Kasetsart Journal of Social Sciences 43 (2022) 1085–1094

Kasetsart Journal of Social Sciences

journal homepage: http://kjss.kasetsart.org

Home-based end-of-life care for Thai elders: Family caregivers' perspectives

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Article Info

Article history:
Received 30 September 2021
Revised 17 Feruary 2022
Accepted 8 March 2022
Available online 12 October 2022

Keywords:
caregivers,
elder,
end of life,
home-based end of life care

Abstract

Thai elders prefer to spend the end stage of life at home. This situation requires family caregivers to provide formal palliative care. This study explored family caregivers' perspectives they faced while providing home-based end-of-life care for elders. This study was conducted in 14 primary care centers located in a southern city of Thailand. A qualitative approach with in-depth interview was conducted among 30 elders and their caregivers. The instruments consisted of in-depth interview questions, non-participant observation, and field notes. Qualitative data were analyzed and synthesized for content analysis. The home-based end-of-life care for elders consisted of five categories: (1) caregivers' burden; (2) symptom management; (3) thoughts about prognosis; (4) unprepared for the end of life; and (5) making decisions regarding treatments and care. Strategies can guide the caregivers to overcome home-based care and develop an effective palliative care for elders.

Introduction

The world population is rapidly aging. The proportion of individuals over 60 years of age is expected to double from 11 percent in 2000 to 22 percent in 2050 (United Nations, 2019). In Thailand, the aging population will increase from 13 percent in 2020 to 25 percent in 2060. Thai elderly are living longer with an average life expectancy of over 74 years, and it is predicted that 12.1 percent of the population will be 80 years and over in 2030 (Prasartkul et al., 2019). This change in life expectancy comes with a greater level of disability and comorbidity, consequently higher demands for palliative care (Milintarangul, 2015). In the past, palliative care was typically offered to cancer patients, however, nowadays it is part of the care pathway for a wide variety of nonmalignant diseases (Pairojkul, 2016).

The goals of palliative care are to improve the quality of life of patients and their families who are facing a myriad of problems associated with life-threatening illnesses. In contrast to ever-more advanced medical technology, palliative care for end-stage patients remains

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https://doi.org/10.34044/j.kjss.2022.43.4.34
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outdated in the Thai health system. Many Thai citizens still suffer from chronic health illnesses despite the existing universal health coverage (UTC) (Intarasombat, 2014). Without comprehensive palliative care, people at the end-stage of life will face suffering and may receive useless treatment which results in high healthcare costs (Pairojkul, 2014).

In the past, most Thai elders suffered from acute infections but today a high number die from cancer, heart disease, or other chronic health problems, yielding rise to the need for final-stage care. However, a lack of knowledge and skills concerning palliative care in medical and nursing staff results in delayed access to such care or services (Nilmanat, 2016). The last stage of life, therefore, is spent at home with limited support from the health care system to facilitate a peaceful and painless death. Pairojkul (2016) reported that expenses incurred during the year before dying ranged between 10,000 and 230,000 Baht (equivalent to 400–9,000 US$). One-third of these patients were nearly bankrupt as a result.

Providing end of life care at home preserves dignity for older people who are going through the final phase of life. Home-based care allows the older people to spend this critical milestone within the comfort of their own homes, and together with relatives who can offer a more emphatic level of support (Gomes et al., 2013; Wu et al., 2020). In addition, a study by Behm (2015) showed that home-based end-of-life care reduced hospitalizations and enhanced cost-effectiveness. Moreover, home-based caregivers and their families reported high levels of quality of life and satisfaction with care. However, Thailand's health care service system has not yet integrated end-of-life care at all levels, particularly in primary care. Therefore, implementation of home-based end of life care only exists in home care service but without a specific care for the dying older adults (Pairojkul, 2014). In addition, since 2011, the National Health Security Office (2011) has established and approved the "LIFESS" (L= Living wills, I = Individual belief, F = Function, E = Emotion and coping, S = Symptoms, S = Social and support) framework to guide healthcare providers to assess and deliver their care to people and their families facing palliative and end of life stage.

Several studies explored healthcare providers' experiences in caring and promoting home based care for end of life older persons (DeMiglio & Williams, 2012; Heydari et al., 2019; Salifu et al., 2021), but less is known from the perpectives of the family cargivers, especially their needs and obstacles when they act and care for their end of life older persons within the home environment. Understanding the caregivers' perspectives will thus lead to a more targeted and effective intervention from healthcare providers as well as contribute to the appropriate political strategies to coordinate and support care for older people in the end of life care at home.

Literature Review

According to the literature review, challenges to providing home-based palliative care for the elderly in Western countries were reported in four categories: (1) institutional-related; (2) interest-related; (3) value-cultural-related; and (4) idea-related. Institutional-related barriers consist of funding problems in bureaucratic procedures. Interest-related barriers refer to the problem related to autonomy on the healthcare provider team. Value-cultural related barriers are issues of cultural norms and cultural taboos. Idea-related barriers include hospital staff's lack of understanding about palliative care and lack of care plans on palliative care in general (DeMiglio & Williams, 2012).

For home-based palliative care for elders in Thailand, Thai elders prefer to live and die at home (Pasri, 2014). Studies regarding interventions in palliative care for elders focused on improving care during hospitalization among cancer patients. However, there are still no practice guidelines specific to home-based palliative care for Thai elders (Sawasdeenarunat et al., 2015). Therefore, existing palliative care models are not suitable for older people because they need both palliative and geriatric care (World Health Organization [WHO], 2021).

The quality of home-based palliative care thus relies on the family caring (Bray et al., 2018; Milintarangul, 2015). The World Health Organization (WHO) (2020) has argued that families must become progressively involved as care partners of their families. The WHO considers palliative care as a way of improving the quality of life, for it has a holistic view and takes physical, mental, social, spiritual, and economic dimensions into account (WHO, 2020). People often have active and dynamic lives until death (Tipseankhum et al., 2016). Home-based end of life care supports families of older people during illness, death, and even after death, and makes bereavement more peaceful and acceptable for families (WHO, 2020).

This study, therefore, aimed to identify the home-based care for Thai elders at the end of life based on family caregivers' perspectives.

Methodology

A qualitative design was used to identify home-based care for elders at the end of life as perceived by family caregivers. This approach was selected to enable the researcher to gather, analyze and interpret the perspective of care, realities, and meaning from the participants in this research in a way that was culturally appropriate and used subjective perceptions of their lifes to construct knowledge and build understanding of the research question (Lincoln & Guba, 1985). The open-ended dialogue was used during in-depth interviews with family caregivers. The interactions were recorded, then analyzed and verified in follow-up interviews. Between 2017 and 2018, two or three interviews were conducted to each participant at the elders' homes. Non-participant observation and field note were also operated.

Research Setting

The study was conducted at the older persons' homes located in a city in southern Thailand. The participants had been receiving care services from the local primary care centers via a long-term care service system consisting of mainly home visit (nurse, physical therapist, and healthcare volunteer) to provide health care facilities (medical auxiliaries/ equipment) and social support for the homebound and bedridden elderly (Sasat et al., 2013).

Participants

The participants consisted of 30 caregivers actively caring for elders in their families and 30 elders spending the end of life at home. The list of the elders was reviewed by nurses in primary care centers. The elders were selected based on the following eligibility criteria: (1) elderly with cancer stage III-IV to; (2) end-stage organ failure assessed by Palliative Performance Scale (PPS) with score less than 30 percent; and (3) frail elders determined by the level of Barthel Activities of Daily Living (ADL) with less than score, 70 years of age or over with dementia/ Alzheimer's disease (either moderate to severe levels). The criteria for choosing the family caregivers were as follows: key primary caregivers and unpaid caregivers.

Recruitment of the participants

Participants were recruited by the following procedure: The registered nurses who served as a designated contact in primary care centers were introduced to the research project, objectives, and the participants' recruitment criteria. Then, the researchers reviewed the name list and medical records to gather basic information of elders and their caregivers. The researchers invited participants to participate in the study by phone. An interview appointment along with permission to visit their homes was obtained by the researchers. One-on-one interviews between the researcher and each participant using audio-recording were conducted. The recordings were transcribed verbatim. All data from digital recordings, transcription, and field notes were analyzed.

Ethical Consideration

The study was approved by the ethics committee, Faculty of Nursing, Prince of Songkla University (No 0521.1.05/883). All participants gave their consents and were informed of the voluntary nature of their participation, which meant that they could withdraw from the study at any time without any consequences. Caregivers' interviews were suspended and rescheduled if the participants became sick or in distress. Confidentiality of all data including anonymity for participants in the published results was explained and guaranteed.

Data Collection

Data were collected at the elderly' homes. Non-participant observation and field note-taking were also utilized.

Instruments

Guideline questions for in-depth interviews were used to ask about patients' health, needs, obstacles, or difficulties providing care for the elders at the end of life using LIFESS (L= Living wills, I = Individual belief, F = Function, E = Emotion and coping, S = Symptoms, S = Social and support) framework (National Health Security Office, 2011). The National Health Security Office (2011) established and approved the "LIFESS" framework to guide healthcare providers for the assessment and implementation of care for people and their families facing palliative and end of life stage. Examples of interview questions were as follows: "How do you plan to care for the elderly at the end-stage of life?"; "How do your beliefs influence care?"; "How can the elderly care for themselves?"; "How do you feel about or cope with the situation?"; "How do you manage the signs and symptoms of the elderly's decline?"; "How do you manage economic issues and what support do you receive from other family members or resources such as neighbors or home health care?".

Guideline questions based on LIFESS framework and the study's objective were provided to the three experts to evaluate for instrument validity using the Indexes of Item-Objective Congruence (IOC). In this process, each guideline question was checked by the three experts including one advanced practice nurse in palliative care and two nurse lecturers with expertise in palliative care and advanced qualitative research. The Item-Objective Congruence (IOC) was used to evaluate each guideline question based on the score ranged from -1 to +1, Congruent = + 1, Questionable = 0, Incongruent = -1. The question that had scores lower than 0.5 were revised. On the other hand, the ones that had scores higher than or equal to 0.5 were reserved (Polit & Beck, 2012). Based on these criteria, the IOC of the guideline questions yielded the result of 1.

Data Analysis

Content analysis was used to analyze data (Speziale & Carpenter, 2011). The analysis sessions were conducted in conjunction with a team of researchers. After each interview, audio-recorded interviews were listened to and were transcribed. Each transcribed interview was read again and again to obtain the sense of the whole. All the codes extracted from the interviews were reviewed by the researchers. After agreement among the members of the research team, all codes were grouped into sub-categories and compared based on differences and similarities. In the categorization process, sub-categories were sorted into broader groups and the categorization was finished when a reasonable explanation of the study was reached and agreed by the research team.

Trustworthiness

Trustworthiness has been described by Koch (2006) and Sandelowski (1993) addressing the rigor and validity of qualitative research and containing the concepts of credibility, dependability, and transferability (Guba & Lincoln, 1989). Firstly, credibility means reliance in the truth of data and interpretation from the researcher. This study used prolonged engagement by visiting the participants weekly, which averaged 10 times, taking about 60-90 minutes for each interview, conducting triangulation (in-dept-interview, a questionnaire, observation, and playing back the audio-recordings), member checking, and peer-debriefing (Polit & Beck, 2008). Secondly, transferability means the findings can be utilized in other settings or group (Koch, 2006; Polit & Beck, 2008). This study recruited participants at the end of life phase at home. Thirdly, dependability entails certifying that the data collection and data analysis procedures are worthy of trust. (Koch, 2006; Polit & Beck, 2008). The interviews were transcribed verbatim and the transcription process was checked for accuracy (Speziale & Carpenter, 2011) by listening to extracts of digital recordings by another who spoke the Thai language. In addition, the method of naming themes was checked for recognizing of categories and themes (Speziale & Carpenter, 2011).

Results

Personal Data of The Elderly and Their Primary Caregivers

The sample consisted of 30 elders, 15 males, and 15 females. Most elders were aged 81–100 years (mean age = 84.34 year). Most participants were Buddhist (27 persons). Eleven elders had advanced chronic organ failure, eight of them were diagnosed with cancer, eight elders experienced frailty, and three of them were living with disabilities caused by accidents. For marital status, most elders were married. Only eight elders were able to share information with their caregivers while the rest were unable due to debilitating health status.

There were 30 caregivers: 24 were children family member, five were their spouses, and one was a grandchild. Most caregivers had the high-school level of education while the rest had finished primary school. Most of them were workers/farmers, eight were unemployed, and three used to be government employees.

Challenges to Providing Home-Based Care for Thai Elderly

The family caregivers identified challenges to providing care at home within five categories: (1) caregivers' burden; (2) symptom management; (3) discrepant thoughts regarding diagnosis and prognosis between the caregivers and the elderly patients; (4) unprepared for the end of life; and (5) making decisions regarding treatments & advanced directive care. Each will be described below. Quotes can be found in Table 1.

Table 1 Challenges of findings

Challenges	Expression
1. Caregivers' burden	
Physical	"I don't know who will die first between my mum and me. I have to get up at night to turn the sleeping position of my mum about three times per night. When I move her position, I am tired. I do not request my child to help me move my mum's position because I am afraid that it will disturb them". (Caregiver of dementia person) "I feel tired both physically and mentally because other siblings cannot join to take care of their mother". (Caregiver of chronic renal failure person) "When my mother gets worse, at the same time my health will be getting worse too such as exhaustion, dizziness, and difficulty breathing". (Caregiver of dementia person)
Psychological	"Providing care alone for my husband made me feel a heavy burden. I think that if someone can help me, I will not feel so heavy a burden like this. (Caregiver of dementia person) "If I do not take him to the hospital, I will not feel comfortable and the other relatives may blame me." (Caregiver of dementia person) "Taking care of my husband when I get older (72 Y) creates more burden than when I was young". (caregiver of dementia person)
Social	"I cannot go anywhere, it makes me feel bored, slouchy, and I do notfeel happy. (caregiver of dementia person)
Financial	"I need to leave from my work to take care of my mother. It caused my husband to become the only earner in my family. (caregiver of end-stage chronic renal failure person)
2. Symptom management difficulty	
Uncertainty in an emergency	"We decided to take dad to the hospital to seek help from the doctor. Even though he was cared for at home, and we had done the best we could do, at that time he did not recover as he used to. He had severe tremors and we could feel the bed was shaking. Normally when he had fever and secretion, we gave him medications. Then he would recover but this time he did not. (Caregiver of elderly with stroke and dementia). "My mother was having convulsions, so we needed to bring her to the hospital. We could not deal with her symptoms, we called the rescue unit but her symptoms stopped" (Caregiver of cancer person)
Inadequate knowledge to manage	"My mother usually has nausea and vomiting, but the hospital did not give her any medicine, so I don't know what to do " (Caregiver of cancer person) "We knew all the time that father had cancer since the disease started, but we asked the doctor to conceal this from him because we were afraid he could not accept it. We never wanted anyone to talk about his diagnosis. We were afraid this could make him feel hurt" (caregiver of elderly with stroke and cancer)

Table 1 Continued

Challenges	Expression
3. Thoughts about prognosis	“My mother used to say: “don’t do anything for me to suffer. Let me die”. But when she got worse, I could not tolerate seeing her die in front of me, so I took her to the hospital and asked the doctor to help as much as he could, so my mother was intubated and cardiac massaged and has become bed-ridden since then”. (caregiver of elderly with stroke) “When my father was healthy, he did not discuss anything about the end of his life. I am the eldest in my family, and I am authorized to make all decisions about my father. It is difficult to talk about palliative care with him because this ending situation has not occured yet, and I cannot imagine when it will come”. (caregiver elderly with congestive heart failure) “In my family, we do not communicate or plan about the end of life care for our father because we think that he will have a long life. I think that he can eat more and get better than before” (Caregiver of elderly with dementia)
4. Being unaware/not recognizing end-of-life preparation.	“We have not considered death and have not planned for the end of life care for my father because I think that he can recover from the accident (unconscious) and he can get better. (caregiver of elderly with accident) “I know that the illness of my mother is not bad because she needs general care. She can tell me about her illness symptoms, and I can still provide care for her. (Caregiver of elderly with chronic renal failure) “My father's symptom is stable. We have not planned for the end of his life yet. For instance, whether we will give him CPR or not. (caregiver of elderly with cerebrovascular disease) “Big brother is the one to authorize the decision for our mother. For my decision, I will not allow the doctor to do a tracheotomy because it will make my mother suffer. (caregiver elderly with dementia)
5. Difficulties in decision regarding elderly treatments & advanced directive care	“There was no talking about what to do if that day came. I did not dare to talk to my children so we have never talked about this matter yet. I was afraid that if deciding as I thought (no CPR), they might not agree. But I did not dare to start talking to them”. (Caregiver of elder with Alzheimer) “I thought his condition was not too bad, not worse than previously. In my view, I felt he was better. If he got worse and acted violently again, I wouldn’t know what to do. We never discussed this in the family if that day comes (the elder getting worse) (caregivers of elderly with cardiovascular disease)

1. Caregivers’ burden

Several family caregivers faced tremendous physical-psycho-social-financial burden. They expressed that providing end-of-life care was hard work because the demand for care was regularly.

Providing care for the elders can be physically demanding such as bathing, turning positions, feeding, and managing waste. The caregivers experienced various physical burdens such as sleep disturbance, fatigue, muscle weakness, exhaustion, dizziness, and breathing problem. Some caregivers, especially the ones that were 60 years of age and over, had health problems such as rheumatoid arthritis and cataracts. The health problems as leg pain and vision problems reduced their ability to provide care. The psychological burden included emotional distress, exhaustion, worry, fear, guilt, loneliness, and helplessness. Most caregivers who provided care for a long time without relaxing time were elders’ wives and daughters. Their roles made them bored and depressed. Furthermore, several caregivers reported they suffered from ineffective communication with other family members. Some caregivers could not deal with medical expenses. Many caregivers felt they did not receive help from other members.

2. Symptom management

In this study, two main aspects regarding symptom management refer to lack of confidence or knowledge to manage any emergency or crisis.

2.1 Lack of confidence to manage an emergency or crisis

More than half of the elders had not planned for their end of life while they were healthy. Thus, the family members who suddenly took on the role of caretakers had no preparation when facing an emergency or crisis. For example, when the elders experienced severe dyspnea or pain due to the advanced stage of cancer, the caregivers suffered with the feeling of uncertainty and helplessness on how to assist. Moreover, the caregivers also felt ashamed and afraid of being neglectful.

2.2 Inadequate knowledge

The lack of home-based palliative care provided by professional healthcare providers at any primary health center is common in Thailand (Tipseankhum et al., 2016). The lack of care plan to serve patients' palliative care caused them limitation to provide proper care. It was not surprising that most of the elders and their family caregivers in this study did not receive any information on palliative care from the healthcare providers. They only obtained routine care.

3. Thoughts about prognosis

The findings showed eight elders with cancer were concerned about their prognosis. Only four out of twenty-two elders with chronic illnesses had ready prepared their care plan while they had full consciousness. This meant that the majority of the elders had no opportunity to discuss any treatment plan for their serious illness with doctors. It was the result of the caregivers fear to burden their elders with the grave prognosis. In addition, our findings showed that the elders who were informed of their poor prognosis expressed their wishes to die without pain from any medical treatment, such as retaining endotracheal tube. However, several caregivers did not consider the elders' wishes. These conflicts between the caregivers and elders resulted from a lack of communication to manage care and fulfill the elders' wishes.

4. Unprepared for the end of life

Both elders and their caregivers did not consider the onset of the end of life period. If the elders perceived that they could still perform ADL themselves, they would not discuss the end-of-life care plan. When they became unconscious, the caregivers would make decisions about the care plan. In cases of chronic illnesses, the caregivers perceived that the elders could recover, thus, there was no need to plan for the end of life. Cultural taboo combined with denial and attachment makes this process extremely difficult. Cultural taboo in talking about death and dying caused the family to avoid talking of the elder's terminal illness. There was a barrier to start advanced palliative care plan between the healthcare team and family. Reluctance to discuss death could represent conflict of caregivers. Families therefore decided not to discuss death even if family members anticipated the elderly could not surviving the illness, and this nondisclosure could interfere with preparation for dying.

5. Making decisions regarding treatments and care

More than half of the elders had no plan for their end of life while they were well. Without any end-of-life plan, making decisions for treatments or care would be increasingly difficult among caregivers. In Thai culture, the eldest brothers or male members were the decision-makers of the families. The youngest daughter or females members were the primary caregivers. This cultural expectation imposed caregivers' burden. In addition, the lack of advance care or treatment plan led to further conflicts within families.

Discussion

This study explored the perspective of caregivers to care for elders in the end of life care at home. The findings contribute to the understanding of providing care to their loved ones based on their experiences and perspective. Five themes found in this can be explained: (1) caregivers' burden; (2) symptom management; (3) thoughts about prognosis; (4) unprepared for the end of life; and (5) making decisions regarding treatments and care.

Several family caregivers expressed that providing end-of-life care was hard work and caused tremendous physical-psycho-social-financial burden. The physio-psycho-social burden imposed upon home caregivers has been reported in several previous studies. Nayak, George and Vidyasagar (2018) reported that up to 82 percent of caregivers of cancer patients had sleep disturbance, which was significantly associated with depression and anxiety. Limpawattana et al. (2015) found that caregivers shouldered a high burden as a result of caring for individuals with dementia, advanced cancer, and cerebrovascular disease, which affected their overall health status. Furthermore, this study's result is congruent with the study by Coumoundouros et al. (2019), which revealed that the long-term financial impact of caregiving includes loss of caregivers' savings. In Thailand, 86 percent of caregivers reported that their incomes were insufficient for care expenses; finding additional income was necessily (Limpawattana et al., 2015).

For symptom management, although some elders received general care provided by a home visit team, home-based palliative care was still inaccessible. This finding is congruent with the report by Pairojkul (2016), which stated that home-based palliative care is insufficient to help both elders and their caregivers to manage the end-of-life care. The caregivers had limited knowledge for symptom management such as opioid usage. As a result, pain is under-treated for elders, which is consistent with Thongkhamcharoen et al. (2014), who surveyed the opioid drug used and found that though caregivers were permitted to use opioid drugs, opioid drugs are not simply accessible and/or access to them is limited through laws and bureaucratic red tape.

For the discrepant thoughts between caregivers and elders regarding diagnosis, prognosis, and living will, family members have an authority to make decisions for treatments when the elders' health has deteriorated. Several studies supported the idea that elders with chronic illnesses prefer to make those decisions themselves (Rukchart et al., 2014). Other studies supported that informing the patients about their prognosis and diagnosis is vital to advance care for patients (Vleminck et al., 2014). Patients who have a chance to make a living will by themselves will fulfill their wishes (Tipseankhum et al., 2016) for preparing to die (Pautex & Zulian, 2014).

For being unprepared for the end-of-life care, the findings showed the illness perception among the elders and caregivers. Many elders lived with chronic illnesses and required preparation for death as their symptoms gradually deteriorated. This finding could be explained by the study of the perception of terminal cancer patients. The study showed that the patients only thought about death when severe symptoms occurred (Rovers et al., 2019). This result was also consistent with the study of Safdar and Rahman (2016), which found that advance care planning would be difficult if patients lack awareness of their diagnosis/prognosis and health care providers lack familiarity with the terminal phase. Advanced care plan should be initiated early when the clinicians understand the illness prognosis and allow the patients and their families to accept ~~percep~~ the illnesses (Nilmanat, 2016). Similarly, open communication about the dying should be arranged between physicians, nurses, patients, and family caregivers (Keeley, 2017).

For making decisions regarding treatments, the findings showed that the lack of an end-of-life care plan would result in difficulty in the decision making, conflict among family members, and the misunderstanding of patients' wishes. This result is similar to that of Bute et al. (2015), who reported that having no decision for the end of life would result in limitations for the surrogate's decision making and conflicts between family members. In addition, there was lack of discussing plans with the patients among family members and doctors that would not fulfill the patients' wishes. This result is incongruent with the study of Trees and Ohs (2016), which found that the preferences for advanced directives at the end of life by patients and their surrogates was different. The patients were not served their wishes. For example, when the elders became unconscious when their condition worsened, the surrogates would send them to the hospital even though their wish was to stay home.

The challenges to providing home-based care for the Thai elderly found in this study are quite different from Western countries (DeMiglio & Williams, 2012). The difference could be because the data in this study were gathered from caregivers' perspectives instead of from healthcare providers. In addition, the formal home-based palliative care support in Thailand is still in the development stage, thus, faces many challenges including unavailability of palliative care services and inadequate well-trained healthcare professionals (Nilmanat, 2016).

Conclusion and Recommendation

The challenges to providing home-based care for Thai elderly at the end of life as perceived by family caregivers consisted of: (1) caregivers' burden; (2) symptom management; (3) discrepant thoughts between caregivers and elderly patients regarding diagnosis and prognosis; (4) unprepared for end of life; and (5) deciding on the elderly's treatments.

These challenges can be overcome by strategies and interventions to improve home-based palliative care programs. The study's findings can also contribute to creating a palliative health care policy to support family caregivers. Better communication and cooperation between health care providers and caregivers of the elderly should be facilitated to initiate discussion. Finally, health care providers should understand the palliative home health care services process and support the caregivers to provide better care for their elders in order to minimize caregivers' burdens.

Conflict of Interest

The authors declare that there is no conflict of interest.

Acknowledgments

The authors would like to express special thanks to the Research Center for Caring System of Thai Elderly, Faculty of Nursing, Prince of Songkla University, and the National Research University Fund, for providing scholarship to this study. The authors are also truly grateful to all participants for sharing their valuable experiences.

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