Exploring Caregivers’ Understanding of Palliative Care for Older People in Thailand

By

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CONTENTS

ABSTRACT

Background

The number of people who need palliative care is rising due to the increase of an aging population. Most people receiving palliative care are older people who live in their homes and are cared for by family caregivers. Barrier to providing palliative care for this population are widely reported in the literature. One of factors contributing to the situation is the lack of support for family caregivers of older people receiving palliative care.

Aim and objectives

The aim of this study was to explore caregivers’ understanding of palliative care for older people who live with a life-threatening illness in the Thai community. The objectives were to identify caregivers’ perceptions of: 1) enablers in palliative care and 2) the barriers of palliative care for community dwelling older people in Thailand.

Methods

The study was conducted using descriptive qualitative methodology. Semi-structured interviews were used to collect data from 13 caregivers. Thematic analysis was used to analyse the data.

Results

Three themes were identified from data analysis, and they were: 1) Various understanding of palliative care; 2) Palliative care services; and 3) Caregiver stress and coping strategies. First, caregivers showed different levels of understanding of palliative care depending on their experiences and knowledge about palliative care. Caregivers received little to no information about palliative care from health professionals. Therefore, they showed very limited understanding about the meaning of palliative care. Second, although palliative care services had been provided in Thailand, caregivers perceived barriers to receiving palliative care, especially health education for caregivers and continuity of palliative when the people they cared for were discharged from hospital. In addition, caregivers perceived difficulty in providing care for people receiving palliative care. They experienced stress and distress.

Conclusion

This study illustrated that palliative care for older people in Thailand was available, but health education for caregivers and care services that support family caregivers to care for older people living with life-threatening diseases was lacking. Findings have implications for policy, care services and education, and resource development in palliative care in Thailand.

Keywords Palliative care, older people, caregiver, understanding of palliative care.

DECLARATION

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

Signed……..Pattaraporn Koonmee…….
Date…………27 August 2021……………..

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CHAPTER 1 INTRODUCTION

1.1 Introduction

This chapter introduces the background of the study starting with the overall issues identified in palliative care for older people who live with life-threatening illness in Thailand that are discussed the current situation and palliative care problems in Thailand and in the globe. Furthermore, the significance of the study, aim and objective and an overview of all chapters in the thesis are also presented in the chapter.

1.2 Background

Palliative care is defined by the World Health Organization as ‘an approach that improves the quality of patients life and their families facing the problem associated with life-threatening illness, through the prevention and relief suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (World Health Organization, 2014). People are living with life-threatening illness and their caregivers gain benefit from palliative care by focusing on the quality of life and the relief of symptoms (Etkind et al., 2017).

The palliative care demand rising globally due to the growth of the aging population (Etkind et al., 2017). The increase of population aging is associated with the growth of the prevalence and incidence of chronic diseases and mortality and morbidity from these diseases worldwide (Etkind et al., 2017). because the populations are ageing globally, the care pattern changed ; for example more people died due to chronic diseases that are care complex, complicated treatment and symptoms management, and some palliative care needed (Voumard et al., 2018; World Health Organization, 2011). Moreover, the statistics showed that 25 percent of people who are older than 85 years old have dementia and this situation also demands palliative care for this population (World Health Organization, 2011). These changes of the trend of health issues and ageing population support that palliative care is very important nowadays (Voumard et al., 2018).

Palliative care helps to reduce both physical and emotional distress for the person receiving the care and their family caregivers (Bajwah et al., 2013; Brazil et al., 2012; Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015). However, this care approach is usually poorly understood. People receiving palliative careand caregivers show misunderstanding about palliative care meaning and the effect on the caregivers providing the care to palliative patients (Sullivan et al., 2019). Studies indicate that there are many factors affecting the provision of palliative care and one of those is the caregivers' knowledge. It is very challenging,, especially for developing countries (Abu-Odah, Molassiotis, & Liu, 2020) and Thailand. Developing countries apart from the lack of caregivers' knowledge, there are other factors affecting the palliative care provision including lack of funding, health workforce, and physical infrastructure (Abu-Odah et al., 2020). Moreover, sometimes the culture and beliefs of developing countries are against care compared to developed counties where people have higher education (Abu-Odah et al., 2020). Thus, good palliative care policy and care services that promote understanding are highly needed.

Presently, Thailand also has population aging. Thai older people are 10.7% of all the population in 2007 and estimated population will reach 20% by 2025 (Thiamwong & Pungchompoo, 2018). As the aging population has been increasing, the number of older patients who live with life-threatening illness and required palliative care is rising as well. According to Pairojkul (2015), more than half of patients receiving palliative care in Thailand were over 60 years old (Pairojkul S., 2016). Consequently, palliative care has become very important.

Although palliative care has been established for decades, it is still in an early stage of development to improve care services for group of an older population and their family caregivers (Nilmanat, 2016). Access to palliative care services is a barrier for older people living with life-threatening illness. Studies in Thailand research reported that older patients living with life-threatening illness had a delay in referring to a palliative care team (Nilmanat, 2016). Most older patients living with life-threatening illness are referred to palliative services when they are in the active dying stage (Buss, Rock, & McCarthy, 2017; Nilmanat, 2016). Thus, it is important to explore caregivers' perceptions of factors affecting older patients living with life-threatening illness to access and utilize palliative care services.

The understanding of family caregivers towards palliative care is one of the essential factors for older people living with life-threatening illness to approach palliative care on a timely manner (Boucher et al., 2018; Supaporn, Isaramalai, & Suttharangsee, 2019). The diseases and health conditions in older people living with life-threatening illness also influence family caregivers to seek palliative care. For example, older patients with end-stage renal disease and older patients with dementia might have influenced caregivers to consider palliative care approach differently (Hansen, Rosenkranz, Wherity, & Sasaki, 2017; Maddalena, O'Shea, & Barrett, 2018; Poole et al., 2018. A study identified that most caregivers are lacking a proper understanding of palliative care (Poole et al., 2018). Although they played a key role in providing care for older patients and received support from health care providers, many caregivers showed a lack of palliative care (Ciemins et al., 2015; Hansen et al., 2017; Maddalena et al., 2018). The caregivers also indicated that they need more information and support from health care providers (Boucher et al., 2018; Fox et al., 2017; Hansen et al., 2017; Maddalena et al., 2018; Poole et al., 2018; Soroka, Froggatt, & Morris, 2018). As the literature review, palliative care is needed more but it still has a lack of promotion. Some carers do not even know or hear the word "Palliative care" because of false palliative care perceptions (Boucher et al., 2018; Maddalena et al., 2018).

Misunderstanding of existing palliative in caregivers (Abu-Odah et al., 2020; Maddalena et al., 2018; Nilmanat, 2016) . According to the reviews, there are two main misunderstandings of palliative care. Firstly, they believe that palliative care is changing to take care of patients at home without any treatments. On the other hand, some palliative patients still need treatment, but it is conservative treatment. Secondly, most of the carers think that palliative care means people who are going to die soon or they are in the last stage of illness (Maddalena et al., 2018; Nilmanat, 2016).

Most people who receive receiving palliative care who received palliative care are discharged from hospital and they are cared for by family members at home because they do not need further treatment (Poole et al., 2018; Soroka et al., 2018). Caregivers perceived that health care providers provide minimal support for them after hospital discharge (Hansen et al., 2017; Maddalena et al., 2018). Studies identified that caregivers perceived still need full support from the health care providers. They need the health professionals to reassure that good action for patients. (Boucher et al., 2018; Ciemins et al., 2015; Fox et al., 2017; Hansen et al., 2017). The participants said that they have narrow knowledge about the methods of taking care of the patients at home (Fox et al., 2017; Hansen et al., 2017). Sometimes they have to search the internet to confirm the correct information to understand palliative care (Ciemins et al., 2015; Hansen et al., 2017; Soroka et al., 2018). The caregivers said that the presence of health care staff does not make them feel like they are being abandoned (Ciemins et al., 2015). Moreover, their care confidence for the patients also depends on the support from the health care providers (Ciemins et al., 2015; Soroka et al., 2018).

Some hospitals provide home health care for both patients and caregivers. Patients and carers could ask all questions related to the treatment process. However, the number of patients and responsible staff who take care of palliative patients are not enough (Hawley, 2017). Causing patients to not get enough services and have a false palliative care perspective. Another misunderstanding is that palliative patients who are cancer patients and are going to die soon. There are two main reasons to have this misunderstanding. The first reason is because of the referring delay to receive palliative care services (Maddalena et al., 2018; Nilmanat, 2016). Although palliative care means taking care of patients who have a disease that could not be cured, it does not mean that they are dying. For example, people who are suffering from dementia could live longer if they get good care and slow down the diseases' progress (Poole et al., 2018). The different disease needs different care, and the care is also specific for each patient (Hansen et al., 2017; Maddalena et al., 2018; Poole et al., 2018). Dementia is an example to show that palliative care is not for only the person who is at the end of life but a patient could live in a long-term condition. The second reason is that most palliative patients, especially cancer patients suffer from severe pain (National Cancer Institute, 2021). Despite the carers not having a clear understanding of the purpose of giving an opioid drug to patients due to the lack of knowledge. As a result, carers do not have proper pain management. The more caregivers see the patients suffer from the pain, the more misunderstanding they have toward palliative care (Hansen et al., 2017). These issues show problems in providing palliative care services to patients and family caregiver. The caregivers have a false perspective that needs to be clarified and improved.

As the palliative care background in Thailand mentioned above, the palliative care problems are increasing the number of older people, lack of palliative care knowledge, difficulty accessing palliative care, and shortage of healthcare workers. The number of Thai older people is increasing, and palliative care is health care integrity for the population in the health care system, but, resources and patient support and their caregivers are under-developed. Therefore, it is imperative to explore caregivers' understanding of palliative care in order to generate research evidence to inform practice.

As a result, the research question of this study is the caregivers' understanding of palliative care for Thai older people. The purpose of this study is to explore caregivers understanding of palliative care in Thai older people. The researcher would like to clarify the caregivers' perspective so that health care staff could understand what they need to provide the best care for patients and improve their life quality as well as the quality of palliative care in Thailand.

1.3 Significance of the study

Palliative care in Thailand has been established in Thailand, however, there are delays in patients referring problems to a palliative care team and lack of health promotion (Buss et al., 2017; Nilmanat, 2016). This problem causes a misunderstanding about palliative care in caregivers of older people living with life-threatening illness. Findings will support the health care system to develop policy, resources, and palliative care services to address the problem and also assist health professionals gaining an understanding of caregivers involved in palliative care. Therefore, they may develop activities or programs to support patients and family caregivers in accessing and utilizing palliative care services (Supaporn et al., 2019). The anticipated improvement in palliative care services in this study will also benefit older patients receiving palliative care including improved self-esteem and dignity in the phase of life-threatening illness, fewer side effects from inappropriate palliative care and improved quality of life. Ultimately, the findings will contribute to of the palliative care system development in Thailand.

1.4 Aims and objectives

The aim of this study was to explore caregivers’ understanding of palliative care for older people who live with life-threatening illness in the Thai community. To achieve the aim, the researcher creates these objectives:

1. To identify enablers in palliative care for older people in Thailand
2. To identify the barriers of palliative care for older people in Thailand

1.5 Methodology

The researcher uses a qualitative study using interviewing to help in achieve the goals. The qualitative study is appropriate gaining the information related to people’s experiences and perceptions (Almeida, Faria, & Queirós, 2017; Polit & Beck, 2017; Schneider, Whitehead, & LoBiondo-Wood, 2016) as the aims of this study is to understand the caregivers’ perspective toward palliative care in older people. Family caregivers of older people receiving palliative care will be recruited to be participants. The researcher uses semi-structured interview questions to elicit the participants’ perspectives because the interview helps in gaining more in-depth information and give chances for participants to ask questions that exchange their opinions (Jameel, Shaheen, & Majid, 2018; Schneider et al., 2016). The participants will be asked to share their understanding of palliative care understanding for older people with life-threatening illness through online platform. The online platform that was used for data collection is Line application. The function of this application is similar to others well-known online platform such as Skype and Zoom, but is widely used for everyday communication in Thailand The interview is 45-60 minutes long. The participants' information gaining will be interpreted into themes using Microsoft Word program and will be descriptively reported as a student thesis using IMRAD pattern. Ethics in doing human research is considered as well, Participants’ privacy and confidentiality will be ensured at all times.

1.6 Overview of chapters in the thesis

This thesis consists of five chapters. The first chapter has provided a palliative care background, particularly in Thailand. The statistics of older people who need palliative care which shows the importance of palliative care and improvement need. The perception of palliative care of caregivers reveals the gaps in palliative care services providing to support the health care providers to create the programs and provide the best care to patients and family caregivers

According to chapter two, the researcher presents the literature related to caregivers' perception toward palliative care and identify the existing gaps in the research. This chapter has discussion about the four themes that emerged from nine qualitative articles from the literature review including changing from care services receiving at the hospital to home, the responsibility to the best care for patients providing, the need of both emotional and physical support, and death and a tradition to die peacefully. In conclusion, this chapter has summarized the current palliative care situation and the gaps of palliative care revealed from caregivers' perspective of palliative care.

Next, the third chapter l presents the methods used in this study. This chapter has discuss about the qualitative research approach, and the research methodology justification. Then the ethics approval process and considerations will be explained. The setting and the participants characteristics are described. The data collection process is described in this chapter from participants recruitment, interviewing process, until data analysis.

Then, the study findings through a thematic analysis is reported in the fourth chapter. This chapter has discussion about the interpretation of the information received from the participants' interview.

In conclusion, the researcher provided summary about caregivers' understanding of palliative care of Thai older people in the fifth chapter. Throughout this discussion, the results of the study are considered within the existing literature context. The implications of the study's findings are argued and provide avenues related to palliative care research in the future. The conclusion will make recommendations for future research and suggestions for palliative care policy and practice in Thailand.

1.7 Summary

This chapter has discussion about the palliative care issues in Thailand, which cause the caregivers to have a false palliative care perspective. The palliative care background mentioned in the chapter helps the researcher to come out with the research question and finally become this thesis. The researcher also describes the significance, aim and objectives of the study in this chapter. Next chapter has discussions about the literature review related to the study.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

This literature review explores the study of the caregivers' perspectives on palliative care. The findings from this literature will validate the caregivers’ understanding of palliative care which helps to see the gaps between health care system and clients who received services and indicates whether they understand palliative care properly. The eleven articles review the evaluation using the AXIS tool checklist (Appendix 1) and the critical appraisal tool to analyse the quality of the articles (Critical Appraisal Skills Program, 2018) (Appendix 2) and also have critically analysed the strengths and limitations. Consequently, those articles' findings were categorized by using thematic analysis. There are four categories emerged from the review: different palliative care services received at the hospital and home, responsibilities in providing care to the persons living with life-threatening illness, the emotional and physical support needed, and death and a tradition to die peacefully. These categories explore how caregivers understand palliative care, what palliative care is, what they need to provide the best care to the people receiving palliative care who are their relatives, and what outcomes that they need in palliative care terms. The author used a “Preferred Reporting Items for Systematic Reviews and Meta-Analyses” (PRISMA) flow diagram to present the literature review process (Figure 1) and used summary review table to organise and summarise the review (Appendix 4).

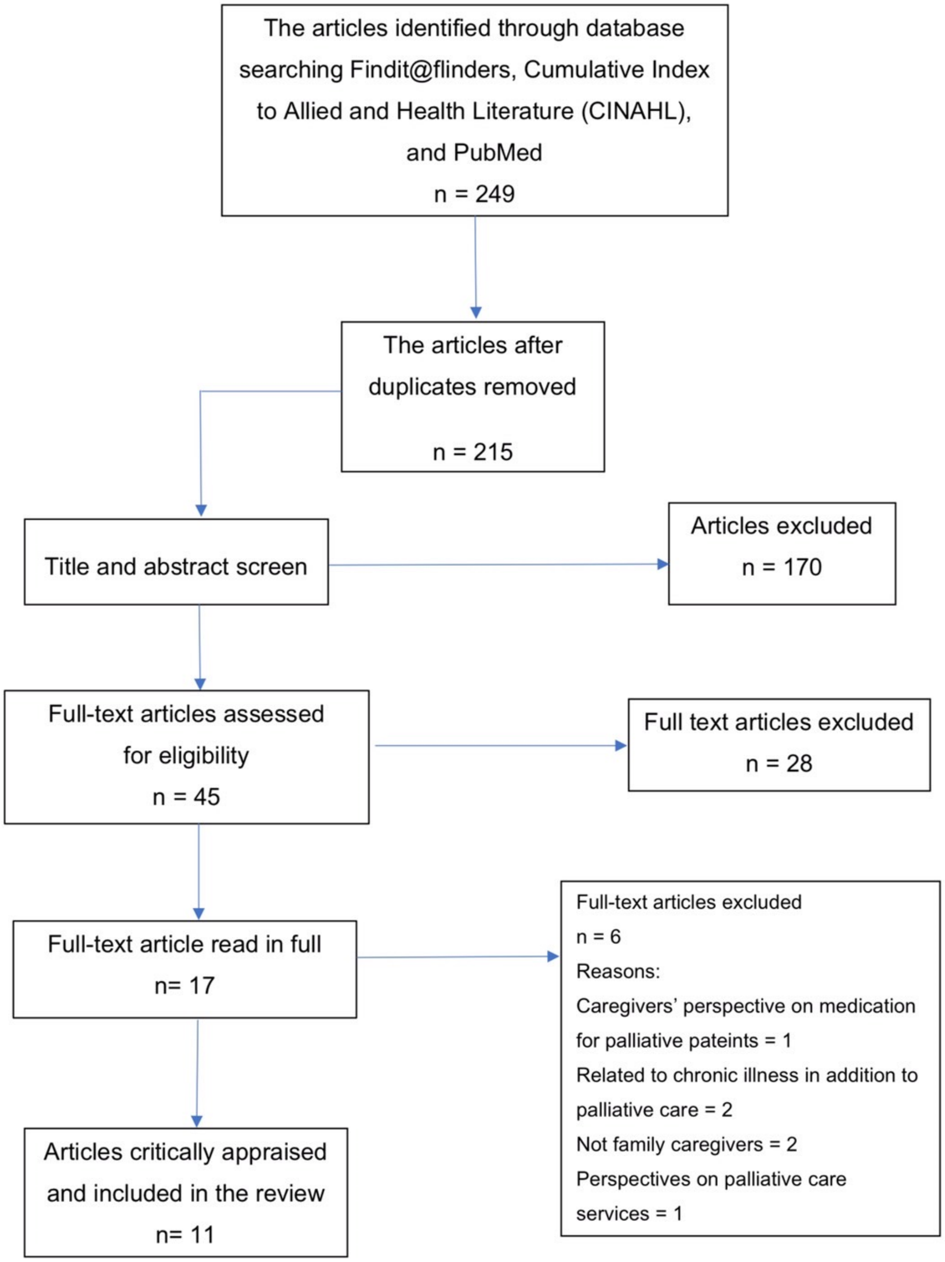
2.2 Article Selection Process

The articles related to the research topic were found by using electronic databases which are Findit@flinders, Cumulative Index to Allied and Health Literature (CINAHL), and PubMed. The reason why using CINALH and PubMed is the databases that have all kinds of academic articles and are related to the nursing field and health sciences (Polit & Beck, 2017). According to

Findit@flinders, it is the database collection is easy to use. The search terms used that are palliative care, end of life care, elderly people, aged, older adults, caregiver*, carers*, family members, exploring, understanding, perception, perspective, rural, community, Thai community, Thailand, and home health care. Searching was limited to primary research peer-reviewed and published in English between 2010-2020. The inclusion criteria for the chosen articles are the studies that related to caregivers' and patients’ perspectives or experiences in providing care for people living with life-threatening illness at home. The studies are about palliative care. The articles that focus on health professionals’ perspectives, not family caregivers, and not related to palliative care are excluded.

The total of 249 articles are from all databases. There are 215 articles left after removing duplicate articles. After title and abstract screening, 170 articles were excluded, and 28 articles have no full-text eligibility access. The 17 articles were read in full-text and 6 articles were excluded because the participants are not family caregivers. In conclusion, there are 11 studies in this literature review that search outline was presented a PRISMA flow diagram (Figure 1).

Figure 1 PRISMA flow diagram of search outcomes



2.3 Critical Appraisal and Critique

As a result, eleven articles of the selection process were appraised by use the tools to check that they are good enough for using in the literature review. As there are both quantitative and qualitative studies, the author used different tool specific to each of the study designs . The two quantities studies were assessed use the Appraisal tool for Cross-Sectional Studies (AXIS tool). The nine selected articles which are qualitative studies use the Critical Appraisal Skills Program (CASP) quality appraisal tool (Critical Appraisal Skills Program, 2018) (Appendix 2). Regarding the Critical Appraisal Skills Program (2018), each study should have a clear statement of aims and methodology. If these two things are not related to the research question and not appropriate, those articles will be excluded. Besides, the studies included in this literature review should be clear statements about ethics consideration or informed consent.

2.4 Thematic analysis process

Thematic analysis categorized the results from the review and the thematic analysis identified the emerged themes from the information (Nowell, Norris, White, & Moules, 2017). The researcher followed the six phases of thematic analysis which are familiarization, coding, themes searching, themes reviewing, themes defining and naming, and writing the report (Clarke, Braun, & Hayfield, 2015). The researcher read and re-read the articles to find the common terms then label them. The relevant data to caregivers' understanding of palliative care were placed under appropriate themes and were presented in summary themes emerged from the review table (Appendix 3).

2.5 Findings

Literature review findings were found that the caregivers have a misunderstanding about palliative care. Most of the carers believe that palliative care is for people who are going to die, cancer patients or he last stage of illness patients (Maddalena et al., 2018; Nilmanat, 2016). Moreover, some carers do not even know or heard the word "Palliative care" (Boucher et al., 2018; Maddalena et al., 2018). After a critical analysis of the literature review, four categories related to caregivers' views about palliative care were identified from the studies reviewed. Firstly, caregivers described different palliative care services received at the hospital and home. Secondly, caregivers identified their responsibilities providing care to the patients living with life-threatening illness. Thirdly, caregivers described the emotional and physical support needed for caregivers. In addition, caregivers explained their views about death and a tradition to die peacefully (Appendix 3).

2.5.1 Different Palliative Care Services Received at The Hospital and Home.

As most palliative patients do not need further treatment at the hospital, doctors will discharge patients to home or hospice where is the place for caring people at the end of life. Moreover, both patients and caregivers prefer to spend their time at home rather than a hospital (Poole et al., 2018; Soroka et al., 2018). According to Soroka et al. (2018), the participants said that they know health care providers at the hospice are empathetic and could provide the best care for patients at the end of life. However, the respondent does not want to let their relative to others responsibility. They feel more comfortable relying on other family members rather than hospice (Soroka et al., 2018). The carers try to provide the best care to prevent unnecessary admission (Poole et al., 2018).

In addition, the caregivers identified that looking after palliative care patients was challenged (Fox et al., 2017; Hansen et al., 2017). Each patient who was diagnosed with different diseases also needed care in a different way. For example, palliative patients with cancer or organ failure need different care, that is dementia, who tend to live longer (Hansen et al., 2017; Maddalena et al., 2018; Poole et al., 2018). Medication for palliative care is also a challenge for the caregivers, especially medicines for pain management. The carers do not have a clear understanding of the reason to give an opioid drug to patients (Hansen et al., 2017). Moreover, some patients who have complications need to follow up with the palliative care team to assure that they do not suffer from those problems. Due to these issues, some of the patients still receive home health care services from health care providers. Consequently, some caregivers have no strong understanding of palliative care to think that palliative care means taking care home help (Fox et al., 2017).

The carers stated that they still need full support from the health care providers to reassure them they do the correct way for patients (Boucher et al., 2018; Ciemins et al., 2015; Fox et al., 2017; Hansen et al., 2017). The participants said that they have little knowledge about how to take care of the patients at home (Fox et al., 2017; Hansen et al., 2017). Sometimes they have to search the internet for further knowledge. They do need correct information to gain their understanding of palliative care (Ciemins et al., 2015; Hansen et al., 2017; Soroka et al., 2018). The presence of health care staff does not make them feel being abandoned (Ciemins et al., 2015). Moreover, their care confidence for the patients also depends on the support from health care providers (Ciemins et al., 2015; Soroka et al., 2018).

2.5.2 Responsibilities providing care to the people living with life-threatening illness

In the studies, the caregivers believed that taking care of the people living with life-threatening illness is for their family responsibility (Fox et al., 2017; Soroka et al., 2018; Supaporn et al., 2019). Even though they do not thoroughly understand palliative care, once their relatives are sick, they have to look after them. Especially, Thai culture, Thai people are likely to live as an extended family. Parents and children live together for a whole life span. When the caregivers were young, their parents provided love and care to them. Thus, when they grow up, they would like to give the best care to their parents as repaying (Supaporn et al., 2019).

On the other hand, this big responsibility makes people feel it is a burden (Hansen et al., 2017; Maddalena et al., 2018). This burden does not happen after they have to look after the pperson’s receiving palliative care at home. The stress has come since the first-day doctors told them to make a decision whether they will care for their relatives with life-support or let them die naturally, especially persons who are in a crisis period. When the patient is unconscious, it is a big responsibility for family carers to do and decide everything themselves. Regarding the study written by Fox et al. (2017), one participant said that they could do everything, even choose to have full life support so that the patient can live longer. The problem is this idea makes patients suffer from that (Fox et al., 2017). Most carers do not prepare for end-of-life care (Fox et al., 2017; Hansen et al., 2017). Caring patients who are at the end-of-life stage change caregivers' lives (Hansen et al., 2017; Maddalena et al., 2018). The participants in Hansen's study (2017) said that taking care of palliative patients causes them to have less freedom. Caring for palliative patients even causes them to change their employment status. Some carers need to stop working to provide full-time caring for the patients (Hansen et al., 2017).

However, the care provided to the patients also depends on the relationship between patients and caregivers such as how close they are and how the patients bring the caregivers when they are young (Hansen et al., 2017; Soroka et al., 2018). Some families their relationship became closer because while taking care, they spend more time with each other (Mori et al., 2012; Supaporn et al., 2019). According to Mori et al. (2012), the relationship between family carers and the patients might not change after the diagnosis. That the reason is carers still have their job have other responsibilities in addition to caring for the patients (Mori et al., 2012).

2.5.3 The Emotional and Physical Support Needed for Caregivers

Awareness of Illness that could not be cured has a significant impact on the emotion of both caregivers and patients (Hansen et al., 2017; Supaporn et al., 2019). However, the patients who were diagnosed with a terminal illness went to see doctors only for the reasons of physical problems and their emotional distress were largely overlooked (Mori et al., 2012; Supaporn et al., 2019). Caregivers' perspectives, palliative patients do need more emotional care in addition to physical care (Hov, Bjørsland, Kjøs, & Wilde-Larsson, 2020; Poole et al., 2018; Soroka et al., 2018; Supaporn et al., 2019). However, according to Bainbridge and Seow, the caregivers have more focused on pain management rather than emotional and spiritual supports (Bainbridge & Seow, 2017) The caregivers sympathized with patients' emotions even they have unstable feelings due to the disease progress (Mori et al., 2012). According to Supaporn et al. (2019), caregivers try to provide the best care to minimize the patients' feeling of being abandoned. In addition, one study mentioned feeling secured while receiving palliative care at home (Hov et al., 2020). Hov and friends (2020) indicated that both patients and their relatives have low sense of security in palliative care at home, especially the relatives who provided care for patients and their feeling can affect the care (Hov et al., 2020). Physical supports, family caregivers also stated that one of the essential things for palliative patients caring is being comfortable and having no pain (Mori et al., 2012; Poole et al., 2018). Pain management is one of the big deals that caregivers need to learn, especially medicine (Maddalena et al., 2018).

2.5.4 Death and a tradition to die peacefully

Death talking helped patients and family members feel that death was a normal part of life. Therefore, they were not afraid to the last moment of patients' life (Mori et al., 2012; Soroka et al., 2018). The caregivers adjust to living with a terminal illness (Soroka et al., 2018). The study even mentioned that health care providers must not be afraid to discuss death with them (Mori et al., 2012). Using machine support might cause suffering to patients. The doctors have to tell them both benefits and disadvantages for each treatment (Maddalena et al., 2018; Mori et al., 2012). While some people prefer to use a respirator or life-support equipment to help the patients, the family members in the reviews stated that palliative care is better for patients to die peacefully (Mori et al., 2012; Soroka et al., 2018; Supaporn et al., 2019), especially when the patients involved in decision making.

Religious activities also had a significant impact on patients as well. In Thai culture, most people are Buddhist,the caregivers believe that making merit will help the patients to relieve pain or any kind of burden (Supaporn et al., 2019). As a result of the study conducted in the United States also mentioned that having a strong faith while taking care of palliative patients assists them to pass a difficult time (Soroka et al., 2018).

2.6 Discussion

The study findings indicate that the understanding and palliative care perspectives in caregivers are important for the care provided to patients in home care environment (Boucher et al., 2018; Supaporn et al., 2019). The different disease affects family caregivers to provide care to the patients. For example, elder patients are in end-stage renal disease and with dementia may require a different way to approach palliative care (Hansen et al., 2017; Maddalena et al., 2018; Poole et al., 2018). Although most carers in the study do not have a clear understanding of palliative care (Poole et al., 2018), they can provide appropriate care for patients by getting supports from health care providers (Ciemins et al., 2015; Hansen et al., 2017; Maddalena et al., 2018). This literature review indicates that both caregivers and patients showed a lack of palliative care. Knowledge Furthermore, they need more information and support from health care providers (Boucher et al., 2018; Fox et al., 2017; Hansen et al., 2017; Maddalena et al., 2018; Poole et al., 2018; Soroka et al., 2018). This study shows the weakness of the palliative care system which needs to be improved.

There are some limitations of as follows; Firstly, the study was limited to only English language articles. Some articles that have been published in Thai language were excluded even if they were related to the research topic. Another limitation is most of the articles' titles are specific to the disease, not the age. The researcher needs to look into the participants' criteria, whether it is related to older people as a research question or not. Furthermore, most articles study caregivers' burden in an overview, not only about their understanding of palliative care. Lastly, the literature included the studies from various countries which might not share similar situation of palliative care in Thailand. However, the palliative care system and problems related to palliative care founded from the studies are quite similar.

2.7 Summary

This literature review aims to explore the caregivers' perspectives on palliative care. The relevant article's findings identified four categories related to caregivers' views about palliative care. The four categories are different palliative care services received at the hospital and home, responsibilities providing care to the patients living with life-threatening illness, the emotional and physical support needed for caregivers, and death and a tradition to die peacefully. The main reason that they look after the patients is that they would like to repay their parents as traditional culture and good relationships. The carers do not have a comprehensive understanding of palliative care and show a lack of knowledge to achieve palliative care goals. Hence, the caregivers need support from the health care providers even if the patients were changed from caring at the hospital to home. Therefore, the caregivers' understanding of palliative care needs to be clarified. This study will assist health care providers to understand what caregivers need. Understanding caregivers' perspectives of palliative care will help to improve the quality of palliative care in Thailand as well as the patients' and caregivers' quality of life.

CHAPTER 3 METHODOLOGY

3.1 Introduction

The previous chapters have discussed the background of the study and the literature review related to caregivers' perception of palliative care for older people in Thailand. This chapter presents, the reason for methodology selection, methods, and ethical considerations for a planned study on caregivers' understanding of palliative care in older people in Thailand.

3.2 Methodology

3.2.1 Research paradigm

As this study focuses on caregivers' understandings of palliative care in older people living with life-threatening illness, a qualitative approach is most suitable for the study (Almeida et al., 2017; Schneider et al., 2016). The qualitative study has been used widely and as a result, there are very useful health care service improvements (Hunter & Howes, 2020). The data collection is non-numerical data, but the data are words, concepts and themes (Jameel et al., 2018).

The method of this study is a qualitative description (Polit & Beck, 2017; Schneider et al., 2016). The qualitative description provides direct description and has the least in relating to theory (Sandelowski, 2010). This methodology emphasizes on describing rather than conceptualizing or interpreting (Hunter & Howes, 2020; Polit & Beck, 2017). The researcher uses this method to describe findings (Gray & Grove, 2010). The purpose of qualitative description is to describe and enhance understanding of human experiences or events which might not be commonly described or understood (Schneider et al., 2016; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). The qualitative description is different from other type of descriptive study. While most of descriptive study such as descriptive phenomenological research focuses on people's experiences within specified theoretical framework or theory, qualitative description that focuses on understanding the people experience or other factors that shape people's experiences without referring to a specified theoretical framework (Ranse, Yates, & Coyer, 2012; Willis et al., 2016). This study is beneficial for the researcher seeking the description from the participants until it is clarified (Willis et al., 2016). This is useful for summarising and understanding the interest, especially when the researcher explores people's understanding or belief (Ranse, Yates, & Coyer, 2012).

Although the study using qualitative description sometimes, it may not identify a theoretical framework, the findings could help in improving health care services by creating policies related to the issues found from the participants' experience (Doyle, McCabe, Keogh, Brady, & McCann, 2019) As the findings are quite straightforward, it is easy to understand not only the health care providers but also the people receiving palliative care and their families (Willis et al., 2016). Finally, the health care providers can use those information to contribute evidence-based practice (Gray & Grove, 2010).

3.2.2 The Reason for Methodology Selection

There are many qualitative approaches including phenomenology, ethnography, standard theory and qualitative description (Hunter & Howes, 2020; Schneider et al., 2016). The qualitative description has been chosen as the aim of this study is to describe participants' experiences in palliative care, rather than developing theory that requires standard theory design. The advantages of qualitative description is to provide comprehensive data collected from participants (Schneider et al., 2016). According to Doyle (2019), descriptive study provides straightforward description which help the researcher to see the problem clearly and has been used in nursing area widely because it shows exploring the healthcare problem from personal experience or perception (Doyle et al., 2019). According to Jameel and friends (2018), qualitative research has a great potential to develop programs, policies, protocol which is suitable for each area (Jameel et al., 2018).

However, there are some limitations of qualitative study. The sample size in qualitative research is small, consequently, the findings will be limited to a particular group and cannot give reliable and consistent data (Rahman, 2017). Moreover, it is difficult and impossible to simplify findings and observations because it is about people's perspective (Eyisi, 2016; Rahman, 2017). For instance, some people give low credibility to qualitative study and prefer to use quantitative as references (Rahman, 2017).

3.3 Aims and objectives

3.3.1 Aim

To explore caregivers' understanding of palliative care for older people who live with life-threatening illness in the Thai community.

3.2.2 Objectives

1. To identify enablers in palliative care for older people in Thailand
2. To identify the barriers of palliative care for older people in Thailand

3.4 Research methods

The data collection is a semi-structured interview in which the interview allows respondents to freely express their feelings, opinions, and experiences (Jameel et al., 2018). There are various types of interviews: unstructured, semi-structured and structured interview. The semi-structured interview questions are informed by literature. The researcher created semi-structured interview questions including open-ended questions related to their perspective regarding palliative care for older people with a life-threatening illness and demographic information about caregivers and older people receiving palliative care such as age, gender, and health conditions. The researcher discussed about the questions with supervisors about these questions as shown in Appendix 7. All the questions for the participants are related to the aim and objectives of the study. The researcher did pilot study by interviewing two friends who had experience in taking care of older palliative patients to see if the questions were easy to understand and good enough to get rich information.

According to Willis and friends (2016), it is common to use individual interview or data collection processes when we need more information to develop educational programs, interventions, or explore people’s beliefs and attitudes (Willis et al., 2016). The semi-structured interview enables the researcher to conduct participants' dialogues in order to elicit their understanding of palliative care. The questions could be changed and added to probe and get deeper answer based on the participants’ response (Willis et al., 2016). Furthermore, the interview is the method to get direct conversation. Therefore, participants have a chance to ask questions if they do not understand anything related to the questions (Schneider et al., 2016) and the interviewer can also observe participant’s non-verbal language. Subsequently, interviewing will assist the researcher in getting in-depth information and understand the message that the participants would express more from their verbal and non-verbal language.(Eyisi, 2016; Willis et al., 2016).

3.5 Setting

Out-patient Palliative Care Department of the hospital in Thailand.

3.6 Participants and Strategic Recruitment

The sample in this study are family caregivers of elder patients receiving palliative care service from the Faculty of Medicine Hospital, Mahidol University, Thailand. The inclusion criteria are primary family caregivers of elder patients aged 60 years old or over who live with life-threatening illness and receive palliative care services from the Home Health Care Department at the hospital in Bangkok, Thailand. The sample are 18 years old or over. The sample need to have experiences in taking care of elder patients receiving palliative at least one month which means that they had experience in the care of palliative patients for a while and could share enablers and barriers in when caring for family members who received palliative care. They must be able to access social media so that they can have an interview via line application with the researcher. Primary family caregivers who cannot understand Thai language, impaired cognition, or psychotic problems were excluded.

The participants were indirectly approached by the research assistant at the Home Health Care Department, at the hospital in Bangkok, Thailand. The researcher presented posters in rooms where family caregivers meet health professionals or in-patient restrooms. The posters included brief information about the study and eligibility for participants in the study. and the researcher's contact detail so that potential participants who are interested in the study could contact the researcher. The researcher will meet them face-to-face or on the phone to discuss the purpose of study, process, what the participants will involve in the study, the benefits of the research and participants' rights to withdraw from the research. Information sheet and consent form will be given to the potential participants at this time. Also, the researcher will confirm participants' eligibility to participate in the study and also give participants a chance to ask any questions.

As two co-investigators of the study are employed by the hospital in Bangkok, Thailand where the study will be conducted, there might be power difference issues. However, the researchers do not involve and to provide direct services to the potential participants. Furthermore, the researcher avoids conflict in the recruiting process, all participants will be informed that their decision not to participate or to withdraw from this research study will not affect their relationship with the hospital.

There is no specific number of participants for the qualitative study but it usually requires 8-20 participants in qualitative research(Schneider et al., 2016). or until the information is saturated (Polit & Beck, 2017). Participants are 13 family caregivers in the study.

3.7 Ethics Consideration

As this study is conducted overseas and related to humans, ethics issues are considered. The researcher gets an ethics approval from two committees before doing research to ensure that the purposed plans meet the requirements, the study is not illegal, and the researcher has strategies to minimize all risks that might happen (Polit & Beck, 2017). The first committee is The Social and Behavioural Research Ethics Committee (SBREC) of Flinders University (Appendix 4). After getting approval from Flinders University, the researcher submitted this approval to the Institutional Review Board (IRB) of the Faculty of Medicine Hospital in Thailand to conduct the research (Appendix 5). The approval process by committee is at least 4 weeks to 3 months (Flinders University, 2020). After getting the approval. The participants were provided an information sheet and consent form to ensure that they understand the information about the study, and they are volunteers.

Although this study was considered as a negligible risk project, the researcher provided strategies to ensure participants' confidentiality, respect their rights and minimize all conflict that might occur in the study. Due to the nature of the study that requires to meet the researchers, the participants' anonymity could not be avoided in a face-to-face meeting. However, their confidentiality of information will be maintained by keeping the data in the password-protected electronic file, only researchers in the project could access the data and participants have the rights to withhold the information. The data will be stored securely at the College of Nursing and Health Sciences, Flinders University for five years after publication.

The researcher also concerned about the questions used for interviewing. According to the discussions about palliative care with the caregivers, they might trigger emotional distress for them when they recall their experience in dealing with sadness about the life-threatening illness the older people experience. Therefore, the participants could select questions to answer. If the participants feel uncomfortable due to this study, they could tell the researcher at any time. In this situation, the researcher will stop the interview immediately. Then, the researcher comforts the participant and contacts the service provider for a supporting information sheet.

3.8 Data Collection

The period of data collection started from December 2020, right after getting ethics approval, until February 2021. The study used an online platform for the interview with caregivers of older people receiving palliative care in the community care setting in Thailand. The online platform used in this study is Line application because it is widely used in Thailand in everyday communication. The researcher used semi-structured interview questions that were created for asking the participants. Before starting an online interviewing, all participants were informed about the research; the process, purpose of the study and their rights participating in this study.

Interviewing occurred in a private room of both interviewer and interviewee so that it can help to keep privacy and convenient for the participants to take an online interview without disruption. The duration of an interview is no longer than one hour per person. While interviewing, the conversation was recorded using an audio recorder and this recorder will be kept in the password-protected electronic file. In this process, ethics issues are also considered. The participants will be asked to sign a consent form and permission to record the conversation in the recruiting process and they will be asked to confirm this participation again before starting an interviewing. The participants have the rights to choose the time to make an appointment. Also, the participants could select questions to answer. To respect the respondents' rights, they could withdraw from the study at any time and they have rights to withhold the information (Polit & Beck, 2017). All participants will get a palliative care book as a reimbursement after finishing the interviewing.

3.9 Data Analysis

After completing the interview process, the information was transcript from an audio recorder to change from sound into text information. (Van Nes, Abma, Jonsson, & Deeg, 2010). Then, the information was proved by the research assistant in Thailand who are native speakers to ensure accuracy of the translating data. The researcher carefully thought about the problems that might be occurring in this process, for example, the change in meaning or words that used do not express an intended meaning (Van Nes et al., 2010). The researcher had used strategies according to Regmi, Naidoo and Pilkington (2010) which are using two bilingual people to do forward-translation, translated into English, and then the research assistant translated back into Thai. After the translation process, the researcher compared both versions to check an equivalence of the data (Regmi, Naidoo, & Pilkington, 2010).

The researcher saved the data in a password-protected electronic file and organised the data by using Microsoft word program. It is similar to using computer-assisted qualitative data analysis software (CAQDAS) called the NVivo program (Harding, 2018; Schneider et al., 2016) but the data are organised manually. The researcher used Microsoft word program to interpret the data by using thematic analysis which means categorizing the data into themes and label codes for each theme. It helps the researcher to work with the large amount of data efficiently (Bengtsson, 2016; Nowell et al., 2017). Thematic analysis framework described by Nowell and colleague (2017) was applied to the data analysis process which helps in providing comprehensive data and organizing large data set. The researcher analysed the data by following six phases in establishing trustworthiness thematic analysis, which are familiarizing with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Nowell et al., 2017). The researcher used this 6-phase method in revision of data and had discussed with supervisors throughout the process of data analysis to identify sub-themes and themes. These phases of thematic analysis helped to explain the results of the study as a group by coding. Thus, it is easier for the reader to follow much information (Schneider et al., 2016) and also easier for the researcher to have a critical analysis of the data because the information was categorized in group and was coded. Then, the result was concluded and shown as a table. According to a whole study, it was reported by using the IMRAD format (Polit & Beck, 2017). Computer software helps to reduce time in data management. However, the researcher had done double-check data to confirm that it does not have any errors in the information. 3.10 Rigor of the study

The rigor of the study or trustworthiness is the confidence in data, interpretation, and methods used to ensure the quality of a study. There are four topics that should be considered as a study rigor: credibility, dependability, confirmability, and transferability (Connelly, 2016; Nowell et al., 2017). The researcher applied strategies in phases of thematic analysis in the data analysis process to ensure the trustworthiness of the study. According to qualitative research, the researcher used the member checking strategy by asking the respondents to check their transcripts of dialogue. Moreover, the researcher sent the results of the study to the participants to feedback and check the information. This method is to ensure the data accuracy and ensure participants' expression and equivalent report by the researcher (Nowell et al., 2017). Another technique used in this study is triangulation. There are two forms of triangulation; the use of different methods and a wide range of informants (Shenton, 2004). As there is only individual interview in this study, the researcher will use a wide range of participants. During recruitment process, the researcher does not limit the age and gender of the participants. Therefore, there are more chances to get various characteristics of caregivers. Moreover, the researcher applied the researcher triangulation strategy into the study that helps to address the credibility of the study (Nowell et al., 2017).

3.11 Summary

The chapter provides a descriptive discussion of the relevant methods in the study including research methodology, populations, strategies used to ensure ethical standards, data collection, and data analysis. The researcher used descriptive qualitative design the data collection is a semi-structured interview. The samples were the caregivers who were taking care of elder palliative patients. The study was approved by the SBREC at Flinders University and the Institutional Review Board at the Faculty of Medicine Ramathibodi Hospital, Thailand. The data were analysed by using Microsoft Word Document Program. This study findings will be discussed in the next chapter.

CHAPTER 4 RESULTS

4.1 Introduction

In this chapter, the demographic data of the participants are reported, followed by the findings of the data analysis from interviews about caregivers' perspective towards palliative care. The findings were analysed by using thematic analysis and identified into three main themes. This chapter is organised under four major headings: 1) Participants demographic information; 2) Theme 1 Various understandings of palliative care; 3) Theme 2 Palliative care services; and 4) Theme 3 caregiver stress and coping strategies.

4.2 Participants Demographic Information

In this study, 13 informal carers of older people receiving palliative care participated in interviews. Most of the participants are female. There are 10 females (76.92%) and 3 males (23.08%). The range of the participants' age is 33 to 53 years old. The participants graduated from different educational levels: grade 12, diploma, bachelor's degree, and master's degree. The participants who graduated from grade 12, diploma, bachelor's degree, and master's degree are 5 (38.46%), 1 (7.69%), 3 (23.08%), and 4 (30.77%), respectively. Moreover, the occupation, almost half of the participants are business owners (46.15%)., there are 3 housewives (23.08%) and the rest of them are bankers, public servants, employees, and postman. All participants are family caregivers and most of them are patients' children (84.62%). There are 8 and 3 participants who are patients' daughter and son, respectively. Only 2 participants are niece and wife. The range of their caring experience was from 2 to 60 months. The demographic characteristics of the participant characteristics are summarised in Table 1

Table 1: The Participant Characteristics

No.	Participants (Pseudonym)	Code for participants	Age (years)	Gender	Education	Occupation	Relationship with persons	Exp (months)
1	Patsorn	CG1	34	F	Grade 12	Business Owner	Niece	60
2	Nawapol	CG2	38	M	Master's degree	Business Owner	Son	3
3	Orn-Anong	CG3	47	F	Bachelor's degree	Banker	Daughter	6
4	Supamart	CG4	50	F	Bachelor's degree	Public servant	Daughter	12
5	Jintana	CG5	49	F	Master's degree	Housewife	Daughter	12
6	Kamolned	CG6	54	F	Grade 12	Business Owner	Daughter	5
7	Karnruethai	CG7	33	F	Grade 12	Employee	Daughter	7
8	Angkana	CG8	49	F	Master's degree	Business Owner	Daughter	2
9	Leelavadee	CG9	41	F	Bachelor's degree	Housewife	Daughter	2
10	Danai	CG10	48	M	Diploma	Business Owner	Son	5
11	Petchara	CG11	50	F	Grade 12	Housewife	Wife	13
12	Piyabutr	CG12	38	M	Grade 12	Postman	Son	7
13	Supaporn	CG13	52	F	Master's degree	Business Owner	Daughter	24

Note: CG = Caregiver; M = Male; F = Female; Exp = Experience; persons = persons receiving palliative care

4.3 Research findings

Three main themes were identified and described as 1) Various understandings of palliative care 2) Palliative care services and (3) Caregiver stress and coping strategies. Each theme included sub-themes as listed in Table 2. All themes address the aim and objectives of the study.

Table 2 Themes and Sub-Themes

Themes	**Sub-themes**
Various understandings of palliative care	Providing conservative treatment
	Maintaining comfort and spiritual wellbeing
Palliative care services	Health education and hands-on skill training
	Continuing support from health professionals
	Barrier in receiving palliative care
Caregiver stress and coping strategies	Burden and emotional stress
	Family supports
	Hiring private caregiver

4.3.1 Various Understandings of Palliative Care

Participants have various understandings of palliative care that to relate with their experiences in palliative care and how their caregiving activities were acknowledged by healthcare providers. The caregivers' understandings of palliative care could be identified into two sub-themes presentation as follows:

Providing Conservative Treatment

Most participants showed a good understanding of the palliative care meaning. They described that palliative care was conservative care and did not provide treatment that added suffering on persons who receive palliative care. One of the participants, Jintana, stated that palliative care did not provide aggressive treatment to cure the disease, but conservative treatment. She said "…It is the care that just do conservative treatment… It does not focus on treating the disease anymore…The patient might not be better even receiving the full treatment…" (Jintana, Caregiver 5, p.22).

Similar point of view from another participant, Kamolned, explained that palliative care was a conservative treatment as well, but it did not do any invasive intervention to people receiving palliative care. She said "As I understand, it (palliative care) means conservative treatment. It is focusing on her feelings. Do anything to make her happy. Don't do any invasive intervention." (Kamolned, Caregiver 6, p.32).

Piyabutr also has the same opinion toward palliative car. He stated "It is the care when the patient does not receive any further treatment. We have to help the patient to do daily routine until the last day of their life. Just a conservative treatment." (Piyabutr, Caregiver 12, p.61). He further explained that although his family would like his mum to receive an aggressive treatment at first, they accepted the situation and her desire to receive palliative care. His mum believes that palliative care can help her to be less suffered. He stated:

> *I have heard about this (palliative care) some, not much. My mum is the one who request to receive palliative care. At first when we talked with other people in the family, they want my mum to receive an aggressive treatment if it can help her to live longer but my mum told the doctor that she wants to receive palliative care. She doesn't want to be*

> *suffered from the disease any longer and we respect her decision. (Piyabutr, Caregiver 12, p.60)*

This statement not only showed the family caregiver's opinion toward palliative care but also the persons receiving palliative care's understanding of palliative care and indicated that their opinion was important for making decisions for palliative care.

Besides, Angkana emphasised that receiving aggressive treatment in palliative patients affects the worse condition, especially for her father who was an elder. She shared that her dad's condition got worse after receiving a further treatment, so she decided to receive palliative care as she thought making him feel comfortable was the most important thing. She stated:

> *Palliative care is the care that does not do any further treatment but conservative treatment. The patient will continue receiving care at home and we have to make them feel comfortable as much as we can…Don't make them feel more pain by doing invasive treatment to him. You know? The first three months when he was at the hospital, he's fine. But the more we treat him, the worse his condition is as he's getting older and older. (Angkana, Caregiver 8, p.42)*

Some participants had never heard about palliative care. The participants think that palliative care is the conservative treatment for people who have severe disease or people who are going to die soon. They cannot do anything by themselves and entirely need support from the caregiver. Patsorn, she described the palliative care meaning as the care for people who cannot walk by themselves and palliative meaning in Thai language is supporting people when they cannot balance themselves when they would like to walk. She explained the according to her experience as she helps her aunt to walk or go somewhere:

> *I don't wholly know what palliative care is, but I guess it means patients cannot do anything by themselves, and we have to support them…when they would like to go to the toilet or would like to eat, we have to help them because their disease or illness is too severe. (Patsorn, Caregiver 1, p.2)*

Karnreuthai, the caregiver of a palliative patient with severe condition, had been looking after her father who suffered from the last stage of lung cancer for 7 months. She also understands that palliative care is the care of people who are going to die soon and what we can do for the patient is doing something that can help them to have less pain. She remarked that "I think palliative care is the care for people at the end of life, who have severe health problems and are going to die soon. We have to use morphine when the patient has pain or dyspnoea." (Karnruethai, Caregiver 7, p.36).

Danai, who had experience in taking care of his mum for five months. He also said that healthcare providers did not tell him about palliative care, but he guessed it was a conservative treatment. His mum did not need to see the doctor unless she had a serious condition. He mentioned "I guess it means conservative treatment. If there is anything serious, just go to see the doctor and do as the doctor said." (Danai, Caregiver 10, p.52). However, his statement shows that even though he understood that palliative care was a conservative treatment, he still wanted his mother to receive aggressive treatment when her condition got worse.

Maintaining Comfort and Spiritual Wellbeing

There are various statements by participants highlighting the significance of maintaining comfort, such as good hygiene, good food, enough sleeping, and pain reduction. Their perspective towards palliative care related to their experience in providing care to persons who receive palliative care. For example, Patsorn, she had looked after her aunt for five years. Her aunt has pressure sore at coccyx and every time the nurse come to visit at home, the nurse always mentions good hygiene and food. So, she thought that having good hygiene and eating good food were the most important thing in taking care of persons who receiving palliative care:

> *…I think hygiene and food are the most important…if she has poor hygiene, it will be easier to get an infection. The healthcare providers always mention this too. For food, she has been eating less and less recently. I'm afraid that she might not get enough nutrition and it might affect her health later. (Patsorn, Caregiver 1, p.4)*

Jintana also mentioned about making persons who receive palliative care feel comfortable as well. She believes that providing full treatment might cause them to have more pain and be less comfortable. On the other hand, good hygiene can help them to feel comfortable. She stated:

> *…Instead of giving treatment, which might make the patient more in pain and uncomfortable, it's better to just treat the symptom day by day…making the patient feel comfortable as much as we can is the most important…it is important to clean, to make him has good hygiene... (Jintana, Caregiver 5, p.27)*

Similarly, Kanruethai said that her feeling comfortable is the first priority in providing care for her father. She stated:

> *I don't really expect anything. I just want him to feel comfortable as much as I can help at the last stage of his life. No more suffering from the disease. If possible, I would like him to die peacefully… (Karnruethai, Caregiver 7, p.39)*

Also, Supaporn's point of view, although she said that no one has explained to her what palliative care is but she believes it is the best care for her father which can help him to feel comfortable rather than suffering from having many medical equipment on his body:

> *The healthcare providers have never explained to me about palliative care. I have read about this a little bit from the website, but still do not understand clearly. There is someone said that it's good so I thought it would be good for him as I don't want him to be suffered. I don't want him to have equipment but feel comfortable as we can. I don't want him to on tracheostomy etc. so I chose not to receive aggressive treatment. (Supaporn, Caregiver 13, p.63)*

Supaporn further narrated that she understood his father's condition. She knew that he could not be fully recovered but palliative care is the care that can help him to feel comfortable and die peacefully in the end:

> *I believe that palliative care will help him not to be suffered and help him to die peacefully when it's time. I knew that it couldn't be cured. It's impossible to be full recover. The doctors and nurses always tell us about this. So, we just did whatever that can help him to feel comfortable. (Supaporn, Caregiver 13, p.64)*

Apart from maintaining comfort, mental health and spiritual support are the things that caregivers believe there are important for people receiving palliative care. They would like their relatives to be happy at the end of their life. They tried to provide emotional support in many different ways. Nawapol thought that mental and physical health are related to each other, and feeling is the most important thing we need to concern. If we can make the patient be happy, it can help both patient and caregiver pass through this tough situation. He narrated that "… feeling is the most important. Even though the patient is very in pain, if we have anyway to make them feel calm, do not afraid or sad, both caregiver and patient will pass through it a little by little." (Nawapol, Caregiver 2, p.8).

Petchara, another participant who thinks that maintaining mental wellbeing is the most important, said that she tried to be happy in front of her husband so that her husband does not feel like he is the reason to make her feel bad. She stated "…I care about his feeling the most…I've never cried in front of him…I always smile and let him know that I'm happy…I often play the music he likes to make him feel good and relax." (Petchara, Caregiver 11, p.58).

As the participants whose families are Buddhist, they spiritually support their relatives by playing the praying sound so that they will feel calm and relax. Kamolned stated "We turned on the radio which has praying sound so that it can make her feel calm and relax…" (Kamolned, Caregiver 6, p.33).

One of the participants explained that she did not expect anything from palliative care. Even though she would like him to stay longer but now she understands the situation. She said she can accept whatever that will be happened in the future as long as her father feel happy at the last period of his life:

> *I didn't expect anything. At first, I would like him to live longer. The doctor told us he's not gonna live longer than one month. However, even if he will die sooner, we all are okay and accept that. We will be there to support him and try to do everything to make him feel happy, not stressed. (Leelavadee, Caregiver 9, p.49)*

Many participants support their relatives' feelings by doing what their relatives' desire for the end of their life. To give an example, older people who receive palliative care do not want to stay at the hospital. They would like to stay at home surrounded by people they love. So, the family caregiver chose to receive palliative care at home instead of receiving further treatment.

> *…we have to think about the patient's feelings… I knew what my mum wanted, and I tell the doctor since her condition was bad that we do not want to insert the tube or do CPR…when she was at home, her mental was so good, and I can feel that she was very very happy. Even when she died, she died peacefully (happy voice)… (Supamart, Caregiver 4, p.19)*

Another family caregiver, Kamolned mentioned that she chose palliative care as she thinks it is the best way to make her mum happy. Her mum wanted to stay at home at the last period of her life and response to her desire is the most important thing for persons who receiving palliative care:

> *We decided to continue receiving palliative care at her hometown…She's happy to be at home. She even said that she's at home now, so it's okay if she's going to die soon…focusing on her feeling and her desire at the last moment of her life are the most important. (Kamolned, Caregiver 6, p.31)*

Piyabutr also highlighted the important things in taking care of persons who receiving palliative care. He said that everything we did could improve patient's health outcome, but mental health is the most important thing as his mum's condition cannot be better:

> *Actually, I believe that everything we do for her are important and affect her health outcome. But I think mental health is the most important. If she's happy, she might feel like she wanted to live with us longer…We know that she cannot physically improve so it is better to make she feel happy. (Piyabutr, Caregiver 12, p.61)*

Findings showed that the participants' understandings of palliative care in various ways. However, the similar thing that can be found from the findings is that those family caregivers would like their relatives to be less suffered at the last stage of their life. Therefore, they prefer to choose palliative care which is a conservative treatment rather than receive an aggressive treatment due to they believe that it might cause the patient to be in more pain. Furthermore, the participants thought palliative care can help their relatives to die peacefully if they provide good care by maintaining comfort and spiritual support for them.

4.3.2 Palliative Care Services

The palliative care services that participants mentioned in the interviews are health education, continuing care by home visiting, following up, online support, and phone contact. However, the participants also have difficulty in receiving palliative care services as well. In this section, there are four sub-themes as follows:

Health Education and Hands-on Skill Training

In palliative care services, healthcare providers will prepare the patient and family before discharge by providing health education for them. As taking care of patient at home is something new for the family caregiver. There is a healthcare team teaching both the patient and caregiver about the caring specific for individual patient. For example, in the case of Petchara, her husband has pharyngeal cancer. He was undergoing tracheostomy and had a big wound near his ear resulting from the metastasis of the cancer. When he got back home, she had to dress his wound and everything herself. Moreover, the nurse at the word he admitted taught her about wound care, tracheostomy care, and normal care in daily life such as changing position. She explained:

> *The nurse taught me how to look after him at home…she helped me to prepare everything before going back home including help me plan what the medical equipment we need, how to help him change his position, dressing would…I knew how to dressing*

> *wound and what I need to do since he was admitting at the hospital… (Petchara, Caregiver 11, p.59)*

Nawapol and Kamolned also mentioned about getting health education from healthcare providers when the patient is admitted at the hospital. They both said that the healthcare providers had taught and demonstrated the procedure they need to do to them. Nawapol shared “Before discharging, the healthcare providers had explained and demonstrated what should we do when we go back home...” (Nawapol, Caregiver 2, p.7). Similar to Kamolned, she narrated that “…the doctor referred him to the palliative care unit and a palliative care team came and talked with us about the plan of further the treatment and teach us about what we have to do after discharging.” (Kamolned, Caregiver 6, p.35).

In case persons who receiving palliative care’s family hire the caregiver, the nurse will provide health education to the caregiver, too as that caregiver will be the main person who look after the patient at home. Supaporn shared that she had to prepare many things before continue receiving palliative care at home and the caregiver she hired came to learn at the hospital with her, too. She said:

> *…We had to prepare a lot. We had to learn everything related to the care because when we were at the hospital, there are nurses to look after him. We need to know about morphine and other medicines as well…we learned from the nurses at the hospital. They had taught us and prepared us before going back home for weeks. The caregiver I hired also went to the hospital and learned with us. (Supaporn, Caregiver 13, p.65)*

Not only at the hospital that the healthcare team provide health education for patient and caregiver, but they also provided further information when they follow up by home visiting as well. Patsorn shared that there is rehabilitative team came to visit at home as her aunt has brain trauma, which effect on the functional of arms and legs. The rehabilitative team taught her how to help her aunt to the exercise so that her aunt's body will still have strong muscle even though she is bed ridden. She narrated:

> *… There is a rehabilitative team to help me…we have to follow up every month and they sometimes come to visit us at home… they demonstrated how to do it properly. They gave me information about how to take care of her when we go back home…they taught me how to help her exercise, such as lifting her arms or legs. (Patsorn, Caregiver 1, p.2)*

All the statements in this sub-theme illustrated how important health education is in providing palliative care at home. The caregivers need to prepare and learn both theory and practical skills from the healthcare providers before continuing providing care for palliative patient at home.

Continuing Support from Health Professionals

Palliative care services included home visiting and following up. Although palliative patient does not need any further treatment, they still need continuing care and supports from the healthcare providers. There sometimes nurses or other multidisciplinary patients visit palliative patients and family at home to see whether the care is going well, assess their care management at home and maybe provide health education and promotion. Orn-Anong shared her experience towards palliative services. She said that there are healthcare providers provided services since her mum father was staying at the hospital and follow up by visiting at home:

> *… there is a nurse from the home health care unit who taught me about the caring and the important procedure we have to do after discharging since when he was admitted at*

> *the hospital and they came to visit us at home to see if we can provide the care properly. (Orn-Anong, Caregiver 3, p.13)*

Technology has been used in providing continuing care for palliative patients and their family caregivers. Apart from phone contact, Line application has been used widely in Thailand and this application is another main way healthcare providers use to contact clients after they went back home. Many participants have mentioned this application and said that they use it to consultwith doctors and nurses when they have questions about caring at home. Supamart said that she has line application contact with healthcare providers. There is a group chat and, in that group, has multidisciplinary team who she can ask questions after her husband continues receiving palliative care at home. She shared "…there is a group chat for people receiving palliative care to consult with nurses and doctors…we still can consult with doctor, nurse, and pharmacist via line group chat…" (Supamart, Caregiver 4, p. 18).

Also, Angkana and Danai said that they still keep in touch with the doctors and nurses. They can ask them any questions regarding the care via Line application and there will be someone to answer but the way they get the information from healthcare providers are different. For Karnruethai, she can contact the doctors and nurses directly. She said "…we still keep in contact. We have a group chat for asking questions, and there are nurses and doctors answer for us." (Angkana, Caregiver 8, p. 43)

On the other hand, Danai does not have the direct contact with the doctor and nurse via Line application. He said there is the hospital contact in Line application that he can ask any questions and there will be someone to answer later:

> *If I have any question, I can text to ask via line application but it's not direct contact. There will be computer automatically answer first. I have to wait for a while until the*

> *real person answer. It's better than there is no one to help but it shouldn't be an emergency as it has to wait. (Danai, Caregiver 10, p.54)*

In addition, Leelavadee remarked that she got both phone contact and Line application contact. When there is nothing emergency, she prefers to contact the doctor via Lin application:

> *The doctor gave us both line contact and phone number, said that we can contact whenever we have questions. But I'm afraid to call because sometimes we have problems at late night, sometimes it's 2-3 a.m. …I prefer to message via line application instead. (Leelavadee, Caregiver 9, p.49)*

Although some of them do not have group chat via Line application to talk with multidisciplinary team, they still can keep in contact by using the traditional way, phone contact. Many participants stated that they have phone contact of the doctors and nurses.

> *I don't have their contact in Line application like others, but I have phone contact with the doctor and nurse from palliative care unit. I sometimes call them when I have questions regarding the care. (Supaporn, Caregiver 13, p.65)*

Barrier in palliative care services

The main barrier in palliative care is do not getting enough information. Many participants mentioned having a short time to consult with the doctors when they came for follow-up. Due to the lack of healthcare workers but lots of clients who need to receive healthcare services, they have limited time meeting with healthcare providers. One of the participants, Orn-Anong, she said that she needs continuing care and supports from the healthcare providers even his mum is receiving palliative care, but when the nurse came to visit at home, the nurse said that it will be the last time. She understands that it's because her mum does not have severe condition needed to follow up, but she still wants them to continue following up. "…I would like them to visit more often if possible…last time they came to visit, they said that this is the last time. Maybe my mum's condition is stable, but I still want them to visit." (Orn-Anong, Caregiver 3, p.16).

Similarly, Danai and Petchara said that a nurse from the home health care unit came to visit only once. They would like the nurse to visit more often. This indicates that there still arethe barriers in providing continuing care. Besides, Danai said that he faced difficulty in contacting the doctor and he needs more information about caring from healthcare providers. The time for seeing doctor is too short. "…we have only a short time to see doctor…I feel like they should give me more information…I didn't get enough information and it's very difficult to contact with the doctor…" (Danai, Caregiver 10, p.55).

Jintana also has the same problem when receiving palliative care services. She would like to have time with the doctor longer so that she can ask questions about caring at home more. Sometimes the information they provided is very brief and she still does not understand clearly. She remarked:

> *…when we were at the hospital, no one explained it in in-depth information. I just understand when we went back home by calling to ask a nurse myself. I would like them to explain more, give patients and families more information. Sometimes they just explain shortly. Both patient and family are still confused. It's not clear… (Jintana, Caregiver 5, p.23)*

According to the interviews, it shows that the participants still need continuing care from the healthcare providers even though the patients were discharged and continue receiving palliative care at home. Also, it shows that apart from health education, another palliative care services providing for patients and families is home visiting. There are home health care unit and palliative care team that help and support patients and families even when they are at home. In addition, the healthcare staff have used technology in providing care so that it will be faster for clients to access palliative care services. However, there is the barrier in accessing to palliative care. Due to the shortage of healthcare providers while the numbers of clients who receive palliative care is increasing, there is the limit of time to provide the information for patients and caregivers. As a results, the caregivers feel that they do not get enough information and it affects the caring at home.

4.3.3 Caregiver Stress and Coping Strategies

Burdens and Emotional Stress

Caring palliative patient for a long time needs a lot of money. As a result, some participants have been facing financial problem. Karnruethai had been working as an employee before but now she has to be a full-time caregiver. She said that she quit her job so that she can have time to look after her father all day and this causes financial problem as she still needs to spend money on living expense and specific food for her father. She remarked:

> *…I quit my job and we have a little problem about financial…We need to buy specific food for him at least 4 bags per month. It's quite expensive…Apart from food, I have to pay for the water that uses with oxygen, around 20 bottles per month as my dad needs oxygen all the time. He's tired easily. (Karnruethai, Caregiver 7, p.36)*

However, the hospital has home health care service that provide the benefit sources and information for patient and family. Karnruethai further explained about her management with financial problem that she asked some help from the hospital to find the equipment and the hospital helped her to find available oxygen concentrator for free so that she does not have to pay a lot of money:

> *He needs to use oxygen concentrator which is very expensive. Luckily that there is one left at the hospital. The hospital lends us. At first, they told us to rent from some private company and it is around 30,000 Baht per month. I told them that I could not afford it, I'm unemployed. So, the hospital helped me find, and yeah, there is one left for me. (Karnruethai, Caregiver 7, p.38)*

Not only financial issues that the family caregivers have to manage while taking care of palliative patients. It cannot be denied that looking after palliative patient, especially when they are someone in your family, can affect their feelings. Moreover, taking care of palliative patient is something new to the family. Patsorn, the caregiver who graduated from grade 12, said that it was difficult for her to look after palliative care patient as she does not have much knowledge. Also, her aunt suddenly became bed ridden from the accident and it has a big impact on both her and her aunt. She remarked:

> *…I have to do everything on my own…I don't have much knowledge about how to take care of bed ridden patient. As you know, I just graduated Grade 12…it was very shocked. Before the accident, she can do almost everything by herself just need some supports as she's older people. Everything changed after that. (Patsorn, Caregiver 1, p.3)*

She further mentioned:

> *…my life has changed, and her life changed as well. I didn't work as before and almost be the only one who looks after her. It's quite stressful…apart from her physical, I have to manage her emotions, too. (Patsorn, Caregiver 1, p.3)*

Karnruethai said that she has never taken care of palliative patient before and she was afraid if there is something happened at home as she does not know what to do. She said:

> *…I had never taken care of palliative patient before, so I can help him only basic tasks like daily routine, eating, sleeping and hygiene. If he has bad condition at home, I might be shocked and do not know what to do. (Karnruethai, Caregiver 7, p.38)*

Also, Orn-Anong told that caring at home was different. She has less knowledge and experience in taking care of palliative patient, and this make her feel worried:

> *At the hospital, there were nurses to help me taking care of her. They know how to take care properly, so I don't have to be worried. But when we are at home, I sometimes worried as I have less knowledge and experiences in taking care of palliative patients. (Orn-Anong Caregiver 3, p. 11)*

Supaporn shared that it was difficult to see the one she loves being suffered and painful. Also, she felt bad that she would like to do her best to response his father's desire, but she did not know what he wanted as he could not speak:

> *Of course. I was stressful at that time. He's unconscious and when I called him, he didn't even response. I felt he was very painful and suffered from the illness. He couldn't do anything himself and I couldn't tell what he wanted when he couldn't speak. So, I was very worried. (Supaporn, Caregiver 13, p.64)*

Nawapol also stated that there is a difference between caring at the hospital and at home. His mum's condition got worse faster than he thought. What the nurse taught when his mum admitted at the hospital did not work when she went back home, and it was bad to see his mum suffered and he could not do anything to help her feel better:

> *…Her health condition got worse very fast. They taught me that we should take care of her like this at the hospital, but when we went back home, it is not as same as when we were at the hospital. She sometimes vomited or breathing heavily, and we didn't know what to do...It is like when we saw her feel bad, and we could not do anything with it. That's the worst feeling ever. (Nawapol, Caregiver 2, p.9)*

Furthermore, it might cause physical burden due to spending much time and energy in taking care of palliative patient. Leelavadee shared her experience when she was looking after her dad who had sleeping problem. She said that it was very tired because when her dad could not sleep, she had to sleep late, too. She said:

> *The problem was he couldn't sleep easily. During first week after coming back home, he didn't sleep for almost 2 days, I think. And when I couldn't sleep, I couldn't sleep, too…I would like him to have enough sleep so that it would be good for both of us. I will have time for some rest, too. Before going back home, we thought that we can deal with the problem but it's not like what we think at first…You know? he didn't sleep even we gave him sleeping drug. (Leelavadee, Caregiver 9, p.48)*

She also mentioned there are many problems resulting from not having enough sleep. Her father is always confused at night and sometimes pull out an NG tube or oxygen, which cause her to be more worried as her father needs oxygen 24/7. Also, when he awaked at night, he has a lot of sputum and she need to suction more often. She compared the caring at home and the hospital, said that it was different. She stated:

> *At the hospital, there were many nurses to look after him. They have shift and can change to another person in different time. They know how to manage with the patient… caring at home is different…I was very tired because when I he couldn't sleep,*

> *he had lots of sputum and I had to suction more often. Also, he sometime pulls the NG tube and oxygen out. (Leelavadee, Caregiver 9, p.47)*

Some participants mentioned about back pain, especially the caregiver who have to look after the bed ridden patient alone. It is difficult for the caregivers to help the patients change their position. Patsorn emphasised that caring her aunt cause her to have back pain because her

> …she's too heavy, and I cannot do it (changing position) myself. I have to wait for his son to help me lift her up and change her position. There is no one to help me during the day because they all go to work…I started having back pain now... *(Patsorn, Caregiver 1, p.5)*

Caring palliative patients is hard work. The caregivers have to spend time and energy in taking of their relatives which might result in physical burden in a long-term caring. However, the caregivers can find a way to manage the burden. Some of them have family to support and talk with when they feel stress from caring palliative patient. For those who do not have enough time to look after their relatives themselves, they decided to hire the private caregiver.

Family Supports

After discharging, the caregivers had to plan about the care management at home. Some of them have to look after the patient alone all day and night but they still have other family members to help and support when they could not deal with the problem. Patsorn is a full-time caregiver. She has been looking after her aunt for five years alone. She sometimes has stress, but she can manage well and has family to support:

> *I try to talk with someone when I'm not feeling okay and find something to do, like watching TV. Actually, her condition is just worse for the past 2 years because of*

> *pneumonia. She just became full bed ridden last year. So, I still have time to adapt, and it's not that bad because I am close to her. Also, my cousin, his son, help me to manage everything. Other family members are also ready to support me. (Patsorn, Caregiver 1, p.4)*

Kamolned is working in Bangkok. She took care of her mother herself at first but because her mother would like to go back to hometown after discharging, she asked some help from her relatives. Normally, her mother lived independently so she was very worried that there might be no one with her but her family helped her to look after her mother by moving to live together with her mother. She said:

> *I was worried that there might not have anyone with her during daytime. I worked in Bangkok, and she lived alone there. Luckily, my sister told me she's gonna live with her. My family members who are living there move to stay with her at that time, her children, her cousins, her grandchildren… (Kamolned, Caregiver 6, p.32)*

Another participant, Jintana, stated that her mother needed to be fed via NG tube and all family members knew how to feed via NG tube. Thus, the family members could help each other to look after the mother and it is not an overload for only one person. She needed to be fed very often. She remarked:

> *…We all know how to do it. Sometimes my brother feeds, and sometimes my mum or grandchildren. We all can do it, but my mum is the main one because she is with him all the time…we have to feed him many times in one day. We just change, like, okay, this meal you feed, this meal another one feed… (Jintana, Caregiver 5, p.23)*

These statements illustrated that all members in the family play an important role in providing care for palliative patient. Family supports help the main caregiver to cope with stress and burden from taking care of palliative patient.

Hiring private caregivers

Some participants who did not have time to take care of their relatives, they managed with this problem by hiring private caregiver.

> *No one look after him during daytime because we all go to work…He stayed at neighbour's house. My neighbour used to be a nurse before, and she helped me to look after my dad…She knows how to take care of palliative patient better than us. Well, we can say that it's private homecare. (Leelavadee, Caregiver 9, p.48)*

Similarly, Supaporn highlighted that she had been facing the same situation.

> *My mum couldn't take care of him herself as she is old and other people have to go to work so we decided to hire the caregiver. She looks after 24/7…she's not a nurse but she had been looking after him since before he received palliative care …I had hired the caregiver for almost 2 years… (Supaporn, Caregiver 13, p.64)*

However, hiring a caregiver might not be as good as they expected. It is like allowing stranger to live in the same house and no one know whether the caregiver can be trusted. It takes time to get used to each other and know each other well. Orn-Anong shared her experience when she hired private caregiver. She thought it is better to hire caregiver as she does not have time to look after her mother all day and night. Unfortunately, the caregiver that she got did not look after her mother very well and even deceived her. She narrated:

> *I hired from a private healthcare centre, but she is not as good as I expected. The first caregiver we hired deceived us, also the second one. And when we got the good one, she is with us only for a short period and then she was sent to another house who can give them more money…After the company provide us new caregiver, I looked from the CCTV and found that she didn't feed her every meal, also the medicines. She didn't even change her position. Finally, we decided to let her stay at the healthcare centre. (Orn-Anong, Caregiver 3, p.11)*

4.4 Summary

This chapter has discussed the findings of the interviews, which can be identified into three themes. The enablers of palliative care in Thailand have been demonstrated in the theme "Various understandings of palliative care" and "Palliative care services". The caregivers' care management at home were presented in the theme "Caregiver stress and coping strategies".

In various understanding of palliative care theme, two sub-themes were presented from the caregivers' perspective of palliative care. The first sub-theme is providing conservative treatment. The participants understood that palliative care is a care that do not do any aggressive treatment but conservative treatment. Another sub-theme is maintaining comfort and spiritual wellbeing. The participants believe that these are the most important things in providing care for palliative patient. Palliative care will help their relatives to be more comfortable at the last stage of their life. The patient would have less pain and suffer if they receive palliative care.

According to palliative care services theme, three sub-themes emerged: health education and hands-on skill training, continuing care, and barrier in receiving palliative care. This theme has mentioned palliative care services in the hospital in Bangkok, Thailand, which is the study setting. The services are health education including providing healthcare knowledge and skills specifically for individuals who receive palliative care and their family and providing continuing care both offline by home visiting and online by using the Line application and phone calls. This theme also has shown the barrier in receiving palliative care services. The main barrier that participants have remarked from the interview is not geting enough information due to the time limitation.

The third theme is caregiver stress and coping strategies. This theme revealed how the caregivers manage their caring at home such as having family supports and hiring private caregiver. Also, the theme has shown that the caregivers have a burden and emotional stress from taking care of palliative patients.

Next chapter will discuss the comparison between the outcomes from the research and the previous studies.

CHAPTER 5 DISCUSSION

5.1 Introduction

The purpose of this chapter to interpret the findings from the previous chapter which were presented into three major themes including various understandings of palliative care, palliative care services, and caregiver stress and coping strategies. In this chapter, the findings will be discussed and compared to the existing literature to gain in-depth understanding of palliative care in older people in Thailand. The discussion mainly focuses on the main findings of caregiver's knowledge and understanding of palliative care, palliative care system in Thailand, caregiver's burden, and family dynamics. The limitation of the study will also be presented.

5.2 Providing Palliative Education and Training for Informal Carers

The present study identified the lack of palliative care understanding. For example, some participants stated that they have never heard about palliative care before and thought that the palliative care meaning as the care for people who cannot walk by themselves and palliative meaning in Thai language is supporting. According to Boucher et al. (2018) in which caregivers had no idea about palliative care or misunderstood the palliative care meaning.

Previous studies also identified that family caregivers encountered enormous challenges in looking after palliative patient at home (Fox et al., 2017; Hansen et al., 2017). Such situations might be attributed to the lack of palliative care understanding. According to palliative care, each patient is unique and requires specific care (Hansen et al., 2017; Maddalena et al., 2018; Poole et al., 2018). Therefore, caregivers' understanding of palliative care need to be built in their individual situation ,but they received little to no individualised education about palliative care.

In the present study, most palliative patients needed to take lots of medications including opioids. However, most caregivers did not have a clear understanding about the medications. Therefore, their role as caregiver in managing the medications, observing and reporting the effects and side effects were limited. According to a previous study (Hansen et al., 2017). Previous studies also identified that caregivers needed continuing support from the healthcare providers regarding medications in palliative care (Boucher et al., 2018; Ciemins et al., 2015; Fox et al., 2017; Hansen et al., 2017).

The findings of this study showed that some caregivers were worried about caring. They said they had no idea about how to take care of palliative patient. They further stated that the patient's conditions are very complex. Ii is similar to the findings from the literature reviews, the caregivers indicated that they did not have much knowledge about taking care of palliative patient (Fox et al., 2017; Hansen et al., 2017) and they sometimes have to search for the information themselves because they did not get enough information from the healthcare providers (Ciemins et al., 2015; Hansen et al., 2017; Soroka et al., 2018). Healthcare providers could gain their confidence to look after the patient at home (Ciemins et al., 2015; Soroka et al., 2018). Moreover, palliative care education services are essential for the caregivers who need to take care of palliative patient at home.

In the present study, the caregivers highlighted that they needed continuing care from healthcare providers even if the patient had been discharged and continued receiving care at home. They stated that when the patient was at the hospital, there were nurses who explained and taught them how to look after the patient at home. Moreover, there were nurses from the home health care unit and palliative care team came to visit at home, assessed and gave more information about caring. However, the participants also illustrated that they did not have much time to get the information and ask questions related to caring at home from the healthcare providers. Some of the participants did not know what palliative care is. They said they would like to learn and get more information from the healthcare providers. Similarly, the findings from the literature review showed that caregivers still need support from the healthcare providers after discharging and they should come to visit often. Otherwise, they will think that they were ignored by the healthcare providers (Ciemins et al., 2015). Nurses and doctors help them to be more confident in providing care for patients, especially when the patients are old and have complex conditions (Ciemins et al., 2015; Soroka et al., 2018).

The previous studies have shown that there are many factors related to caregiver's knowledge (Harden, Price, Duffy, Galunas, & Rodgers, 2017; Lowe, Plummer, & Boyd, 2018). One of the factors is healthcare providers' knowledge, especially nurses' knowledge. There is a study indicating that improving nurses' performance in providing care by improving their knowledge can help to solve the problems (Harden et al., 2017) as the effectiveness of care is relevant with the development and sustainability of nurse practitioner (Lowe et al., 2018). Nurses are the key healthcare providers who close with patients the most (Harden et al., 2017). As a result, they are expected to have sufficient knowledge to provide the best care for patients (Harden et al., 2017; Paknejadi, Hasavari, Khaleghdoost Mohammadi, & Kazemnejad Leili, 2019). Furthermore, it is said in the articles that a nursing educational program on palliative care is one strategy to improve health service outcome (Al Qadire, 2014; Lowe et al., 2018; Paknejadi et al., 2019). Palliative care education could improve palliative clinical practice through nurses' performance (Prem et al., 2012). Nurses who are educated in palliative care can effectively help patients and their families attain optimal comfort care and management of pain and other symptoms. Therefore, ongoing support and education for nurses are required to ensure continuity (Dredge, Oates, Gregory, & King, 2017).

Regarding Van Riet Paap et al. (2015), there are many evidence-based practices resulting from research study that have not been implemented in practice. The healthcare staff can improve nursing education so that they can improve the health care services by implementing those outcomes into practice (Van Riet Paap et al., 2015) and updating palliative care guideline and policies in providing palliative care (Chaiviboontham, 2020). The nurses better provide knowledge about palliative care to patients and caregivers including the concept of palliative care and how to manage pain and symptoms (Harden et al., 2017). Also, apart from the lack of knowledge, it has been found that caregiver's burden also needs to be more focused. Health professionals in the palliative care area have a lack of understanding the difficulties or unmet needs among patient and family caregivers (S. Choi & Seo, 2019; Wang, Liu, Robinson, Shawler, & Zhou, 2019). It is necessary to have an assessment and get some feedback after implementing the interventions (Lau et al., 2014). The assessment might be a satisfaction questionnaire or the quiz about palliative care for patients or healthcare providers to see whether the intervention is going well (Dredge et al., 2017; Lau et al., 2014; Van Riet Paap et al., 2015).

Knowledge is one of the most essential things in providing palliative care to patient, especially the understanding of palliative care. If the caregivers know what palliative care is, they will know how to provide the proper care for the patients as palliative patients do not need only physical care, but also psychosocial and spiritual care (Hui, Hannon, Zimmermann, & Bruera, 2018). Getting palliative care education will help to improve the quality of care as well as the quality of life of both patients and caregivers (Hui et al., 2018). Moreover, the studies indicated that providing a palliative care education program for patients and family caregivers before discharging is effective in preparing caregivers to provide palliative care at home (G.-H. Choi & Kwon, 2018).

5.3 Incorporating Palliative Care into Community Aged Care

In the present study, the researcher interviewed participants who receive palliative care services from hospital out-patient clinics. Some of the participants are living in rural area but need to come to receive the care from the hospital which is in the city. Furthermore, the result showed limited support for the caregivers while they were receiving services at the hospital and at home due to the imbalance between patients and families who receive services and the healthcare providers. Consequently, they have to spend a lot of time and costs to receive services. As a result, the referral system has more of a role to play in this situation as the participants still need continuing support from the healthcare providers.

The present study identified that community-based palliative care for older people in Thailand has become more important due to ageing population in the country and the cultural beliefs of the care of older people at home. The finding supports previous studies that community-based care has lots of benefits due to the change of family dynamic nowadays (Rosenwax, Spilsbury, Arendts, McNamara, & Semmens, 2015; Spilsbury, Rosenwax, Arendts, & Semmens, 2017; Wright, Youens, & Moorin, 2018). Communities have more of a role for palliative patients, especially people living in rural area who have difficulties in accessing healthcare facilities (Spilsbury et al., 2017). Community-based palliative care has been used worldwide to help alders and families in accessing palliative care services. It’s not only help the client to access to services easier but also help them to reduce cost and improve health outcome (Spilsbury & Rosenwax, 2017; Yosick et al., 2019) However, there are some areas still underutilized (Ghesquiere et al., 2018). The study about palliative care in New York about palliative care in the community showed the lack of collaboration between health professional around palliative care which is similar to the palliative care situation in Thailand (reference). Similar to the present study, the participants in the study by ?? did not receive services from the community settings but care services delivered from the hospital. Apart from the community based-palliative care, the finding supports previous study in which caregivers believed that taking care of palliative patient who were their relatives was their responsibility (Fox et al., 2017; Soroka et al., 2018; Supaporn et al., 2019). In the present study, participants stated that they were happy to take care of patients themselves. Moreover, the patients in the present study also preferred to stay at home with their family rather than staying at the hospital. Hence, the caregivers chose to continue receiving care at home as they would like to provide the best care to their relatives and help their relatives to achieve their desire at the last stage of their life. In the case of Thai culture, people tend to live as an extended family and have strong bond to each other. As a result, they would like to provide the best care to their family members once they are sick (Supaporn et al., 2019). In addition, they do not let others take responsibility even though they know that healthcare workers can do better as they feel more comfortable to rely on other family members rather than hospice. Hence, they prefer to look after their relatives themselves and the care for palliative patient are mainly in the community, not at hospital or any other healthcare facilities (Soroka et al., 2018).

On the other hand, the findings were different from the literature review because the social dynamic has been changing due to the globalisation. Recently, people in younger generations tend to migrate to work in the city rather than living in their hometown and leave the older people at home alone. The number of older people is increasing while the number of family member living in the same household is decreasing (Tantuvanit, 2021) Consequently, nuclear family has become common in Thai society result in the less strong ties of the relationship within family and social relationship in the community (Nilmanat, 2016b). Although the participants did not mention the community care services in this study, community-based care has been remarked other recent studies. According to the statistics, almost 50 percent of Thai people died at home. Therefore, strengthening social relationships and establishing compassionate community-based care are important to enhance end-of-life care in the community and support people to die peacefully at home (Nilmanat, 2016b).

5.4 Self-care for Informal Caregivers

Participants of this study perceived it was very different between looking after the patient at home and at the hospital. At the hospital, there are nurses, doctors, and a multidisciplinary team who know how to take care of the patient properly but they do not. It was very stressful to provide the care for palliative patient, especially when they saw their relatives' suffering, but they could not do anything to help them feel better. The finding is similar to, previous studies that mentioned about caregiver's stress and distress when taking care of palliative patients (Hansen et al., 2017; Maddalena et al., 2018). Caring palliative patient could cause them to be burdened both physically and mentally. The caregivers have not prepared to provide the care for palliative patient, and it was very difficult for them to have such a big responsibility as the patient could not do anything themselves even making a decision (Fox et al., 2017).

Furthermore, taking care of palliative patient needs time and attention. They feel like they have less time for themselves. Also, some of the caregiver have to quit their job so that they can look after the patient which cause them to have financial burden later (Hansen et al., 2017). Same as the finding from this study, the present study indicated that some participants quit their job to be a full-time caregiver. They said that taking care of palliative patient cause them to have no time for themselves. Even some families hired private caregivers as they do not have enough time to provide the care themselves, they were still worried about the care. They are not sure that those private caregivers will provide the care for their relatives properly when they are not at home. Worse than that, one participant had bad experience about hiring private caregiver which cause the participant to be more worried. Although they sometimes can manage with their stress and burden, these still affect the caregiver's health and could affect to the quality of care they provide the patient. Patient caring at home is stressful, especially for those who have never had experience caring for a patient (Ahmad Zubaidi, Ariffin, Oun, & Katiman, 2020; S. Choi & Seo, 2019). One study illustrated that more than half of the informal caregivers experienced burden because caring patient, especially palliative patient, need much time and attention (S. Choi & Seo, 2019). Ahmad et al. (2020) reported that most common psychological manifestation are anxiety, depression, and stress, respectively. The study further explained that the burden is related to the time they spend on caregiving and how severe the conditions of the patients. Also, it will be more stressful when the patients are in the older generation (Ahmad Zubaidi et al., 2020), which is the same as the findings in the present study. Consequently, self-care for the caregivers themselves is essential (Dionne-Odom et al., 2017; Wang et al., 2019).

Caregiver well-being also should be concerned in palliative care (Dionne-Odom et al., 2017). Providing care for palliative patients is very challenging for informal caregivers and it has an impact on the caregiver’s personal life and their ability to perform caregiving role (Dionne-Odom et al., 2017). Dionne Odom et al. (2017) did a survey with informal caregivers about the self-care practice, and it has been reported in the study that there is an association between self-care practice and the levels of caring performance scores. In addition, the participants who have lower self-care practice score are associated with an improper preparedness for caring palliative patients. Moreover, many studies highlighted the importance of improving caregiver self-care (Dionne-Odom et al., 2017; Pope, Giger, Lee, & Ely, 2017). The finding from both previous literature and the present study indicated that most caregivers do not have time for themselves while the balance between time spending for caregiving and for themselves is very essential as it can help to reduce burden (Wang et al., 2019).

5.5 Limitations

There are some limitations to research study. Firstly, this study was conducted overseas. It was very challenging to conduct the study overseas while there was Covid-19 pandemic. At first, the researcher plan to do face-to-face interviewing as the interview questions are about palliative which might be sensitive for the interviewees, who are the family of the patient, and video calling is the way that can help to see the participant's gesture while answering the questions, but because of the pandemic, the method was changed to online interview and did the interview by video calling via Line application instead. Still, there is an internet issue. The signal was not stable while video calling and finally, the researcher decided to use phone call. Although a telephone interview is good as it is more convenient for the participants, the researcher could not see their gestures.

Secondly, there are some challenges in the literature review process. Although there are many articles related to this study, most of those articles are in Thai language. Hence, the researcher decided to choose the articles from other countries which shared similar palliative care issues and were published in English.

Moreover, as this is an oversea study, the researcher had to request for an ethical approval both in Australia and in Thailand. As a result, it took longer for an ethics application. Besides, the interviews were conducted in Thai language. The researcher transcribed from the recorder and then translated into English which might result in the difference in meaning after translation as the words used might not express an intended meaning (Van Nes et al., 2010). However, the researcher solved this issue by comparing both versions after translating to check the equivalence of the data (Regmi et al., 2010).

5.6 Implications for Policy, Resource and Practice Development

5.6.1 Implication for Policy and Resource

Home Palliative Care is increasing. This study found that there is a lack of knowledge among the participants about how to take care of palliative patient at home. Also, there is a difficulty in accessing palliative care services due to the shortage of healthcare workers and time limitation. While palliative care is needed more, the policy for palliative care education is still the same. Based on the research's experience, palliative care education has been put into curriculum in medical and nursing school but only few hours class and no practices session, results in the shortage of palliative care workforce and findings from this study also indicated that healthcare education policy that have been using is not enough compared to the need of palliative care recently. Moreover, the policymaker should develop the policy to mandate palliative care education for healthcare workers and develop resources in palliative care area to support the education in Thailand in order to improve the current situation (Maddalena et al., 2018).

5.6.2 Implication for practice

To use the findings from the study in practice, it might not be able to directly use the outcome but problems about the lack of knowledge of the caregivers and barriers in getting information about caring that emerged from this study help to show that these problems can be solved if palliative care education, both for healthcare workers and caregivers, are improved. The findings showed people who receive palliative care still did not get enough information and require continuing care. Therefore, healthcare staff who work in palliative care area need to improve their practice by providing palliative care information to caregivers. For instance, they can integrate palliative care into the care plan or treatment plan earlier as the evidence showed that most palliative patient were referred to the palliative care team when they are in active dying stage. The earlier patients and caregivers receive palliative care services, the more time for them to get deeper information about caring at home.

5.6.3 Future research

Future research should be the various research methods to get the information in more detail. The researcher might use mix method such as using a survey to explore the factors related to caregiver's understanding of palliative care as mentioned in the previous paragraph that there are many factors related to caregiver's understanding so that relevant people could develop and create the policy to improve palliative care services which is meet the caregiver's needs. In the case of using questionnaires, a pilot study should be conducted with the developers of the questionnaire to enhance understanding of the responses and to improve the efficacy of the study design. In addition, the future research might focus on intervention studies. For instance, palliative care education programs to improve both patients' and caregiver's knowledge in managing palliative care at home in order to improve their quality of life.

5.7 Summary

This study illustrated that the need for palliative care in community care requirement in Thailand is increasing dramatically due to the growing of aging population. Apart from healthcare workers, family caregivers play an important role in providing care for palliative patients. Therefore, their understanding towards palliative care is important as it can affect how they provide the care for patient after discharging.

The study used qualitative methodology by using interviewing method to explore caregiver's understanding of palliative care and the results show that they have various understandings about palliative care. They understand that palliative care is a conservative treatment which can help patient to maintain comfort both mentally and physically. The finding illustrated that there are many factors that can affect the way the caregivers provide the care to palliative patient at home including knowledge, family supports, cultures and continuing care from the healthcare providers. Firstly, the studies indicated that the knowledge about palliative care is very essential in providing care for palliative patients. Both previous studies and the findings from the present study has the similar outcome about caregivers’ understanding of palliative care. The caregiver perceived that they do not know much about the palliative care patient at home. Some of them showed a misunderstanding of palliative care and remarked that they did not get enough information from the health care providers.

Both previous studies and the present study showed the gap between the healthcare system and people who receive care services. The palliative care education services are needed and should be improved so that it will be easier for patients and caregivers to access the services and get enough information about the care. Secondly, Thai culture also plays an important role in palliative care, especially in the community. Family dynamics strongly affect the care management for palliative patient at home. However, due to the globalisation, people tend to work outside and do not have enough time to look after palliative patient at home. Moreover, some family decided to hire private caregiver instead. In this case, it also indicated that the community-based care has significant role in providing care for palliative patient after they have been discharged and continue receiving palliative care at home. Lastly, as most palliative patients have complex symptoms and need lots of care, the caregivers have to spend time and energy which sometimes cause burden to them. Self-care management is needed so that it will help them to have less burden both physically and mentally.

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APPENDICES

Appendix 1 AXIS tool checklist table

Studies	Clear aim	Appropriate research design	Justified sample size	Participant clearly defined	Variables accounted for the design of the study	Appropriate data stattistics and analysis	Results were adequately described	The consistent result	Result presents were described in the method	Discussion and conclusion justified by the results	Identified limitations	Ethical approval
Hov, R. et al. 2020	Y	Y	Y	Y	C	Y	Y	Y	Y	Y	Y	Y
Bainbridge, D., & Seow, H. 2018	Y	Y	Y	Y	C	Y	Y	Y	Y	Y	Y	Y

Abbreviation key:

Y = Yes, C = Cannot tell, N = No

As adopt from critical appraisal tool to access the quality of cross-sectional studies (Downes, Brennan, Williams, & Dean, 2016)

Appendix 2 CASP tool checklist table

Studies/Screening questions	**A clear statement of the aims**	**Methodology appropriate**	**Research design appropriate**	**Recruitment strategy appropriate**	**Data collection method appropriate**	**Power differences have been considered**	**Ethics consideration**	**Data analysis sufficiently rigorous**	**A clear statement of findings**	**Mentioned the value of research**
Boucher et al., 2018	Y	Y	Y	C	Y	C	Y	Y	Y	Y
Ciemins et al., 2015	Y	Y	Y	C	Y	C	C	N	Y	Y
Fox et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hansen et al., 2017	Y	Y	Y	C	Y	C	Y	Y	Y	Y
Maddalena et al., 2018	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
Mori et al., 2012	Y	Y	Y	C	Y	C	Y	Y	Y	Y
Soroka et al., 2018	Y	Y	Y	C	Y	C	C	Y	Y	Y
Supaporn et al., 2019	Y	Y	Y	Y	Y	C	Y	Y	Y	Y

Abbreviation key:

Y = Yes, C = Cannot tell, N = No

As adopt from critical appraisal tool to access the quality of qualitative studies

Appendix 3 Summary themes emerged from the review table

Emerging theme	Theme support from the literature
Differences between palliative care services received at the hospital and at home	Boucher, 2018; Ciemins et al., 2015; Soroka et al., 2018; Hansen et al., 2017; Fox et al., 2017; Bainbridge, D., & Seow, H. 2018
Responsibilities in providing care to the persons living with life-threatening illness	Fox et al., 2017; Hansen et al., 2017; Maddalena et al, 2018; Mori et al 2012; Soroka et al., 2018; Supaporn et al., 2019
The need for emotional and physical support	Mori et al., 2012; Supaporn et al., 2019; Hov, R. et al. 2020; Bainbridge, D., & Seow, H. 2018
Death and a tradition to die peacefully	Mori et al., 2012; Soroka et al., 2018; Supaporn et al., 2019

Appendix 4 Summary review table

Author(s) surnames and year/country Title	**Study aims/purpose**	**Study design/methodology**	**Setting and sample**	**Main findings**	**Strengths and limitations**	**Relevance to research**
Supaporn, K., Isaramalai, S. A. & Suttharangsee, W. (2019) Thailand Exploring caregivers' perspectives on improving care for older people at the end of life in Thailand	To explore caregivers' perspectives for the older person	A qualitative study using semi-structured interviews	10 participants are caregivers of patients who received health services from 14 primary care centers in Thailand	Three themes emerged from the study: characteristics of the participants, caring to repay the older person's kindness, caring to minimise the older person's perception of being abandoned or a burden	Strengths: get in-depth information related to the area of interests Limitations: small group of samples, the findings cannot be generalized to other sample groups	- Responsibility to provide the best care to patients - Need both emotional and physical supports - Death and a tradition to die peacefully
Ciemins, E. L., Brant, J., Kersten, D., Mullette, E., & Dickerson, D. (2015). A qualitative analysis of patient and family perspectives of palliative care	- To explore patient and family perceptions of palliative care - To identify facilitators and barriers to receipt of	A qualitative study using semi-structured interviews	Participants are 3 patients and 11 family members who received palliative care service from	Presence, reassurance, and honouring choices are the main themes that emerged from the study	Strengths: get in-depth information related to the area of interests Limitations:	Changing from receiving care services at the hospital to home

Author(s) surnames and year/country Title	Study aims/purpose	Study design/methodology	Setting and sample	Main findings	Strengths and limitations	Relevance to research
	palliative care services		health services in three states		small sample size	
Mori, H., Fukuda, R., Hayashi, A., Yamamoto, K., Misago, C., & Nakayama, T. (2012). Japan Characteristics of caregiver perceptions of end-of-life caregiving experiences in cancer survivorship: In-depth interview study	To characterize caregiver perceptions of their experiences with end-of-life care	A qualitative study using semi-structured interviews	Participants were recruited from two palliative care units in Tokyo and Kyoto, Japan. The participants are Japanese primary caregivers of adult patients who had died of cancer within the past year	Characteristics of caregivers' perception of palliative care divided into two axes that can change and cannot change. The characteristics depend on the relationship between patients and caregivers	Strengths: get in-depth information related to the area of interests Limitations: The information getting from participants based on memories	- Responsibility to provide the best care to patients - Need both emotional and physical supports - Death and a tradition to die peacefully
Soroka, J., Froggatt, K., & Morris, S. (2018). United States Family Caregivers' Confidence Caring for Relatives in Hospice Care	To explore the views, feelings, and experiences of primary caregivers of palliative patients	A qualitative cross-sectional study using semi-structured interviews	Participants were recruited from 1 hospice organization in the midwestern United States	Caregivers' confidence caring for palliative patients depend on the support they received from the health care providers and the	Strengths: get in-depth information related to the area of interests Limitations:	- Changing from receiving care services at the hospital to home - Responsibility to provide the

Author(s) surnames and year/country Title	**Study aims/purpose**	**Study design/methodology**	**Setting and sample**	**Main findings**	**Strengths and limitations**	**Relevance to research**
at Home: An Exploratory Qualitative Study				knowledge they have	small group of samples, the findings cannot be generalized to other sample groups	best care to patients
Hansen, Lissi, Rosenkranz, Susan J., Wherity, Kathleen, & Sasaki, Anna. (2017) Australia Living with Hepatocellular Carcinoma Near the End of Life: Family Caregivers' Perspectives	To explore family caregivers' perspectives of caring for patients with terminal hepatocellular carcinoma (HCC)	A qualitative descriptive design using interview	The setting for this study is Oregon Health and Science University in Portland and Veterans Affairs Portland Health Care System in Oregon. The participants were 13 family caregivers.	Five themes were identified from the study. The main idea about caregivers' perspective of palliative care is they have little knowledge and need more information	Strengths: get in-depth information related to the area of interests Limitations: small group of samples, the findings cannot be generalized to other sample groups	- Changing from receiving care services at the hospital to home - Responsibility to provide the best care to patients
Fox, S., Cashell, A., Kernohan, W., Lynch, M., Mcglade, C., O'Brien,	- To explore the palliative care and related issues most affecting people with	A qualitative study using semi-structured interviews	13 Participants were recruited from 3 Movement Disorder Clinics in	The participants were not familiar with the term of palliative care and	Strengths: get in-depth information	- Changing from receiving care services at the

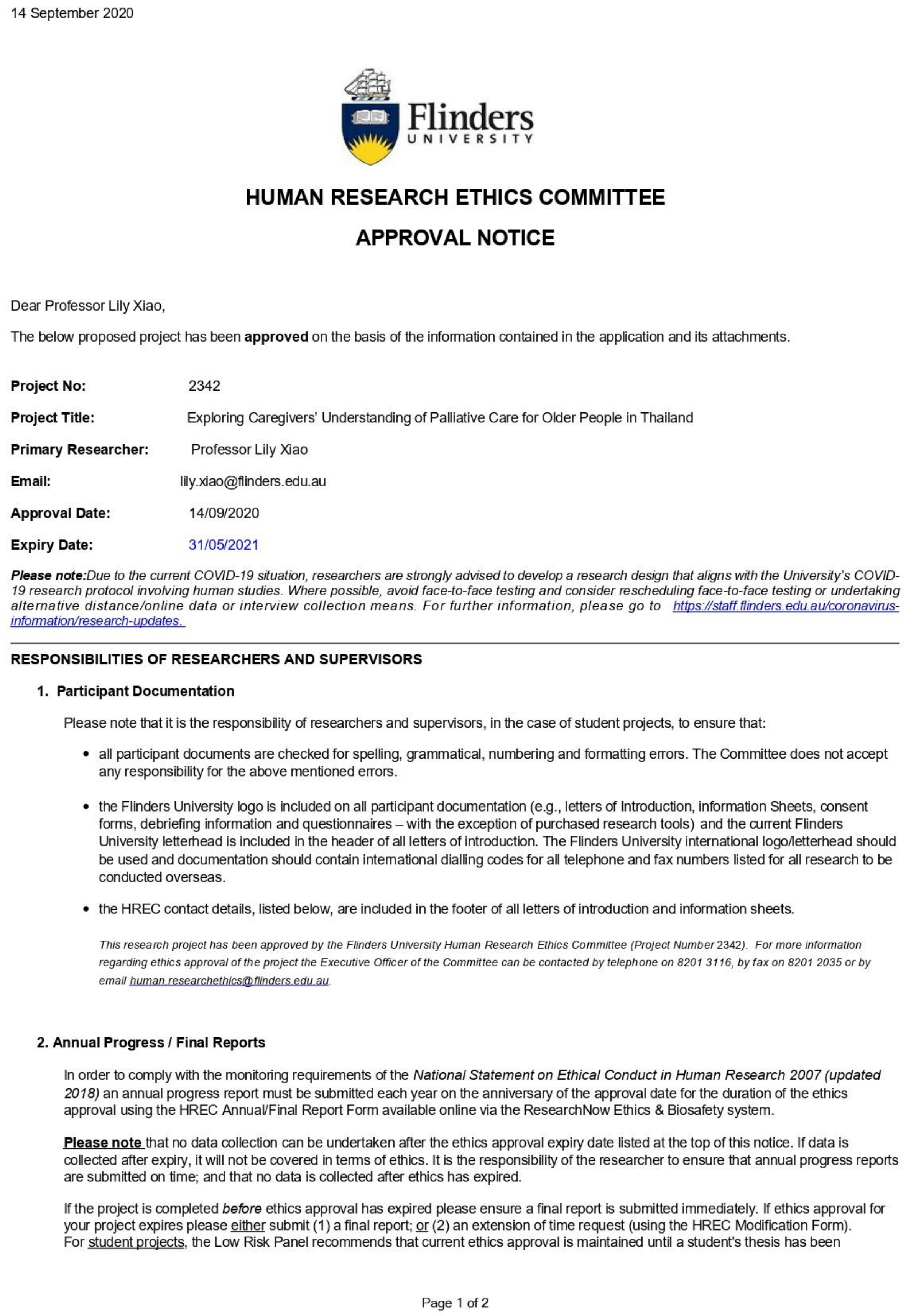
Author(s) surnames and year/country Title	**Study aims/purpose**	**Study design/methodology**	**Setting and sample**	**Main findings**	**Strengths and limitations**	**Relevance to research**
T., . . . Timmons, S. (2017) Ireland Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview	Parkinson's disease and their families - To examine perceptions about/understanding of palliative care.		the Republic of Ireland	they need more support from the health care professionals especially for emotional support.	related to the area of interests Limitations: small group of samples, the findings cannot be generalized to other sample groups	hospital to home - Responsibility to provide the best care to patients
Maddalena, V., O'Shea, F., & Barrett, B. (2018) An Exploration of Palliative Care Needs of People With End-Stage Renal Disease on Dialysis: Family Caregiver's Perspectives	- To explore family caregivers' experiences of caring patients with End-Stage Renal Disease - To explore caregivers' perception of palliative care	A qualitative study using semi-structured interviews	18 family caregivers were recruited through the renal dialysis services of the provincial Regional Health Authorities	The concept of palliative care was not well understood. Taking care of palliative care patients is hard work and cause them to burden.	Strengths: get in-depth information related to the area of interests Limitations: small group of samples, the findings cannot be generalized to	- Changing from receiving care services at the hospital to home - Responsibility to provide the best care to patients - Need both emotional and

Author(s) surnames and year/country Title	Study aims/purpose	Study design/methodology	Setting and sample	Main findings	Strengths and limitations	Relevance to research
					other sample groups	physical supports
Poole, M., Bamford, C., Mclellan, E., Lee, R., Exley, C., Hughes, J., . . . Van Der Steen, J. (2018) England End-of-life care: A qualitative study comparing the views of people with dementia and family carers	To compare the views of people with dementia and family carers	A qualitative study using semi-structured interviews	14 caregivers were recruited through the renal dialysis services of the provincial Regional Health Authorities	The participants think that being comfortable is the most important for caring patients. They need more information and support from the healthcare staff	Strengths: get in-depth information related to the area of interests Limitations: qualitative interviews are inappropriate for seeking the views of people with advanced dementia	- Changing from receiving care services at the hospital to home - Need both emotional and physical supports
Boucher, N., Bull, J., Cross, S., Kirby, C., Davis, J., & Taylor, D. (2018).	To understand study participants' knowledge of palliative care	A qualitative study using interviews and focus group	14 participants were recruited from two hospices in	The participants have little knowledge of palliative care and more than half of	Strengths: get in-depth information	- Changing from receiving care services at the

Author(s) surnames and year/country Title	Study aims/purpose	Study design/methodology	Setting and sample	Main findings	Strengths and limitations	Relevance to research
Unites States Patient, Caregiver, and Taxpayer Knowledge of Palliative Care and Views on a Model of Community-Based Palliative Care			Western North Carolina	them have no idea what palliative care is.	related to the area of interests Limitations: small group of samples, the findings cannot be generalized to other sample groups	hospital to home
Hov, R., Bjørsland, B., Kjøs, B.Ø. et al. (2020) Norway A sense of security in palliative homecare in a Norwegian municipality; dyadic comparisons of the perceptions of patients and relatives - a quantitative study	To describe and compare patient-relative dyads regarding their perceptions of security in palliative homecare	cross sectional questionnaire study	Participants including 60 patients receiving palliative homecare and 38 of their relatives were recruited from an urban municipality	The results showed that relatives' perception of security in palliative care at home is lower compared to patients' perception	Strengths: The researchers who conducted the interviews and filled in the questionnaire were not employed in the municipality so that it can be ensure that they did not influence the answer	- Need both emotional and physical supports

Author(s) surnames and year/country Title	Study aims/purpose	Study design/methodology	Setting and sample	Main findings	Strengths and limitations	Relevance to research
					Limitations: The number of participants is low	
Bainbridge, D., & Seow, H. (2018) Canada Palliative Care Experience in the Last 3 Months of Life: A Quantitative Comparison of Care Provided in Residential Hospices, Hospitals, and the Home From the Perspectives of Bereaved Caregivers	To explore the end-of-life care experiences across various settings from bereaved caregivers	A retrospective, observational design using the survey	1153 caregives in Ontario	The findings emphasize the importance of emotional and spiritual supports	Strengths: Limitations:	- Changing from receiving care services at the hospital to home - Need both emotional and physical supports

Appendix 5 Ethics approval



14 September 2020

HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL NOTICE

Dear Professor Lily Xiao,

The below proposed project has been **approved** on the basis of the information contained in the application and its attachments.

Project No:	2342
Project Title:	Exploring Caregivers' Understanding of Palliative Care for Older People in Thailand
Primary Researcher:	Professor Lily Xiao
Email:	lily.xiao@flinders.edu.au
Approval Date:	14/09/2020
Expiry Date:	31/05/2021

Please note:*Due to the current COVID-19 situation, researchers are strongly advised to develop a research design that aligns with the University's COVID-19 research protocol involving human studies. Where possible, avoid face-to-face testing and consider rescheduling face-to-face testing or undertaking alternative distance/online data or interview collection means. For further information, please go to https://staff.flinders.edu.au/coronavirus-information/research-updates.*

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 HREC 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 Human Research Ethics Committee (Project Number 2342). For more information regarding ethics 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.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the anniversary of the approval date for the duration of the ethics approval using the HREC Annual/Final Report Form available online via the ResearchNow Ethics & Biosafety system.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

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 either submit (1) a final report; or (2) an extension of time request (using the HREC Modification Form).
For student projects, the Low Risk Panel recommends that current ethics approval is maintained until a student's thesis has been

submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

FirstReport due date: 14 September 2021

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, researchers and supervisors)
- 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 to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available online via the ResearchNow Ethics & Biosafety system. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

4. Adverse Events and/or Complaints

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

Yours Sincerely,

AMather

Andrea Mather

on behalf of

Human Research Ethics Committee
Research Development and Support
human.researchethics@flinders.edu.au
P: (+61-8) 8201 3116

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

ResearchNow
Ethics & Biosafety

Flinders University Research Development and Support Proactively supporting our Research

Appendix 6 Thai ethics approval

Human Research Ethics Committee, Faculty of Medicine Ramathibodi Hospital, Mahidol University
270 Rama 6 Rd. Phayatai Ratchathewi Bangkok 10400 Tel.(660)2012175, 2011544, 2010388
Website: https://med.mahidol.ac.th/research/ethics
E-mail: raec.mahidol@gmail.com

COA. MURA2020/1810

Title of Project (English)	Exploring Caregivers' Understanding of Palliative Care for Older People in Thai Community
Title of Project (Thai)	ความรู้ความเข้าใจของผู้ดูแลเกี่ยวกับการดูแลผู้สูงอายุที่ได้รับการรักษาแบบประคับประคองในชุมชน
Type of Review	Expedited
Principal Investigator	Pattaraporn Koonmee
Official Address	Department of Ramathibodi School of Nursing Faculty of Medicine Ramathibodi Hospital Mahidol University
Co-investigator (s)	1. Phattarawadee Cumphan 2. Lily Xiao 3. Anita De Bellis
Approval includes	1. Submission Form Protocol Version 2 Date 28/10/2020 2. Patient Information Sheet Version 2 Date 29/10/2020 3. Informed Consent Form Version 1 Date 22/09/2020 4. Poster 5. Certificate in Ethics Training

Institutional Review Boards in Mahidol University are in full compliance with International Guidelines for Human Research Protection such as Declaration of Helsinki, The Belmont Report, CIOMS Guidelines and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP)

Date of Approval	November 09, 2020
Date of Expiration	November 08, 2021

Signature of Chair...

(Asst. Prof. Chusak Okascharoen, M.D., Ph.D.)

This certificate is subject to the following conditions:

1) Approval is granted only for the project with details described in submitted proposal
2) Submission of modification to the approved project is needed before implementation
3) A yearly progress report is required for renewing of approval
4) Written notification is required when the project is complete or terminated

Appendix 7 Semi-structured interview questions

Semi-structured interview questions

Personal information

Name____Age________Gender_____________

Pseudonym____

Education__________________Occupation____________Telephone number_____________

Relationship with patient __________________Experience of caring for relative_______months

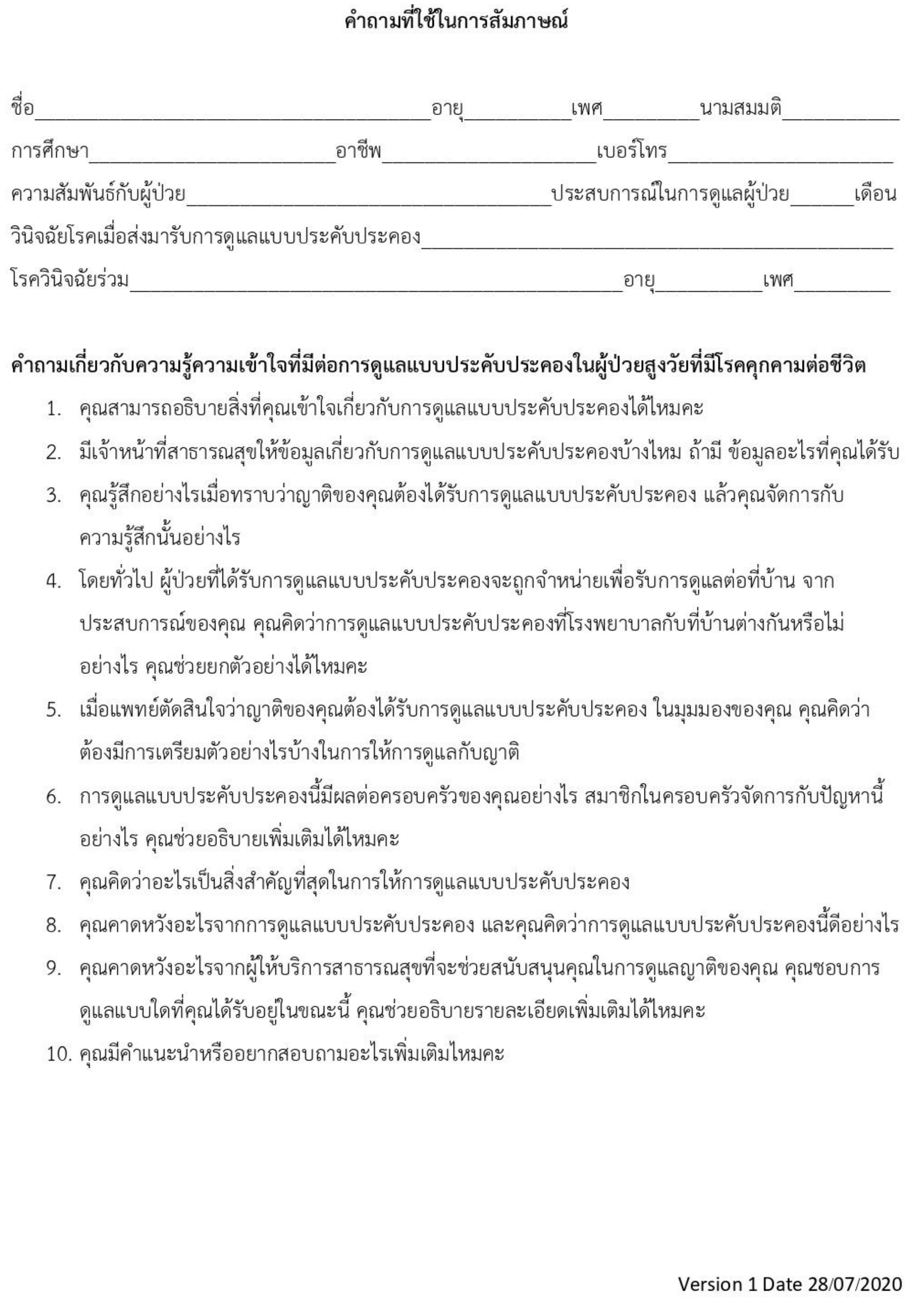
Diagnosis of the patient when referred to palliative care team ___________________________

Other health conditions: _________________________Age__________Gender____________

Questions related to the perspective of palliative care for older people living with life-threatening illness

1. Can you describe what you understand about palliative care?
2. Did any health care provider give you information about palliative care and if so what was the information?
3. What are your feelings after your relative received palliative care? How did you manage with your feelings?
4. Usually, palliative care patients will be discharged to receive care at home, is the palliative care at home and hospital different from your experience? If so, how? Could you give an example?
5. Once the doctor decided that your relative would be treated as palliative care, in your perspective, what did you need to prepare for caring for your relative at home?
6. How is it impacting your family? Could you tell me more about that and how family members manage with it?
7. What are the most important things in taking care of your relative?
8. What are your expectations of palliative care? How is it good for your relatives?
9. What health care services do you expect from health care providers to support you in providing care to your relative? Do you have any preference with regards to the services you have been receiving? Could you explain more about that?
10. Do you have any suggestions, or have you got any questions you would like to ask?

Appendix 8 Semi-structured interview questions (Thai version)



คำถามที่ใช้ในการสัมภาษณ์

ชื่อ______________________________ อายุ__________ เพศ__________ นามสมมติ__________

การศึกษา____________________ อาชีพ____________________ เบอร์โทร____________________

ความสัมพันธ์กับผู้ป่วย______________________________ ประสบการณ์ในการดูแลผู้ป่วย______ เดือน

วินิจฉัยโรคเมื่อส่งมารับการดูแลแบบประคับประคอง____

โรควินิจฉัยร่วม____ อายุ__________ เพศ__________

คำถามเกี่ยวกับความรู้ความเข้าใจที่มีต่อการดูแลแบบประคับประคองในผู้ป่วยสูงวัยที่มีโรคคุกคามต่อชีวิต

1. คุณสามารถอธิบายสิ่งที่คุณเข้าใจเกี่ยวกับการดูแลแบบประคับประคองได้ไหมคะ
2. มีเจ้าหน้าที่สาธารณสุขให้ข้อมูลเกี่ยวกับการดูแลแบบประคับประคองบ้างไหม ถ้ามี ข้อมูลอะไรที่คุณได้รับ
3. คุณรู้สึกอย่างไรเมื่อทราบว่าญาติของคุณต้องได้รับการดูแลแบบประคับประคอง แล้วคุณจัดการกับความรู้สึกนั้นอย่างไร
4. โดยทั่วไป ผู้ป่วยที่ได้รับการดูแลแบบประคับประคองจะถูกจำหน่ายเพื่อรับการดูแลต่อที่บ้าน จากประสบการณ์ของคุณ คุณคิดว่าการดูแลแบบประคับประคองที่โรงพยาบาลกับที่บ้านต่างกันหรือไม่อย่างไร คุณช่วยยกตัวอย่างได้ไหมคะ
5. เมื่อแพทย์ตัดสินใจว่าญาติของคุณต้องได้รับการดูแลแบบประคับประคอง ในมุมมองของคุณ คุณคิดว่าต้องมีการเตรียมตัวอย่างไรบ้างในการให้การดูแลกับญาติ
6. การดูแลแบบประคับประคองนี้มีผลต่อครอบครัวของคุณอย่างไร สมาชิกในครอบครัวจัดการกับปัญหานี้อย่างไร คุณช่วยอธิบายเพิ่มเติมได้ไหมคะ
7. คุณคิดว่าอะไรเป็นสิ่งสำคัญที่สุดในการให้การดูแลแบบประคับประคอง
8. คุณคาดหวังอะไรจากการดูแลแบบประคับประคอง และคุณคิดว่าการดูแลแบบประคับประคองนี้ดีอย่างไร
9. คุณคาดหวังอะไรจากผู้ให้บริการสาธารณสุขที่จะช่วยสนับสนุนคุณในการดูแลญาติของคุณ คุณชอบการดูแลแบบใดที่คุณได้รับอยู่ในขณะนี้ คุณช่วยอธิบายรายละเอียดเพิ่มเติมได้ไหมคะ
10. คุณมีคำแนะนำหรืออยากสอบถามอะไรเพิ่มเติมไหมคะ

Version 1 Date 28/07/2020

Appendix 9 Example of data analysis

Transcripts	Coding	Grouping and summarising coding	Sub-theme	Theme
"…It is the care that just do conservative treatment… It does not focus on treating the disease anymore…The patient might not be better even receiving the full treatment…" (CG 5, p.22).	CG5: conservative treatment	**Providing conservative treatment:** CG5: conservative treatment CG8: conservative treatment	**Providing conservative treatment**	**Various understandings of palliative care**
"Palliative care is the care that does not do any further treatment but conservative treatment." (CG 8, p.42)	CG8: conservative treatment			
"The patient will continue receiving care at home and we have to make them feel comfortable as much as we can…" (CG 8, p.42)	CG8: make them feel comfortable	**Physical support:** CG8: make them feel comfortable CG7: make them feel comfortable, no more suffering from the disease **Mental health support:** CG4: think about patient's feelings CG6: focus on patients' feelings and desire	**Maintaining comfort and spiritual wellbeing**	
"…we have to think about the patient's feelings… I knew what my mum wanted, and I tell the doctor since her condition was bad that we do not want to insert the tube or do CPR…when she was at home, her mental was so good, and I can feel that she was very very happy…" (CG 4, p.19)	CG4: think about patient's feelings			
We decided to continue receiving palliative care at her hometown…She's happy to be at home. She even said that she's at home now, so it's okay if she's going to die soon…focusing on her feeling and her desire at the last moment of her life are the most important. (CG 6, p.31)	CG6: focus on patients' feelings and desire			
"I don't really expect anything. I just want him to feel comfortable as much as I can help at the last stage of his life. No more suffering from the disease. If possible, I would like him to die peacefully…" (CG 7, p.39)	CG7: make them feel comfortable, no more suffering from the disease			