3: Acceptance of responsibility
Theme 3 Care management	3.1: Adjusting lifestyle and being normal 3.2: Thinking positive 3.3: Seeking essential information 3.4: Negotiating traditional and modern medicine
Theme 4 Burden of care	4.1: Physical burdens 4.2: Emotional burdens 4.3: Financial burdens 4.4: Work burdens

Chapter Summary

This chapter has provided the methodology and method. Ethical considerations were approved, while the study design was provided in the methods section. The methods, including the data analysis process, adopted van Manen’s hermeneutic framework to consider the human experience. The following chapters describe the details of the field notes written during the interviews and interactions with the family caregivers. Following this, the findings of the study will be described in Chapters 5 to 8.

PART II

Chapter 4: Field notes: living arrangements

Chapter 5: Theme 1: Family caregivers’ relationships

Chapter 6: Theme 2: Acceptance

Chapter 7: Theme 3: Care management

Chapter 8: Theme 4: Burden of care

CHAPTER 4 FIELD NOTES: LIVING ARRANGEMENTS

Participant Profiles

The following parts reveal 22 case studies of family caregivers exploring various aspects of the caregiving phenomenon (e.g., cultural backgrounds, characteristics, beliefs, attitudes, feelings about caregiver role, and relationships). The participants' stories were based on their real situation providing care for elderly women undergoing treatment for breast cancer. All family caregivers and elderly women were given pseudonyms for anonymity.

Participant 1: Anucha

Anucha was a 36-year-old single son caregiver, who has finished a diploma degree. Anucha had no job because he left his full time job around five years ago and had been receiving financial assistance from his older sister. His older sister lived in another village with her family and provided financial assistance to him and her mother monthly. Anucha lived at home with his mother, Aoy who was diagnosed with the second stage of breast cancer. Aoy also has the following health conditions: heart disease, gout, hypertension, gastritis, and diabetes mellitus. As for Anucha's health conditions, he suffered from hypertension as a result of overconsumption of food and beverages. At first, Anucha was obviously upset when he became quite anxious that his mother had breast cancer and would eventually die. In fact, the breast cancer was discovered after she took hormones to manage menopause. However, he thought risk of breast cancer was affected by menopausal hormone. Anucha described that he did not understand how to appropriately care for his mother during breast cancer diagnosis.

When having treatments including chemotherapy, radiotherapy and hormonotherapy, Aoy felt apathetic because she had suffered from hair loss, fatigue, lost weight, vomiting and nausea. Despite this, her son caregiver did not think his mother would die from breast cancer but rather she may die from the impact of aggressive treatment, especially chemotherapy. After the radiotherapy treatment, his mother had skin in the affected breast area that appeared to be very dry and looked pale. At the time, Anucha said it looked like his mother was suffering from the HIV virus rather than breast cancer. By now, he thought his mother would surely die due to inflammation or infection because no physicians could answer him if she would recover or not. A nurse recommended him to clean his mother's wound at home. Anucha offered help to clean his mother's wound but she refused. When she cleaned the wound by herself, it appeared to be infectious and the size of the wound seemed to be bigger. On occasions, she had helped other neighbours to carry some heavy items. As a result, the wound seemed to become worse and had separated because of delayed-healing wound. Therefore, he decided to transport his mother to the public healthcare service. In his opinion, he believed his mother did not apply the ointment (a kind of Vaseline cream was used on wound after radiation) and the wound remained not healed for ten years. He just understood that daily cleansing of the wound should not be cleaned by herself and she needed to go to the healthcare service to properly receive daily wound care.

Anucha, providing care for his mother, took her to regularly see the doctor and encouraged her when she felt disheartened. When she recovered from treatments, he allowed his mother to manage her own daily routines as he felt it was important that she returned to a normal life and looked after herself. For example, he allowed his mother to perform tasks that she desired to do (e.g. housework, home cleaning, cooking and doing exercise). He realised that he should provide more assistance if his mother became ill. His mother followed the doctor's instructions and did everything appropriately when the doctor advised. Anucha reminded her to take some medicines or supplements every day. She did not need any special care as a patient in the emergency room. Recently, Anucha remained uncertain how to provide the proper care for his mother due to problems with identifying symptoms of breast cancer comparing the symptoms of other diseases such as heart disease.

Anucha had the main responsibility for care of his mother because she had no one else to help her except the family. In total, Anucha had been taking care of his mother for 16 years and he was the only one who was willing to undertake this duty. Although some people may see it was a burden on him, he did not see this care as a problem. However, there were family conflicts between the mother–son relationships in dealing specifically with issues which naturally transpired between family. Anucha and his mother appeared to be close friends as he performed daily care for his mother by 'accompanying her'. If he treated his mother as a patient, she may be unhappy. Sometimes, providing care for a loved one with illness can be financially taxing. Fortunately, he had financial support from his older sister to cover caregiving expenses.

Participant 2: Pimon

Pimon was a daughter caregiver aged 65 years. She was married and lived nearby her mother, Prajan, who was an 86-year-old living with breast cancer and was affected by dementia. Prajan lived alone after her husband died from a stroke and Pimon needed to make daily visits from her home to her mother's home while taking care of her husband and children. Fortunately, her mother's home was not too far away, approximately three blocks from her home. Therefore, it was convenient that she could visit her mother every day.

When Pimon knew that her mother had breast cancer, she felt obviously worried. In fact, Pimon really did not know that breast tumour would develop breast cancer rather than just a lump. Her mother managed to go to the hospital by herself without telling her daughter, however, her daughter caregiver had heard from neighbours. Pimon did not understand why her mother did not tell her. However, she assumed that her mother did not tell her due to not living together and did not want to disturb her. Her mother had made an appointment for an operation and after surgery, her mother's wound had healed. Other treatments that her mother received included surgery and hormonotherapy. As Prajan was too old, she was not eligible for common treatments such as chemotherapy and radiotherapy. However, Pimon said that her mother had experienced numbness around her mouth caused by hormonotherapy.

After being discharged from the hospital, Pimon carried through the responsibility of caring for her mother because Pimon stated, 'she was my mother'. Pimon also had assistance, a sister-in-law to assist her mother with caregiving tasks such as cooking, administering medication, washing and other caregiving duties when necessary. However, her mother was able to manage other tasks by herself. In regard to this, her daughter caregiver became concerned with her mother because her mother did not follow her advice when Pimon tried to persuade her to perform self-care. For instance, her mother did not prefer to have the meals prepared by daughter caregivers but rather cook for herself. The food cooked by Prajan was often left in the fridge for several days until it spoiled. Her mother kept them in the fridge and did not allow Pimon to throw them away, even though it was unsafe to consume. Moreover, her mother did not stay at home but she rather went to the temple or stayed outside. Her mother brought more some food she preferred whereas there was an abundance of old food at home. Pimon was worried and decided to see the doctor for some advice on her mother's mental health. The physician assumed that her mother acted the same as normal elderly people who displayed child-like behaviours. Pimon stated that her mother can remember some events, but other situations were not recognised. Other health conditions of her mother were stable and also she can hear, read, and write. The daughter caregiver had to monitor where her mother went outside.

Pimon performed daily personal care for her mother including bathing, washing hair and cleansing her mother's wound, as instructed by the doctor. Pimon also helped her mother to practice physical therapy exercises such as stretching her arms which helped her mother to recover well. Caregiving may have had negative impact upon the daughter caregiver's physical health. Pimon had osteoarthritis due to a tremendous amount of walking to visit her mother every day. To treat her conditions, Pimon required some medicine from the healthcare service. She was unable to walk since last year due to experiencing pain around her waist, hips, and both knees. She did not require surgery but rather had physical therapy every three days for a month, combined with taking pain medication. Sometimes she went to the clinic to have an injection for heel pain. Regarding traditional beliefs related to caregiving, Pimon took her mother to fortune-tellers and requested supernatural powers to prevent disruption of ghosts during breast cancer therapy and to stop her mother from going outside, though this was not successful. Finally, Pimon had realized that breast cancer was a common disease and the doctor can treat her mother better than traditional ceremonies/medicine. Pimon stated that 'being with the doctor relieved my tension'.

Participant 3: Daow

Daow was a daughter caregiver who was 43 years old and had finished a bachelor degree from the RC University. She had a full time job at the university nearby her home. Daow lived with her mother, Deuan who had been diagnosed with breast cancer, her father and her child. Daow was the family caregiver who took care of her mother and father at the same time whilst raising her child. Daow's father also helped her out sometimes in assisting with daily routines for her mother. Currently, the father cannot take care of her mother due to his own health condition. Therefore, all caregiving duties for the mother were provided by Daow. When the daughter caregiver knew that her mother had breast cancer, she thought her mother was affected by cervical cancer that her mother had faced for the past decade. The doctor had said that her mother’s health would be improved if the breast cancer were removed immediately. The doctor advised her mother that if the breast cancer were not removed it might spread to other organs. The doctor provided advice when the breast cancer was removed and had a 50/50 chance of full recovery. The family caregiver and family followed the doctor’s instructions and knew that the breast cancer was not a major issue when compared to experiencing cervical cancer.

Daow and her mother did not know that the breast lump had become breast cancer because it was not painful. Daow and her mother considered that the breast lump was just a cyst. A few years later, a small lump seemed hard, painful and bigger. Therefore, Daow took her mother to see the doctor and her mother was consequently diagnosed with breast cancer. Other family members and Daow gave her mother the moral support when she was stressed due to suffering from breast cancer therapy. Her mother had completed 12 courses of chemotherapy and 25 courses of radiotherapy. During the chemotherapy, her mother experienced nausea and hair loss. The first day after the operation, she was required to rest in bed. On the second day, her mother could sit up and perform her self-care that she pleased. There were no side effects from other cancer treatment, except for the chemotherapy. The third course of chemotherapy made her feel dizzy and nauseous. The doctor asked her if Daow and her father had enough money to pay for extra medication (worth 2,000 Baht (AU$ 80)), to reduce these symptoms. Then, Daow and her father accepted these terms. Deuan was then injected but still experienced side effects. When the weather was hot, her mother seemed to be moody. Other family members avoided conflicts with the mother and stayed calm when she made complaints. The mother was pleased and had provided the best supportive care as daughter caregiver can. Daow and family tried to avoid arguing with the mother because they understood this situation and accepted her associated mental health issue.

Radiotherapy was quite a complicated process and Daow had to take her mother to hospital quite often. Her duties included transporting her mother to hospitals for medical appointments. During the morning, it was difficult to find car parking and Daow feared of wasting time due to waiting for the doctor. Instead, she took her mother to the special clinic in the evening and paid 100 Baht extra (AU$ 4) and thought the cost was well worth the convenience. During radiotherapy, her mother and Daow also had to wait for long periods of time to finish radiotherapy course due to the process of treatment taking 3-4 hours. After radiotherapy treatment, her mother experienced slight burns of her skin. The doctor told Daow that she should take care of her mother’s wound carefully and not apply powder or chemicals to the skin. As for the cooking, her mother had lost her appetite, and consequently only ate very little due to vomiting. Daow provided proper meals and avoided other foods which affected her health conditions. The doctor gave some advice that her mother should not eat grilled food, preserved or pickled food.

During chemotherapy and radiotherapy treatments, her mother was required to take medication which had a cost of approximately of 200 Baht per tablet (AU$ 8). One package was around 2,000-3,000 Baht (AU$ 80-120). Her mother needed to take medication every day to prevent her skin from dehydrating. After completing the course, she had to take the medicine which costed 15,000 Baht per tablet Baht (AU$ 600). This medicine was in order to increase the bone density because her bones were severely affected by the cancer. However, the cost of medication can be reimbursed, but her father was expected to pay in advance and therefore it took time to process the reimbursements. Daow stated that medical care was expensive and her family had a limited budget. If her father was not a government officer, they may have experienced a financial strain caused by breast cancer treatment.

Daow also used Chinese herbal medicine to promote her mother’s well-being and limit the impact of breast cancer. In regards to knowledge of breast cancer, Daow described that there were no additional care needs to provide for her mother and she performed everyday caregiving tasks as per normal. The provision of care to her mother was already on the responsibility of the health professionals who had specialised knowledge. In regard to religious beliefs, Daow believed in the Buddhism religion which equipped her with positive views and developed self-confidence to have fully understood the complexity of care challenges. In addition to this, she thought that birth, ageing, sickness, and death were a part of the normal cycle of life.

Participant 4: Boonta

Boonta was a 64-year-old younger sister caregiver who cared for her older sister, Boonrod who aged 78 years suffered from breast cancer (stage 1) for three years. Boonta lived independently as she was married. However, Boonta and Boonrod had regular contact everyday due to living in close proximity to each other. Boonrod was also surrounded by other relatives who lived closer to the younger sister caregiver's home. Boonta had two sons which do not live at home, but often visited Boonta from nearby villages. Boonrod also had a son, a police officer who lived near his workplace. He cannot look after his mother but provided financial assistance to his mother every month, whilst Boonta was willing to take care of his mother rather than him.

Boonta's occupation was a freelance worker producing dolls for a private company. However, now Boonta had ceased work due to her health problems. As for her husband, he had retired from working for the government. When Boonta was interviewed, she was unable to see her older sister for a month due to having a bicycle accident, consequently breaking her right leg. Boonrod instead came to visit her every day. Her left leg had an elastic bandage on it and was required to rest. It had been a month and she was able to use a walker to aid her mobility and to minimize weight being put on her right leg. Boonta told her story about her care experiences when looking after her older sister. She stated that Boonrod was old but she was so strong and healthy. When Boonta knew that her older sister was diagnosed with breast cancer, she knew her older sister would be safe. Boonrod did not have any concerns even though the operating date for breast cancer was fast approaching. Boonta said that even though her older sister knew that she had to undergo severe disease, Boonrod decided to buy a silver bowl. This silver bowl would be used as an offering to the monks performing funerals in case of untimely death. Boonrod left the message to Boonta before she was diagnosed with breast cancer. If her older sister dies, the younger sister caregiver had to follow her wishes.

Before having the surgery, Boonrod was also diagnosed with heart disease and took medications every day. After having the surgery, Boonta started taking care of her older sister. Even though Boonrod has breast cancer, she still managed to do daily routines for herself. However, Boonta still monitored her older sister's health and prepared meals for her. Younger sister caregiver daily administered the medications in one package for her older sister. The medications were in the seven packages for a week and had the time and date written on the packaging to remind her older sister when to take the appropriate medicine. If the medications were almost finished, Boonta would administer the next packaged medications for the next week. Boonrod had regularly taken anti-hormonal medicine along with other medications taken at different days and times. Boonrod also had a regular appointment with the doctors and had a mammogram every year.

When Boonrod underwent the operation, her lymph node was completely removed and currently had not found recurring symptoms. Because of Boonrod's age, she was not eligible for treatments such as radiotherapy and chemotherapy. Despite this, Boonrod needed to take anti-hormonal medicine for five years. Boonta and her older sister do not use the medicinal herbs and decided to rely on modern medicine that costs around 2,500 Baht per time. Fortunately, Boonrod has health insurance from her son's welfare because her son was a civil servant. Therefore, all costs were reimbursed, including the cancer operation and treatments. Even though Boonta had to transport her older sister to hospital regularly for doctor appointments, she did not see this issue affecting her life. Boonta undertook all the necessary duties as a family caregiver for her older sister because there was nobody else that could assist because of other family members living in different areas. Boonta was the only relative who had a close relationship with Boonrod and therefore, the responsibility of care fell on her. Boonrod often felt lonely, but she liked watching television (especially sport) which in a way provided her with company and provided her a source of relaxation.

Boonta followed the doctors' instructions on how to prepare and administer the medication for the older sister. Boonta stated she provided minimal input to the caring for her sister due to her being able to do it by herself. Boonta selected healthy food and avoided pickled or fermented foods such as fish, bamboo and preserved vegetables that may be harmful to her older sister's health. Sometimes, Boonrod still used fermented foods in her cooking when necessary.

Participant 5: Pisut

Pisut was a 57-year-old woman who finished a primary education certificate. Her other family members consisted of a husband, two young children and two nephews. She was the principal family caregiver of her aunt, Punsa, which Pisut had been taking care of due to breast cancer for 13 years. They were not living together; however, their homes were in close proximity to each other. Pisut was self-employed running her own business at home.

Punsa was aged 73 years old and had sadly lost her own family which included a husband and a child. Therefore, Pisut was the only living relative which was able to provide care for Punsa. Punsa was in her late stage of breast cancer. In 1997, Punsa's breast had to be removed due to breast cancer and ten years later, another side of her breast was removed when she was approximately 62 years. Punsa had severe pain after an operation and few years later, Punsa also experienced pain and told her niece caregiver about stomach pain. Therefore, the niece caregiver took her straight to hospital. The pain in her stomach was due to seven stones being found in her gallbladder. At the same time, doctor discovered that she had lung cancer. As a result, she then underwent a course of six chemotherapy treatments (this process was done after breast cancer surgery). During the chemotherapy, she had no side effects from this treatment. When the chemotherapy course was completed, she was able to cycle going wherever she pleased. The niece caregiver described that her aunt had a history of heavy smoking since ages of 18 to 70 years. Even though her aunt quit smoking, the impacts of smoking caused her aunt to have a persistent cough, especially in cold weather.

Pisut performed her caregiving duties for her aunt such as taking her aunt to the healthcare service. If she were able to go, her aunt would cycle and met the doctor by herself. Pisut stated that her aunt did not want to be a burden on her. Sometimes, she would ask her son to transport her aunt to the hospital. Pisut and her aunt regularly visited for medical appointments. Pisut felt worried about her aunt as she had poor health and needed her aunt to be in a relaxed state because stress can increase cancer cells. Pisut believed in modern treatment that can treat her aunt's health if her aunt still frequently made appointments with the doctor, and then her aunt may recover from cancer. If there were no appointments made, it conveyed the message that her aunt's condition could not improve and may eventually die. The physician enquired about the older sister's health when having a doctor's visit, and the niece caregiver believed that the physical health of her aunt could be curable. In regard to food, the niece caregiver prepared healthy meals for her aunt including well cooked, fresh, and clean (uncooked food was prohibited). However, her aunt mostly had fermented fish, preserved bamboo shoots and curry in her food. Pisut was likely not to be stressed and worried about caring for her aunt. If she were serious about caring, she would not have the means to take care of herself and her own family. In fact, Pisut perceived that caring for her aunt was not a big issue because her aunt appeared well and liked being on her own. There appeared to be no complications since her aunt underwent cancer-removing operations.

Participant 6: Siri

Siri was a 37 years old female caregiver who lived with her two sons and mother, Srisai, who was living with breast cancer. Siri also had a father but he died from lung cancer years earlier. Siri had been divorced for several years. Previously, her occupation was as an assistant working for a doctor with therapeutic cosmetics. Her duty was servicing facial treatment for customers. Recently, she stayed at home and worked her own business providing customers with loans. Other relatives had moved out to take care of their own families.

Srisai had been diagnosed with breast cancer (stage 3), aged 65 years. Siri felt obligated to look after her mother and felt very sad when she knew her mother had breast cancer. Siri cried because she thought her mother's condition was incurable and that she would die soon. Srisai had completed treatments for breast cancer including surgery, chemotherapy, radiotherapy and hormonotherapy. Her mother received complications from chemotherapy and radiotherapy, especially with chemotherapy which induced vomiting, fatigue, hair loss, skin problems, and appetite loss. Srisai was fairly intolerant of the chemotherapy. As a result, her mother wished to quit this treatment before completing the course and wished to die. After surgery, Siri allowed her mother to perform housework and daily exercise in order to protect her mother's swollen arms. However, her mother's wound seemed to develop a keloid and became itchy.

Siri provided care for her mother every day which proved emotionally and physically taxing. She prepared meals and medicine along with emotional support for her mother. Her mother managed her own duties such as bathing, cooking and washing. Siri also used prickly custard apple leaves (a kind of herbs) and some Chinese herbs recommended by neighbours. In addition to this, Siri found that she had leiomyoma. Then, she applied those herbal medicines in boiled water and drank it as tea that she used for herself and her mother. She described that it could prevent breast cancer and other cancer types. However, Siri decided to use them in small amounts, after she found that some herbal medicines might lead to the liver failure.

At the same time, Siri looked after and provided care for her mother and father and her children. Therefore, she had to take leave from work for a half day to take her mother for having chemotherapy, which she received every fortnight. To make matters worse, her father was sick from emphysema and lung cancer caused by smoking. The doctor also made an appointment for her father at the same time as her mother's appointments. In addition to this, her children were still young and she had to take them to school every day. Even though Siri had a sister that could help her sometimes but she did not need to disturb her sister. Consequently, she had to quit her work because her boss made complaints that Siri was taking too much time off work and thus, she decided to quit her job. Meanwhile, Siri looked for a new job where she can have time to take care of her mother as well. Her father realised that Siri had many obligations. He decided not to see the doctor because he did not want to place additional burdens on Siri. Rather, he let his wife (Siri's mother) continue having treatment. Siri's father still kept on smoking and his conditions gradually deteriorated until he died.

Siri described that breast cancer was based on genetics. For example, Siri's grandmother was also affected by cancer but did not have an operation due to her age. Her aunt also had lung cancer and her mother's cousin had a cancer too. Therefore, Siri knew that she was at greater risks of cancer. Now, she had a cyst at her interstitial part, but it had not yet been removed. Regarding traditional beliefs, in the past two decades, local people called breast cancer as a kind of lump called 'Sarn'. When people ate something wrong, it may cause an allergic reaction through body. At that time, the local people did not realise that lumps or tumours were a cancer and they did not know how cancer could impact on their health. Her mother went to the folk doctor and performed some ceremonies using a magic formula before placing a Betel leaf (a kind of plants) on the lump. By doing this, they believed that lump could be removed. In case of Siri's mother, it disappeared for a while and then returned. The lump then gradually became bigger with severe pain. Therefore, Siri brought her mother to hospital to remove the lump.

Participant 7: Ampai

Ampai was a 47-year-old granddaughter caregiver for Aumpun, who was her grandmother (relative's husband) with breast cancer. Ampai had completed primary school and had been working at a beverage water factory near her home. There were four members in Ampai's family including her husband, two children and herself. Her family and Ampai lived in close proximity to her grandmother. Unfortunately, Ampai's husband was affected by nasal cavity cancer (second stage). In making his recovery, her husband was treated and had completed the cancer treatment course.

Aumpun was a 71-year-old grandmother with breast cancer (final stage) and had never been married. She lived with her brother who was 77 years old, and they were unable to care for each other due to their health conditions. Aumpun's brother was not in good health and had hearing difficulties. Therefore, Ampai who was a niece caregiver had undertaken this responsibility to take care of both of them. Ampai had been providing care to her grandmother since 2002 when her grandmother found a lump. Ampai did not know that her grandmother had breast cancer until she felt a hard tumour around her breast and then told Ampai. Ampai decided to take her grandmother to check her lump. The doctor said that her grandmother was in the last stage of breast cancer. Her grandmother then had treatments of chemotherapy, radiotherapy as well as anti-hormone medicine. Ampai needed to take care of her grandmother and transport her to hospital when having appointments. Her husband was unable to look after his grandmother due to being busy. The patient had breast cancer on the right side and had it removed in the last decade. In regards to cancer therapy, Aumpun had surgery, chemotherapy seven times, and 33 cycles of radiotherapy. The complications from chemotherapy affected the grandmother's health including nausea, vomiting, fatigue and hair loss. The cost of treatments had been covered by her senior care card. This card has covered all treatment expenditure except for the cost of transportation.

Five years later, the grandmother's health had improved. Unfortunately, the cancer was found again and had spread to her right lung. Ampai figured that the cancer might have metastasised due to her grandmother not being careful about her health because she continued to eat pickled food. Despite the fact that Ampai prohibited her grandmother from eating them, her grandmother stated that she just preferred to have them occasionally. Ampai suggested to her grandmother that cancer cells can still be in the body and seemed not to appear until people have low-level immunity or be non-immune. The doctor found that the lump was attached to her main blood veins which can be inoperable but she can have chemotherapy. Ampai did not know how many rounds of chemotherapy her grandmother would receive. Therefore, they needed to consult with the doctor. The daily caregiving duty of Ampai consisted of cooking meals then she returned home and took care of her children. Fortunately, the grandmother was still able to manage tasks by herself, and Ampai assisted her grandmother with administering medications, if needed. Moreover, Ampai also used Thai herbs as she learnt what their benefits might be from a book. For example, Ampai brought bamboo grass and Plu Kaow (Houttuynia cordata, Thumb), pounded, squeezed and boiled them and gave her grandmother them to drink as tea.

When taking her grandmother to the hospital, Ampai needed to hire a car to see the doctor. However, she did not have much money and hiring a car cost approximately 500 Baht ($20 AU) per day. During the course of cancer treatment for her grandmother, she had to take a day off work. Ampai said, “if I do not work and I will not get paid’’. Furthermore, “I also received some criticism from my colleagues”. Recently, her grandmother’s arms had some numbness and her legs were swollen. Ampai said “to be honest, it was the last stage for her”.

Participant 8: Decha

Decha was a 72-year-old husband and undertook a caregiver role for his wife, Daunjai who experienced breast cancer, aged 72 years. Decha finished Grade 4 from the Temple’s School. Previously, he was a farmer and worked in the rice field. Recently, he quit this work due to poor health and old age. He lived with his wife whilst his children lived nearby.

Daunjai had breast cancer since June 2014. She found a lump on her left side of her breast. At first, her husband caregiver did not know and thought it was not a serious problem. Two month later, her breast lump increased in size and was painful. Decha urged his wife to see the doctor at the government hospital. His wife still refused his advice. Therefore, he used ointment to put on her lump but it did not reduce in size. The husband caregiver then decided to take his wife to have an urgent operation. She was admitted to the private hospital because her husband thought the private hospital would provide a quicker service compared to the public hospital, but the cancer treatments were expensive. Both sides of her breasts were removed and after the surgery, his wife experienced pain and stiffness in her chest. Therefore, she needed a few days to recover. Her husband caregiver also accompanied her at the hospital and took his wife to the toilet and her wound was cleaned by nurses every day. After his wife had been discharged, he performed caregiving duties for her at home such as housework, preparing meals and cooking. Decha had to carefully think about what healthy food he should provide his wife and prepared meals such as fresh vegetables, fish and pork and avoided burnt food or overcooked meat. In the past, she ate everything, except for beef and preferred pork, fish and preserved food. Sometimes, his daughter prepared food for her mother before going to work. He asked his daughter to transport her mother to hospital. Decha had health problems such as hypertension and diabetes which are not related to providing care for his wife. He suffered from these diseases before his wife was diagnosed with breast cancer. He was not feeling well because he had knee pain. Therefore, he was not comfortable to walk.

He had no problems with financial issues. Decha said that his wife's life was much more important than money and he was happy when his wife recovered. His wife and himself would go to temple to make merits and to pray for her well-being. He did not know what caused this disease. In regards to traditional beliefs, Decha believed in some traditional ceremonies. He learnt ritual ceremonies from his grandparents and believed they could kill cancer. Decha used to perform the ritual for his wife, however, breast cancer still remained. After the surgical treatment, he did not use any magic formulas and feared her wound may be infected if he blew on her breast wound.

Participant 9: Aom

Aom was a 49-year-old son caregiver. He divorced his wife last year and had one daughter who was 15 years old attending secondary school. Aom lived with his daughter and mother, Aun, who was aged 65 years and diagnosed with breast cancer (fourth stage). Aom had worked at a hotel for more than 20 years.

Aun discovered a breast lump but she let the tumour gradually increase in size for seven years. Her son caregiver tried to encourage her to see the doctor, but Aun dismissed her son's advice. In fact, Aun was afraid of visiting the physicians due to her neighbours who died from cancer a short time after treatments. Instead, Aun requested her son caregiver to see a sharman. The sharman treated her by using holy water and magic spells and she has been treated for around 2-3 months. She believed that her breasts would be healed. The traditional ritual was not effective, her tumour became bigger, and resulted in the tumour becoming inflamed with a bad odour. His mother did not go outside to visit her neighbours. He said his mother might feel embarrassed due to the smell of her wound. Therefore, Aom decided to take his mother to the hospital.

Aun had surgery, radiotherapy, anti-hormone medicine and six cycles of chemotherapy. She had headaches, loss of hair, and loss of appetite as well as feeling fatigued due to the chemotherapy. Aom provided his mother with food and drink recommended by the doctor. The doctor suggested that Aun should drink coconut water and have bananas. Aom followed the doctor's suggestions and prepared a diet of healthy foods when his mother underwent chemotherapy. This was in order to boost her energy and keep her platelets stable. Aom's mother preferred to have self-care such as cooking and doing daily chores. In fact, she preferred to do routines by herself, as she believed she was not ill. He agreed that if he spoiled his mother too much, then she would depend on someone to look after her all the time. In most parts, she looked after herself except after the chemotherapy because she became fatigued, so the son caregiver offered to do housework for her.

The son caregiver said when he had to take his mother to the hospital, he organised the necessary work shift with his colleagues. Aom thought he had very little responsibility to take care of his mother due to her being able to look after herself. His mother was not a burden on him, and his mother was quite independent by doing her own duty. She also did not require any care from him and did not wish her son to do work for her. Aom respected his mother's decision and this can increase feelings of her self-worth. Therefore, Aom did not have stress associated with his mother's illness and still provided care for her as normal whenever she needed. He stated, "I do my job and took her to the hospital when needed to see a doctor when required". In Aom's opinion, cancer was not dangerous, if people regularly checked their health and had proper treatments. After the treatments, there were no additional costs because his mother had a senior card which covered the cost of medical care. Aom only had to pay 500 Baht ($20 AUD) for an overdue bill from staying in the patients' room.

Participant 10: Arthorn

Arthorn was a 34-year-old son caregiver of Ubon, his mother who was diagnosed with breast cancer. Arthorn finished a bachelor degree in the marketing field and had worked at a marketing firm in the city. He was married and had one son then, he moved out with his family to another area within two kilometres of his parent's home. However, he took his son to visit his mother every evening when he finished work. His mother Ubon, aged 61 years, was diagnosed with breast cancer (first stage). She lived with her husband, and her oldest 36-year-old son. Ubon underwent breast cancer surgery and also had to take anti-hormone medicine for five years. However, Ubon did not have chemotherapy due to her age. Doctors were afraid the aggressive treatments may affect her health. Therefore, his mother had 10 rounds of radiotherapy. Her wound dried up well, nonetheless, there were scars and the wound appeared burnt. She also had headaches and dizziness during radiotherapy. Ubon was able to eat as per normal, and still drank and smoked the same since she was a teenage girl. Unfortunately, Ubon had a fall in the bathroom and was required to have a walker for supporting her legs.

Arthorn was very emotional when he found out that his mother had breast cancer. He was shocked as he associated the meaning of cancer with 'death' and he was very close to his mother. Arthorn searched on the internet for breast cancer information and treatments. He constantly questioned the doctor regarding his mother's condition. Arthorn applied to a car insurance company and he was hired but he had to move to another district which was far away from his mother's home. The only other person that could look after his mother was his older brother, but his workplace was a fair distance from their mother's home. Although it would be advantageous to Arthorn with a secure job, living in another place may cause his mother to receive insufficient care. Therefore, Arthorn decided to leave this job and tried to find another job where he was closer to his mother's home. A couple of months later, his mother had the operation, he re-applied for the job at the car insurance company again but this time he was unsuccessful. He felt despair because it was a good job with a good salary.

Arthorn's caregiving duties involved providing his mother with her dietary needs. He prohibited his mother to consume alcohol, smoke and eat grilled food or any meals that were spicy or salty. Arthorn did not let his mother do much housework because he was afraid of his mother's bones being in poor condition and that she may have another fall. Six months after the operation, Ubon continued to have grilled foods when needed and she still smoked as per usual. She smoked roughly half a pack per day when nobody else stayed at home due to doing work. Everyone in family and son caregiver tried to encourage her to stop smoking. His mother often said that she could not sleep if she does not drink and smoke. Although Arthorn had never bought alcohol and cigarettes, she often got her cousins who lived next door to buy them for her.

Participant 11: Srichai

Srichai was a 64- year-old husband caregiver of Supa, who had breast cancer. He was a builder and lived with his wife. They had a son who worked in the city, stayed with his girlfriend, and visited them every weekend. She sewed clothes as her part time job. Supa was 61-years-old and was in stage 1 heading into stage two of breast cancer. After the check-up, a nurse found a lump on her breast and recommended that she should have treatment straightaway. Therefore, she had been transferred to hospital in order to have treatment. Srichai described that his wife could not cope with this situation. Supa felt weak and gave up, she was afraid of death. In the beginning of treatment, she said that her younger sister and her mother had breast cancer and that she did not want to have this experience. Srichai was shocked but continued to encourage his wife to cope with this situation. He pointed out that cancer patients they can still live for more than 10 years after treatment. Srichai could see that his wife became stronger and had the strength to do her work.

During an operation, Srichai said it was quite tough for him because his wife could not help herself and he had to care for her. After two weeks, his wife’s wound became infected, she had a fever, and her arm was swollen. Her wound became painful, red and hot. Therefore, Srichai decide to take her to the hospital and stayed approximately 10 nights where she had antibiotics. In regards to the finances, expenses were largely from travelling. However, her husband only needed to pay the additional 1,000 Baht ($40 AUD), for the staying overnight fee. Supa used the gold card welfare which covered the healthcare service.

Regarding the caregiving situation, Srichai said that there was no one else to takecare of her. Although his wife had a sister who also had breast cancer, she lived in another district. After the operation, the wound healed and dried up well. During treatment, there were six cycles of chemotherapy which included 16 cycles of radiation. The doctor found that Supa had low white blood counts, so she had to cancel the next treatments. Supa was stressed, nauseous and had hair loss. Srichai had to improve his wife’s health by giving her six boiled eggs per day to increase her blood platelets levels. Some people suggested to Srichai to buy sugary drinks, milk, liver, fruits, and coconut water to strengthen her health. For the final chemotherapy treatment, her blood platelets count was low again, but the doctor did not postpone it anymore and gave her injections to increase the blood platelets. The next day she had chemotherapy in addition to the radioactive process.

For the radioactive treatment, Supa became stressed again because she needed to have a blood test and if the result showed low blood platelets, the doctor could not progress with treatment. During the radioactive process, the machine at SD hospital was inactivate, therefore, the family caregivers had to drive Supa to a cancer centre at LP hospital (90 minutes from family caregiver's home). He took her there every day for 16 days of radiotherapy treatment. Srichai met another cancer patient's family whom had rented an apartment near the cancer centre because they could not go back and forth to and from the cancer centre to their home. However, his wife was not allowed to stay in the apartment. Therefore, Srichai took turns with his nephew and son by taking his wife to the cancer centre. When transporting the patient, Srichai left at 5 a.m. and came back at 3 p.m. and he had to cook, rather than buying food because he needed to save money. After radiotherapy process, then they drove back home. Srichai also had to be careful when she took a shower, as she had to avoid contact with water on her wound. During the radiotherapy process, the wound started to turn dark, but did not become inflamed. There was no implication and her health was getting better. She went for the health check again at the government hospital and then took hormonal drugs. Srichai was required by the doctor to take his wife to medical appointments every three months to have an X-ray and ultrasound.

Sometimes his wife patient experienced mood swings. The husband caregiver tried to understand her because he knew that she was a patient. In fact, his wife was a kind person, when her husband drank after work, she did not complain. When his wife was diagnosed, Srichai never argued with her because he was afraid that any stress would cause her health to decline. Currently, Srichai wished his wife a quick recovery and hoped for her to have a happier life. Srichai had high blood pressure and diabetes related to his drinking and stress. He controlled his blood pressure and blood glucose levels regularly by medications. Srichai and his wife selected herb remedies by using herbal leaves suggested by a pharmacist. He boiled Hoan Hoc (a type of Chinese herbs) for his wife and himself to consume every day. He also grew these herbs by himself. He used their leaves to control his levels of blood pressure and blood glucose. Srichai and Supa also had some recommendations from neighbours who had cancer that they should not have pickled fish or any pickled food.

Participant 12: Supod

Supod was a 72-year-old husband caregiver. He finished primary school (Prathom 4). He used to be a farmer but when the farming season finished, he sold dessert fruits in the local market. There were three people in Supod's family including his wife who had breast cancer and himself. He had two daughters with the older daughter being a nurse (aged 50 years) living with him, and the younger daughter who was aged 45 years, married and living nearby.

Sucha was 69 years old and being a housewife for Supod. Sucha had a tumour in her right breast in 1988 that was consequently removed. Two years later, a cyst was found on the other side of her breast. The doctor said it was not a cancer but a cyst and it was also removed. In 2003, once again, she found a tumour in her left breast. She told her daughter who was a nurse and her daughter took her for a medical check-up. The doctor found it was breast cancer (stage 3) and it needed to be dissected. Sucha stayed in the hospital around 10 nights, but there was wound bleeding, therefore, she had to stay 3-4 nights longer. After the surgery, she underwent chemotherapy for 10 cycles, but the chemotherapy process was provided at home. . Her daughter, who was a nurse, managed this treatment for her mother. In total, she had 25 radioactive treatment processes. In 2006, her breast had a recurrence of cancer and it was in the same spot as the previous time. Sucha had to return to the hospital to have surgery. Sucha then had to continue with anti-hormone medication for 5 years until 2011. After, Sucha felt tightening of the skin and sensitivity on her breast. She also had diabetes and hypertension.

During the cancer treatment, Supod took his wife to the bathroom because his wife was weak. She lost approximately 10 Kg of weight after the operation. Supod had to watch his wife until his daughter finished with her daily routines. In addition, Supod helped with house chores when his wife could not do it due to cancer treatments. The husband caregiver gave her water to drink, as some food was difficult to consume. His youngest daughter cooked at home for her mother and the husband caregiver had meals with his wife every day. Supod focussed on his wife's food and did not let her have strong flavoured food. She was unable to have pickled or fermented food such as pickled asparagus soup, which used to be her favourite food. If his wife really wanted it, then her children would complain and would not let her have it. They wanted their mother to have steamed fish, not flavoured soup. Most of the time, his daughter cooked food. Supod mostly provided emotional support for his wife. His wife also had mood swings caused by chemotherapy and she had slight nausea, hair loss and sensitive sense of smell. Supod and his other family members felt stressed when his wife made complaints. Nobody wanted to be near her when complaining. However, Supod did not think that the caring role had much effect on him. Supod said it was very important to take care of his wife because they were a couple who were married and needed to support one another. Supod previously had suffered from his own conditions including diabetes, gout, and high blood pressure. When Supod was not well, he relied on his wife to take care of him. When she had breast cancer, then Supod had to look after her. It was relying on one another and never thought of caregiving for his wife as a burden upon his family.

Supod encouraged his wife for continuous treatment. Luckily, his daughter was a nurse and helped Supod sometimes, however due to her busy work she could not devote her time towards her mother. His daughter reminded Supod and his wife that she had regular appointments. Supod and his wife did everything the doctor suggested. For medicines, on the one hand, Supod did not know much about this issue, so his daughter took responsibility to administer the medication. When the doctor questioned his wife's conditions, his oldest daughter was the only one who was able to answer the questions because it was in technical English terms. He just reminded his wife to regularly take the medication during cancer treatment. In terms of traditional medication, Supod had dried marigold flower. He boiled it for her and used picked durians (a kind of Thai herbs) recommended by a monk. He boiled the dried leaves to drink them as tea. Supod provided herbs for his wife for only a short period because he were afraid that it might affect her liver.

Participant 13: Wanna

Wanna was a daughter-in-law aged 38 years, who had undertaken the task of caregiving. She finished a diploma degree and she was married living nearby her mother-in-law's home. She was a housewife and raising two children. Sometimes, she helped her husband's business with managing finances for her family.

Wan was a 62 year old mother-in-law who had breast cancer (stage 3 going to 4). In 2012, Wan was 60 years old and found breast tumours but thought it was an abscess. Wan did not tell her family caregiver, but she had learnt the traditional ceremony from her older people about how to get rid of an abscess. She put sticky rice on her breast with a magic formula and hoped it would go away. At one point, she bought some cream and treated her breast. A year later, a volunteer from the healthcare service came to Wan's house and informed her to have an annual check-up for breast cancer. Her husband guessed that she may have breast cancer and asked her to have the check-up. Her husband had seen her breast tumour; it was the size of a lemon. He was wondering why Wan did not see the doctor or discuss with him and Wanna about this issue. Wanna said that her mother-in-law did not tell anyone because she thought it would not be a serious issue. Wanna guessed that because her mother-in-law was concerned about her son, she did not want him to be worried. Furthermore, her mother- in-law did not feel any pain in the breast and therefore, believed there was nothing wrong with her health.

Despite this, when the breast lump became bigger and developed pain, her mother-in-law then decided to see the doctor. Unfortunately, the daughter-in-law could not take her husband's mother to hospital because they had to come back to the community health service and wait for the process to transfer additional documents to the hospital. Wanna described this process as very slow, so they went to a private hospital instead. It was a special clinic and the doctor was very good. The documents were sent to the community health service and the patient was transferred to a public hospital. Wan began to have the cancer treatment process. Wan was given six cycles of chemotherapy and could not have an operation. The tumour had spread due to the doctor performing a biopsy on her breast which caused it to break up and spread. Wan had 16 rounds of radiotherapy as well. However, Wan had complications from chemotherapy treatment. She lost her appetite and had an ulcer in her mouth. It was painful and she could not open her mouth. However, Wan was mentally strong and she used medical herbs that were recommenced by neighbours. She boiled them or even chewed them fresh. By doing that, it could numb her mouth. Once, her mouth was numb she could then eat rice. Aloe vera was used to heal her mouth as well. Another herb that was used was called ‘Snow Lotus’ from Tibet. Wanna soaked them with brown sugar and water, then gave it to her mother-in-law to consume. This caused dizziness, so Wanna stopped providing it to her straight away. Eventually, Wanna went to the doctor to buy a spray to reduce Wan’s mouth pain. Until then, Wan only preferred to take the modern medicine.

During the last round of chemotherapy, Wan was unable to receive chemotherapy because of severe weakness. Wanna provided her mother-in-law with egg whites to give her a nutritious meal. Wanna went to the market and bought healthy food for her mother-in-law but did not know what she wanted to eat. She liked to eat traditional food or local food, but Wanna could only cook Thai food or soup. However, Wanna went to the market and bought whatever she wanted and kept some food for her. At the time, the mother-in-law had mood swings and she sometimes yelled at everybody and Wanna. Wanna would allow her to calm down and perform her daily routine. The mother-in-law was lying on the bed all day and did not perform self-care. Her husband gave up supporting his wife. Then the mother-in-law wanted to die, however, Wanna was willing to help her mother-in-law and encouraged her mother-in-law to perform her own self-care. It took a week before her mother-in-law could eat anything but only ate bananas and mangoes. After six chemotherapy cycles, the mother-in-law could then receiv an operation. The mother-in-law felt her skin was tight and was still in pain for a couple of weeks after surgery. Wanna used to ask the doctor about this pain and Wanna was informed that it was normal. The radioactive process did not leave lasting side effects and left just a dark spot around the breast area.

Once, Wanna asked a female neighbour who had breast cancer to come and visit her mother-in-law and share her experience and support her mother-in-law. The woman survived because she made herself happy and lived life as normal. Therefore, her mother-in-law came to visit the neighbour every day. She undertook caregiving tasks on the responsibility naturally. She said ‘this was like a natural process of sunrise and sunset and then it would be finished’. Therefore, it was not a big issue for Wanna and she just provided care for her mother-in-law as best as she could.

Participant 14: Pim

Pim was a 45-year-old daughter caregiver for Pun who lived with breast cancer. She was single and had finished a bachelor degree. She had worked at a company for seven years then quit this job to operate her own business by selling food in the university. There were nine people that lived in the same home of the family caregiver including her father, mother, younger brother with his wife, and youngest sister and husband with two young kids and Pim. Pim was the principal family caregiver because everyone else had his or her own family. Pim was willing to provide care for her mother because she felt obliged to perform care for her.

Pun, who had breast cancer (stage 1), was aged 68 years. She found her lump in her breast in 2014. However, Pun did not tell anyone and she just assumed that it was nothing serious because of a small lump. However, Pun had self-checked and found that the lump increased in size. Then, she informed her daughter caregiver and Pim took Pun to see the doctor to check her knees and also have a breast check. The doctor found that the tumour on the right breast was quite big as a result of cancer. The lump then was removed a month later (October 2015). Pun was quite stressed because it was cancer. She described to her daughter that word ‘cancer’ itself was cruel and those who had it eventually die. Pun also was nervous, and then the daughter caregiver encouraged her mother to continue to live her life as normal. Pim was not shocked and she was quite calm. She thought the cancer diagnosis was nothing serious. Pim had seen many people who were diagnosed with cancer and heard a doctor state that 90 out of 100 people were diagnosed with cancer. However, when her mother had a biopsy, Pim did not know her mother would indeed have breast cancer because the breast tumour was very tiny. Before having surgery, her mother had soursop (a kind of Thai herbs), suggested by a friend who was diagnosed with anal cancer. A friend told her that it helped the wounds dry up after surgery. The daughter caregiver then boiled it and gave it to her mother to drink instead of water. However, once she drank it all day, her throat dried up and her mother could not speak. Consequently, her mother did not want to try any herbs because she might be allergic.

After the operation, there was a bandage wrapped around her mother’s chest. It would tighten up her skin and was used to stop bleeding and discharge from coming out of her wound. Her mother would wear an artificial breast when going out. After being discharged from the hospital, the doctor had her take anti-cancer drugs for five years. As for receiving care from the family caregiver, her mother did not want her adult children to take care of her too much and treat her like a patient. Her mother said that she was not a patient and wanted to continue her life as usual. Pim said her mother did not want to be a patient. Therefore, Pim allowed her mother to take care of herself. Pim thought that it was the only way to avoid thinking about breast cancer and allowing her mother to live and perform everything as normal. She seemed happy because many friends and neighbours regularly visited and supported her. She also still cooked for the daughter caregiver every day. Normally, her mother took care of her own self as she loved to cook for everyone in her family. The daughter caregiver did help with chores because her mother could not lift heavy things. The daughter caregiver and her mother learnt how to live with breast cancer. Pun's mental state was stable because she read religious book, continued going to the temple, and made offerings to monks. Pun learnt that the body was a host and cancer stayed too. Once people die, cancer would die too.

Whilst her mother stayed in hospital, Pim was unable to work and had to close her food shop in the university to visit her mother. Luckily, it was during semester break, Pim was not required to sell her food at the university. When the university was re-opened, Pim had to work and at the same time had to take care of her mother. At night, Pim looked after her mother all night. In the morning, before going to work, Pim prepared meals for her mother and prepared food to sell. Then, she would go to work. In the afternoon, Pim quickly returned to see her mother whilst her younger brother assisted her with selling food. Pim's family registered with the healthcare service who had a partnership with charity project which helped patients who may need assistance with healthcare expenses. People who were registered had to deposit one Baht per day ($0.04 AUD) and the charity would help out with cost of a private room in the hospital for 10 nights (100 Baht for each night ($4AUD), and 200 Baht ($8 AUD), for transportation). Her mother could then reimburse this cost, so there was no issue with finances. However, Pim had to make the payment first before she could be assigned to reimbursement.

Participant 15: Suratin

Suratin was a husband caregiver aged 71 years, caring for Su, his wife who was diagnosed with breast cancer. He lived with his wife and his son. Suratin finished primary school and worked at the market by selling fried chicken. His son aged 35 years, was a freelance builder and fixed houses.

Su was a 61-year-old wife who had breast cancer. She helped her husband selling food. A couple of years earlier, Su found a breast lump but she assumed that it was a small cyst. In August 2014, she found a couple of lumps on her left breast when she was 60 years old. A few years later, it kept growing and his son informed his father that he should take her to see the doctor. During the biopsy, a young doctor trainee said that it was a normal tumour and it may not be a cancer. Therefore, Suratin and his wife did not think it was a serious problem. After the biopsy, another doctor informed Suratin and his wife that she had breast cancer in stage 3. They were confused because the younger doctor just said it was nothing at first. His wife then began the treatment process and had chemotherapy for three cycles to reduce the size of the cancer then she would have surgery. The husband caregiver needed Su to quit her job and stay at home since she had undergone breast cancer treatment. Since then, his wife was carefully being attended to with care provided by Suratin and they took care of each other. His wife did not have any relatives because they had passed away.

His wife was in pain after surgery. However, there was no infection. The nurse cleaned her wound every day. When his wife had to have chemotherapy, she was very concerned. She had dizziness, vertigo, body aches, and nausea. She had radioactive therapy 29 times and took anti-hormone drugs for five years. During the radioactive process, her wound was burnt, scarred and contained some fluid. Suratin took his wife to the community health service to clean her wound every day, until it dried up. Unfortunately, the radiotherapy machine was non-operational. Therefore, he had to take her to a cancer centre for the radiation treatment which was far from his home, requiring two hours of driving. Suratin had to rent a house there for his wife and brought his wife back home when she finished the course of treatment. Suratin took her to the rental home and he returned home to work. It was quite difficult at the time because he had to work and then see his wife in LP cancer centre. Suratin went there once a week and took some money to her for cost of living.

Suratin had to pay for the caregiving costs which included transportation, petrol, and food. Sometimes, he asked his grandchildren to drive him to visit his wife and would compensate them for food and petrol. Suratin felt the financial strain because of caregiving. He lost some income when he closed the shop to take her to the hospital. However, he had no financial reserve, but he managed the best he could. He sold some items to earn more money to support his wife when she had treatment. Sometimes, Suratin borrowed money from his friends from work and then would duly pay them back. His son helped him from time to time. Sometimes, he asked his son to sell stuff at the market while he took his wife to the hospital. Luckily, there was no special payment for cancer treatment because his wife had a senior card. When his wife had the finished treatment course, she managed to do house chores, cooked and did laundry for her husband caregiver. Nevertheless, Suratin did not allow her to go shopping due to her low immunity. His wife believed him and followed his advice. Since she has had cancer, they never argued with each other and understood each other through compromising with each other.

Suratin provided nutritious food for his wife such as brown rice, fish, meat and sometimes only fruit which cost almost 200 Baht ($8 AUD). He bought bird nest, soya bean drink for her. She often liked unhealthy food, such as pickled asparagus, vegetables, and Thai anchovy. However, she could not eat these types of food because Suratin was concerned that her condition might worsen. Suratin also provided Chinese herbal medicines and herbal leaves to maintain his wife's health. She ate Chinese herbs, tea and it appeared to help with cancer, blood pressure, and diabetes. They came in capsules (one box costs 350 Baht ($14 AUD)), which Suratin bought from the traditional drugstore. His wife took two tablets per day. He also grew Jiew-gu-lan (Chinese plants) to boil and drink sometimes. For the traditional beliefs, he did not use black magic. He commented that some fortune-tellers said to him that breast cancer was from past karma and they had to do merit making to dispel karma.

Participant 16: Ann

Ann was a 50-year daughter caregiver for her mother, Ao who lived with breast cancer. There were five family members including two daughters, husband and Ann. Her husband worked at a company. Ann finished high school then she applied to study a nurse assistant course and worked at the hospital for ten years. Ann said that her husband and herself worked hard, often doing many night and day shifts. There was no one to take care of their children and they both worried about their children. Therefore, she quit the job as a nurse assistant and opened a laundry shop in her own home in order to look after her children.

Ao was a 78-year-old mother. She lived with her husband who had a hearing problem (500 meters from daughter caregiver's home). She had her own business in the market. Ao discovered a breast tumour but she thought there was nothing wrong and did not want to see the doctor. Ao believed that she was very old and the doctor may not be able to treat her. When Ann knew that her mother had a breast lump, Ann took her mother to have a mammogram. The result found that her mother had breast cancer (stage 2). Unfortunately, the doctor found that two tumours had spread to the lymph nodes. Therefore, her mother had to have surgery immediately. Ann supported her mother by discussing with other cancer patients at the hospital what would happen. After surgery, her mother received 17 cycles of chemotherapy and five years of hormone therapy. However, her mother had pain after surgery. She experienced fatigue, decreased appetite, nausea and vomiting.

During the time that her mother had chemotherapy, Ann provided her mother with food and drinks. She gave her five boiled eggs, coconut and fruit juice, and sour orange every day. Ann received useful advice from her volunteer friends in the hospital. Her friends received training on cancer and advised her when she needed. Ann did not use herbal medicines because the doctor did not recommend it and believed it may impact on the effectiveness of the cancer therapy. Ann had to leave early to wait all day for the doctor in the hospital to give chemotherapy to her mother. Ann had accompanied her mother until the process was completed that day then she took her mother home. However, Ann did not think of caregiving placing a burden on her even though Ann also had to take care of her children. There was no impact from this caregiving journey because the cancer patient was her mother. Ann said she would continue to take care of her mother until one of them dies. Her mother did a Mammogram every six months and no abnormalities were found. As for cancer treatment expenses, it can be reimbursed because Ann’s older sister was a civil servant but Ann had to make the advanced payment before being reimbursed.

Ann was worried about her mother’s health even though her mother was getting better. Ann and her mother had some family conflicts because her mother did not follow her advice about looking after her own health. Ann advised her mother to stop eating pickled food and meat, but sometimes her mother did not follow this advice. Therefore, Ann had to control her mother’s diet. Moreover, Ann was worried about her mother’s exercise routine. The doctor suggested that her mother should not use her bike, but her mother insisted on doing so. On one occasion, she injured herself and had to see the doctor for two months to treat her bones. Ann had to take time off from work to take care of her mother again. Unfortunately, Ann started to have a lump on her breast. Her breast tumour was on the right breast and it had gone away by itself. After her mother had an operation, Ann's tumour turned up on the left breast, but the doctor had not properly diagnosed it and had set an appointment to meet Ann every 6 months for a mammogram. Ann thought that she might have cancer and that it may come from her family's genetics.

Participant 17: Lapa

Lapa was a 36-year daughter-in-law of Rattana, who had breast cancer. Lapa had finished her diploma degree and she was a housewife helping with her husband's business. However, Lapa and her family lived with Rattana for more than 20 years, until Rattana had surgery due to breast cancer. After her mother-in-law had recovered, Lapa and her husband moved out to a new house. Despite this, Lapa still visited Rattana every day.

Rattana was a 67-year-old who was in her first stage of breast cancer. Her occupation consisted of selling vegetables at the market. Two years ago, she discovered a breast tumour and decided to see the doctor at the local healthcare service. At first, nobody in her family knew what the tumour was. A week later, Rattana was diagnosed with breast cancer and had an operation in conjunction with the plan on the hormonal medication for five years. Lapa took on the caregiving responsibilities for her mother-in-law. She took her mother-in-law to hospital for cancer therapy and visited the doctor to check her health. During her stay in hospital, Lapa cooked food and visited her mother-in-law every day. Sometimes, when Rattana wanted something, Lapa would go and buy it for her. After being discharged, her mother-in-law had to rest at home for approximately a week, Rattana then returned to selling vegetables. Lapa said her mother-in-law was so strong and she preferred to do gardening.

Lapa and Rattana do not talk to each other as much as they did when they lived in the same house. Lapa was not worried because she did not get along with her mother-in-law. However, Lapa would not abandon her mother-in-law, despite them not seeing 'eye to eye'. In addition, it appeared that her mother-in-law did not appear to love her son. She raised him but often put constant pressure on him to do things that she wanted. Rattana re-married again because her ex-husband passed away. Therefore, her son no longer needed to have a close relationship to his mother. Lapa did not want to argue with her mother-in-law because her husband would be in a difficult predicament, as he did not want to choose sides or show bias.

Even though Lapa may not like her mother-in-law, Lapa still was willing to take care of her because Rattana also took care of Lapa when she was ill. Lapa said, ‘we must take care of one another and did our own responsibility. I am her daughter-in-law and it was not wrong if I do not take care of her, but it is not right either. I love her son, so I should love his mother too’. Sometimes, caring for someone was quite stressful as it was for Lapa, when looking after Rattana. Lapa wanted to please Rattana and often it caused conflicts no matter what she did. During the caregiving period, in the morning, Lapa provided Rattana with food. When Lapa returned home, she assisted her mother-in-law with daily chores such as sweeping, mopping the floor and cooking. Helping Rattana with household tasks was short-lived until Rattana felt better. When Lapa and her husband moved out, Lapa still visited Rattana (Lapa lived within a radius of about 10 kilometres from Rattana’s house). Sometimes, Lapa would call Rattana to inform her if she could not visit her. However, Rattana was not a burden on Lapa because Rattana could take care of herself. Lapa thought that some other patients who were very sick might be bedridden, but her mother-in-law was not like that. Sometimes, Lapa gave money to her mother-in-law because she did not have a steady income. Rattana also assisted Lapa and her husband when they were financially unstable as well. Lapa and her husband also bought Rattana biomedicine imported from overseas to promote her health. This medicine was used as a spray, administered under the tongue. The medicine, containing four bottles, cost more than 10,000 Baht ($400 AUD) with the intentions to slow down the ageing process, as well as providing antioxidants to treat her diabetes and breast cancer.

Participant 18: Prakit

Prakit was a 61-year-old husband caregiver. He finished primary school (Phathom 4) and worked at a hotel as a chef for more than 20 years. Since retirement, he operated his own business (food shop) in his home area. Recently, Prakit lives with his wife, daughter, son and nieces.

Prang was a 63-year-old wife who was diagnosed with breast cancer on her right side since 2004. She has completed cancer treatment including surgery, chemotherapy, radiotherapy and anti-hormone drugs. There were no side effects from the chemotherapy or other treatments. A year later, Prakit took Prang to have a check-up at a private hospital because she had back pain. She had an X-ray and found a tumour on her left breast. The doctor said it was in two spots and that it had spread to her lung. Therefore, she had an operation on her left breast on the same day. Prang had been treated with six cycles of chemotherapy. Prakit and his son took it in turns to take care of her and regularly met the doctor every month. While having chemotherapy, Prang was affected by the treatments and had to stop due to her body being weak. She lost her appetite, had a low white blood count and suffered hair loss. She also had her bones checked because the doctor was concerned that the cancer may have spread to her bones. She was not given radiation but received hormonal drugs. She also had kidney calculi but was cured by the operation.

Prakit was quite shocked that his wife had breast cancer reoccurrence. After surgery, he took care of his wife on a daily basis. She had healthy foods which included vegetables, fruits, and fish which were quite nutritious. Prakit did not allow his wife to have unhealthy food such as rare meat, pork, beef or fermented/pickled food, Thai anchovy juice, and crab juice. He did research on how to treat his wife. His colleagues also gave some advice as to what was appropriate or not appropriate for someone with cancer. Prang also was treated with traditional Thai herbs such as Ya Nang leaves, Manoon leaves and Pandan leaves, which were recommended by elderly people that Prakit knew. He also grew those plants and used them as ingredients in foods and drinks. He said it could fight off cancer. Prakit and Prang had a social welfare card to cover the cancer treatment cost and would be reimbursed later. Sometimes his wife was moody because of chemotherapy. Prakit said that his wife was a kind person, and even if she was angry, she did not yell at him. The husband caregiver also stayed calm and knew when she was moody. He did not want to lash out at her either; otherwise, it caused conflicts. As they were together, they had to understand one another because of love. As for religious beliefs, Prakit and his wife had prayed to support her emotional health. During diagnosis, Prakit prayed for her to bring her life some luck. Recently, Prakit had eye problems as his eye vision was not clear. He saw blurred pictures and at times he could not see anything.

Participant 19: Aumara

Aumara was a 60-year-old caregiver to her older sister Arunya. Aumara and her older sister lived in the same house with Aumara’s husband, niece and nephew. Aumara completed secondary school and was a housewife to her retired ex-sailor husband. Aumara had two daughters who were married living elsewhere, whilst Aumara and her husband raised their niece and nephew. Arunya was diagnosed with breast cancer during the end of the year in 2012. She found a breast lump under her arm and visited a doctor then had a biopsy. As a result, Arunya had breast cancer (stages between two and three). Aumara was shocked when she knew that her older sister was sick because her older sister was usually a healthy woman. She and her older sister thought that it only was a lump or an abscess. Arunya required three cycles of chemotherapy to reduce the size of the tumour before surgery. After surgery, Arunya received another three cycles of chemotherapy along with radiotherapy. She had side effects from chemotherapy which included a sore mouth, loss of appetite, and emotional effects.

Aumara said that they had misunderstandings on some issues during caregiving. For example, Aumara advised her older sister as to how to maintain good health. Her older sister did not take on her advice. Therefore, Aumara always reminded her older sister to keep taking the medicines and followed the doctor’s instructions that had been suggested. In addition, Aumara focused on preparing special meals for her older sister including vegetable soups but her older sister did not like them. Arunya used Gynostemma pentaphyllum tablets (Chinese medicine) as a supplement to treat her older sister. She had heard from neighbours that it could improve health as it contained anti-cancer properties and provided relaxation. Aumara did not have the money to hire other people to provide assistance. Therefore, they would take care of each other, Aumara said that ‘it seems like my older sister took care of me more than I did care for her’.

During the caregiving stage, Aumara also was stressed concerning her daughter who had HIV from her ex-husband and moved out to another province. She was concerned with her daughter’s health and tried to advise her how to manage her symptoms, but her daughter did not listen. Aumara also dedicated her time to volunteer for the community as it reduced her stress levels caused by family issues. Personally, Aumara had her own health conditions such as congenital heart disease. In fact, Aumara was concerned that her second daughter had heart disease as well. Aumara felt upset that her family had serious health issues such as HIV, cancer, heart disease and her grandchildren having low immunity and being overweight. She felt these issues should not happen, but even though they were ill, they still can help themselves and not be a burden on her.

Participant 20: Sirimas

Sirimas was a 55-year-old female caregiver of her older sister, Supata. There were six family members within two households living in the same area. Sirimas lived in the same home with her older sister. Sirimas finished high school and worked as a vendor in the market with her older sister. Her husband worked at the garage which was his own business.

Supata was a single, 69-year-old female who had breast cancer. As she had menopause, she had to take menopause hormones for several years. When she was 60, she found a breast lump on her left side of her breast. She decided to go to see the doctor and found that she had breast cancer (stage 1). However, Supata was shocked and very emotional. She cried because she was scared to die. Supata had surgery on her left breast and then was required to take anti-hormone medication for five years. The doctor made regular appointments every six months for five years until she finished the hormonotherapy. In addition to this, she was required to have ongoing check-ups for her blood pressure and have annual breast examinations.

As for the caregiving experience of Sirimas, she said ‘we looked after each other and we were working and living together’. Sirimas was the closest relative to her older sister. When Sirimas knew that her older sister was diagnosed with breast cancer, Sirimas was not afraid because she was familiar with this experience as she had a cyst and had treatment. Even though her older sister needed more time to make up her mind, Sirimas believed surgery should not be postponed as cancer could kill her loved one. Therefore, Sirimas needed her older sister to be treated as soon as possible. Sirimas kept supporting her older sister and stayed with her when she had surgery. After the operation, Sirimas went to support her older sister every day. She helped her older sister with providing personal care routines including bathing, showering and toileting. Furthermore, Sirimas administered daily medication for her older sister. Sirimas prepared herbal drinks for her older sister and herself such as centella drink, ginger, black mushroom and bamboo. Sirimas and Supata also encouraged and supported each other to share their daily activities and did some exercises at home. Sirimas cooked for her older sister and they ate together. They have been sharing their daily activities together since Supata has had breast cancer. Sometimes, Sirimas asked her husband to transport her older sister to see the doctor. Sirimas understood that a person who had cancer treatment experienced mood swings. Therefore, her older sister can easily be upset and sometimes was hot tempered. Sirimas had to keep calm and support her emotions. As for spiritual and religious beliefs, Sirimas did not have any such beliefs but did believe in the power of healing of modern medicine. However, Supata meditated at the temple every Saturday to keep herself calm.

Sirimas had four health conditions including diabetes, blood pressure, high cholesterol, and anaemia. When she was 18 years, she found a cyst on her breast. She went to the hospital and had it dissected. Sirimas thought that women in her family have large breasts, which was a big risk factor for breast cancer.

Participant 21: Suchada

Suchada was a 70-year-old single female caregiver to her younger sister, Sai who had been diagnosed with breast cancer. Suchada had been providing care for her younger sister for six months. Suchada lived with four people in a home consisting of a younger brother, younger brother's wife and his daughter and Sai. Suchada completed primary school and operated a local restaurant with a family member. Her family members and Suchada had been selling food during the evening time from 4 p.m. to 8 p.m. They closed early and re-opened the next day at 9 a.m. until 2 p.m. They used the break to prepare and cook more food. This had been their daily routine for approximately a year.

Sai was a 60-year-old single female who was diagnosed with breast cancer. She retired from being a teacher in another province but then returned home and assisted in the restaurant with Suchada and her brother. Sai did not know that she had cancer but she found a lump when she had a shower though it was not painful. Therefore, she assumed that it was just a lump. Her friend advised her to see the doctor. Sai then found out that she had stage 2 of breast cancer in her right breast. She then had an appointment to have an operation. She was required to have health checks before having an operation due to her health conditions which included high blood pressure, diabetes, high fat levels, heart problems and obesity (weighed 90 kilograms). The doctor dissected her right breast, as well as lymph nodes. Before she had an operation, she started to exercise daily. After surgery, she had no complications but she had a dry throat and had discomfort due to some pain. Sai did not undergo chemotherapy or any other treatments and just had anti-hormone medicines for five years.

Suchada provided care for since her younger sister had surgery and stayed in hospital. Suchada was willing and took on this caregiving responsibility because she was her younger sister. Suchada said, ‘I am her older sister, so I have to feel calm around all of my younger siblings’. There were some impacts at the beginning of caregiving. Suchada had to stop her work to visit her sister in the hospital whilst the other family members sold food in the morning. Suchada reminded her sister to take medicines every day. Sometimes, her younger sister forgot and therefore, Suchada had to remind her regularly. Suchada also had to help her change her clothes and wrap the bandage around her breast and also prepare meals for her. When Sai went to see the doctor at the hospital, she felt bored because there were many people from different places. She felt uncomfortable and did not want to go to the hospital again. Suchada told her sister that it was not possible and she had to attend her appointments twice a month. Her younger sister did not use any herbal medicines and focused on modern medicines, as her doctor suggested. Suchada had high blood pressure for 10 years resulting from stress, so she had to take medicines to stabilise her blood pressure. Suchada did not think that providing care for her younger sister was a burden to her. She stated she did not provide much care because her younger sister could take care of herself. Recently, Sai could do personal care by herself. Moreover, her sister does help out with cooking and selling food in the evening.

Participant 22: Siriluk

Siriluk was a 55-year-old daughter caregiver. She had divorced and had no children. Siriluk completed primary school and sold vegetable and eggs in the market. She lived with her mother and older sister. Her older brother lived at another home nearby with his family. Her older sister had eye problems from her work. Therefore, her older sister left her job and just stayed at home.

Jai was an 80-year-old mother who had breast cancer. Her husband passed away in the last ten years due to diabetes. Jai had breast cancer since 2014 which had to be dissected. At first, Siriluk did not know her mother had breast cancer because her mother did not tell Siriluk. Instead, her mother told the neighbours that she had an unknown tumour on the right side of her breast. Siriluk found out two months later when the neighbours told her. Therefore, Siriluk brought her to the hospital when her mother had an appointment as she had diabetes; there her mother would have a breast examination as well. Siriluk recognised that she did not feel good when her mother had cancer. Siriluk understood that her mother did not tell her because she did not want her daughter to be worried. On the other hand, her mother needed to consult with neighbours because she was concerned about her health. Jai finished the cancer treatment including surgery and took anti-hormone drugs for five years. The doctor considered that chemotherapy and radiation were not suitable for a female aged 80 years and older. After the operation, there was liquid leaking from her wound. When her mother was discharged, Siriluk kept cleaning her mother's wound as demonstrated by a nurse. Siriluk cleaned her mother's wound every day in the morning before she went to work. Siriluk was afraid the wound would be infected but fortunately, there was no infection. The doctor set a medical appointment every three months until her wound dried up. In addition, Siriluk helped her mother to change her clothes and did her mother's laundry. She helped her bathe and she was very careful of making sure her wound did not get wet. Siriluk provided her mother nutritious meals including vegetables, fish but no beef, chicken, or pickled/fermented food. Her mother could look after herself and could organise and administer her own medicines. Siriluk described that everything was back to normal and things were just difficult at the beginning. Besides, her mother had other health conditions including diabetes, cholesterol, and arthritis. Therefore, her mother used a walker to support herself, as she could not walk. Siriluk transported her mother to the hospital for a doctor's appointment regularly. Regarding the healthcare service system, Siriluk was not satisfied because there were many patients. However, it was understandable and Siriluk came to realise that she would lose one day of work. Currently, her mother can barely hear, so she does not listen to whole conversations which sometimes caused arguments because her mother did not understand what Siriluk tried to explain.

Siriluk thought that the caring for her mother affected her daily life. However, Siriluk was unable to leave her mother, but she had to work. Siriluk cannot take care of her all the time. However, Siriluk would not hire anyone because her older sister can sometimes manage tasks on her behalf, when she went to work. However, her older sister could not provide care for her mother at all times because she had a problem with her eyes. Her brother could not help much either, but if it was necessary then he would. Siriluk said she could not be sick and she had to stay strong. She ‘sighed’ a lot when she was stressed, which became her habit. Siriluk stated that the caring role affected her work when she took her mother to the hospital and she would lose income as well. Siriluk was a quiet type and she thought too much. She felt she could not tell anyone about her issues and could only discuss issues with her older sister.

CHAPTER 5 FAMILY CAREGIVERS' RELATIONSHIPS

This chapter presents family caregivers' relationships, describing a sense of the relationship between family caregivers and other parties, including elderly women with breast cancer, other family members, professional staff, and healthcare systems. Fauth et al. (2012) revealed that close relationships within the family create positive consequences of caring for other family members. Relationships are associated with both physical and emotional aspects of well-being. Family caregivers’ relationships in this study refer to the different types of relationships that family caregivers have with individuals during their role. The first sub-theme shows family caregivers’ relationship with elderly women with breast cancer in relation to caregiving. The second sub-theme describes the relationship between family caregivers and other family members related to assisting family caregivers with activities. The third sub-theme presents family caregivers’ relationships with professional staff concerning guidelines and advice on patient care. Finally, the fourth sub-theme reveals family caregivers’ relationship with healthcare systems where family caregivers deal with medical care services (Figure 5.1).

Theme 1: Family Caregivers’ Relationships

This theme relates to perceptions of relationships between family caregivers and other parties, including elderly women with breast cancer, other family members, professional staff, and health service systems. Sometimes, relationships were positive and sometimes they were negative or that the relationships were different through the care experience. Family caregivers had a closer relationship with elderly women than other family members who had not developed close relationships. Elderly women trusted and believed in family caregivers who took care of elderly women’s physical and mental health and well-being. The relationship between them created a positive view of maintaining the quality of care for elderly women. However, family caregivers involved in the life of the cancer patient, which is engaged the life did not give him/her the time to adjust their lifestyles and health patterns to provide caregiving tasks including doing house chores, transportation, shopping, and cooking. The family caregivers' emotional, social, financial, and practical necessities often remain unrecognized and unmet (McDonnell et al., 2019; Stolley, Sharp, Wells, Simon, & Schiffer, 2006).

In some cases, family caregivers reported that elderly women might not believe in family caregivers' suggestions. Family caregivers motivated elderly women to achieve physical self-care; nevertheless, patients often refused to follow family caregivers' advice and preferred to manage their physical health based on their knowledge and attitudes. As a result, several suggestions on cancer care were rejected by patients. Family conflicts among other family members can occur when they have different views on caring, which may have an impact on building positive relationships. The relationship among them may deal with the changes in their new caregiving role as a family caregiver. These disruptions in role or lifestyle led to communication challenges and conflicts.

Relationships between family caregivers and other family members were related to physical and emotional assistance. The pattern of the close family/relatives is shaped by social relations through family work (Lindenmeyer, Griffiths, & Hodson, 2011). Other family members may help family caregivers in relation to family activities but some members might be unable to or cannot help for all requests because of their obligations. Where extra help was required, relationships with professional staff were built up through providing advice and support processes. These relationships were able to help family caregivers to apply and perform appropriate care for their elderly women. Family caregivers perceived that elderly women would recover if they had been treated by doctors. Nonetheless, insufficient information and poor communication between family caregivers and professional staff may affect the quality of care. Family caregivers of breast cancer patients were more likely to engage in information needs on cancer therapies, understanding clinical trials, survival chances, causes and effects that impact upon their quality of life associated with daily activities (Adams et al., 2009). Accessibility and equality in the healthcare system were an important factor that enabled family caregivers to reach services and medical care for elderly women. The relationship between the healthcare system and family caregivers, therefore, may be considered as a negative relationship if inadequate services are available. For example, an error of a radiation therapy machine, and failure to properly inform the family caregivers, which can lead to delay in medical treatment.

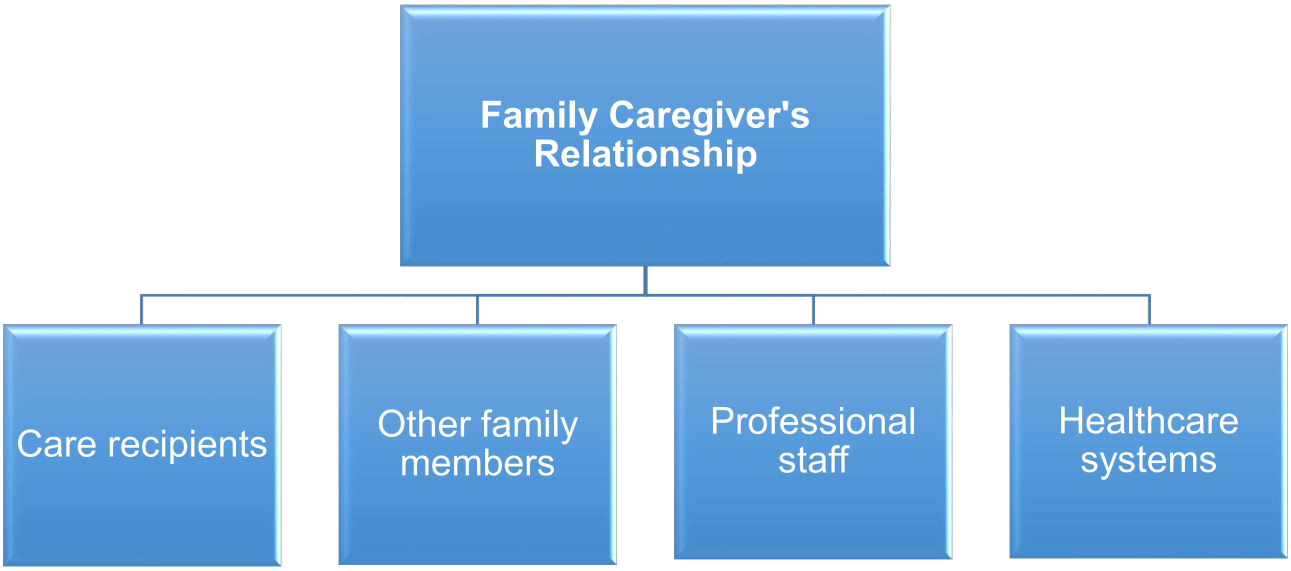


Figure 5.1 Family Caregivers' Relationships

Care recipients

This sub-theme reflects the relationship between family caregivers and care recipients (elderly women with breast cancer) in relation to how they deal with the caregiving, maintain relationships, and avoid possible conflicts between them. There were positive and negative aspects of caregiving in the carer-patient relationship (Bachner et al., 2009). The finding showed that family caregivers sustained positive relationships rather than negative relationships in order to maintain the physical and psychological well-being of the care recipient. However, some relationship conflicts occurred and were mostly derived from personal relationships related to caregiving, while few conflicts were reported by family caregiver in relation to the decisions-making process about the patient's cancer treatment. The interview revealed more than half of those family caregivers describing conflicts. On the other hand, in some cases, caring for care recipients helped improve relationship balance and reduce conflicts between the family caregiver and patient.

Lapa presented positive consequences of providing care to her mother-in-law. Lapa who was a daughter-in-law caregiver built up a closer relationship during the caregiving period between her and her mother-in-law. In the first instance, she struggled in the relationship as she did not fully respect her mother-in-law because of her personality. Her mother-in-law made several complaints about Lapa's caring performance. However, Lapa did not leave, she stayed calm and avoided arguing during face-to-face situations. Sometimes, Lapa kindly asked what her mother-in-law required and offered assistance. Ultimately, positive caregiving improved the family caregiver-patient relationship because Lapa became more attached to her mother-in-law than her own mother.

> *"I do not think there was any negative impact. It was even better that she changed into calmer person… At least there was some sort of bond for example when I came to see her and she was not there, I felt concern and called her right away. I needed to know where she was and what she was doing. If she were fine then it was good, but when I met her face to face, I did not talk much and just kept calm. If she was not there or did not pick up the phone then I will ask whether she was okay. If she was then that was it… Even though I did not like it, I still have to take care of her. It is the bond because I have been with her more than with my own mother. (Lapa, a 36-year-old woman, unemployed, caring for her mother-in-law)"*

Prakit experienced both positive and negative effects on the relationship regarding providing care to his wife. He stayed calm when his wife underwent treatment that affected his wife's emotions. Sometimes, his wife was angry with him during the care process. Prakit had a hard time dealing with negative emotions in the close personal relationship between husband and wife. However, he encouraged her to cope with the difficulty of complications of cancer treatment. He maintained the strength of their relationship by reducing his tension along with avoiding arguments. He pushed her to fight against the disease and cope with adverse reactions from the chemotherapy.

> *"Sometimes she got angry but she did not showed it. I stayed calm and knew when she was moody. I did not want to lash out at her either; otherwise, it will be 'get out of hand'… I had to tell her to fight and had to face the cancer. Nobody wants to be with the cancer, but if we already got then we had to fight. Fight until the end even though sometimes it would so tired, very tired… I tried avoiding the part where we disagree and try to be nice to her. When we were argued, it could bring her down or depress and could stop her from keep going. …. we have to keep battering the disease, such as if she has appointment for chemotherapy tomorrow, I tell her to fight. (Prakit, a 61-year-old man, employed, caring for his wife)"*

Negative emotional consequences can be drawn from arguments about appropriate patient care. Most family caregivers would like elderly women to follow the doctors' advice for preventing recurrence of breast cancer such as healthy eating and quitting smoking. However, some elderly women did not obey the guidance of medical practice. The current study showed that half of those family caregivers came into conflicts that arose from different views of care between cancer patients and family caregivers. Some patients had many physical health problems caused by personal behaviours that can increase a chance of recurrence of breast cancer and they ignored family caregivers' suggestions on how to improve physical and mental health. Arthorn explained that his mother did not stop smoking and alcohol drinking after the diagnosis and treatment of breast cancer.

His father and him tried to help her quit alcohol and cigarettes but were sadly unsuccessful.

> *"I can only advised her to smoke less, but she did not believe me. Everyone at home tried to stop her including my father but she did not listen. She often said that she could not sleep without drinking and smoking, but I thought it was an excuse… I have tried every way. She is stubborn, but as you know, I work during the daytime too and I am not with her all the time. By the time I arrived home, it is already evening. I have seen that others relatives bought her alcohol and cigarette. Everything was done before I arrived.… Everyone like to please her, if she can stop smoking then it would be the best. I tried to stop her, tell her off, but she was not listen. She is stubborn and the more I complain, the greater amount she have them. She hid her drinks and cigarettes. (Arthorn, a 34-year-old man, employed, caring for his mother)"*

Ampai was concerned that breast cancer can be recurrent and suggested her grandmother avoid some food that can increase the risk of breast cancer. Ampai suggested to her grandmother that cancer cells were embedded in the human body and will not appear if we have a good immune system. For a few years, grandmother's health improved after treatment because Ampai encouraged her to have a healthy diet that maintained her condition. However, grandmother tried to debate that some food did not affect the risk of breast cancer and she preferred to keep having her favourite dishes that the doctor advised her to avoid. A few years later, the health condition of Ampai's grandmother went wrong with the recurrence of metastatic breast cancer.

> *"During 2003, her condition was improved. Afterwards, she started the same eating habit despite the fact that I suggested her avoid eating it. She said that she wanted to eat it and it was alright as she was fully recovered. I told her that cancer was still in our body and it did not appear at that time. It depended on immunity of each person. If she has no immunity, so the cancer will spread. However, she was still stubborn. (Ampai, a 47-year-old woman, employed, caring for her grandmother)"*

Other Family members

This sub-theme refers to the relationship between family caregivers and other family members regarding the availability of assistance from other family members when needed. Family caregivers and other family members provided care for the patients and also support each other during caregiving. In describing this situation, family caregivers were the principal carers, while the other family members were temporary family caregivers assisting when needed. Family caregivers felt more comfortable and safe if a person in their family could understand what the patients needed and what family caregivers required under their family environment. Family caregivers described that other family members can provide more appropriate care than a paid caregiver. They have daily plans and divided time to take care of patients and help each other when someone is not available. Tasks that other family members could help family caregivers with included daily care routines, personal care, housework, medication reminders, and medical appointments, as well as care for the patient in the hospital. They stated they "asked for help", to provide care for the patient which also strengthens relationships within the family. For example, Siri said that no one would help her to take care of her mother except her sister. Sometimes, she had to transport her father and mother to the hospital at the same time. Also, she missed the job because of caregiving. Caring for parents during work time may affect her employment because she had to get a day off from work for parents' doctor appointments. She was afraid she would get fire. Therefore, she then asked her siblings to help look after her parents.

> *"There is no one, except us. I cannot leave everyone here. For example, my dad was sick and I had to take him to the hospital. At that time, I looked after both parents and my child. I was so tired as I took them to the hospital and took a leave for taking mom to see the doctor. For my mom's appointment, it was on every Tuesday and for my dad's appointment, it was scheduled on every Wednesday. I was afraid that my employer would fire me. Therefore, I asked for help from my sister. (Siri, a 37-year-old woman, employed, caring for her mother)"*

Some other family members assisted family caregivers with managing medication for patients. For example, Supod could not provide details of his wife's health condition to a doctor and asked his daughter to stay with him to help in providing clearer details during a medical consultation with the doctor. Also, Supod did not understand about the medications that were used to treat his wife. He asked his daughter to help with managing medication, even though he could remind his wife to take medications. His daughter also guided him on how to manage medication, when she was busy.

> *"For medicines, I did not know much about it, so my daughter took care of it. When the doctor questioned about my wife's condition, my daughter was the one who answered that. If you ask me about the medicines that she took, I was not able to inform you. Our daughter can answer that because it was in technical English terms…Our daughter managed the medication and I reminded my wife to take medication. When my daughter was not available then I did it. Our daughter told me how to do it. She could not miss her medication… We helped each other and we were not affected by it and we did not have to pay anything extra. (Supod, a 72-year-old man, employed, caring for his wife)"*

Prakit asked his sister-in-law to stay with his wife when he had important business. Also, he asked his son to help look after his mother by assisting her to the bathroom and showering. Prakit explained that he had much support from his family, including relatives, younger and older sisters, as well as his children who were ready to help him. He stated that his family helped and took care of each other in all situations not only caregiving.

> *“I was not retired yet. I can still work, therefore I asked my sister-in-law to look after my wife when I go to work. When I came back home, I continued to take care of her... Sometimes our son helped carry her to the bathroom, wiped her, washed her, and washed her hair. When I finished from work, I continued to look after her …we have many people in family helping us. There were my relatives, younger and older sisters, as well as our children who take care of their mum when I was away. Most of the time, we support one another. We still take care of each other. We have our children that take care of us. We have been together taking care of one another for long (Prakit, a 61-year-old man, employed, caring for his wife)”*

Family caregivers needed help from other family members to reduce stress in the caregiving situation. They understood each other and shared responsibility for taking care of patients. On some occasions, other family members helped family caregivers handle family business or caregiving tasks when family caregivers were not available. Other family members may help out for a few hours to facilitate care for patients such as taking patients to the hospital or alternatively assisting with business work when the family caregiver was dealing with caring tasks. Suratin described that his son can help him at the business when Suratin took his wife to the hospital. He asked his son to assist with work at his shop. However, his son can only contribute from time to time as he had to arrange his own work as well.

> *“…My son has his own work, while I took care of my wife. He helped from time to time. Sometimes I asked him to work at my shop at market, when I took his mother to the hospital. Sometimes, I asked my grandchildren to take me to hospital and I paid for cost and food. There was no extra payment for them though. We can rely on each other and helped one another… (Suratin, a 61-year-old man, unemployed, caring for his wife)”*

Decha explained that he needed help from his daughter when his wife had medical appointments. However, his daughter could only help him sometimes because she works every day. His daughter took him and his wife to see doctors and visit half-days in hospital. His daughter often visited Decha and her mother to see if they need help and assisted when Decha required.

> *“Only required help from our daughters for going to the hospital. Sometimes, I went with them and accompany with my wife as our daughter took a mother to the hospital but she cannot spend whole day at the hospital. We see each other every day. She is fine…our daughters come to see her every day as they live not far from us. They give us many supports. (Decha, a 72-year-old man, unemployed, caring for his wife)”*

Aom needed his sister to take care of their mother when he was unavailable. Normally, Aom did not need help from his sister all the time because she was married and living with her family. She appeared busy with managing her own duties, both work and family responsibilities. However, his sister was able to provide some assistance when Aom required.

> *"If I were extremely busy then I asked my sister for help, but that would be when I really need her help. If it were not necessary then I would not ask her because she is married with family. My sister is also in management position, so she has high responsibility. I do not want to bother her so much and would let her do her thing. She does come to visit our mother. (Aom, a 49-year-old man, employed, caring for his mother)"*

Professional staff

This sub-theme presents the relationship between family caregivers and health professionals, including physicians and nurses. Health professionals provided health information and cancer treatments for patients and also communicated with family caregivers in regard to treatment and caregiving throughout the care and treatment process. Family caregivers understood that physicians and nurses were the main resources of health information and knowledge related to care for them. Ten family caregivers described that they followed doctors' instructions to increase their knowledge about providing care including medication management, cleaning wounds and assisting with care routines. Most family caregivers continued to take patients to meet physicians and reported there were no serious challenges in care processes if patients had regular appointments with the doctor. They believed the treatment provided by doctors could improve patients' health conditions. According to healthy food guidelines recommended by the doctor, Aom followed the doctor's instructions on preparing food for his mother. The variety of foods that he selected was based on the physician's suggestions and the patient's choice such as milk, coconut juice, and bananas. He thought that healthy meals were equally important to special care for his mother. His explanation was:

> *"…I did what the doctor suggested. What the doctor asked her to eat, such as milk, coconut juice, and banana. The doctor said it is up to the patient's favour as well. If they do not like then there was not much to do… For special care, I followed the doctor's advice, which food she should eat and I will prepare it for her (Aom, a 49-year-old man, employed, caring for his mother)"*

Supod discussed with his wife about the neighbours who died from cancer at a young age, younger than his wife. Those neighbours did not have regular check-ups and found that they had the final stage of cancer when it was too late for treatment. Supod then reminded his wife to regularly see the doctor and have the treatment and he followed the doctor's advice and instructions on treatment and care at home.

> *"… Our neighbours were in stage 3 and 4 and eventually died, even though he was younger but he found out too late. Some people were in their 30's, but they found out later on at*

> *stage 4... We then went for continuous treatment. We did everything as the doctor suggested. (Supod, a 72-year-old man, employed, caring for his wife)"*

Aumara believed that medications prescribed by a physician for her older sister can protect the patient's health. She said some people might not take medication because they do not pay attention to their heath. The doctor told her that some patients did not attend to their health when they felt better. Therefore, Aumara encouraged her sister to follow instructions and advice provided by the doctor.

> *"The medicines can protect her. Some people believe it is okay, and do not take it. The doctor suggested that it cannot be cured forever but it does mean you do not have to take it when you become stronger. We need to take the medicines. We have to keep taking them and follow what the doctor has suggested. (Aumara, a 60-year-old woman, employed, caring for her older sister)"*

Some patients were unable to quit smoking and family caregivers cannot stop patients smoking. However, family caregivers took patients to meet doctors in every appointment in order to check up on patients' health. Family caregivers believed if patients kept meeting with doctors, cancer could be treated. Arthorn cannot stop his mother smoking, but he expressed appreciation when she attended medical appointments. He confirmed that he could perform the best care for his mother if the doctor organised regular appointments with her.

> *"I do not think she can stop smoking, but I am sure that she will still see the doctor and I can still take her there. I am sure that I do the best care for her. (Arthorn, a 34-year-old man, employed, caring for his mother)"*

Pisut clarified if the doctor arranged regular appointments for her aunt, it will help to improve her aunt's health and eventually she could be fully recovered. On the other hand, if some people with cancer had no regular appointment, it showed that their health condition might not improve. In case of her aunt, the doctor always followed up the results of therapy during the medical appointments after therapy, Pisut, therefore, believed that seeing the doctor regularly could ensure the good health of her aunt.

> *"…If the doctor makes regular appointments, she will meet the doctor every time…She met the doctor regularly on her appointments. If the doctor made an appointment, it meant that she could be recovered. If no appointment like other patients, it was really conveyed the meaning that her condition could not be improved... For her case, the doctor always asked her about her conditions after taking some medicine. This confirms that her illness is still curable… (Pisut, a 57-year-old woman, employed, caring for her aunt)"*

Healthcare systems

This sub-theme describes the relationship between family caregivers and the healthcare system. These relationships focused on how family caregivers dealt with the hospital system where family caregivers experienced healthcare systems through medical appointments and treatment processes. The healthcare system involves many medical care procedures and treatment processes, including patient medical profiles, disease diagnosis, treatment, chemotherapy and radiotherapy, health check-ups, and documentation. Most family caregivers did not know the length of these processes in the hospital, but they had to follow the system until the completion of all processes. Family caregivers perceived that the hospital system was complex system and consisted of several guidelines for treatment and it is a time-consuming process to engage with the system. They reported when the patient had an appointment at the hospital and they had to wait for several hours from early morning to late evening. Sometimes, they needed to come to the hospital much earlier than the appointment time because they had to spare time for finding a car park due to limited space in the car park around the hospital. Some family caregivers preferred a private hospital to the public hospital because they can spend only half-day or less for doctor appointment in private hospital compared to a whole day in the public setting.

Siri explained that she accompanied her mother because her mother was not familiar with the process in the hospital, and she had to wait for several hours to meet the doctor. Siri was concerned about her mother in regard to hospital appointments; therefore, Siri managed everything for her mother when she had appointments at the hospital and was with her until the treatment process was completed. Siri also mentioned that there was a lack of car parking. Siri had to go to the hospital early in the morning before the hospital open time. Siri would spend a full day at the hospital for a whole process of health services such as medical appointments and receiving treatment.

> *"We had to wait for a long time. When she went to the hospital, I waited for her. She did not know much about the process in hospital. Sometimes, she did not hear when she was being called to meet a doctor. I managed everything for her and accompanied with her. After she finished from chemotherapy, I took her home and look after her… Furthermore, parking in hospital was troublesome due to a lack of parking lots. I cannot let my mom walk alone in the hospital while I park my car. I will manage everything for her and allow her to have a seat and wait... Thus, it will take a long time for them to finish the whole process... (ask) (Siri, a 37-year-old woman, employed, caring for her mother)"*

Aom managed the referral process for his mother to be transferred from the primary health setting to a secondary hospital for treatment. He mentioned that the healthcare system process consumed all day to complete. However, Aom understood that he had to manage time off to take his mother to the hospital and look after her during a waiting period of the treatment.

> *"I always have to process my mum referred from primary health service to a secondary hospital. This process often takes me all day to complete before I take mum to the hospital and had to process the paperwork on our own at the hospital. I had to look after her as well. I knew that when we go to the hospital, we will loss a day. There was nothing else that we could do. (Aom, a 49-year-old man, employed, caring for his mother)"*

Suratin experienced long queues when his wife had hospital appointments. Suratin spent all day waiting for the doctor and also saw many people waiting for their treatment. Suratin did not complain about the health professionals who work in that area because he understood that all clients required treatment and had followed-up for their health. He just waited with his wife until she was called.

> *"I was the first one and got the 100th in the queue. By the time, she finished a check-up, it was 3 or 4 P.M. If there were over 1000 persons then we may return home at 5 P.M. The person who had to wait suffered. We found patients everywhere when we looked around. Everybody wanted to be treated and she or he needed to have the check-up. I was waiting there with her. (Suratin, a 61-year-old man, unemployed, caring for his wife)"*

Regarding radiotherapy, some family caregivers experienced the same problem of the malfunctioning machine for several months. They were concerned that if they were still waiting for the radiation machine, the treatment would be delayed, and breast cancer may spread to other parts of the body. Thus, family caregivers decided to take patients to another hospital to receive treatment where the machine is available for radiotherapy. In some cases, they had to travel to another city where the machine was available. Srichai stated that the radiation machine in the hospital was broken; therefore, he took his wife to another hospital that has the cancer centre. During radiation treatment for 16 days, he transported his wife every day. He drove in the morning and returned home in the evening every day until the process had finished.

> *"… During the radiotherapy process, the machine at SD hospital was broken, so I had to drive to Cancer centre at LP hospital. I took her there every day for 16 days… We did one-day trip for every appointment until it was finished. (Srichai, a 64-year-old man, employed, caring for his wife)"*

Another case, Wanna had heard that her neighbour with breast cancer was waiting for a radiation machine to be fixed for four months, sadly the neighbour developed a late stage due to metastasis referring to the liver. Wanna had received a notice of a month waiting period for fixing the radioactive machine; however, her mother-in-law did not waste time waiting for the machine at LP hospital. They decided to have her receive the radiotherapy as soon as possible somewhere else, and Wanna took her mother-in-law to another hospital to obtain a proper treatment which they believed was a better way for her mother-in-law.

> *"Prior her operation, there was someone at SP hospital who had an operation before her, cannot have radiotherapy at hospital. They waited until the machine was fixed at CM. While she was waiting, it was spread to her liver. My mother in law went for her treatment through the proper process at another hospital because she did not wait for months until the machine can be fixed. She did not want to wait, so that's the good thing that was she fought hard and went through actual process. (Wanna, a 38-year-old woman, unemployed, caring for her mother-in-law)"*

Several patients in hospital were waiting for the doctor, not only Siriluk and her mother. Therefore, family caregivers and patients understood the process and accepted that they had to invest their time in the waiting area before receiving the treatment. However, at the first appointment of treatment, she found it unpleasant because there were a huge number of patients admitted to the hospital and waiting for the same treatment as her mother.

> *"We were not the only one at the hospital. It was understandable and we came to realize that we would lose one day… In the beginning, I did not feel happy because there were many patients. (Siriluk, a 52-year-old woman, employed, caring for her mother)"*

Generally, public hospitals provide several healthcare services based on certain guidelines and complex processes. As a result, many treatments and services may take a long waiting time or the services may be insufficient for all clients who require particular treatments. Some health professionals may express inappropriate manners to clients due to the high workload. Some family caregivers experienced an inappropriate manner from some health professionals, for example, one mentioned that 'they spoke improperly to the patients even though they are health professionals.' However, they realized that it can happen in every hospital. In other words, the healthcare system caused minor problems to many family caregivers as they focused on the early treatment and proper care for patients to prevent the progression of cancer. Ampai stated that she was satisfied with the healthcare service to some degree and was willing to follow the healthcare policy. It took a long day to treat her grandmother due to a huge number of patients, and the therapy procedures, but Ampai understood and accepted these circumstances in the public hospital.

> *"I think it was good enough because there were many patients. Service was based on the*

> *workforce of professionals. However, some of them speak improperly to the patients even though they are health professionals. I think it was true and we understand that it was her duty. I did not request for any special service. We always follow their instruction and process.” (Ampai, a 47-year-old woman, employed, caring for her grandmother)*

Chapter Summary

Family caregivers maintained relationships with other parties to deal with the caregiving role and prevent breast cancer recurrence. There are positive and negative aspects of caregiving in the carer-elderly relationship. Some patients agreed with family caregivers to improve their physical and mental health during treatment. However, some conflicts occurred because of different views on managing self-care and maintaining their routines. Relationships between family caregivers and other family members helped to reduce the burden of caregiving as other family members could assist family caregivers with housework, travelling, shopping and family business. Also, they shared a caregiving role when necessary and took care of each other. Family caregivers believed in doctors’ advice on caregiving duties such as medication management, medical treatment, cleaning wounds and assisting with care routines. They recognised that health professionals were an important source of health information that helped them to gain more knowledge in cancer care. Family caregivers maintained a good relationship with healthcare systems; nonetheless, some negative relationships built up during the care and treatment process due to challenges such as long waiting times in the healthcare setting or broken machines.

CHAPTER 6 ACCEPTANCE

This chapter presents the theme of acceptance emerged from the process of analysis reflecting participants' experience of being a family caregiver. The findings showed different levels of acceptance in different stages of caregiving based on their experiences, knowledge, attitudes, beliefs and backgrounds. The concept of 'acceptance' has been used and defined in previous studies. LeSeure and Chongkham-ang (2015) link 'the acceptance of family caregivers in cancer patients' to the adjustment in care situations combined with balancing both positive and negative emotions. In this study, acceptance was defined as willingness or unwillingness perceived by family caregivers to take on the caregiving role. This theme comprises three stages, including *unprepared for being a family caregiver*, *being together* and *accepting responsibility* (Figure 6.1).

Theme 2: Acceptance

According to the data, there were three sequential stages of acceptance of the caregiving role. At the first stage, family caregivers were not fully prepared to embark on a new role where a variety of caring tasks were required. They showed moderate degrees of emotional distress when perceiving that patients have breast cancer which may affect the family caregiver's daily life. Family caregivers experienced different emotional distress such as shock, fear, uncertainty, and worry about the diagnosis and complications of treatments of cancer. Some family caregivers said after knowing the diagnosis of the patient that, 'I cried a lot', 'we were worried', and 'I was totally shocked'. Those described their feelings and emotions of their crisis circumstances.

They seemed to be unsure whether they could perform appropriate care for patients. The majority of family caregivers showed their willingness to provide care to the patient at the early stage, while some family caregivers reported this feeling at the later stage of the caregiving role. In this description, the lack of knowledge was reported by caregivers who explained that they do not know how to provide care for their patients. They had insufficient information because they had no prior experience and some of them stated that they received limited health information from physicians. They reported difficulty in communicating with professional staff and did not know how to communicate effectively. Therefore, they considered it is not easy to accept a family caregiver role in the first place.

In the second stage of acceptance, family caregivers gradually learned how to adjust to the caregiving role. They lived with the patient and learned what the patient needed from them and also they learnt how to work with each other to provide appropriate care. They shared common activities in daily life and supported each other in many situations. They considered that only the early stage of the role affected their life, but later they accepted the new role when they were familiar with providing care. Additionally, they felt less stress when patients could managed self-care activities and did not always need support from family caregivers. Family caregivers perceived that taking care of patients was not always overwhelming and eventually, they perceived that providing care for patients was an acceptable duty. In other words, family caregivers accepted it by learning to live together with the patient and importantly, family caregivers respected patients as a senior member in the family who deserved appropriate care from junior members whether they were mother, wife, grandmother or sister. The sense of responsibility was also based on culture, religion and beliefs.

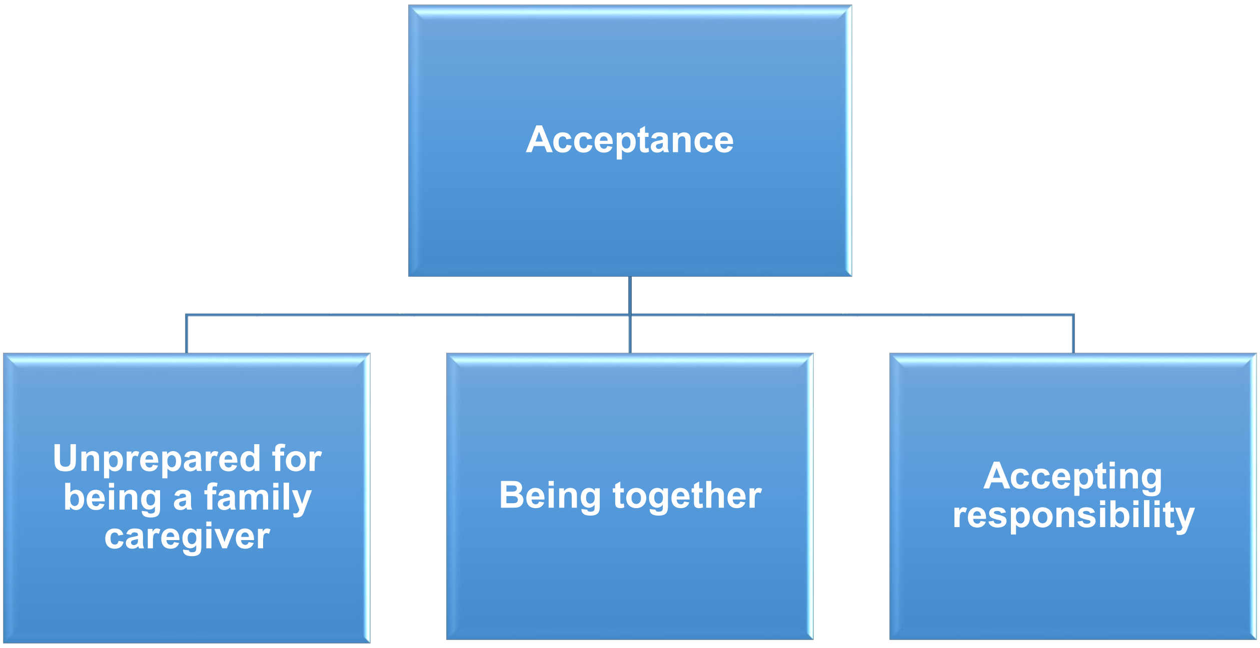


Figure 6.1 Acceptance

Unprepared for being a family caregiver

This sub-theme presents the first stage of acceptance, ‘unprepared for being a family caregiver’. At this stage, family caregivers were concerned about how to deal with the caregiving role due to lack of knowledge and feeling unprepared to accept a major change in their life. As explained by family caregivers, feeling unprepared for being a family caregiver refers to feeling emotionally unprepared to perform care. Family caregivers experienced a high level of emotional stress when they first were informed about the diagnosis. Some family caregivers experienced negative emotions such as anxiety, fear, stress and shock when the elderly member of their family was diagnosed with breast cancer. They felt worried, anxious, afraid, shock, disbelief, sadness, and sympathized and cried with their care recipient. They recognised that care recipient with cancer might not recover and might die early. They knew that it could not be cured if the breast cancer had entered a late stage. They were concerned about their care recipient, that they might fear the treatments and suffer from their side effects. Wanna described her feeling as being worried when she was informed her mother-in-law had breast cancer. In the beginning, she expected that cancer might not be as severe as she expected, but she started to get worried when her mother-in-law was diagnosed as the late stage of cancer.

> *“In the beginning, no one thought that it would be severe, but once we found out we thought about it and we were worried because at that stage it was bad. (Wanna, a 38-year-old woman, unemployed, caring for her mother-in-law)”*

Siri who was a daughter family caregiver was crying when she was informed that her mother had been diagnosed with breast cancer. She believed that people who had cancer would die early, and her mother would not live long. She felt terrified that breast cancer cannot be cured and her mother may die eventually.

> *“... On the day, we knew the result, I went alone and she did not come with me. The result showed that she had cancer. I cried because I thought that the patient with cancer would die and it was incurable. (Siri, a 37-year-old woman, employed, caring for her mother)”*

Arthorn was shocked when he and his family were informed that his mother had breast cancer. He recognised that cancer is a serious condition for anyone. He cried and was concerned when his mother underwent the surgery. Arthorn was quite anxious about his mother’s mental health because she was afraid of surgery.

> *"In the beginning, my family and I including herself were shocked and we were concerned because she's very afraid of having an operation. I cried on my own when I knew that my mother had breast cancer. I was totally shocked by the word "cancer". This word was horrifying! (Arthorn, a 34-year-old man, employed, caring for his mother)"*

Some family caregivers described that they did not realise that the tumour in the patient's breast was cancer. Family caregivers reported that when patients found a lump in their breast, they often avoided seeing the doctor and did not inform family caregivers. Patients ignored it because they thought it would not cause any serious issues. Patients perceived that the lump was just a cyst and it would recover itself. Therefore, family caregivers did not know until they found that the patient was diagnosed with breast cancer. For instance, Suchada was not aware that breast cancer had occurred with her younger sister because her younger sister did not tell and discuss with Suchada. She was told by her younger sister that a lump did not cause any pain and assumed that it was just a lump and did not inform the doctor when she had checked her health at the hospital.

> *"At first she did not know that she had cancer. She found the lump but it did not pain, so she assumed that it was just a lump. She did not feel much and when she went to the hospital, she did not even tell the doctor and asked them to check it. (Suchada, a 70-year-old woman, employed, caring for her younger sister)"*

Ann described that her mother found a lump in her breast, but her mother was not concerned about it. She also thought that the doctor might not pay attention to her mother and may not consider any treatment because her mother is an elderly woman.

> *"My mother found tumour in her breast. She thought there was nothing wrong and did not want to see the doctor, as she believed she was very old. The doctor would not have done anything for her. (Ann, a 50-year-old woman, employed, caring for her mother)"*

Insufficient knowledge

Most family caregivers stated, "what is going on?" and "we were worried about this disease", implying their unpreparedness for the situation. At the first stage of caregiving, family caregivers were often unable to accept their role. As they described, they lacked the knowledge and had inadequate information to perform proper care which meant they did not feel confident to take care of patients. This finding showed all family caregivers had insufficient knowledge of caregiving and treatments, including chemotherapy, surgery and hormone therapy. All family caregivers described that they did not know how to take care of the patient during cancer therapy. Most of the family caregivers followed the doctor's instructions at the initial stage and later they adjusted to new caregiving routines after the recovery period of the patient. Family caregivers mentioned that information about breast cancer could be guided by health professionals that would help them understand, gain some knowledge and develop some care skills through the essential information. The terms relating to the insufficient knowledge expressed by the family caregiver included "…do not know...", "what is the process of treatment" and "how many times of treatment process are needed".

Ampai who was a granddaughter caregiver explained that she and other family members did not understand the treatment of breast cancer and did not know how to provide care for her grandmother. She would like to know how many cycles of cancer therapy her grandmother required for the whole course. Therefore, Ampai discussed with the doctors the treatment process.

> *".... We did not know how many times she should undergo in this process and we needed to consult with the doctor. (Ampai, a 47-year-old woman, employed, caring for her grandmother)"*

Boonta had no information about how to take care of her older sister and deal with doubts of caregiving. She explained that she just followed the instruction suggested by health professionals and managed medications for her older sister.

> *"I did not know exactly how to take care of her. I helped manage the medicine as told by the doctor and tell her to follow the doctor's instructions. (Boonta, a 64-year-old woman, unemployed, caring for her older sister)"*

Low confidence

Some family caregivers with a low level of education had low confidence in order to take on a family caregiver role. In addition, several family caregivers felt low confidence in providing care due to inadequate health information. They were uncertain in providing care because they did not know how to deliver proper care for their patients. Some family caregivers described that they do not understand what stages of breast cancer their patient was at. They did not recognise how to provide suitable care and how to suggest to the patient to properly behave after the treatment. Health professionals did not communicate sufficient information about the disease, treatment and caregiving. Pisut mentioned that she only completed primary school. Therefore, she was not ready to take care of her aunt who was diagnosed with breast cancer. Pisut described that she just had a low educational level. Therefore, she cannot pay attention to providing care due to not having enough knowledge. Rather, she needed to focus on her work instead of caregiving.

> *"I only completed my Grade 4, so I do not have enough knowledge. I will focus only on my own family. (Pisut, a 57-year-old woman, employed, caring for her aunt)"*

Ann implied that she was unclear on the health information associated with a healthy diet and how to advise her mother to avoid or choose healthier meals. Ann did not know what diet she should provide for her mother. She was unfamiliar with breast cancer and lacked knowledge and skills related to how to advise her mother.

> *"When she was diagnosed with breast cancer, I did not know what she should have avoided or eaten; how she should have behaved. (Ann, a 50-year-old woman, employed, caring for her mother)"*

Siriluk did explain that the breast cancer that her mother experienced did not inform itself in any signs and symptoms. She was not clear what stage of breast cancer was diagnosed for her mother and what proper care was provided. Doctors also did not inform the stage of breast cancer to Siriluk.

> *"I looked at her breast and it looked normal. I did not notice the tumour and did not know which stage she was... The doctor could not tell me either…I do not know what to provide her. (Siriluk, a 52-year-old woman, employed, caring for her mother)"*

Being together

This sub-theme revealed the second stage of acceptance. During this stage, family caregivers learnt how to provide care and assist patients through daily routines. They also learnt how to provide suitable care and work with patients to perform proper care. Being together refers to patterns of life of taking care of patients. Family caregivers performed to care for patients by doing the daily routine together and they spend time together in various activities, including preparing meals and cooking, travelling, shopping, laundry, and working. Half of those family caregivers managed to balance care duties with their family commitments and also provide emotional support for patients. Family caregivers described that being together was a good strategy as they lived in the same house that helped save time in managing their tasks and made them gradually accept this role. The terms they used to describe the experience reflected the positive feelings such as "we have to be together" or "we are like friends". Srichai managed his own routines combined with caregiving tasks as he lived with his wife. He described that the demands of caregiving limited his private time; therefore, he and his wife shared and discussed what she needed and what he could provide during care activities and managed time together. They shared their everyday stories of bad and good things in family matters. Srichai maintained his family commitments in everyday caregiving.

> *"We managed to live and it depends on how we treated it… We will be together and had not much time. We will be together until we are old. In the evening, when we return home, we talk to each other about the good and the bad thing. (Srichai, a 64-year-old man, employed, caring for his wife)"*

Prakit lived with his wife for more than a decade because of love and they shared their time together in many ways. He discussed with his wife that they needed to understand each other including listening, particularly when during the caregiving period. Prakit described that if they did not accept each other, then they would not be together.

> *"I told her that if we were to be together for a long time… She should listen to me if we wanted to be together for a long time. Because if we were to be together then we had to understand one another. If we were not meant to be together, then we would not have been together. We are a couple and we have to be together no matter what… but we are together because of love. We have to go places together and never be far apart... This is because we are together. (Prakit, a 61-year-old man, employed, caring for his wife)"*

Acceptance of responsibility

This sub-theme described the third stage of acceptance, 'acceptance of responsibility'. In this process, family caregivers perceived that providing care was not as complicated as they expected. They learnt how to adjust themselves in the caregiving role, deal with emotional distress and maintain ordinary life. There were various rationales for acceptance in this third stage based on relationships, beliefs and cultural practice. Although the burden of care was undeniable for some family caregivers, the majority of family caregivers still accepted this role. They revealed reasons for accepting this role as the main person in helping patients, including family relationships, short-term caregiving and patient's self-care management.

Family relationships

First, the majority of family caregivers perceived that they accepted their family caregiver role because of family relationships. They expressed their sense of emotional bond with the patients, including respect, care, love, and trust; as a result, they thought they could provide better care for other family members than other people. A close relationship within the family could occur between family members who were blood relative or relative by marriage. The family relationships in this study included mother-daughter, mother-son, husband-wife, and younger-older sister as well as mother-in-law and daughter-in-law. Some family caregivers stated that they help each other because they are in the same family with patients.

Pimon stated that she was the only one in the family who could take care of her mother. The other family members were unable to take this responsibility, even though her mother has many relatives. Pimon was her only daughter and had a closer relationship with her mother than other blood relatives. Therefore, Pimon was a suitable person who must provide care for her mother.

> *"She has nobody. She is also my mother and I am her daughter… She has no one. She is my mom. Even though there are several relatives, I can give her good care... (Pimon, a 65-year-old woman, unemployed, caring for her mother)"*

Srichai was the only family of his wife living under the same roof. His wife had siblings, but they lived in another town. Therefore, Srichai was a principal family caregiver because he had a close relationship with her and no one else was available. Srichai described that husbands and wives should take care of each other more than other family members. He discussed and shared his everyday experience of caregiving for his wife.

> *"Because there was no one else. There is only two of us. My wife had a sister who had breast cancer too, but she lives at another district and the other sibling is male. It was not like husband and wife who are closer because the person would tell you more than they do to others… (Srichai, a 64-year-old man, employed, caring for his wife)"*

Caring for an elderly person with a health condition in the family was considered as a responsibility of other family members. The family did not hire a paid carer because they believed the family caregiver role should be arranged within a family. Anucha can manage himself to take responsibility for his mother because no one can provide suitable care as best he could. He mentioned that other carers might not understand what his mother needed when providing care. Therefore, he can adjust himself in this providing care.

> *"Someone who takes care of them is hired. We cannot help them understand it. The problem is that we must adjust ourselves. (Anucha, a 36-year-old man, unemployed, caring for his mother)"*

Lapa had to take the family caregiver role for her mother-in-law because her husband was in full-time employment. Although she did not get along well with the mother-in-law, she accepted this family role as other family members were unavailable.

> *“I might be here in her son’s place, so I have to substitute him because otherwise, no one is going to take care of her… (Lapa, a 36-year-old woman, unemployed, caring for her mother-in-law)”*

Caring and respecting to the elderly is the norm in Thai culture and helps improve the bond and trust between patient and family caregiver. The majority of family caregivers explained that they would like to express appreciation and gratitude to the senior by taking care of them. Aumpai has only been providing care for her grandmother for over ten years. Her grandmother’s brother cannot look after her grandmother because of his health problem. Aumpai explained that she had a close relationship with her grandmother more than anyone.

> *“She is a senior relative. I am her grandchildren, so I need to take care of her…It is my responsibility because she has no one… I am a granddaughter of her eldest brother. She lives with another brother who is not healthy…. (Aumpai, a 47-year-old woman, employed, caring for her grandmother)”*

Short-term caregiving

Family caregivers described that taking care of patients may be difficult at the first stage but finally it can be acceptable. Family caregivers explained that there was no special care required for patients because it was short-term care during cancer therapy. Patients suffered from side effects of the therapy and subsequently, they required appropriate care. Family caregivers experienced both physical and psychological health issues arising from the family caregiver role; however, the care situation could be managed by 2-3 months or 6-12 months from the beginning of the role depending on the stage of breast cancer. Family caregivers learnt from their experience how to cope with this difficult matter and learnt how to provide proper care for patients, and then they finally accepted the new role. Some statements that the family caregiver used supporting this message, “it takes a couple of months”, “it was only once a month”, “it was a short period” and “it was quite tough in the beginning”.

Srichai explained that the surgical treatment option made him concerned about his wife’s health. Its complications may affect the physical and mental well-being of his wife and he was aware of those adverse effects that treatment may cause such as her loss of functional ability. Srichai kept encouraging his wife to fight the disease and motivating her to understand that many patients with breast cancer underwent the same treatment. For a couple of months, he found that she returned to normal and started to have her own activities.

> *"After the operation, it was quite tough because she cannot help herself and I had to care for her. However, it took a couple of months. I told her that everyone else had the same problem as hers. It should be okay. (Srichai, a 64-year-old man, employed, caring for his wife)"*

Pisut explained that providing care for her aunt who was diagnosed with breast cancer was for one month. Her aunt handled the cancer treatments and then she could recover in a short time. Sometimes, her aunt needed help from Pisut when she required assistance in travelling to the hospital.

> *"She did not cause any problems. Just in a short period of time. She asked me to take her to the local health station. Sometimes, she rides a bike to hospital to ask for some vitamins…It was only once a month. Thus, it did not cause any problems for me. (Pisut, a 57-year-old woman, employed, caring for her aunt")*

Patient's self-care management

The majority of patients could perform self-care and they did not need help from family caregivers for all tasks. Cancer therapy caused only temporary side effects for some patients and many patients experienced a low level of undesired effects from cancer treatment. Therefore, the caregiving role can be perceived by family caregivers as not causing a high level of burden. Over half of those family caregivers said they can handle the caregiving situation because patients were able to manage self-care tasks. Thus, family caregivers had a positive experience in providing care as they felt less overwhelmed. Eventually, most family caregivers considered that the caregiving role was not too difficult because the patient could manage some care tasks by themselves.

Lapa stated that looking after her mother-in-law was not a burden on her because the patient had few effects from cancer therapy. Some patients may have trouble with side effects of treatment but after treatment, her mother-in-law was recovered in a short time and could take care of herself and was able to do her work.

> *"She was not a burden to me because she can look after herself. She was not like some other patients who experience terrible side effects. She was able to get to a state where she was able to get back to work right away. I did not have to take care of her too much as she can help herself. (Lapa, a 36-year-old woman, unemployed, caring for her mother-in-law)"*

Pisut who was a niece caregiver described that taking care of her aunt did not cause trouble. Her aunt could manage her own routine; also, Pisut did not live with her aunt. Therefore, her aunt did not require help from Pisut all the time because she could manage self-care and preferred to cope with the disease by herself.

> *"I did not think that she is my burden because she did not live with me all the time. She managed everything on her own. She did not cause any trouble for me at all. (Pisut, a 57-year-old woman, employed, caring for her aunt")*

Chapter Summary

The sense of being unprepared for being a family caregiver was due to lack of knowledge and lack of confidence in family caregivers at the first stage of the new role. There were emotional concerns affecting family caregivers in dealing with preparation to perform care. This issue contributes to an unready sense of performing caregiver role. Feelings of being together can help save time and reduce stress in the new role. Being together was the second stage of acceptance; they worked together and performed the same activities. Family caregivers learnt how to manage care for patients with daily routines in providing proper care. Accepting responsibility was the last stage of role acceptance where family caregivers felt less overwhelmed when they had learnt how to adjust and perform care for patients. Patients also could adjust and manage self-care in coping with the disease and treatment to return to normal life, which helped reduce the burden on family caregivers. In the Thai context, family caregivers accepted that the elderly as a senior family member should deserve to receive proper care with respect from their family.

CHAPTER 7 CARE MANAGEMENT

This chapter presents care management provided by family caregivers, which revealed how family caregivers manage care for patients after diagnosis and treatments. Care management involved care activities in the hospital and domestic settings during cancer therapy courses. Care management is defined as a care process where family caregivers provide daily care for patients in order to maintain the patient's physical and mental health while also keeping up with their own daily routines. This theme is categorised into four sub-themes: adjusting lifestyle and being normal; providing emotional support; seeking essential information and negotiating traditional and western medicine (Figure 7.1).

Theme 3: Care Management

Adjusting in lifestyles and being normal is the first sub-theme, which explained that family caregivers adjusted their daily life during commencing the caregiving role and tried to live their lives by maintaining their caregiving routines as close to normal as possible. Family caregivers managed the patients dealing with cancer treatment and maintaining their quality of life during a stressful time. The second sub-theme shows how family caregivers provided emotional support to patients in various situations by using *positive thinking*. *Seeking essential information* about breast cancer treatment is the third sub-theme, which revealed how the family caregiver accessed health information sources related to care practice, disease, and treatment available in the healthcare system and public. Lastly, *negotiating traditional and modern medicine* presents how each family caregiver helped their patient to receive both traditional and modern methods to support physical and mental health and well-being. The contexts of care management are described through family caregivers' accounts of their experience in adjusting to the lifestyle. The family caregiver's normal routines were changed and re-established with self-management tasks incorporated. Family caregivers prioritised both physical and mental care for patients. Family caregivers also assisted patients with daily activities such as eating, cleaning, toileting, cooking and shopping. Family caregivers provided mental health support when the patient experienced a tough time coping with the side effects of the treatment. They encouraged patients to stay positive, which improved the emotional and physical well-being of the patient and therefore helped them to cope with cancer and treatment. Family caregivers reported seeking information relevant to managing care for patients. Family caregivers accessed essential information based on their backgrounds and knowledge. Traditional and western medicine was integrated into cancer treatments. Both the family caregiver and the patient could discuss and negotiate benefits in the use of traditional or western medicine. Mostly, traditional treatments were required by patients to treat their breast lumps prior to receiving western remedies. Traditional treatments such as religious practices and medical herbs were recommended by patients and their social networks. Family caregivers were required to use modern medication rather than traditional medication. However, family caregivers decided to use both treatments as they preferred to use Thai and Chinese herbs alongside western medicine to improve the patients' health.

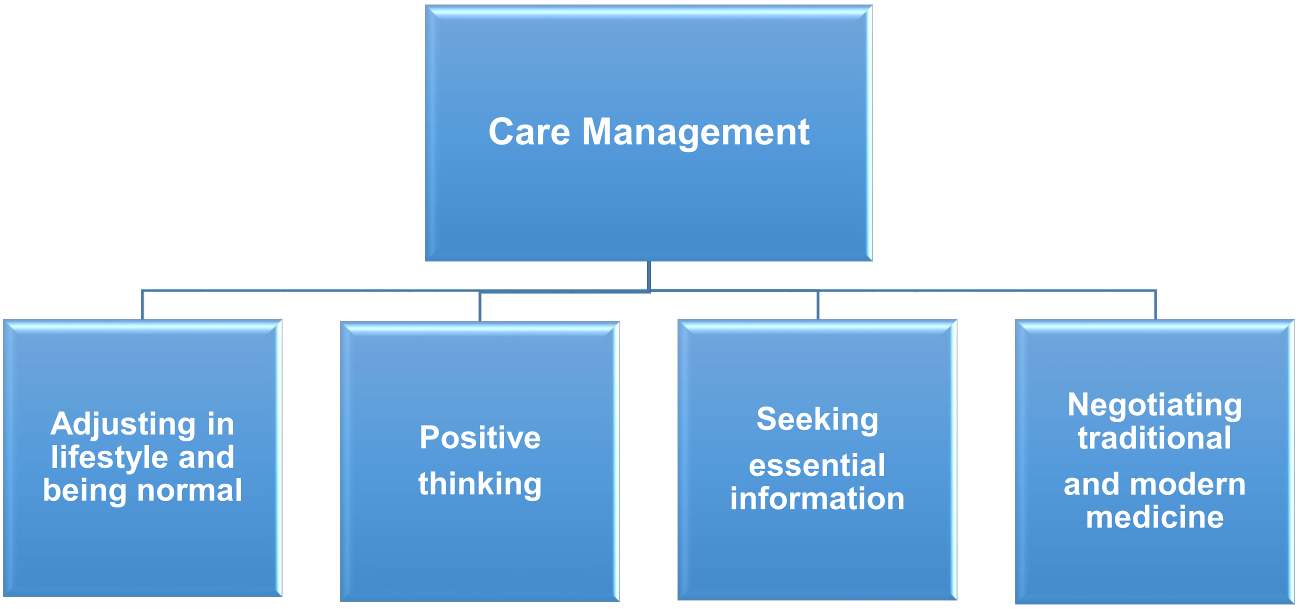


Figure 7.1 Care Management

Adjusting in lifestyle and being normal

This sub-theme found that family caregivers adjusted their daily routines in order to effectively perform their caring tasks for patients. Family caregivers helped patients to perform several everyday tasks and provided healthcare. At first, the caregivers found the healthcare tasks to be difficult, as they mentioned that ‘It’s just difficult towards the beginning’. However, family caregivers were given clear instructions by the doctors for special care such as medication management, cleaning wounds, and changing position after treatment. This made their duty less difficult. Moreover, family caregivers used a patient-centred approach to maintain patients’ daily lives to cope with disease and treatment. Family caregivers provided care to the patient when they saw it was most appropriate so that the patient could maintain their lifestyle. If the patient did not appear to be very sickly to the family caregiver, then the caregiver would return to their daily routine after treatment. As they said, ‘We just do our own duty’. For example, ‘She (patient) prepared stuff in the kitchen, while I worked at the front area’.

Some family caregivers explained that their lifestyles changed very slightly because they were able to adapt their new caregiver role into their normal lifestyle. Assisting with daily activities included personal care activities and household tasks at homes, and primary healthcare centres and hospitals. For domestic care, the majority of family caregivers performed personal daily living activities such as showering, cleaning, cooking, toileting, transportation, and medication management in home setting. They also collected the patient’s health information and reminded them of doctors’ appointments. For care in hospitals, most family caregivers visited patients daily at the hospital and looked after patients in the ward before leaving the hospital. Family caregivers learnt how to clean patients’ wounds and provide care at home from health professionals. When patients were discharged, family caregivers encouraged the patient to complete their own daily tasks. Most patients could perform domestic tasks and later they could return to normal life. Some family caregivers described that caregiving for patients was difficult at the beginning stage. Then, they learnt how to provide assistance with daily routines for patients such as dressing wounds, preparing meals, and medication management. For instance, Siriluk stated that her daily schedules returned to normal after the patient who was her mother with breast cancer underwent treatment. She said it was a difficult time in the beginning. Now she can clean her mother's wound as taught by the nurse. Furthermore, her mother can now perform self-care activities related to healthcare such as drug administration and preparing food. Siriluk maintained the personal hygiene care for her mother such as bathing and wiping her body. Her mother could perform other daily routines.

> *"Everything is back to normal. It was only difficult at the beginning. I only cleaned the wounds for her and she can organize the medicines herself. I take care of her food, bathe or wipe her. She can sleep or do other activities on her own... (Siriluk, a 52-year-old woman, employed, caring for her mother)"*

Supod who started being a family caregiver stated that "I was her arms and legs". In the beginning, he changed his daily routines when his wife who had breast cancer undertook treatment and was not able to take care of herself. Supod, therefore, provided personal care for his wife. For example, he carried her to the bathroom, cleaned her body and changed clothes for her.

> *"My routine changed when she cannot do things on her own and I had to do them for her. Sometimes, I took her to the bathroom and changed her clothes for her. I cleaned her body because she cannot do it. In the beginning, I was her arms and legs. (Supod, a 72-year-old man, employed, caring for his wife)"*

Some family caregivers learnt how to take care of their patients after the surgery. Some family caregivers looked after their patient in the hospital or primary healthcare centre. Some family caregivers learnt some special care in the home setting educated by health professionals such as wound care, and position change after treatment. One family caregiver needed to change the patient's position every hour after taking a bone pill (after chemotherapy). Some family caregivers learnt how to care for the patient's wound at home as instructed by the doctor. However, one family caregiver struggled to appropriately clean the patient's wound at home so the patient's wound had to be cleaned by the nurses at a primary healthcare station. Daow described that caring for her mother's breast cancer was not complicated. She took care of the patient (her mother) as normal. She said that she cared for her mother as an ordinary person who needed bone pills; the complicated medical care was the duty of the doctor, not hers. The doctor taught Daow to provide special care as she had to adjust her mother's position every hour until treatment had finished.

> *"It is not complicated. I take care of her in general. For special care, it is the jobs of doctors and nurses. The doctor told me to take care of her as a normal person. No special needs are required. Only on the days that she needs to take the bone-lining protector, she will require special care where I had to change her position every hour. (Daow, a 43-year-old woman, employed, caring for her mother)"*

Boonta cared for her older sister's wound as the doctor had advised. She showered her older sister and always kept her older sister's wound clean and dry otherwise, the wound would become infected. When her older sister's wound healed, Boonta allowed her older sister to shower by herself.

> *"I had to shower her because the doctor told me the wound must not get wet. After she recovered, she continues to shower herself… (Boonta, a 64-year-old woman, unemployed, caring for her older sister)"*

Anucha took care of his mother in the ward. Right after his mother was discharged, Anucha cleaned his mother's wound at home. However, Anucha had to take his mother to the primary healthcare centre to get her wound cleaned due to a wound infection. From then on, Anucha took his mother to the primary healthcare centre to receive proper wound treatment from a specialist.

> *"When she was at the hospital, I stayed with her... Only thing is cleaning the wound. I have been cleaning her wound the way I learnt from the nurse but her wound was infected. Therefore, I take her to do it at the public health centre. Alternatively, she goes there by bicycle. (Anucha, a 36-year-old man, unemployed, caring for his mother)"*

Most of the family caregivers helped patients with their daily routines such as bathing, toileting, cooking, preparing pills, changing clothes, as well as transporting to the hospital and work for some patients. Supod provided care activities for his wife in the hospital after treatment. He assisted his wife with toileting, carrying her to the restroom and taking her out of the bed. He stayed at the hospital for approximately ten days with his wife to provide help with daily activities before leaving.

> *"While at the hospital, I assisted her with toileting, took her out of bed because she was quite a big person. Therefore, I carried her off the bed... I was the one that stayed over with her for over 10 days and never returned home until she was discharged. (Supod, a 72-year-old man, employed, caring for his wife)"*

After breast cancer surgery, Sirimas assisted her older sister with personal care activities such as bathing and drying off the skin. She managed the medications for her older sister during their stay at the hospital.

> *"I took care of her by making sure she takes the medication... When she left the operating room, I bathed her and dried her. (Sirimas, a 55-year-old woman, unemployed, caring for her older sister)"*

Most family caregivers developed a patient-centred approach to providing care in the home setting. Family caregivers assisted patients with various activities based on patients' needs, such as transporting to and from hospitals, preparing food and medication, reminding them about medical appointments and shopping. The type of care that the patients required was based on their physical well-being and ability to perform their daily activities. Family caregivers stated that patients desired to continue with their life as usual. Family caregivers helped the patients to cope with physical and emotional difficulties during cancer therapy. The family caregiver motivated the patients to achieve self-care management to improve their physical and mental well-being. Some family caregivers expressed that they were a part of the patient's experience and performed daily care together. If an unexpected situation occurred which affected the patient's physical health, family caregivers would bring the patient to the hospital. Some family caregivers explained that they continue to live their lives normally and encouraged patients to perform daily tasks whenever they can. For example, family caregivers allowed patients to go to the market and communicate with friends. Sometimes when patients needed help they would ask for help from family caregivers.

Decha stated that he and his wife (patient) took care of each other the way they have been doing prior to the caregiving situation although there were some tasks, such as cooking, where Decha had to do it instead of his wife. Whenever his wife experienced some health conditions from cancer, he would take her to the health care professionals.

> *"… We take care of each other as the way we usually do. She will ask me to do something that she wants. She cannot do some tasks such as making the chilli paste or cooking food so I do it for her. Apart from doing the shopping at the market, we do everything the way we normally do them. If there were something wrong, we would go see the doctor. (Decha, a 72-year-old man, unemployed, caring for his wife)"*

Pisut puts her focus on her daily care routines for her aunt and her everyday job. She and her aunt live a very normal life. However, she advised some healthcare practices for her aunt including sleeping and eating. Sometimes, Pisut transported her aunt to the primary healthcare centre to have a health check and receive medication. All daily activities such as domestic housework tasks were performed by her aunt.

> *"I do not care too much about the way I live or die. If I am still alive, I will carry on with my job as a tailor… It is our common way of living... She followed my suggestion as she goes to bed around 7 p.m. and wakes up at 8-9 a.m. After eating, she goes outside. It is very common for human beings. We do not need to worry… Just sometimes, she asked me to take her to the local health centre… All activities were usually done by herself, including the housework. (Pisut, a 57-year-old woman, employed, caring for her aunt)"*

Most family caregivers stated that they considered the patient as an ordinary person rather than a patient. According to family caregivers' experience, breast cancer can be treated by doctors and patients would recover from treatment and return to their usual life. If patients were treated with excessive care, they would think their health condition was severe. Patients may feel stressed and worried. Some examples of the care experience are described below.

Suratin did not provide care all the time for his wife who had breast cancer because she was not a bedridden patient and her condition was not severe. She could perform daily household tasks including cooking, house chores. Suratin only needed to help her with shopping. Therefore, Suratin believes that his wife was unlike other patients as she could independently perform various tasks.

> *"I did not have to watch her all day long because she was not bedridden... It was not as the patient was so sick that she could not do anything. She could help herself by cooking, doing house chore. She could do it all. I went to the market to buy rice, fish, and meat for her to cook. She picked fish and I picked the meat. It was not as she was so ill that she could not get out of bed. (Suratin, a 61-year-old man, unemployed, caring for his wife)"*

Pim would only provide care to her patient, her mother when needed. She explained that when she took care of her mother too much it made her mother feel as if she was very sick. Her mother also felt that she was burdensome to Pim and other family members. Pim did not provide extra care for her mother because she did not see her mother as very sick and was rather capable of doing things on her own.

> *"…I'm not sure whether other families share the same experience as us, but we found that over-caring for someone can have a negative impact on the person. It makes them feel very sickly and burdensome to others. I have not put too much effort into caring for her that much … she does not look like a sick person, she looks normal. (Pim, a 45-year-old woman, unemployed, caring for her mother)"*

Thinking positive

This sub-theme presents how family caregivers provided emotional support to patients in various situations and balanced the emotions and mental health when patients were undergoing cancer treatments. Emotional support included encouraging patients to perform self-care when they felt depressed. For example, family caregivers encouraged patients to do their daily routine if they were able to. Most family caregivers encouraged patients to manage self-care such as housework and shopping. Some family caregivers did not force or push patients to carry out every task. The family caregivers encouraged patients to perform their favourite activities and assisted the patients with some daily routines when patients could not complete it. All family caregivers encouraged patients to build confidence in their own ability. Family caregivers provided emotional support and comfort when patients struggled with the complications of treatment. Some family caregivers encouraged the patients to “fight the disease”. They suggested the patient learn about other patients’ cancer experience. Patients learnt to reduce stress by turning negative thinking into positive thinking. Patients used positive thinking skills to cope with the disease and the treatment. Here are some examples of emotional support encouraged by family caregivers.

Srichai encouraged his wife to look at the survival rate of cancer patients who underwent cancer therapy. He pointed out that many people experienced their hair loss during treatment and that some patients spent 30 years battling cancer and survived. He and his wife had discussed with each other and shared their understandings of everyday caregiving for handling problems while encouraging his wife to cope with her breast cancer. This lifted his wife’s spirit and made her stronger.

> *“I asked her to look at the people who had gone through therapy and how they managed to live on for over 10 years. Some spent up to 30 years with cancer and they were still alright. Lately, I could see that she has become stronger and she had the strength to do her work. When we took her to receive radiation therapy, we saw many people whose hair had fallen off. They were like us so we talked to them. My wife was not too stressed as she saw others with a similar condition. We exchanged knowledge and past experiences with other patients. (Srichai, a 64-year-old man, employed, caring for his wife)”*

Wanna encouraged her mother-in-law to visit a woman in the neighbourhood who had the same type of cancer. Wanna invited the lady over to her house and had a discussion on the coping methods and the lady’s experience. Wanna later shared this experience with her mother-in-law. From then on, her mother-in-law visited the woman at the market and talked to her almost every day. Her mother-in-law went back to work not long after, and the woman said that her mother-in-law looked much better.

> *“The neighbour who lived five houses down the road also had breast cancer. She was like her...actually, she was skinnier. I asked the neighbour to pay her a visit. My mother in law went to the market and saw the lady every day. Soon later, my in-law went back to work, and the lady gave her support and said that my in-law looked much better than her. (Wanna, a 38-year-old woman, unemployed, caring for her mother-in-law)”*

Pisut encouraged her aunt to fight the disease when she lacked emotional support. Pisut was there for her aunt when she needed someone. Also, she sought the best hospitals with health professionals who could provide the best care for her. Pisut was always with her during treatment and provided her with emotional support.

> *“At the first time, she did not have a lot of emotional support. When she asked me to stay with her, I did not refuse. We went to several hospitals that claimed to have the best cancer treatments...I was with her all the time. I did not want her to worry. Now she is free from anxiety and lives well. (Pisut, a 57-year-old woman, employed, caring for her aunt)”*

Seeking essential information

This sub-theme describes how family caregivers gained access to health information. There were several available sources where family caregivers learnt about care management. All family caregivers gained knowledge of treatments from health professionals. All family caregivers searched for additional information from the mass media, books and documents to further their understanding of the disease. They also obtained health knowledge through other people such as health professionals, volunteers, friends, neighbours and cancer patient groups. The following examples reveal that both family caregivers and patients searched for health information through various sources. Some family caregivers stated that they obtained information by reading books and mass media. Most family caregivers were educated by health professionals in addition to gaining information via the mass media. Some family caregivers gained information on treatment and care from the display boards around the hospital wards. Some family caregivers had previous experience as local health volunteers before being a family caregiver and therefore had some basic knowledge of healthcare.

Suchada found that reading helped her to understand cancer and the treatment process. It also provided her with some knowledge of the appropriate care practices.

> *“…I read them because they give me a rough idea of what I have to do. (Suchada, a 70-year-old woman, employed, caring for her younger sister)”*

Decha did not rely on the internet to find information as he was not too comfortable with using it. Therefore, the majority of the information came from the health professionals he met at the hospital. His community also had a monthly public announcement for health check-ups.

> *“…The doctors told me a lot of useful information when I was the in hospital with her. I am not too familiar with finding information from the internet despite the fact that I can read. The village occasionally makes a public reminder for medical check-ups once a month or two. (Decha, a 72-year-old man, unemployed, caring for his wife)”*

Arthorn searched for information on caregiving and cancer treatments from the internet to find the best care for his mother. He said that most health knowledge he gained was from the doctor.

> *“Since then I have searched on the internet for information on treatments. I also asked the doctor about my mother’s condition... (Arthorn, a 34-year-old man, employed, caring for his mother)”*

Ampai works at the public health centre as a local volunteer. She was able to obtain knowledge of healthcare from her work. She also said that she gained knowledge through reading.

> *“…I also work as a local health volunteer. Most of the health-related knowledge were obtained through my reading... (Ampai, a 47-year-old woman, employed, caring for her grandmother)”*

Several family caregivers gained information from their peer groups such as friends, other family members and neighbours who had cancer experiences, whether as a patient or a family caregiver. Sometimes, some advice and information from peer groups can confuse the family caregiver as it does not coincide with the individual’s experience. Wanna experienced this confusion when the people around her told her different information, suggesting different caring methods and told her to follow their advice. However, Wanna expressed her trust in modern medicine and said that she would only consider the alternative methods afterwards. She did not buy certain ingredients and herbs that were suggested to her as she feared that it put her patient’s health at risk.

> *“… In the beginning, it was very confusing because there were people who told me things and suggested using alternative methods, ‘why didn’t you buy it’. However, I thought she should use modern medicines before trying anything else. We did not know if the ingredients were good or not. It could be harmful to her health; it could speed up the cancer rate. Eventually, we decided against it. (Wanna, a 38-year-old woman, unemployed, caring for her mother-in-law)”*

Negotiating traditional and modern medicine

Some family caregivers managed treatment for their cancer patients through various types of treatments. For example, some family caregivers worked with their cancer patients through various types of treatments. Another example described that one caregiver mentioned ‘Sarn’ as ‘The local people call traditional treatment as a kind of “Sarn”. Another respondent said that “The older lady came to perform “Yo-Lay” to my mom”. The traditional belief was claimed to maintain psychological wellbeing and promote healing wound such as modern and traditional treatment. Traditional treatments and beliefs varied among Thai cultural groups. According to the Northern culture, in the words of the family caregivers, traditional treatments performed by shamans can improve patients’ mental health. Family caregivers used traditional practices if requested by the patients. Most patients requested family caregivers to take them to the shamans to perform an ancient ritual to remove any evil spirits infested inside the tumour such as “Yo-Lay” and “Sarn”. For example, “Yo-Lay” was a powerful ability of individuals to remove any evil spirits infested inside the tumour. “Sarn” was a foreign object implanted in the human body which it may arise from sin or karma that can affect health risk. Although some family caregivers did not share the same belief as to the patient, they still followed the request of the patient as they believed it could improve the patient’s emotional well-being. Several family caregivers explained that patients felt better after having ceremonies performed by a shaman. Patients stated that ancient rituals could reduce pain from breast tumours. However, rituals were not as effective after using this approach for several years. The tumours gradually grew as time went by and eventually patients returned to modern treatments.

Some family caregivers took their patients to receive traditional medicine. The shaman used sacred words and performed rituals to remove the lump. One family caregiver described that some shamans visited his house to help his mother, the patient. They performed a ritual called “Yo-Lay”, and his mother felt better afterwards. Another family caregiver described breast lump as a “Sarn”. This indicated that something might be wrong. Therefore, the family caregiver was asked to take the patient to see the shaman. One family caregiver performed an ancient ritual on the patient’s lump. Another patient used sticky rice mixed magic formula to put onto her own breast. The family caregivers took the patient to receive modern medication when the patient started to feel severe pain.

Siri stated that the lump on her mother, which the local people called “Sarn”, as a result of an allergic reaction. Siri and her mother did not realise that the lump was cancer; therefore, she took her mother to the folk doctor (shaman) and performed some ceremonies before seeking a modern doctor. Siri explained that this traditional ceremony was said to have cured the lump for some people. However, this ritual could not treat her mother.

> *“For several years. The local people call that kind of mass as “Sarn”. At that time, we did not think that it was cancer and local villagers did not know much about this disease. She went to the folk doctor and did some ceremonies before chanting the magic formula on the betel leaf and placing it on the mass ... Some people said that this ceremony got rid of the*

> *mass for them. In my mom's case, it did disappear for a while before coming back. (Siri, a 37-year-old woman, employed, caring for her mother)"*

Although Arthorn did not believe in any ancient rituals, his mother did. He said that she was being treated by a woman who would visit his mother's home and perform a ceremony named "Yo-Lay". This ritual was a religious practice for certain groups. Arthorn stated that this traditional belief helped his mother to be at ease.

> *"I do not believe any of that, but an older lady came to perform "Yo-Lay", where the lady would transfer her energy transfer to my mother through their palms. It was a belief of a religion. They came to our home to send energy to my mother. My mother was asked to sit down, and they put their palms on her to make her feel better. (Arthorn, a 34-year-old man, employed, caring for his mother)"*

Wanna's mother-in-law thought that the lump on her breast was just an abscess, so she covered her breast with sticky rice and she hoped the abscess would be gone. However, the abscess remained on her breast. Her mother-in-law then brought some medicines to treat the lump by herself instead of going to visit a health professional.

> *"At first, she thought it was an abscess, so she put sticky rice over it and hoped it would go away. However, it was not the case and it was still there. She did not intend to go to the doctor so she brought medicine cleaned the wound herself… (Wanna, a 38-year-old woman, unemployed, caring for her mother-in-law)"*

Aom said that when his mother had breast cancer, he asked her to go see a modern physician. He believed that a shaman could cure the wounds arising from diseases such as Herpes Zoster. However, he did not believe that cancer could be cured the same way. Nevertheless, his mother preferred to have a traditional ceremony. She asked him to take her to receive the ritual from shaman several times. Aom found that the lump on his mother had grown into an ulcer. He thought that it came from the shaman's saliva when he blew water onto her breast. His mother realised that this traditional treatment could not cure her disease. Aom stated that he did not believe in the traditional treatments but it helped with his mother's mental health so he followed through with her requests.

> *"With cancer, you need a proper doctor. I believe in something such as Herpes Zoster can be cured by a witch doctor. However, cancer is different. I absolutely do not believe it can be cured by a witch doctor. The tumour was found deep under the skin and could decay... At the time, she was 65 years old. I mean, she did not want to see a proper doctor and chose the witch doctor, so I took her to see them. They kept blowing sacred water onto her. There was saliva in the sacred water and it was blown onto her breasts. That is how the bacteria spread, I think, and it grew into an ulcer …At first, she said she felt it burning her skin but felt better when the witch doctor blew scared water on her. Now she realizes that it was no good and it was only personal belief and the peace of mind … I just think of it in the medical perspective... Just whatever pleases her! It was just before the operation*

> *when I took her to see a witch doctor. I never actually believe that the witch doctor could cure her. (Aom, a 49-year-old man, employed, caring for his mother)"*

Decha believed in traditional rituals as he had experienced as a shaman. Previously, Decha described that people used this ceremony to treat all types of tumours. He learnt a ceremony from previous generations that cure people's diseases. He used this ritual to treat his wife. He believed that his ceremony could cure the visible part of the lump but not the part on the inside. She was experiencing severe pain so Decha took her to see the doctors.

> *"I believe some. I do it for her like reciting incantations for the cancer treatment. I learnt it from my grandparents. I believe that it can cure cancer on the outside but not on the inside. In the past, people used this magic formula to treat cancer. Anyway, when I use it on her, the cancer was still there because it was inside her body. When it caused more pain, I took her to the hospital... (Decha, a 72-year-old man, unemployed, caring for his wife)"*

In the case of the medical herbs, half of the family caregivers used herbal plants for medicinal purposes. They allowed patients to use both traditional Thai and Chinese herbal medicine such as Yanang, Angle Grass and Soursop leaves to improve patients' health alongside western medicines. They believed, based on their knowledge, that those medical herbs could kill cancer cells. Some family caregivers learnt how to use them from websites and TV programs. Several family caregivers were recommended to use herbs by their neighbours and friends. Some family caregivers grew various herbs in their gardens to enhance the herbal approach. They stated that it was better to drink medicinal herbs as hot as possible. Prakit supported his patient to take both western and traditional medicine. He made tea using Thai traditional herbs Yanang and Pandan leaves. He encouraged the patient to drink this herbal tea with every meal. He learnt this herbal approach from a group of elders experienced in traditional herbs.

> *"There's modern medicine, traditional medicine, herbal medicine. We extracted the juice out of Ya nang leaves, pandan leaves. We grew our own Manoon leaves and used them as ingredients. We heard it from elder people that it does help. However, there is no academic to support their claims. Nowadays I make the herbal drink for her to drink with every meal. I put them in the pot as a regular drink. Tomorrow she will receive another Chemotherapy. (Prakit, a 61-year-old man, employed, caring for his wife"*

Anucha used Angle Grass, a Chinese herb, for his mother. She brought Angle Grass from her neighbour who had experience with cancer. The neighbour grew Chinese herbs as a business and sold to his mother for around 10 Baht to 20 Baht (90 cents). Anucha's mother used those herbs for her drinks.

> *“It is called Angle Grass. It is Chinese grass. My neighbour had cancer on his head before. He plants a lot of Angle Grass in his front yard and he sells them to my mum for 10 Baht or 20 Baht. Mum will wash it first before pounding it. (Anucha, a 36-year-old man, unemployed, caring for his mother)”*

Siri also used Angel grass to treat her mother as advised by her friends. Siri explained that Chinese herbs could treat her mother’s wound. Her mother ate raw leaves after she had surgery.

> *“Beijing grass or Angel grass. Someone at the salon shop had advised me to let my mother eat it. This grass can heal up the wound. She ate fresh, only the leaves. She ate it after operations to heal up the wound. (Siri, a 37-year-old woman, employed, caring for her mother)”*

Srichai provided Soursops tea (a kind of Thai herbs) for his wife. He also received Hoan Hoc leaves, a Chinese herb, from the patient’s sister. As recommended by a pharmacist, Srichai explained that if his wife continued to have Hoan Hoc herbs every day, the production of cancer cells would stop. Srichai and his wife started using them afterwards. His wife ate seven raw Hoan Hoc leaves every morning before their meal. His wife also drank lemon juice mixed in warm water. Srichai also ate and drank the same things as his wife every day because of his chronic disease including high blood pressure and diabetes. They believed that those methods could maintain a constant level of blood pressure, blood glucose and could stop cancer cells. Since they had them every day, they found that they could control their health conditions. For example, their blood glucose remained stable and their health improved.

> *“She ate Prickly Custard Apple or Soursop. We boiled it! We also grew them ourselves. She ate them every day. It was called Hoan Hoc, a Chinese herb but we have our own species. Her sister gave it to us to grow and we have been growing that for many years. She took the leaves and eat it in the morning, before meals. She ate seven leaves each day fresh. She also drinks 1 teaspoon of lemon juice mixed with warm water. We had it every day and it helped to control the blood pressure and maintained the glucose level. Ever since I ate them, my diabetes has not gotten worse. We had it every morning together, then our sugar level did not rise, and we managed to control our blood pressure, in which both of us have problems. A pharmacist at Nakhon Ping suggested that we kept eating them and we will be cancer-free. My wife never had those until she had cancer. (Srichai, a 64-year-old man, employed, caring for his wife)”*

Chapter Summary

Family caregivers adapted their caregiving tasks to their lifestyles while they also maintained a normal life for their patients. Family caregivers performed their daily activities combined with providing personal care tasks during treatment at hospital and home. They saw the patients as a normal person rather than an ill person, which encouraged the patients to cope with the disease and treatment. They encouraged patients to manage self-care and maintain physical and mental health. They did not see the patients as an ill person as the patients were able to perform their daily routines and managed self-care. Family caregivers maintained patients’ emotional well-being and created positive mental balance. Family caregivers gained information from various sources such as mass media, health professionals, and peer groups. That information reduced the stress of the family caregiver role. Some family caregivers and patients believed that traditional treatments could support the mental health of some patients. Several family caregivers believed that ancient rituals could help.

CHAPTER 8 BURDEN OF CARE

This chapter presents theme four, the burden of care, which revealed the impact of caring, including physical, mental, financial, and work burdens. The family caregiver role affected the lifestyle of the family caregivers which caused the burden of care. Caring for an older patient adversely affected both the physical and emotional well-being of the caregiver as well as costing them socially and financially (Haley, 2003; Jayani & Hurria, 2012). The burden of care in this study is defined as the degree of physical, emotional, social, financial and work consequences experienced by the family caregivers. This theme of the burden of care is divided into four sub-themes: physical burdens, emotional burdens, financial burdens and work burdens (Figure 8.1).

Theme 4: Burden of Care

Caring for a patient with breast cancer may cause physical, emotional, financial and work burdens on family caregivers. Physical burdens can be caused by caregiving routines that the family caregivers performed daily. Physical burdens that family caregivers faced contributed greatly to chronic stress including headaches, eye problems, tumours, back pain and osteoporosis. Several family caregivers reported that providing care affected their physical health conditions at a moderate level. According to emotional burdens reported by family caregivers, they described a moderate level of emotional distress, including exhaustion, tiredness, feeling overwhelming and fatigue arising from the demands of care. For the financial burdens, family caregivers dealt with a constant financial problem at a moderate level due to some out-of-pocket expenses including transportation, petrol, medical expenses and food. For work burdens, several family caregivers arranged their time for regular work hours depending on their caregiving schedules. Some family caregivers reduced their workdays, some quit their jobs and others looking for new jobs to manage caregiving responsibilities.

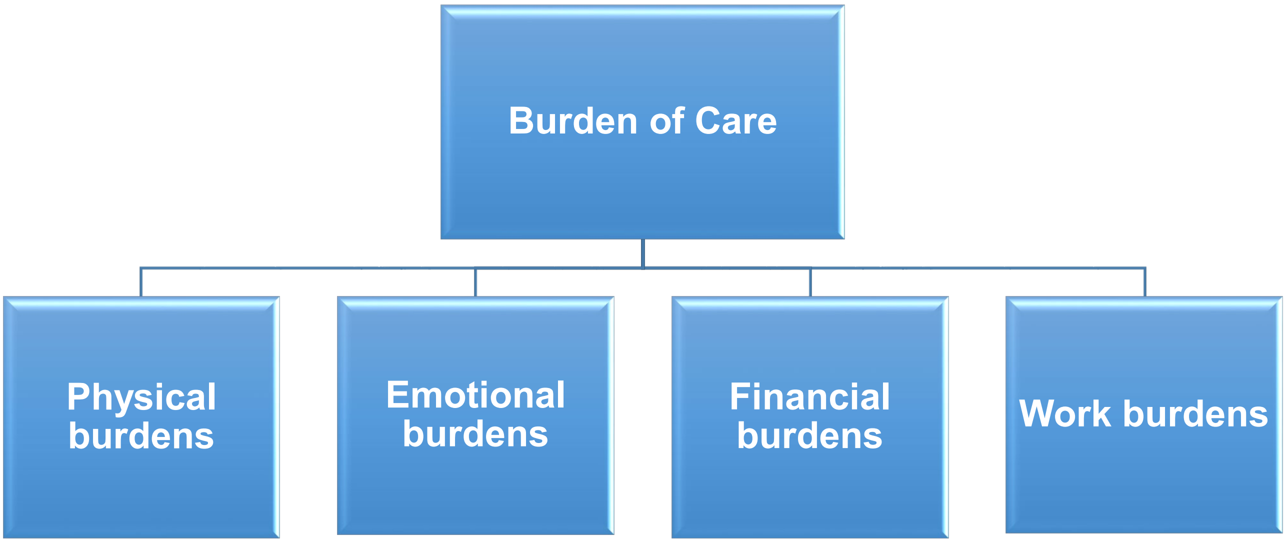


Figure 8.1 Burden of Care

Physical burdens

Physical burdens presented the effects of the caregiving role on family caregivers' health. The caregiver burden involved multiple tasks to manage care for the patients and arranged within the family roles. Family caregivers performed care routines varied in activities of daily living for patients including bathing, cleaning, and cooking. At the same time, they took care of their children and helped partners to work or run businesses. They were expected to provide this type of help based on a sincere faith commitment. Therefore, this helped to reduce feelings of guilt and the negative impacts of caregiving. Over half of family caregivers stated that they experience a moderate level of physical stress such as osteoarthritis, hypertension, headache, back pain, and eye problems. For example, several family caregivers experienced physical consequences from providing care for both of their parents where their mother had breast cancer and father had other health conditions. One family caregiver had headaches due to the daily routines of caregiving. Another caregiver stated that she had a tumour in her breast caused by stress related to providing care and genetics. Some family caregivers had leg problems because they walked from their home to the patient's home daily.

Another family caregiver had eye problems as a result of long-term caregiving. However, the rest of family caregivers (seven cases) reported a low level of physical burden because they thought their health conditions might be due to their old age, work-related stress and physical problems, accidents, health behaviour and congenital disease which may not relate to caregiving. During caregiving, Aumara described that she had terrible headaches and sometimes could not get up in the early morning. As of late, Aumara reported that her mental health was manageable but her physical health was not. Aumara said she could perform daily activities but she would frequently pass out.

> *"If you think physical strain, sometimes I cannot help her much. Sometimes I have a bad headache and could not get up... For the past couple of months, I am mentally strong, but my body is weak. I can do everything when I am strong such as gardening, but lately, I pass out quite often. (Aumara, a 60-year-old woman, employed, caring for her older sister)"*

Ann found out she has had a tumour on her right breast for two years. As a family caregiver, she mentioned that she felt stressed about her tumour. The tumour disappeared for a while before re-emerging after her patient's surgery but on her left breast. Fortunately, the tumour was not spread. She still worried that the tumour may develop into breast cancer so she took a safety precaution of an annual check-up.

> *"I started to have a health problem. My tumour was on the right breast and 2 years after she had cancer, it had gone away by itself. After she had an operation, my tumour turned up on the left breast, but it has not been properly diagnosed by the doctor. I guess it was the build-up... It had not spread… I was sad and thought that I had cancer because I thought it was genetic. I would have another check-up next February. (Ann, a 50-year-old woman, employed, caring for her mother)"*

Prakit mentioned that he had eye problems as a family caregiver for more a decade. For two months, he had double vision and it caused some mobility issues. He went to see the doctor and the result was found that he had a blood clot in his nerves. He did not have surgery because it was too risky. The doctor suggested that he should have palliative treatment rather than surgery.

> *"I have eye problems when I was caring for my wife. My vision was blurry and I saw duplicated images that went up and down as if I am about to fall into the hole… The doctor told me I have blood clots in my nerve... I have been with this condition for the past 2 months ... The doctor did not treat me with surgery because it could be dangerous. (Prakit, a 61-year-old man, employed, caring for his wife)"*

Emotional burdens

Emotional burdens were the consequences of caregiving caused by lack of social support, and handling complications after the patient underwent treatment. When caregiving demands were high, the emotional distress from care was also increased. The majority of family caregivers felt overwhelmed by the family caregiver role. Some family caregivers expressed that they felt stressed, conflicted, and exhaustion due to lack of support. Some family caregivers had no support from other family members. Some family caregivers felt overwhelmed by caregiving roles and work. Side effects of cancer treatments can also cause patients' emotional disturbance. Over half of family caregivers said they were stressed when the patients underwent treatment. During cancer treatment, patients displayed some inappropriate manners towards family caregivers such as complaints, frustration, and tantrums which caused emotional burdens on family caregivers.

"Everything was on my shoulders," said Siriluk. She was the only one providing care for the patient, though her sister helped her from time to time. Siriluk had to deal with her work and care for her mother. Her brother had his duties with his family so she did not want to ask for his help. She often felt overwhelmed.

> *"I have to work. My sister used to work as a caddy at a golf course, but she quit her job because of her bad eyesight. Nowadays she just stays at home. I had to do what is necessary. There is no one to help me out. My brother does not help much...Everything is on my shoulders ... I cannot talk to anyone else, just my sister… I sighed a lot and it became my habit now. (Siriluk, a 52-year-old woman, employed, caring for her mother)"*

Pim said that she was willing to care for her mother even though the role often exhausted her. She mentioned that she had never given up on helping the patient because the patient was her mother.

> *"I was willing, but I was tired. However, I never felt about why it had to be me because she is my mother. (Pim, a 45-year-old woman, unemployed, caring for her mother)"*

Supod experienced emotional issues after his patient underwent chemotherapy. He handled the issues by remaining quiet to avoid conflicts. He received encouragements from his daughter to keep calm and be strong. Whenever his patient complained, Supod would remove himself from the area to avoid getting into a conflict. He let his patient adjust her emotions then he would return to her.

> *"At that time, I tried to remain calm; otherwise we would be angry at each other. Our daughter told me to be strong and it will go away. If I were not around even for a short while, she would start complaining. However, if I stayed, she also complained. People had to understand her and tried to adjust themselves to her. ... When she complains a lot I would just get up and leave then come back when she felt better... (Supod, a 72-year-old man, employed, caring for his wife)"*

Ampai had emotional distress during her grandmother's chemotherapy process. She felt stressed and annoyed because of her role as a caregiver. However, Ampai and her grandmother never argued with each other. She was concerned about her young children while providing care for her grandmother.

> *"Sometimes I felt stressed and annoyed with the daily care routine. However, she does not shout at me. She was weak after her chemotherapy so I need to help her... I cooked and brought food to her before I went back to take care of my children because they were very young at that time… I worry about my children and everyone at home. (Ampai, a 47-year-old woman, employed, caring for her grandmother)"*

Financial burdens

Travel costs such as public transportation fees for patients were paid by family caregivers to help patients get to their medical appointments. The healthcare cost affected many family caregivers financially. The majority of the family caregivers in this study had low incomes. Hence why most family caregivers reported a high level of financial burden, while some family caregivers reported a moderate level. The medical care expense such as room and treatment costs were not covered by healthcare insurance. Other expenditures included travelling, food, rent, medications and petrol. The family caregivers attempted to save sufficient money for medical cost and transportation due to the financial strain of caregiving. Having a financial reserve to cover the caregiving cost was an essential part of caregiving management. Daow could use welfare benefits which allowed her to reimburse all cancer treatment expenditures by claiming the government. However, she had to pay in advance because healthcare systems could not provide a direct claim and then needed time to process a refund. Daow described that she had to ensure that the cost could be reimbursed before the next payment because she just had only one reservation for the next healthcare cost.

> *"In the past, we paid the whole amount first with no direct claim for medical care. I made contact with the financial officer to ask about the process of reimbursement to ensure that the process effectively runs and we will have enough for the next payment. We do not have enough reservation for other payments. (Daow, a 43-year-old woman, employed, caring for her mother)"*

Srichai said that his financial burdens were the travel fees and treatment expenses. His patient had healthcare welfare but still had to pay extra charges for a room in the hospital. Therefore, during caregiving, Srichai needed to cook food for his wife rather than buying food in order to save his money for petrol and treatment costs.

> *"Most of my money was used up by travelling expenses. For the treatment expenses, she*

> *used gold card welfare. I paid the extra 1000 Baht for the staying over. During this time, we had to cook our own food because we needed to save money. (Srichai, a 64-year-old man, employed, caring for his wife)"*

Suratin reported that he was the main financial support for his family and patient. He had to pay the bills for petrol, transportation, rent and food. He mentioned that his income was quite low, and he had managed his business every day to earn enough money to support his wife. When he took workdays off to take her to the doctor's appointments, he would lose his income from his business. He had just enough money for food but did not have any money kept in reserve. He borrowed money from his friends and would pay them back after he earned the amount of money he borrowed.

> *"Her lymph node was taken off and she stayed in a shared room. I mainly look for money to pay her medical bills and for transportation, and food... We lost some income but we could go on. We still had food to eat, but I had no financial reserve… She has to go to the hospital this week for an appointment, so I sold some stuff and collected money and sometimes I borrowed from my friends. Then I worked to repay them. I run my own business, so I could take days off unlike office job. I close the shop to take her to the hospital. (Suratin, a 61-year-old man, unemployed, caring for his wife)"*

Work burdens

Work burdens referred to work management associated with balancing work hours and caregiving time for patients. More than half of family caregivers reported that the caregiving roles interfered with their work. Family caregivers reported that caring responsibilities had a high impact on their employment. Several family caregivers re-scheduled their work time for their caregiver role. For example, some family caregivers had to leave their work to transport patients attending doctor's appointments several times. They felt uncertain about their future and were afraid of losing their jobs due to caregiving. Family caregivers considered quitting paid employment due to caregiving. Another family caregivers received complaints from their co-workers for their frequent absence. A family caregiver decided to find a new job closer to their home for convenience. Some family caregivers changed their work shifts to take patients to medical appointments. Some family caregivers temporarily stopped their businesses to transport patients to hospitals.

Siri took half a day off from work to take her mother to the hospital. Her mother underwent treatment chemotherapy for a couple of months. During this treatment, Siri also provided care of her father who had other health problems. She said she was concerned about her work due to frequently taking days off.

> *"At that time, I had to take leave for half a day... I took a half-day off twice a month to take my mom to get chemotherapy. On top of that, my dad was sick with Emphysema. The doctor also made an appointment at the same time, so I take days off quite often... (Siri, a 37-year-old woman, unemployed, caring for her mother)"*

Ampai took leave during her grandmother's radiotherapy. She had to work for five days a week; otherwise, she did not have enough income to support her family. Ampai also mentioned that she struggled with criticisms from her co-workers. It was her responsibility to take her grandmother to the hospital.

> *"…I asked for my business leave from my employer. I work only for five days. During the course of radiotherapy, I stop working. I need to work here every day. If I have a day off, I was criticised by my colleagues. I work here as I need the money to support my child's education... My husband does not take the patient to the hospital because it is too busy around here. If both of us were busy, I would take the patient to the hospital. (Ampai, a 47-year-old woman, employed, caring for her grandmother)"*

Arthorn secured a job at a famous company but he decided to not take the job because of care responsibilities. When his mother had the operation, he had to take care of her. His brother works in another city far from the patient's home which poses a travelling issue. Arthorn decided to take the responsibility of being a family caregiver. Arthorn looked for a new job near his mother's home.

> *"I applied for a job at Wiriya Company and got hired, but I needed to move to Samerng which is far away from my mother's house. At the time she was about to have an operation and my brother also works at Lumpoon province and it takes a while to travel here. He could not go back and forth. I just was hired, so I decided against it and tried to find the job near home. (Arthorn, a 34-year-old man, employed, caring for his mother)"*

Siriluk said that providing care for her patient affected her work which caused her to lose income. She had to transport her mother to the hospital for doctor's appointments. Siriluk spent all day at the hospital to accompany her mother when having treatment. Then, she managed to have work off for one day when her mother had appointments with the doctors.

> *"It affected my work. When I took my mother there, it took a long time which resulted in a loss of income. We spent the whole day at the hospital... I had to take care of everything and we were not the only ones at the hospital. It was understandable, and we soon realised that we were going to lose one day. (Siriluk, a 52-year-old woman, employed, caring for her mother)"*

Chapter Summary

Family caregivers coped with being a family caregiver though most family caregivers experienced physical stress at moderate levels. At the same time, family caregivers dealt with family obligations and took care of their children. The majority of family caregivers encountered emotional distress when there was a demand for care responsibilities. Some family caregivers lacked social support to help them cope with emotional distress. The side effects of cancer therapy cause emotional distress to both the patient and the family caregiver. Providing care affected family caregivers' incomes due to the medical costs of cancer treatment and transportation. Sometimes, some family caregivers were in debt because of insufficient money to support their patient. Family caregivers reported a high level of financial burdens because they needed to manage their incomes and salary to support the patient and their family. The family caregivers in this study reported their caregiving affected their employment at a high level.

PART III

Chapter 9: Discussion

Appendices

References

CHAPTER 9 DISCUSSION

Introduction

This chapter presents a detailed discussion of the caregiving experiences outlined in the research findings. The purpose of the study is to describe the care experience of family caregivers in providing care for elderly women undergoing breast cancer therapy. The research question is ‘What are care experiences in family caregivers providing care for the elderly women undergoing treatment for breast cancer in Thailand?’ The study used phenomenology to examine the experiences of family caregivers in order to gain a deeper understanding of the participant's life-world through an interpretive dialogue, that is, a phenomenological approach as stated below. Hermeneutic phenomenology then enabled the researcher to deepen the analysis by reflecting on the topic from the multiple perspectives within the participants' stories. These stories were recorded on a digital audio-recorder, while descriptions of each participant's non-linguistic behaviour were made. Transcripts are constructed texts and different parts of the text are interpreted during the task of writing (van Manen, 1990).

> *Phenomenology is a philosophical “method/practice” of observing, recording, and interpreting “lived experience” through vivid and detailed descriptions ... Philosophical hermeneutics is a philosophical “practice” of interpreting “texts” of all types, e.g., works of art, literary texts, human beings, social institutions, etc ... (Magrini, 2012; p. 1-2).*

The participants were family caregivers who played the vital role of providing care and were able to share their experiences and caregiving perspectives. In total, 22 family caregivers volunteered to participate in the study all of whom were fluent in spoken and written Thai. The participants were asked about the caregiving experience while providing care for cancer patients from their own understanding. They openly shared their stories of the caregiver role and the burden associated with interacting with patients, other family members, health professionals, and the healthcare system.

Semi-structured interviews were conducted and digitally audio-recorded, after which the interview transcripts were analysed using van Manen's hermeneutic phenomenological method. During the data analysis phase, the description and interpretation gained from the participants’ aspects were shaped by the researcher’s knowledge, assumptions, and beliefs.

The analysis followed van Manen's six steps of philosophical hermeneutics. The NVivo software package was used to manage and synthesise the themes. The findings included four major themes, including family caregivers' relationships, acceptance, care management, and burden of care which reflected the unique Thai caregiving context. These themes illuminated family caregivers' sense of care experiences. In addition, cultural background, beliefs, alternative treatments, and the healthcare system were influences on the family caregivers' views that revealed cultural differences in caring and in the complexity of family issues. The guided reflections based on van Manen's theoretical framework involving lived space (spatiality), lived others (relationality), lived body (corporeality), and lived time (temporality) are discussed at the end of each theme. van Manen's theoretical framework has been described in Chapter 3. The limitations and strengths of the study are then described in the next section, followed by recommendations for future research as well as the implications of the research.

Review of Findings, Theme 1: Strengthening Relationships

Family caregivers and patients

Family caregivers valued their relationships with the patients, as they believe that a bond between them helped improve the physical and psychological health of the patients. The current study found that family caregivers showed both positive and negative caregiving characteristics, but they felt more positive than negative overall. The most positive aspects were shown in the relationships between a patient and a family caregiver who were spouses or children. In the extended family, less positive relationships were found in the in-law relationships (e.g., mother-in-law and daughter-in-law relationships). In the case of the relationship between spouse and patient, spouse caregivers felt great sympathy for their loved one, and truly loved caring for them. Spouse caregivers showed their feelings in this regard; for instance, 'We were being together to do care', and 'I do care because I love her'. While providing care, they came to a compromise when they disagreed: 'I tried to keep calm down when misunderstood' and 'we were not argued during providing care'. This might be due to maintaining physical and psychological well-being for the patients. The relationship between the patient and the family caregiver who are daughter and son mostly showed a sense of moral obligation, obedience, and guilt in caring for their mother who suffered from breast cancer. Their feelings were reflected in comments such as ‘She is my mother’ and ‘It is my duty’.

The relationship between patients and blood relative caregivers involving siblings were characterised by the expression of sympathy. They felt responsible for the patient, because the basis of providing care was formed by the family relationship, and caregiving was a priority for them. They implied that ‘I tried to do my best for her’. They reasoned that they had commenced caring because ‘it was because she is my relatives’. This could be described as providing a sense of love, caring, obligation, and respect for the patient, which is a basic form of sympathy associated with family relationships by responding to the expression of feelings and emotions when providing care. In addition, family caregivers dealt with their caregiving in relation to maintaining relationships and avoiding possible conflicts with the patient. They maintained family relationships to share emotions with patients which were strengthened by the care circumstances. The strong family-centred values strengthened the relationships of family caregivers who had close relationships with patients, which were of benefit when providing care. These findings have been further supported by many studies (Bachner et al., 2009; Duggleby et al., 2014; Fergus & Gray, 2009; Hodges, Humphris, & Macfarlane, 2005; Snellman, Gustafsson, & Gustafsson, 2012). For example, the relationship between husband and wife focused on the importance of relationships rather than physical health. The husband always shared mutual moments and gave hope with his wife for a longer life-span (Duggleby et al., 2014). A relationship between a family caregiver and a patient provides a sense of respect and mutuality during the caregiving process. The family caregiver and the patient work together through mutual respect. This mutuality demonstrates the significance of a meaningful care relationship for both patients and family caregivers (Snellman et al., 2012).

Conversely, some relative caregivers, including daughters-in-law and nieces reported emotional distress when providing care (e.g., worried, sad, and irritable), associated with the status of the relationship. Examples of daughter-in-law caregiver statements were, ‘She does not trust me in regard to following my advice’ or ‘We seemed incongruent with each other’. This might be due to the relationship status that might affect different viewpoints about caregiving. Relative caregivers may not appear as close to each other as children and spouse relationships. This suggests that the purpose of caregiving might differ depending on relationship status and socio-cultural background.

Relative caregivers might also expect to achieve the goal to improve a patient's wellbeing and patients' satisfaction.

In the Thai setting, the sense of perceived caregiving burden is very positive; in particular, the relationships between child caregivers and their mothers, and relationships between partner caregivers and their wives. Family relationships are strengthened further with caregiving responsibility. Family members contributed to a great deal of family business involving cultural considerations, as elderly Thai people tend to live at home even with a chronic illness, and the Thai structure has currently been maintained through the extended family (Chunharas, 2007). Cultural relationships are valued by Thai people as children were taught and taken care of by the elderly patient. Spouse caregivers and cancer partners were caring for each other in dyadic relationships.

Family caregivers and other family members

In the case of other family members who were relatives of family caregivers, the current study highlighted that other family members played a vital role in helping family caregivers during caregiving activities. Other family members, including siblings and children, helped with routine care for the patients whenever possible. Family caregivers stated that 'We helped each other' or 'I asked them for help', which meant other family members took responsibility to help the family caregivers. Other family members shared the caregiving burden to complete the caregiving duties, which eased the burden on the family caregivers. This suggests that caring for elderly patients with breast cancer can be a physical burden; thus, family caregivers needed someone to help them and also to share their emotions with (Haley, 2003; Northouse et al., 2012). Concerning family relationships, family caregivers naturally depended on other family members to maintain the caregiving responsibilities (Junda, 2004; Youngmee Kim & Schulz, 2008). They were close to the other family members and felt free to call on them to complete their caregiving routines (Rolland, 2005; Youngmee & Given, 2008). Other family members felt an obligation to help each other and to be considerate of family caregivers. They stated, 'We were relatives' and 'We were dependent on one another'. This finding shows the importance of the relationships between family caregivers and other family members in helping each other with the caring responsibilities, which was influenced by the requirements of the caring situation.

The family caregiver, health professionals, and the healthcare system

Family caregivers reported both positive and negative outcomes in regards to their relationships with health professionals and the healthcare system. They followed doctors' instructions involving the provision of care. They frequently stated that 'I did what the doctor suggested' or 'I just keep the practice whatever the doctor said'. This suggests that family caregivers trust in the health professionals that they can possibly improve cancer patients' symptoms. Health professionals also help to relieve caregivers' anxiety levels, even though medical appointments could not reduce their caregiving burdens. As they described, 'If the doctor makes regular appointments, my patient would fine'. This was because they did not have to be worried about the patient's illness if the patient had follow-up appointments managed by the physicians during treatment. They believed that 'The treatment could protect her (patient)'. This attitude suggests a perception that the patient's life was already in the doctor's hands. Such positive aspects of the family caregiver-health professional relationship was also found in previous studies (Francis et al., 2011; McDonnell et al., 2019; Mitnick, Leffler, Hood, American College of Physicians Ethics, & Committee, 2010; Youngmee & Given, 2008). Francis et al. (2011) revealed that families and care providers are frequently involved in the relationship for the ongoing provision of proper care for cancer patients. Relationships can be for better or for worse, which influences the family caregivers' experiences and emotions. Healthcare professionals can influence the caregiving experiences of family caregivers in relation to physical, psychological, spiritual, and emotional needs, and in recognising the value of the family caregiver's role (Mitnick et al., 2010).

Family caregivers also reported a lack of knowledge of how to navigate the healthcare system. They had limited experience with healthcare processes because they had struggled to manage the patient's health. For example, most family caregivers faced a breakdown of the radiotherapy machinery during treatment, which resulted in interruptions to the treatment process. They pointed out that 'We did not know much about the hospital's processes', and 'We have to wait for a long time'. As well, most family caregivers and patients had lived in remote areas where the primary healthcare services are of a poor standard and are insufficiently supported. Also, the transfer process from primary healthcare services through to the secondary or tertiary healthcare services can cause delays. This issue can cause a physical and mental health crisis for patients and family caregivers. For example, family caregivers stated that ‘It has been many steps to transfer the patient from primary health service to a secondary hospital’. Most patients and family members often waited for a long time to see their doctor, to receive treatment, and to have an x-ray (Sandén, Nilsson, Thulesius, Hägglund, & Harrysson, 2019). In particular, these types of delays were highlighted as a major concern for family caregivers. Most family caregivers did not know how long the overall process would take. They were concerned that the effects of delaying treatment would lead to a worsening of the patient’s breast cancer; they concluded that ‘I do not want to wait because cancer may cause her health to decline’. Healthcare teams were also likely to avoid explanations associated with delayed treatment processes. This suggests that health professionals might be afraid of relationship conflicts. Therefore, the hopes of family caregivers in the early stages of treatment were unfulfilled in relation to the services being provided. Also, the family caregiver and the health professionals were less likely to communicate about the subsequent health outcomes of the patients. As one family caregiver stated, ‘They spoke improperly to the patients.’

This finding can be explained that even though most Thai family caregivers reported positive feelings about their relationships with health professionals, the communication that resulted from a lack of knowledge between the family caregiver and health professionals was negative. Family caregiver and physician reported that communication about cancer care differ depending on educational levels and backgrounds among them, and agreement on communication is limited. This might be due to communication has shown directly with personal relationships in the Thai context. The cultural background that influenced communication between family caregivers and health professionals is complicated, and this was exemplified through the difficulties they faced in discussing medical information. The caregivers indicated that they did not know much of the detail about the healthcare process and particular therapies. However, they did not ask the health professionals, but rather, they tried to understand the information based on their cultural beliefs, as they indicated that ‘We understand because treatments are provided based on specialists in health workforce’. This suggests that family caregivers might conceal what they did not know, and they chose to not address the issues arising from information they did not understand. This finding in relation to communication barriers is consistent with earlier Thai studies (Junda, 2004; Limpawattana et al., 2013; Meecharoen, Northouse, et al., 2013; Meecharoen, Sirapo-ngam, et al., 2013). Previous studies across the globe have also concluded the same challenges being faced (Baider & Surbone, 2014; Mystakidou et al., 2004; Senden et al., 2015; Wright et al., 2008).

In the Thai healthcare system, public hospital services are made available centrally by the Ministry of Public Health (MoPH). Public hospitals in Thailand are classified into three groups: primary, secondary, and tertiary health services (Valdmanis, Kumanarayake, & Lertiendumrong, 2004). Tertiary hospitals are more capital- and technology-intensive than primary and secondary healthcare services. Therefore, different care services and advanced treatments are provided by the different types of hospitals (Valdmanis et al., 2004). It is also important to consider the number of patients and family caregivers that lead to an increase in primary health service utilisation. Service provision can also be delayed due to access to tertiary hospitals. Public health policy might provide insufficient resources depending on government funding, the available workforce, and the hierarchical process in medical and healthcare decision-making. Therefore, the number of health staff, and the amount of medical equipment were limited and insufficient for managing care.

Reflection of Lived Others to Strengthening Relationship

Lived others (relationality) is the lived human relations and maintain with others in the interpersonal space that we share with them (Heinonen, 2015). When individuals have related to others, they gain an impression of what other people are like, which can be developed or altered in their interactions with them (Krumwiede & Krumwiede, 2012). Lived human relations are reflected in the development of relationships between family caregivers and other parties, including patients, other family members, and health professionals. In this study, lived others are underpinned by social and cultural relationships in which family caregivers are considered to be the person to take on the role. The family caregiver lives the experience of being a significant other of a patient with cancer and handling the illness of the patient. The patient also lives their situation from diagnosis through to, during, and after treatment. Other family members and health professionals live in concern about the other's health. Family caregivers shared a variety of stories or kept the secret of caregiving depending on their relationships with particular parties. Family caregivers developed their relationships with other parties through their communication. Social norms played a key role in the positive relationships between family caregivers and patients, even though they may have had conflicts with each other. They shared their actual experiences with other family members who understood their lifeworld in relation to everyday care, experience, and respect. Nevertheless, sometimes they did not share their experiences with others when they felt uncomfortable. Family conflict may also occur because of differences in attitudes towards family issues and differences in relationships between blood relatives and ‘in-law’ relatives.

The relationship between family caregivers and the other parties, including patients, other family members, and health professionals have been considered to be of great value throughout their entire lived experience. According to the family caregivers’ experience, their relationship with the patients was a ‘lived other’ relationship due to their bonds. Most family caregivers expressed a sense of love and caring embedded in mutual understanding. Regarding the relationships between family caregivers and other family members, they interacted with each other, as they are siblings or blood relatives in a family. Family caregivers shared their experiences of everyday caregiving and attitudes with other family members. Other family members realised that caregiving for the patient was also their obligation, and therefore, they helped the family caregivers manage the caregiving activities. Thus, their lifeworld can be known in a shared knowledge of value caring, to share tasks and responsibilities, and to share communication. In the case of the relationship between family caregivers and health professionals and the healthcare system, they kept contact with health professionals to improve caregiving performance and to gain knowledge about cancer. Family caregivers accepted that ‘It was the doctor’s duty’ or ‘We accepted any assistances from the health professionals’. They understood that they were in the same world of the caregiving situation and were connected by social and community relationships.

Review of Findings Theme 2: Acceptance of Caregiver Role

The acceptance of a new role as ‘family caregiver’ varied between acceptance and a lack of acceptance depending on the phase of the caregiving role. The family caregiver demonstrated their care experience through two different perspectives. There were potential rationales under these experiences which can explain how family caregivers accepted their role before starting their tasks. At the initial phase of the role, family caregivers felt for a sense of fear about losing their loved one as they knew the cancer diagnosis would affect the patient's health. They also felt worried and uncertain about their unpredictable future and how the progression of the cancer would affect the patient's life. Family caregivers mentioned that 'In the beginning, we were worried because of breast cancer' or 'I was totally shocked due to the word 'cancer'. In Thai culture, people tend to avoid talking about serious conditions, including cancer, with the patient as they believe that a conversation about illness can create negative feelings in the patient such as sadness, stress, and anxiety. These situations occurred because they lacked prior experience and the skills needed to manage cancer care in the home.

Another reason they may feel 'unwilling' or 'unaccepting' to provide daily care is because they were unfamiliar with the new tasks in which they were not confident about 'doing' or 'not doing' particular activities with, and for, the patient. Most caregivers stated, 'What is going on?' and 'What should I do?' They were required to adjust their life to maintain their daily routine and in addition to scheduling a care plan for the patient. Initially, they had only limited knowledge and understanding of the disease and how it affects the patient's health, which caused them confusion and anxiety in starting their caregiver duties. As a result, they feared for their ability to cope with the new role, and felt uncertain about their future and the patient's life, and thus, were unsure about accepting the caregiving role (Doumit, Huijer, & Kelley, 2007; McIlfatrick, Sullivan, & McKenna, 2006; Peacock, Duggleby, & Koop, 2014; Prechavittayakul, 2006; Wennman-Larsen & Tishelman, 2002). However, within six months to one year of commencing the caregiving role, they reported a positive understanding of their new job, and eventually, they were able to accept it by trying to reduce their anxiety and stress. Therefore, most family caregivers implied that 'It just quite tough at the beginning', and 'It was a short period'. These comments suggest that in the later phases of caring, family caregivers accepted the role after a period of necessary adjustment to their daily life and their patient's needs.

The relationship between the family and social norms plays a crucial key in accepting the caregiving role in Thai culture. Family caregivers is signaled by the primary responsibility for families to look after their parents and the senior members of their family, after which they gradually accepted their new responsibility of caring for the patient with cancer. Being together in a close relationship demonstrates why family caregivers must accept their role. For instance, most relatives and children caregivers stated that 'We have to be together' or 'She (patient) has nobody and I am her daughter'. Most spouse caregivers mentioned that 'We are like a friend' or 'I do not leave her (patient) alone'. This suggests that in the Thai context, children, relatives, and partners who are principal caregivers are unlikely to leave their elderly patients in aged care facilities even when they have insufficient income to support the patients at home. To provide more context, an aged care facility in Thailand is completely different from those in the western world, because an aged care facility in Thailand is a free government service for elderly people who have no-one to care for them and no financial support. Caring for the elderly is considered an important task in relation to religion and spirituality that helps family caregivers find meaning in their caregiving role (Sethabouppha & Kane, 2005). In the Thai context, caring for the elderly patient is embedded in culture, beliefs, attitudes, and religion through which people feel deep gratitude towards their parents who raised and cared for them. Relative or spouse caregivers also treated their partner's parents as their parents because they have been taught to respect each other's families. It is unacceptable for a person to refuse to care for their other family members, especially the elderly and senior members, according to Thai social norms and social justice. The contributions of religion to the acceptance of the family caregiver role have been reported in many Thai and international studies (Junda, 2004; Kitrungrote et al., 2008; Meecharoen, Northouse, et al., 2013; Sethabouppha & Kane, 2005; Sterba et al., 2014; Vithayachockitikhun, 2009).

Interestingly, breast cancer patients in the current study were more likely to accept their cancer diagnosis than family caregivers. For example, a daughter caregiver said 'My mother believed she was very old and the doctor would not have done anything for her.' This implies that patients were able to accept death if their disease could not be treated, as they accepted that time is already short for elderly people. Conversely, family caregivers expressed more stress and anxiety than the patients, which is consistent with previous studies (Buhr, Kuchibhatla, & Clipp, 2006; Rhee et al., 2008; Winterling, Wasteson, Glimelius, Sjödén, & Nordin, 2004).

Preparing for becoming a family caregiver

Family caregivers felt unprepared for performing their new duties because of a lack of essential knowledge and understanding of cancer and cancer care. Most family caregivers expressed their deep concern about preparing themselves to become a family caregiver, and they accepted this role with great stress and anxiety. They described themselves before starting their caregiver role in the following ways: 'I do not know what to do' or 'I did not know what happened next?'. A family caregiver, for instance, stated that 'I only completed my Grade 4, so I do not have enough knowledge.' Thus, these were reasonable explanations that they did not know how to perform care in the initial phases and did not understand much about cancer and its treatment in their discussions with health professionals. This was also found in other studies (Giacalone et al., 2005; Giacalone et al., 2008, 2009; Locatelli et al., 2010). More than half of the family caregivers who participated in this study had low levels of education. This suggests that low education may lead to poor health literacy, which can be a potential barrier against the understanding of health information and can hinder caregiving among these family caregivers (Chapman & Rushy, 2003; Khanjari et al., 2014; Li & Loke, 2014; Yun et al., 2010). Ambiguity arose when family caregivers had limited knowledge and information, which made them lose confidence in providing care and discussing a care plan with the patient.

Reflection of Lived Body, Lived Time, and Lived Others in Acceptance of the Caregiver Role

According to van Manen, the *lived body* describes the feelings of people shown in their body language when they consciously and unconsciously perceive complex situations. In regard to the findings in Theme 2: the acceptance, family caregivers expressed their feelings through a sense of acceptance shown in negative emotional responses to the diagnosis of cancer, including their fears, shock, depression, and anxiety. However, these feelings could become positive when family caregivers had accepted their new role in their mind.

Lived time is described in the context of the caregiving role varying in the present, past, and future of the caregiving environment. Family caregivers are persons who live the timing of entry into the caregiving role. From the time prior to caregiving, they have been accustomed to a normal situation without considering the provision of care for another person until the caregiving commences. During the current caregiving, time reflects the caring situation in which the family caregiver provides the care and have altered their lifestyle to do so. As this time, family caregivers worry about getting an unfamiliar task and a new caregiving role. For example, some family caregivers expressed their feelings of the lack of acceptance of their role; ‘Do not know’ and ‘How to provide care’ or ‘I am not ready to help’ were often mentioned in the lived time of the initial phase of caregiving which corresponded to the patient's initial phase of the disease. However, they had to accept their caring role without considering their knowledge and skills. Some family caregivers demonstrated that they were ‘Willing to do provide care’, and ‘I can do no matter what’, even though they had little or no preparation. This was a culturally acceptable form of compensation when lived time and lived body had affected feelings about the care experience. They felt familiar with the situation when passing through each task of the caregiving process. They might be unhappy or enjoy themselves when providing care, but lived time-related caregiving may reduce or increase suffering when people are busy with their roles and responsibilities. Eventually, the lived time of the future describes that the patient still lives with their family during palliative care or in the late stages of the disease, and that family caregivers continue to adjust their daily lives due to their continuing responsibility for the patient. Besides, the lived time of the future can help them to accept their caregiver role and increase positive thoughts about accepting their perceived moral obligation. This future time can reduce the impact of stress and anxiety related to the caregiving burden.

Lived others are oriented by relationships related to the acceptance of the caregiver role. Family caregivers provided their rationales for the acceptance of their new role, as the patient is their loved one or a relative in the family. Relationship status, whether they be a spouse, daughter, or siblings, contributed to accomplishing the role and duties in which family caregivers are most likely to perform care. This dimension is likely to be reflected in the family caregiver’s perspectives in line with Thai norms and cultural expectations. The caring responsibility in the Thai context is related to the degree of obligation that other family members feel. Most of the participants’ comments illustrated that ‘Caring for my patients (e.g., mother, sister, and wife) is my duty’, which reflects why they accepted the caring role. Therefore, acceptance typically came from cultural considerations and relationship status in the family, rather than from the family caregivers’ sense of satisfaction.

Review of Findings Theme 3: Care Management of Family Caregiver

Adjusting life for the patient

The current study found that family caregivers experienced difficulties in managing new challenges facing their lives and needed time to make attitude adjustments. Most family caregivers generally did not seem to be distressed about their life adjustment at the time of the interview. However, some of them still mentioned the stress they were experiencing in managing their routine in supporting cancer patients. In the early stages of the caregiver role, all family caregivers reported a significant impact on their everyday lives, including socialisation, lifestyle, relationships, and attitudes toward their new caregiving role. They mentioned ‘I was her arms and legs’, which resonated in adjusting their life for the patient. Caregiving can be challenging on both family caregiver's psychological and physical well-being when the family routine changes as a result of the patient being diagnosed with breast cancer. Family caregivers stated that, ‘My routine has changed when she (patient) cannot do and I did activities for her.’ This suggests that the initial stage of life adjustment occurred in the early stage of the cancer diagnosis and treatment, which was a period of six months to one year. After this, the carer can manage both the daily routine of the patient in addition to their own role; here, they described this process as ‘Everything is back to normal mode because it is just difficult towards the beginning.’ This shows that family caregivers were likely to adjust in their own way within the context of the later stages of caregiving. This finding is consistent with the findings from previous studies (Carlson, Bultz, Speca, & St. Pierre, 2008; Youngmee & Given, 2008).

The current study has also found that family caregivers used the patient-centred approach for both physical and mental support of the patients’ needs and to develop a sense of normality. Most of the family caregivers said that ‘I will do everything that she (patient) wants’, meaning that they prioritised the patient’s care over other tasks and intended to motivate the patient to perform self-care. In daily activities, family caregivers followed the patient’s needs including eating, cleaning, toileting, shopping, transport, medication management, and symptom monitoring. Sometimes, the family caregivers allowed the patients to perform their own activities; for instance, they said, ‘All activities are regularly done by her, including the housework’. Being normal was demonstrated by most family caregivers stating that ‘We take care of each other as the way we usually do’. This management of providing care is natural in the context of maintaining a family caregiver’s lifestyle adjustment for the patient. These findings suggest that family caregivers perceived a range of specific approaches that focused on ‘Placing the patient to the centre of care’ and ‘Being normal’, which is supported by many studies (Baider & Surbone, 2014; Jarin et al., 2014; Petricone-Westwood & Lebel, 2016; Prouse & Phillips, 2013; Rabow, Hauser, & Adams, 2004).

In addition to cancer research, this approach has been used in other diseases such as Human Immunodeficiency Virus (HIV), dementia, and stroke (Lawrence & Kinn, 2012; Vega et al., 2009; Vithayachockitikhun, 2009). Nevertheless, the findings of the current study have suggested that some caregivers reported a fairly smooth integration of the caregiver role into their daily routine, yet the new role was a time-consuming duty which could limit their time on other responsibilities. There are some potential explanations for these findings. First, some caregivers had prior caregiving experience and were familiar with adjusting their life under changed situations. Second, the personal relationship between the caregiver and the patient could influence the positive attitudes towards providing care for elderly patients with breast cancer who they love and share a life together with.

Thinking positive

The findings revealed positive attitudes and perceptions expressed by family caregivers when asked how they coped with caregiving. They concluded that they should be positive because they thought it would be better for their loved one. Family caregivers seemed to understand that patients faced many difficulties with their treatment and were also concerned about dying, which has an enormous impact on patients’ psychological health. Even though most elderly patients with breast cancer were not likely to focus on their illness, their serious condition, also affected by complicated treatment, needed to be supported by the family caregivers. Thus, the family caregivers helped the patients to cope with their emotional strain and to support their physical well-being during cancer treatment. Most of the family caregivers avoided forcing patients to do every daily task, but encouraged them when they felt the patient could manage. For instance, when patients were physically and emotionally suffering from chemotherapy and radiotherapy, family caregivers encouraged them to maintain their daily activities and ‘fight the disease’. They protected the cancer patient from suffering negative emotions with religious beliefs that would make them more positive. They needed their patients to learn from other cancer patients. They provided positive examples to their loved one, such as ‘How other cancer patients can manage their healthcare to live over 10 years’. Therefore, family caregivers allowed their loved one to participate and learn from the everyday life of other cancer patients when facing difficulties. This finding suggests that the challenges of caregiving affect the negative and positive perceptions about the cancer experience of both the family caregiver and the patient. Family caregivers tried to decrease the negative emotions and to increase positive reactions by adopting a positive approach (Keefe et al., 2003; LeSeure & Chongkham-ang, 2015; Sterba et al., 2014). This strategy by family caregivers can help patients to turn negative thinking into positive thinking. Consequently, the positive thoughts of family caregivers can help in producing positive health outcomes, which also support patients to be able to deal with stressful events and can lead to better adjustment in life between caregivers and patients.

Seeking essential information

The current study found that family caregivers had limited access to health information, particularly information related to providing cancer care at home. Health professionals were identified by family caregivers as the primary source of knowledge providing information about cancer and the initial caring tasks and processes. In the current study, family members stated that they needed more information about breast cancer including therapy options, the effects of cancer, prognosis, chances of survival, and the effects on their lives and how to adjust to the caregiver role. Unfortunately, a lack of support in terms of further information and a lack of clear communication with health professionals were the main issues. Family caregivers stated that ‘I was not familiar with finding information in regard to breast cancer’. This study found that family caregivers faced difficulty in understanding cancer information provided by health professionals, including cancer care, which is consistent with previous studies concerning lack of information and communication with healthcare providers (Giacalone et al., 2005; Giacalone et al., 2008, 2009; Locatelli et al., 2010; Youngmee & Given, 2008).

There are some available sources that can provide family caregivers with important information to improve their knowledge and confidence in providing cancer care. Family caregivers illustrated that ‘Whichever I could read, and then I would read to give me some idea of how to providing care‘. They gained knowledge from health information broadly, and from brochures available in hospital and healthcare settings. Moreover, the mass media, booklets, television programs, local radio programs, and websites were the most common sources of information available to everyone. Furthermore, they can obtain some information from people with cancer-related experiences, including relatives, friends, doctors, neighbours, and other cancer-patient groups. Some family caregivers had also participated in volunteering jobs at the hospital and, as a result, had some knowledge of cancer. This suggests that family caregivers might develop self-efficacy and health professionals might help them to relieve their stress by providing health information and assisting them along their caregiver journey, particularly the starting steps. These findings are supported by previous studies in Thailand and internationally (Junda, 2004; Youngmee & Given, 2008). Sometimes, they had conflicting information from other people who had various levels of knowledge, stating that 'It was very confusing because there were people who had suggested in a different method to provide care'. This suggests that people who family caregivers had consulted often have varying levels of knowledge depending on their cultural beliefs under different experiences and situations. Therefore, family caregivers had to apply this knowledge to manage proper care.

Adapting existing knowledge

The current study showed that both traditional and modern treatments were adopted by family caregivers based on their backgrounds, beliefs, and culture. The patients were likely to prefer traditional treatments, whereas most family caregivers preferred western therapy. Consequently, in most cases, some family caregivers explained that 'We do not believe any of traditional ceremony that can help the patient from breast cancer but we just wanted to please her (patient)'. However, they decided to use a combination of both choices in order to support the emotional wellbeing of the patient. They replied that 'At least, I needed to make her (patient) feel relieved', which showed that they just need to support the physical wellbeing of the patient. Some family caregivers reported that the patients met a shaman to remove evil spirits from the body which helped to reduce their sense of fear. In Thai culture, particularly in northern Thailand, some ancient rituals known as 'Yo-Lay' and 'Sarn' were performed to make the patients feel less tense, and some patients believe that breast tumours can be killed by ancient ceremonies. Therefore, within Thai culture, family caregivers might allow patients to regularly receive traditional medicine to improve their mental health. The results demonstrated that most family caregivers believed in modern treatments rather than in shamans, and perceived that traditional rituals could not help the patients' physical health outcomes. Nevertheless, they perceived that traditional beliefs could positively support patients' mental health outcomes.

Interestingly, some family caregivers used Thai and Chinese herbs to treat the patient, which was supported by another previous Thai study (Junda, 2004). They decided to use these herbs based on their existing knowledge and beliefs that some herbs can cure cancer. For example, they used sour soup leaves (a Thai herb) instead of plain water. This finding demonstrates that patients and some family caregivers perceived that breast cancer could not be cured by modern medicine due to the lack of clear information about cancer and cancer treatment. Therefore, they tried any approach that was available in the hope of a miracle, such as performing rituals as an add-on to modern treatment. Traditional treatment and beliefs varied among Thai cultures in different local areas. Traditionally, Thai people have used different types of treatment, including modern and traditional methods (Junda, 2004; Meecharoen, Northouse, et al., 2013; Prechavittayakul, 2006). When they have been diagnosed with serious conditions, including cancer, they often consult with their family and friends who might recommend alternative treatments and traditional medications.

Reflections of Lived Space and Lived Time to Care Management

Lived space reflects the caregiving space of the family caregivers who use a space to perform care at home. For example, the home was used as a landscape of care activity where they frequently were required and managed care for the patients. Family caregivers provided care in the home as a caregiving space, disclosing a sense of one's place in the world. While providing care, the impact on caregiving is illustrated in both the hospital and home setting. They felt more 'room' at home than 'room' in the hospital to manage care, which is reflected in their care activities (e.g., practising positive thinking, caregiving tasks, and seeking information to support patients). They also provided a space for patients in performing their self-care and supporting patients' needs and desires. This lived space lead them to more easily manage their caring roles and adjust to their daily caring responsibilities. *Lived time* reflected the care management of family caregivers during the period of caring. *Lived time* is likely to be a long-term process of managing in providing care during the transition from hospital to home, while *lived times* reflects managing their (family caregivers) short-term care. After the patient has been discharged, the family caregiver spends much time at home to arrange daily activities.

Review of Findings Theme 4: Burden in Life

Physical and emotional burdens

The physical burden related to caregiving can be categorised into two phases. The first phase occurs at the beginning of the role when family caregivers reported a high degree of physical burden. The second phase involved only a minor burden after patients had completed their course of treatment. There are a number of potential explanations for these findings. In phase one, patients had a high demand for physical support for everyday activities such as bathing, cleaning, cooking, and shopping. This can be due to the effects of the initial treatment, such as patients suffering from the complications of surgery (e.g., pain, wound infection). There is also the potential during this phase for the devastating side-effects of chemotherapy (e.g., hair loss, nausea, loss of appetite). Patients receiving radiotherapy might also suffer from wound inflammation and burns. As a result, taking care of patients after cancer treatment placed a substantial responsibility on family caregivers, particularly in terms of physical support.

Family caregivers perceived a physical burden as well: 'Everything was on my shoulders' and 'During caregiving, I was so concerned about my own family at home'. In addition to their caregiving role, family caregivers needed to manage time for their children, relatives, and partners, which unavoidably limited the time available for their social activities. Unfortunately, some family caregivers experienced the need to provide care for both a breast cancer patient and another family member diagnosed with a serious health condition, such as lung cancer or cataracts. As a result, they experienced stress related to the physical burden which affected the family caregivers' wellbeing. Many physical conditions were reported by the family caregivers as a consequence of their role, including osteoarthritis, hypertension, headaches, back pain, tumours, and eye problems. For instance, family caregivers described that 'Sometimes I have a headache and could not get up in the morning. During caregiving, I was mentally strong but my body is weak' or 'After taking care of my mother, I started having a health problem, the tumour was found on my breast'. The heavy physical burden reported during the initial stage of caregiving was consistent with many previous studies (Bevans & Sternberg, 2012; Goldzweig et al., 2012; Stenberg et al., 2010; Swore et al., 2008).

The current study found that some family caregivers reported minor physical burdens or no physical burden at all during the second phase of caregiving. Patients who required assistance with basic daily routines in the initial phase of care were competent enough to engage in some self-care after completing their course of treatment. Most elderly patients, in particular, tried to help themselves rather than relying on their family caregivers. Consequently, during this phase, family caregivers had more time to attend to other members of their family as well as their own physical well-being. Furthermore, some health conditions of family caregivers might not have been related to their role, but rather from pre-existing health problems (e.g., prior to taking on the role as caregiver). For instance, one family caregiver stated that 'I was sad, I had tumour because I thought it was genetic'. This suggests that the family caregiver expected that the tumour had occurred because of family genetics, which was not related to the caregiver role.

Family caregivers often made their feelings known. They expressed the need to 'Keep it (their role) going', as 'I had to understand and tried to adjust myself for her (patient)'. They considered their own physical burden as being secondary to the caregiving tasks. For example, a daughter caregiver said 'I never felt about why caregiving duty had to be me', as they were willing to look after their patients, even under trying conditions. Such experiences are similar to those reported in other studies (Doumit et al., 2007; Peacock et al., 2014). In the Thai context, a sense of moral and social justice contributed to the positive attitude of engaging with the caregiver role. It is a norm in Thai culture and Buddhist practice that the family should be willing to engage in the caregiver role, as it is a normal responsibility to look after senior family members who are respected and honoured. The current findings concerning minor physical health burdens are also similar to previous studies of caregiving conducted in the Thai context (Limpanichkul & Magilvy, 2004; Limpawattana et al., 2013; Muangpaisan et al., 2010).

Psychological issues were also reported to be a burden of life that was attributable to the caregiving role. In fact, most family caregivers reported a higher degree of emotional than physical burden. These emotional burdens were reported to be frequent in the early stages of caregiving immediately after the acknowledgement of the cancer diagnosis and the start of treatment, and the common adverse reactions associated with the treatment. The emotional burden increased within the first six months after diagnosis and commonly lasted for over a year of providing care. The majority of patients needed emotional support following diagnosis, and they also often required more support when suffering the side-effects of the treatments. It is inevitable that cancer patients feel uncertainty in their lives, which also contributed to family caregivers' stress and anxiety. Family caregivers reflected that they felt overwhelmed, stressed, anxious, depressed, and lonely. For example, they described that 'I cannot talk to anyone else', 'Nobody could help me', and 'I sighed a lot and it becomes my habit now'. This means that the family caregiver might feel lonely, stressed, and overwhelmed. They also reported a lack of support from both the healthcare system and their social network from the beginning of their caregiving role. Some family caregivers reported that their emotional strain was related to the patient's mood swings, and the behavioural changes after therapy associated with a reluctance to follow their doctor's instructions and advice.

Another concern for family caregivers was the progression of their relative's cancer to a more serious status, including metastatic breast cancer. Family caregivers were prone to an even greater emotional burden in this situation, which increased again if patients entered the terminal stage of cancer (Bernard & Guarnaccia, 2003; Francis et al., 2011; Germain et al., 2017; Govina et al., 2015; Grunfeld et al., 2004; Longacre et al., 2012; Stafford & Judd, 2010). These reflections demonstrate that providing emotional support might be more of a challenge than physical care and support, and this message is supported by several previous studies (Kitrungrote et al., 2008; LeSeure & Chongkham-ang, 2015; Meecharoen, Northouse, et al., 2013; Meecharoen, Sirapo-ngam, et al., 2013; Rha et al., 2015).

Financial and employment burden

The financial burden was another significant issue that had an impact on family caregivers. The financial strain was largely caused by increased expenditure such as the cost of cancer treatment, care management costs, and extra care-related household costs. Apart from patients' healthcare costs, family caregivers had to bear the responsibility of their immediate family and their own healthcare costs, as well as school fees and other living costs. The majority of participants in this study were experiencing financial hardship due to low levels of income and a lack of financial support. More than half of those interviewed earned less than $300 per month, which was not sufficient to support both the patient and their family. Cancer care also has many hidden costs such as extra travelling costs for medical appointments, meals, petrol, and hotel accommodation while having radiotherapy in another city; as one family caregiver said 'Most of my money was used up by travelling expenses'. According to the Thai healthcare system, some healthcare expenditures are out-of-pocket expenses such as private rooms in the hospital, and the non-National List of Essential Medicines are not covered by universal health coverage. Extra health insurance is needed to cover such additional healthcare costs. One family caregiver shared their experience as 'In case of the treatment expenses, the patient had gold card welfare and I paid the extra 1,000 Baht up, for other expenditures by myself'.

Although Thailand has universal health coverage, in 2017, 12% of total health expenditure was reported to be out-of-pocket costs, resulting in approximately 100,000 people living in poverty (Bundhamcharoen, Limwattananon, Kusreesakul, & Tangcharoensathien, 2017). In particular, elderly patients with multiple illnesses have to bear the additional costs of cancer care compared to other age groups including, but not limited to, transportation, medications, and special meals which are classified as non-reimbursable expenditures (Bachner et al., 2009; Borstelmann et al., 2015; Glajchen, 2012; Grunfeld et al., 2004; Siefert et al., 2008). Due to insufficient funds to cover all expenses, family caregivers, patients, and their families were burdened with crippling debt. Some caregivers had to sell their assets to cover these debts, as they had given up their employment to engage in the caregiving role. Most family caregivers had full-time employment while others had casual jobs; however, they had to work every day. During caregiving, they often took a day off, giving their reason to their employer as 'I needed to take my mom (patient) until completing the cancer course'. Indeed, a number of family caregivers reported that their role had a significant impact on their employment status. Many of them had to reduce their working hours or resign from their job because of their inability to balance work and life. For example, one son caregiver needed to quit his job because of his caregiving responsibilities for his patient. He stated, ‘I decided to quit the secure job and tried to find another one near home due to caring for my mother (patient)’. After commencing the caregiver role, most family caregivers were employed only in a casual capacity or as freelance workers to earn some income. The acceptance of a low income, which was attributed to their caregiving duties, is understandable in the Thai context. Priority was given to the caregiver role, with less focus on employment. This reinforces the moral belief in Buddhism for the need for strong relationships within the family.

Reflections of Lived Time and Lived Body to Burden in Life

Lived time reflects the burden in the life of family caregivers because the caregiving burden reflects a temporary time in the caregiver's routine. *Lived time* explains the life cycle of family caregivers when providing care and shared mutual experience with someone in the family under a caring situation based on their attitude and knowledge. There are past, present, and future times in which the caregiving role is shared by family caregivers. Past time shows the previous experience that family caregivers have to help them cope with their everyday tasks and routines before providing care. In the present time, lived time demonstrates that family caregivers commence their obligation to ensure compliance in everyday caregiving. They often felt a high degree of care burden and became overwhelmed with the new role. The high demand for physical and emotional support is required in everyday caregiving which can lead to physical and emotional illnesses. However, the caregiver role can be reduced when time passes into the later phases of caregiving. *Lived time* demonstrates the future events in which family caregivers perceive only a small degree of caregiver burden when patients have completed the cancer treatment course. The future time of caregiving still continued until the patient reaches the terminal phase of breast cancer as recalled by the family caregivers.

Lived body reflects the burden with which life struggles which they bear a heavy load in their physical body expressed by family caregivers’ emotions and body language portraying how they feel and cope with the burden. According to the findings, the caregiving role caused a physical, psychological, and financial burden for them in addition to job strain. Most family caregivers felt an obligation because the patients are their loved one or relatives in a family guided by their social and cultural context. Facial expressions and emotional body language are shown or concealed to reflect their experiences which varied by relationship status and family issue. They might express their feelings as uncomfortable, concerned, uncertain, grateful, loving, affectionate, or respectful depending on the degree of burden and the complexity of the relationship.

Limitations

There are a number of limitations to this study. In the case of the data collection method, the care experience of family caregivers might not fully convey their own opinion because of cultural considerations. In discussing caregiving matters, feelings of caring and sensitive issues such as family conflicts might not be openly discussed. Talking with the researcher (who was a stranger to them) might have resulted in the caregivers concealing some of their attitudes and opinions as well as some background information. Therefore, it was difficult to approach in-depth issues in the initial stage of each interview. However, the data obtained from all family caregivers was sufficient for data analysis in all the required aspects of the study. The family caregivers were regularly visited to build rapport until the family caregiver trusted and openly discussed the essential aspects of their lived experience. All the data are rich in information. The translation of the data between Thai and English and vice versa might have some impact on the interpretation of the data. However, all the data were translated by academic professionals who have a proficient level of both Thai and English. In addition, there was only a short period of data collection (three months) that might have limited the time for reflection due to the PhD requirements of the data collection. However, all the data were saturated which is an important component of rigor as it was a criterion to evidence the quality of this qualitative study.

The data collection for this study took place in a specific geographical area of northern Thailand. The findings were derived from participants living in the Thai context providing insight into their unique experiences of caregiving which may be different from findings in other cultural contexts. Nevertheless, Thai culture has the same socio-cultural considerations and beliefs across all of

Northern Thailand. There were 22 family caregivers recruited from one province as volunteer caregivers who participated in this study. This small group of participants might not sufficiently reflect the entirety of the lived experience of all family caregivers. However, all the participants were recruited from different districts and came from the most populous province, which represents the whole area of Northern Thailand. Coding of the interview transcripts and pseudonyms for the participants were used in the analysis and contributed to the interpretation of the actual lived experiences.

Strengths

The sample in this study was recruited through health professionals from 20 primary healthcare services. There were a variety of family relationships between family caregivers and patients, including parents and children, siblings, relatives, and partners, voicing a range of different aspects that contributed to the study and advocated methods of achieving phenomenological seeing. The data analysis and interpretation provided a deep insight into, and in-depth information on, Thai culture by a Thai researcher who understands the Thai social and cultural context as well as understanding the varied relationship patterns among Thai families which influenced the range of issues covered in this study. Phenomenological theory directs us to explore 'lived experience' and to gain actual phenomena which are straightforward to reach agreement through exploring the knowledge base by using phenomenological lens. The six steps of van Manen's framework was used to demonstrate the scope of the method and to guide the analysis of the themes. The interpretation presented here reflects both the participants' and the researcher's accounts, which controls for researcher bias.

Implications

This study reveals family caregivers' lived experience as having significant roles and duties. They are affected by the caregiving role, including both the positive and negative impacts of caregiving. Physical, emotional, and financial burdens and employment difficulties are the greater impacts of caregiving that emerged from the contribution of the family caregivers' experiences. The positive aspects related to the benefits of caregiving included positive feelings of love, caring, self-worth, valued relationships, religion-related coping practice, socio-cultural context, and knowledge gained during caregiving. These findings suggest that the physical burden might not have a major impact on family caregivers; however, they reported facing many difficulties when commencing the caregiver role. This is because they believed that caring for someone in the family, in particular caring for an older family member, is a ‘normal disruption’ of caregiver duties that they seemed to handle. They valued and accepted the caring by viewing it through building stronger relationships and cultural obligation. Most caregivers perceived that elderly patients deserved more attention and should receive proper care from their relatives who can be responsible for their loved one in the family.

The psychological impacts report high levels of burden and stress in commencing the caregiving role. Several family caregivers reported feeling overwhelmed by their caregiving tasks. A moderate degree of emotional distress related to caregiving was reported, but reduced in the later phases of caregiving. In this phase, they had more time to care for themselves and their family after late stages of a caregiving trajectory. However, a sense of grief and bereavement was also apparent, related to the possibility and reality that the elderly patient might die from the disease. As a result, it can be predicted that they could be at high risk of mental health problems when the elderly patient reaches the terminal stage of breast cancer.

In most cases, Thai family caregivers faced limits in social support including financial, social, cultural, and educational support, on top of facing job strain. Regarding educational support, they need knowledge support from health professionals. Diagnosis and stage-related cancer care and treatment processes need to be explained more clearly, with more information for family caregivers. In terms of the economic impact, out-of-pocket caregiving expenses mostly occur in travel, medical prescriptions, and special food when having doctor’s visits, which represents a lack of further support and inadequate financial support by government, the community, and private agencies. In addition, family caregivers’ experiences in seeking information related to social and cultural beliefs recommended by other cancer patients, friends, and neighbours encompassed by traditional and western treatments being combined and applied to help the patients. The following research implications are addressed in three sections including for nursing practice, nursing education, and health policy. Thai family caregivers' experiences related to the burden of care based on the results of this study need to be considered. Insights into the care experience can enhance clinical nursing practice, educational programs, and further research. Health agendas in relation to supporting family caregivers can be developed by policymakers in order to reduce the caregiver burden.

Implications for nursing practice

The findings have implications for nursing practice in healthcare services in Thailand, as follows:

1. Improving healthcare practice through developing programs or interventions for health professionals to support family caregivers and patients. For example, family support related to preparing family caregivers for their new role in providing care should be applied to nursing care plans to remind nurses of their role in supporting family caregivers. An understanding of the ability of the family caregiver should be considered in terms of their ability to articulate this role before commencing. Therefore, nurses could play a vital role in supporting family caregivers by preparing and teaching them how to cope with their new role.

2. Intervention programs should be provided based on the family caregiver's knowledge and background, including information about the disease and the stage of breast cancer, the nature of the caregiving role, and cancer care related to a specific phase of breast cancer. In addition, nurses can help family caregivers' self-confidence and their ability to prioritise and manage the patients' healthcare so that they can perform caregiving activities and continue to care for the patient at home.

3. Health professionals need to support family caregivers' feelings in the initial stage of caregiving because they frequently feel overwhelmed by their caregiving duties. This might reduce the uncertainty they experience in providing care. Further supporting their emotional distress is required when the patient reaches the end of life stage, and they should be aware of spiritual aspects, religious beliefs, ritual activities, and the social and cultural context associated with the particular patient.

4. Group networks supported by the community can help family caregivers, particularly if they are working. These networks can also help to organise a caregiving plan for family caregivers when

providing care.

5. Regarding economic support, information about finances related to the existing resources in the community should be provided in order to help family caregivers with some financial support for providing care. In addition, the welfare and healthcare systems provided by the government could assist with some medical prescriptions for family caregivers when needed.

Implications for nursing education

In nursing education, information about the family caregiver role should be included in a variety of topics in nursing curricula in relation to theory, research, and clinical practice. The objective for nursing programs could include family caregiver issues in theory and practice (e.g., the assessment of the physical and psychological needs in relation to various issues involving family caregivers, assisting the family caregiver in preparing and adjusting their life in relation to the caregiving role, and the existence of social support for family caregivers). Nursing students might not be aware of how to address family caregivers about the caregiver role and providing care for the patient at home. Therefore, nursing students should be educated in supporting family caregivers and raising their awareness to focus on both patients and family caregivers. Cultural norms and expectations, and religious and traditional beliefs in the Thai context as revealed in this study should be extended to the family concept which influences nursing students in having a better understanding of the real experiences of the caregiver role. Nursing students should learn how to communicate and provide encouragement to help build self-esteem for both family caregivers and patients related to caregiving practice. In addition, considerations for educational research should be conducted in regard to family caregiver subjects to construct more research to inform evidence-based teaching. This warrants further qualitative and quantitative academic research.

Implications for health policy

The findings suggest that elderly patients with breast cancer have some impacts on caregivers' burdens including physical, emotional, financial, and employment effects. Thus, health policy is crucial in improving social support programs in relation to supporting family involvement in preparing for care management that could help family caregivers by reducing the caregiver burden. This study provides useful information for policymakers so that they can be more aware of the caregiver burden and understand the subjective experiences of the caregiver role in order to develop health agenda to overcome barriers, as recommend in the following seven suggestions:

1. The public health agenda should be developed to advocate government and non-government agencies to help with reducing the caregiver burden.

2. Health policies should be developed for family caregiver support planning to help family caregivers to prepare for, and adjust to their new caregiver role based on family caregivers and patients' cultural beliefs, knowledge, and background.

3. Health professionals should educate family caregivers during the caregiving phase, in particular, the initial stage of caregiving. Social and cultural gaps and communication barriers between clients and health professionals should be eliminated to balance client needs and health service utilisation to deliver better services.

4. General volunteer support programs should be developed to help with caregiving hardships for family caregivers. Volunteer support or self-help programs should be established to train family caregivers in practising care in the hospital and at home. Peer groups can recruit volunteers to help family caregivers to look after patients by assisting them with some of the caregiving activities in the home when needed.

5. Western and traditional treatments, including Thai and Chinese herbs, should be promoted in both education and research practice to develop cancer treatment in Thailand.

6. Financial provision should be supported by the healthcare system and the community to provide adequate financial resources for communities to sponsor family caregivers when they need to travel to the hospital during care provision.

7. Government agencies should increase funding for basic research and to conduct more qualitative and quantitative research to learn more about caregiving outcomes that affect family caregivers' lives. The research outcomes will help policymakers to formulate policy to develop the healthcare

system and improve the quality of life of family caregivers.

Recommendations

The results of this study contribute to an understanding of the experience of family caregivers in providing care for elderly women with breast cancer in Thailand. The personal beliefs and practices of caregivers have been reported in relation to different issues in the Thai context. Research recommendations are provided below.

The findings of this study need to be expanded upon to explore the experience of family caregivers for patients with other types of cancer (e.g., lung cancer, bladder cancer, brain cancer, cervical cancer, and ovarian cancer). The care experiences of family caregivers can vary according to the degree of difficulty of the caregiving experience. Addressing the difficulties of family caregivers' needs might decrease the family caregiver burden and improve their quality of life. More qualitative research on other factors should be conducted including explorations of different cultures in other countries related to the caregiving experience. This may vary along with the differences in cultural approaches to breast cancer under various caring situations. In addition, a study into some of the factors that have an impact on various issues associated with caring would be useful, including studying the gender of family caregivers and of patients, studying relationship status within the family, and studying elderly women who are at varying stages of breast cancer, as well as studying other phases of the caregiving experience. Alternative treatments for breast cancer, including modern and traditional therapies and their effects, need to be studied in other contexts that might differ according to the various stages of cancer care.

Further quantitative research also needs to be conducted; for instance, interventions to improve the quality of care provided by family caregivers is warranted and might reveal the diversity of the different aspects of the caregiving journey. These interventions could include different levels of knowledge and skills, different degrees of caregiver burdens and care demands, or the amount of assistance from social support services that family caregivers experience. Longitudinal studies also need to be undertaken across the caregiving trajectory to reveal the optimal timing for changes in family caregivers' adjustments to, and perceptions of, the everyday caregiving experience.

Conclusions

This study has provided insights into the lived experience and perspectives of family caregivers in relation to their caregiver roles. There are very few research studies on the subjective views of family caregivers providing care for elderly patients during treatment for breast cancer in the Thai context. This study describes the particular care experience that influences family caregivers' shared meanings in the life adjustment of the family unit and in care management. The research question was answered in terms of what their understanding meant to them in relation to caregiving for elderly patients with breast cancer. The previous literature focused on how family caregivers experience providing care for women with breast cancer and suggested that their family functioning is altered and limited. The literature addressed the family caregivers’ care situation that contributed to unique caregiving experiences in other countries and in the Thai cultural context. The phenomenological approach, and in particular Max van Manen’s hermeneutic phenomenology, were used as the methodology and method. A phenomenological hermeneutical methodology for researching lived experience is considered to be a way of more deeply moving into the nature and dynamics of human beings through a naïve understanding. As a whole with caregiving, phenomena are highlighted as the key concepts in understanding the family caregivers’ lived experience.

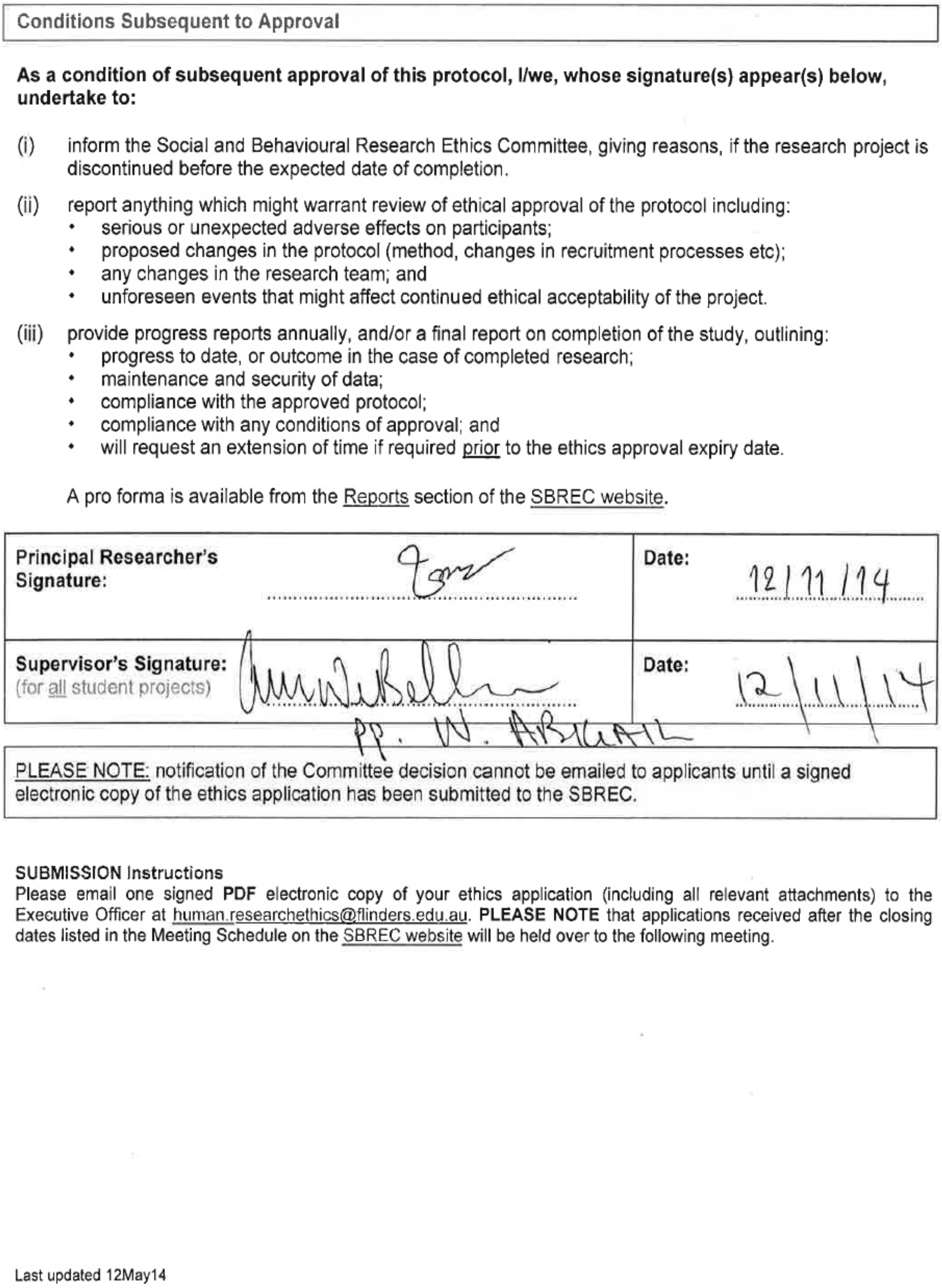
These findings have suggested that the caregiving experience for elderly patients with breast cancer negatively and positively affects the family caregiver’s life. Caregiving provided in a more positive, sensitive, respectful, and supportive way is based on beliefs, and prior knowledge and background within the Thai cultural context and family system. In terms of the negative aspects, family caregivers received little preparation, information, and support to perform their critical role. Cancer care affected family caregiver’s experiences including a lack of knowledge, lack of basic communication skills with health professionals, financial hardship, loss or limiting of employment, and healthcare systems that are a barrier to caregivers’ efforts to seek support and manage care for elderly patients. Also, they sought other support from networks involving family, friends, relatives, and traditional treatments to help them to support the patients. It is understandable that caregiving support varies in particular in the initial phase of caregiving during diagnosis and treatment along with the perceptions, reactions, and adjustments of family caregivers. The outcomes have led through the concept in providing value to improve healthcare quality for the elderly.

Overall, family caregivers perceived a very positive worldview of their caregiver roles. The aspects of obligation that made family caregivers willing to care reflects religious practice in the Thai culture. This study has demonstrated the importance of cultural values in family caregivers’ perceptions that shape family support, acceptance, and responsibilities, even though family support and caregiving perspectives differ from western culture. Culture influences the role of family caregivers’ perceptions of cancer care centred on their spiritual beliefs, values, and family support. This suggests that family caregivers continue to support patients because the caregiving experience maintains family relationships through the positive aspects of caregiving self-efficacy, according to the varied caregiving experience.

The importance of the current findings in relation to nursing practice, nursing education, health policy, and further research have been presented to inform health professionals in their understanding of family caregivers and their positive worldview of the caregiver role, and to improve nursing practice and nursing education into the future. This would help health professionals to manage family concerns and to advocate and take action to prepare family caregivers to cope with and enhance their role performance. As a result of this study, this perspective has also informed policymakers’ understandings of the need to support family caregivers and to promote the caregiver role in the community. The welfare system is required to provide sufficient support for the family while they assist the elderly in Thai society.

APPENDICES

Appendix I Ethics Application



Conditions Subsequent to Approval

As a condition of subsequent approval of this protocol, I/we, whose signature(s) appear(s) below, undertake to:

(i) inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion.

(ii) report anything which might warrant review of ethical approval of the protocol including:
- serious or unexpected adverse effects on participants;
- proposed changes in the protocol (method, changes in recruitment processes etc);
- any changes in the research team; and
- unforeseen events that might affect continued ethical acceptability of the project.

(iii) provide progress reports annually, and/or a final report on completion of the study, outlining:
- progress to date, or outcome in the case of completed research;
- maintenance and security of data;
- compliance with the approved protocol;
- compliance with any conditions of approval; and
- will request an extension of time if required prior to the ethics approval expiry date.

A pro forma is available from the Reports section of the SBREC website.

Principal Researcher's Signature:		**Date:**	12/11/14
Supervisor's Signature: (for all student projects)		**Date:**	12/11/14

PP. W. ABIGAIL

PLEASE NOTE: notification of the Committee decision cannot be emailed to applicants until a signed electronic copy of the ethics application has been submitted to the SBREC.

SUBMISSION Instructions
Please email one signed **PDF** electronic copy of your ethics application (including all relevant attachments) to the Executive Officer at human.researchethics@flinders.edu.au. **PLEASE NOTE** that applications received after the closing dates listed in the Meeting Schedule on the SBREC website will be held over to the following meeting.

Last updated 12May14

Appendix II Ethics Approval

Dear Chayanisa,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.: **6762**

Project Title: Family Caregivers' Experiences of caring for Elderly Women undergoing treatment for Breast Cancer in Thailand

Principal Researcher: Miss Chayanisa Kemathad

Email: kema0002@flinders.edu.au

Approval Date: 18 February 2015 Ethics Approval Expiry Date: **31 December 2019**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment(s):

Additional information required following commencement of research:

1. Please ensure that copies of the correspondence granting permission to conduct the research from the individuals and/or organisations outlined are submitted to the Committee *on receipt.* Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 6).

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- All participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- The Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- The SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by emailhuman.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **18 February** (approval anniversary date) for the duration of the ethics approval using the annual / final report pro forma available fromAnnual / Final Reports SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **18 February 2016** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change of project title;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, and supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Formto the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submittedprior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 orhuman.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Andrea

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday, Wednesday and Thursday morning
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au

Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

Appendix III Participant Letter and Project Information

Miss Chayanisa Kemathad
School of Nursing & Midwifery
Faculty of Nursing & Health Sciences
Flinders University
GPO Box 2100
Adelaide SA 5001
Tel: [redacted]
Kema0002@flinders.edu.au
CRICOS Provider No. 00114A

INFORMATION SHEET

Title: ‘Family Caregivers’ Experiences of Elderly Women undergoing treatment for Breast Cancer in Thailand’

Investigator:
Miss Chayanisa Kemathad
School of Nursing & Midwifery
Faculty of Nursing & Health Sciences
Flinders University
Ph: [redacted]

Description of the study:
This study is part of the project entitled ‘*Family Caregivers’ Experiences of Elderly Women undergoing treatment for Breast Cancer in Thailand.* This project will investigate what the experiences of family caregivers of elderly women undergoing treatment for Breast Cancer have been in Thailand. This project is supported by Flinders University, Nursing & Midwifery& Health Sciences department.

Purpose of the study:
This project aims to find out if the *experiences of family caregivers and providing care for elderly patients undergoing treatment for Breast Cancer:*

- Explore the experiences of family caregivers in providing care to elderly women with breast cancer during treatment.
- Discover the essence of lived experience perceived by family caregivers while older women received treatment using a phenomenological theory.
- Identify family caregivers’ perceived burdens and enablers associated with caring for older women with breast cancer undergoing treatment.

What will I be asked to do?
You are invited to attend a one-on-one interview with a PhD student who will ask you a few questions about your views about the experiences of family caregivers and providing a care for elderly patients undergoing treatment for Breast Cancer on your experience. The interview will take about 45-60 minutes. The interview will be recorded using a digital voice recorder to help with looking at the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file.

What benefit will I gain from being involved in this study?

The sharing of your experiences will improve the planning and delivery of future programs. We are very keen to deliver a service and resources which are as useful as possible to people.

Will I be identifiable by being involved in this study?
We do not need your name and you will be anonymous. Once the interview has been typed-up and saved as a file, the voice file will then be destroyed. Any identifying information will be removed and the typed-up file stored on a password protected computer that only the coordinator will have access to. Your comments will not be linked directly to you.

Are there any risks or discomforts if I am involved?
The investigator anticipates few risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator. The researcher will have the following list of counselling during all interviews with participants that they could attend if required as this below:
Donkeaw of District Health Promotion and Prevention Centres, Maerim District, Chiang Mai Thailand 50100 Tel.(+66-53) 121572 E - Mail : donkaew.hc@gmail.com

How do I agree to participate?
Participation is voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and send it back to me by email kema0002@flinders.edu.au. or by telephone [redacted]

How will I receive feedback?
Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.
Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6762). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix IV Ethics Approval (Thai Healthcare Service)

[redacted]

6 March 2014

Dear Miss Chayanisa Kemathad

Topic: Approval for data collection in Donkaew Health Service

I am Mr. Sudtha Prasri, Director of The Donkaew District Health Promotion and Prevention Centres in Maerim District, Chiangmai, Thailand. I approve Miss Chayanisa Kemathad, a PhD student at Flinders University, Australia, to collect data. The staff in organisation will assist the researcher by posting flyers on the notice board and inform the participants who are the family caregivers of the elderly with breast cancer, to make contact with the researcher.

Kind Regards

[redacted]

APPROVE

[redacted]

Appendix V Semi-Structured Interview

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Topics for Interview questions

Title: 'Family Caregivers' Experiences of caring for Elderly Women undergoing treatment for Breast Cancer in Thailand'

Interview questions of the study:

The following examples of semi-structured questions of initial interview used in this interview are:

- Tell me about your experience of caregiver roles?

Prompt questions that are used as encouraged:

Experiences:

1. What the meaning of caregiving by your experiences?
2. Can you tell me more about that?
3. What do you know about treatment for your older women?

Problems:

4. Could you explain to me what impact have you done on a caregiver role? (such as physical, cognitive, visual, spiritual, emotional)
5. What happened next?
6. Has caregiving affected other members of the family?
7. What are side effects of treatment affecting on your older members?
8. Do you have any problems during care for elderly member? How?
9. Do you have any health problems during care for your senior member? How?

Issues:

10. How did you adjust to be a caregiver?
11. How did that make you feel?
12. How did you feel after your older woman had treatment?
13. How did you feel when you provide care for your elderly woman every day?
14. What is your daily routine for before and after care for your elderly woman?

Appendix VI Flyer

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Attention

Are you providing care for an older woman with breast cancer in a caregiver role?

If so please consider being part of a research study, if you are:

1. 18 years or older;
2. providing care for an older woman with breast cancer undergoing treatment

Participants will involve being interviewed about experiences.

Please contact Nicky to talk about the story on +66 ...., or by email (kema0002@flinders.edu.au).

Thank you for your interest.

inspiring
achievement

Appendix VII Ethics Modification Approval

[redacted],

The Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University has reviewed and approved the modification request that was submitted for project 6762. A modification ethics approval notice can be found below.

MODIFICATION (No.1) APPROVAL NOTICE

Project No.:	**6762**
Project Title:	Family Caregivers' Experiences of Caring for Elderly Women Undergoing Treatment for Breast Cancer in Thailand
Principal Researcher:	Miss Chayanisa Kemathad
Email:	kema0002@flinders.edu.au

Modification Approval Date:	28 May 2018	Ethics Approval Expiry Date:	**31 December 2019**

I am pleased to inform you that the modification request submitted for project 6762 on the 23 May 2018 has been reviewed and approved by the SBREC Chairperson. Please see below for a list of the approved modifications. Any additional information that may be required from you will be listed in the second table shown below called 'Additional Information Required'.

Approved Modifications	
Extension of ethics approval expiry date	
Project title change	
Personnel change	X
Research objectives change	
Research method change	
Participants – addition +/- change	
Consent process change	
Recruitment process change	
Research tools change	
Document / Information Changes	
Other (if yes, please specify)	

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

Additional Information Required
None.

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

  This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by emailhuman.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

Please be reminded that in order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on **18 February** (approval anniversary date) for the duration of the ethics approval.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your next report is due on **18 February 2019** or on completion of the project, whichever is the earliest.The report template is available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the*Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page.Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Executive Officer if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer immediately on 08 8201-3116 orhuman.researchethics@flinders.edu.au if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Wendy

On behalf of Andrea Mather

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**

Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather | Monday - Friday	[redacted]
Ms Rae Tyler | Monday, Wednesday and Friday mornings	[redacted]
A/Prof David Hunter | SBREC Chairperson	[redacted]
Dr Deb Agnew | SBREC Deputy Chairperson	[redacted]
SBREC Website	[redacted]

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

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