Development of an Ideal Set of Nursing Care Activities for Home-Based Palliative Care to Enhance Care Quality and Reduce Caregiving Burden among the Family Caregivers of Thai Elderly

Kanyanat Supaporn

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy in Nursing (International Program)
Prince of Songkla University
2019

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Major Program	Nursing (International Program)

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This is to certify that the work here submitted is the result of the candidate's own investigations. Due acknowledgement has been made of any assistance received.

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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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ABSTRACT

The purpose of this technical action research was to develop an ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce caregiving burden among the family caregivers of Thai elderly. Ten elderly participants, and their family caregivers who met inclusion criteria participated in this study. The researcher acted as a nurse. The elderly and their family caregivers resided in the areas which received health services from two out of fourteen primary care centers located in Hat Yai, Songkhla Province. This study was carried out from May to December 2017.

The data collection consisted of in-depth interviews, non- participatory observation, field notes, photos, and an outcome evaluation questionnaire: 1) the Thai version of the Palliative Care Outcome Scale (POS), 2) the preferences of the elderly and their surrogates for advance directives at the end of life, 3) the caregivers' capabilities in responding to the spiritual needs and the perceived caregivers' compassion to the spiritual needs, and the 4) Thai version of the Burden Interview. Content analysis, descriptive statistics, Wilcoxon matched pair and signed rank test were employed to analyze the data. The major findings were presented in three parts: reconnaissance phase, spiral action research process, and outcome evaluation.

The reconnaissance phase revealed the main situations of: 1) situation analysis of home-based palliative care for the Thai elderly, 2) caregivers' perspectives on improving care for Thai elderly in the palliative stage, and 3) caregiving burden among family caregivers. During the spiral action research process, three activities were developed through this study: 1) mutual understanding on care requirements, 2) skill building in the caregiver role, and 3) enabling the family environment to promote spiritual well being. The outcome evaluation on this model revealed significant enhancing of care quality and reduced caring burden. Moreover, after implementation on three nursing care activities, the findings were emerged to evaluate by observing as: 1) fulfilling the elderly family member’s needs and 2) improving the ability of care giving skills.

This study provided essential care in the use of nursing care for the elderly and their caregivers in the palliative stage at home in Thai culture. The study proposes and assists the nurses in a primary care center in providing for the elderly and their family caregivers. It is encouraged that other primary care centers should develop similar care activities to serve as guidelines for nurses on their practice for patients and caregivers with palliative and end of life care. In the future, an ideal set of nursing care activities will be applied for the development of the program to provide accurate evidence on the effects of the model on care quality and caregiving burden.

ชื่อวิทยานิพนธ์ การพัฒนาชุดกิจกรรมการพยาบาลสำหรับผู้ดูแลผู้สูงอายุไทยระยะประคับประคองที่บ้านเพื่อเพิ่มคุณภาพการดูแลและลดภาระการดูแล

ผู้เขียน นางสาวกัญญาณัฐ สุภาพร

สาขาวิชา การพยาบาล (นานาชาติ)

ปีการศึกษา 2561

บทคัดย่อ

การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อพัฒนาชุดกิจกรรมการพยาบาลสำหรับผู้ดูแลผู้สูงอายุไทยระยะประคับประคองที่บ้าน เพื่อเพิ่มคุณภาพการดูแลและลดภาระการดูแลสำหรับผู้ดูแลผู้สูงอายุไทยที่อาศัยอยู่ในความรับผิดชอบของศูนย์บริการสาธารณสุขเขตเทศบาลนครหาดใหญ่จังหวัดสงขลา โดยใช้กระบวนการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมกับผู้สูงอายุ 10 คน และผู้ดูแล 10 คน ตั้งแต่เดือนพฤษภาคม ถึง ธันวาคม 2560

การเก็บข้อมูลเชิงคุณภาพโดยสัมภาษณ์แบบเจาะลึก การสังเกตแบบมีส่วนร่วม การบันทึกภาคสนาม การถ่ายภาพ และการใช้แบบประเมิน 1) แบบประเมินผลลัพธ์การดูแลผู้ป่วยแบบประคับประคอง 2) แบบสอบถามผู้ตัดสินใจแทนผู้สูงอายุถึงความต้องการเกี่ยวกับการแสดงเจตนาล่วงหน้าในการรักษาพยาบาลระยะสุดท้ายของผู้สูงอายุ 3) แบบวัดความสามารถของผู้ดูแลในการปฏิบัติการเพื่อตอบสนองความต้องการด้านจิตวิญญาณของผู้สูงอายุ และ 4) แบบวัดภาระในการดูแลผู้สูงอายุในระยะสุดท้าย วิเคราะห์ข้อมูลโดยตีความ สรุปประเด็น สร้างชุดกิจกรรมการดูแล และการใช้สถิติเชิงพรรณนา สถิตินอนพาราเมตริก (Wilcoxon matched pair and signed rank test)

จากการเก็บข้อมูลเชิงคุณภาพในระยะประเมินสถานการณ์เบื้องต้นพบ 1) การเข้าใจสถานการณ์การดูแลผู้สูงอายุที่บ้าน 2) ทัศนะของผู้ดูแลต่อการส่งเสริมการดูแลผู้สูงอายุในระยะประคับประคอง 3) ภาระการดูแลของผู้ดูแล และผลการวิจัยพบว่า ชุดกิจกรรมการดูแลผู้สูงอายุในระยะประคับประคองที่บ้านประกอบด้วย 1) การสร้างความเข้าใจความต้องการการดูแลร่วมกัน 2) การพัฒนาบทบาทผู้ดูแล และ 3) การสร้างความเป็นไปได้ของสิ่งแวดล้อมครอบครัวในการส่งเสริม

ความผาสุกทางจิตวิญญาณ การประเมินผลลัพธ์การดูแลต่อชุดกิจกรรมการดูแลพบว่าคะแนนคุณภาพการดูแลเพิ่มขึ้นและคะแนนภาระการดูแลของผู้ดูแลลดลงอย่างมีนัยสำคัญทางสถิติ.

การวิจัยครั้งนี้พบว่าชุดกิจกรรมการดูแลสำหรับผู้ดูแลผู้สูงอายุในระยะประคับประคองที่บ้านช่วยเพิ่มคุณภาพการดูแลและสามารถลดภาระการดูแลของผู้ดูแล อีกทั้งผู้สูงอายุได้รับการตอบสนองตามความต้องการเมื่ออยู่ในวาระสุดท้าย ได้รับการดูแลตามความต้องการอย่างต่อเนื่องและผู้ดูแลมีความสามารถในการดำรงบทบาทการเป็นผู้ดูแลได้อย่างมีศักยภาพ พยาบาลสามารถนำชุดกิจกรรมการดูแลสำหรับผู้ดูแลผู้สูงอายุในระยะประคับประคองที่บ้านนี้ไปประยุกต์ใช้กับผู้ดูแลผู้สูงอายุที่อยู่ในระยะประคับประคองที่บ้านได้เพื่อเป็นแนวทางในการปฏิบัติการพยาบาลได้อย่างตรงตามความต้องการของผู้สูงอายุและผู้ดูแลที่บ้านมากที่สุด

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Introduction

Background and Significance of the Study

The world population is rapidly aging. The proportion of the world's population over 60 years of age is expected to double from 11% in 2000 to 22% in 2050 (WHO, 2013). In Thailand, the aging population will increase from 13% in 2020 to 25% in 2060 (Prasartkul, 2013). The Thai elderly are living longer with an average life expectancy of over 74 years, and it is predicted that 12.1% of the population will be aged 80 and over in 2030 (Prasartkul, 2013). This change in life expectancy results in being dependence and having multiple illness and disabilities with consequently higher demands for palliative care (Milintarangul, 2014).

In the past, palliative care was typically offered to people with cancer. However, nowadays palliative care is included as part of the care pathway of a wide variety of nonmalignant diseases (World Health Organization, 2011). Person can be divided into three groups (Lunney et al, 2003): short period of evident decline (typically cancer), end-stage organ failure (e.g. heart failure, end stage renal failure and chronic obstructive pulmonary disease), and prolonged dwindling (e.g. the frail elderly and those with dementia/Alzheimer). The elderly with cancer mainly face a rapid deterioration in the last 3 months of their life. The elderly with end-stage organ failure already have impairment in the activity of daily living (ADL), and their functioning gradually decline. However, they have some periods of rapid decline. The frail elderly and dementia/Alzheimer's disease group have a low level of ADL functioning and show a progressive decrease in physical ability in the final year of their life.

As mentioned, the demand for palliative care of the elderly has increased, whereas, the national health service system for palliative care is inadequate for Thai elderly and their family caregivers (Milintarangul & Thumtutaree, 2014; Pairotkul, 2014a, 2014b). Palliative care for the Thai elderly nowadays is not quite congruence with health reform (Milintarangul & Thumtutaree, 2014; Pairotkul, 2014b).

According to a report by the World Health Organization (2014), Thailand is classified as having a low level of palliative care development. Thailand is classified in category 3a from seven levels of palliative care development, which is only an isolated provision, characterized by its inconsistent in scope and not well supported, sourcing funds is heavily donor dependent, limited availability of morphine, a small number of hospice-palliative care services, most are home-based in nature and relatively limited to the size of the population. National policies play an essential role in extending access to palliative care. However, implementation of palliative care into practice is limited. The presence and effectiveness of palliative care services depends on the palliative care service of health system and the government throughout the country.

There are several factors that are related to implementing palliative care policies into practice in Thailand: the health care system, human resources, the availability of opioid drugs, and public awareness of palliative care. Firstly, the Thai government has led the strategy for the development and promotion of national palliative care. There are limited mechanisms in real practice (Nitikul, 2016). Regarding to the bureaucratic structure, palliative care is exiting under home care service system but it does not show specific in palliative care (Milintarangul & Thumtutaree, 2014; Pairotkul, 2014b). Secondly, health care staffs have less experience in palliative care in relation to knowledge and skills (Artsanthia et al, 2011). In addition, there is a lack of health care professionals in palliative care (Thongkhamcharoen et al, 2013) and less professionals in regards to the psychosocial approach such as psychiatric nurses and social workers (Krongyuth et al, 2014). Thirdly, opioid drugs are not available for using by health care staffs (Thongkhamcharoen et al, 2013). It is restricted by laws and bureaucratic structure (Phenwan, 2016). Finally, the public has limited understanding and awareness of palliative care services (Milintarangul, 2014), due to lack of information from government (Milintarangul, 2014; The Economist Intelligence, 2015). Thus, community efforts are important to awareness of palliative care and to encourage people to talk about death and dying. These factors are influencing to the successful implementation of palliative care service in Thailand (Milintarangul, 2015).

According to the literature review of the Thai elderly with a terminal illness, it was found that elderly need palliative care at home (Masucci et al., 2010; Pasri, 2014; Samaksaman, 2007; Srinakharin hospital, 2012). However, the elderly rarely access palliative care services at home (Kosolnakhon, 2014). As a result, quality of palliative care service is not a standard level (Milintarangul, 2014; Milintarangul, 2015). Many Thai older people are not receiving palliative care (Milintarangul, 2014), instead they are only receiving general care provided by home care services (Intarasombat, 2014). However, Thai government supports palliative care service for elderly in primary care recently.

Palliative care service in primary care for the elderly is implemented via the long term care service system since 2015 (National Health Security Office, 2015). However, service lacks of practice guidelines and a home-based care program specifically for palliative care (Intarasombat, 2014; Pairotkul, 2014a). Hence, developing a palliative care program is very important to help the elderly and their family caregivers receiving high quality care.

Currently, the quality of palliative care for the Thai elderly at home depends on the management of the family system. Even home-based palliative care is able to provide via the long term care service system, it is in the early stage of development for home-based palliative care. Awareness of policy makers and lack of healthcare professionals to provide care services is core barriers in driving the emerging care program. The health care service system is not developed for palliative care at all levels, particularly in primary care (Milintarangul, 2014; Milintarangul, 2015; Pairotkul, 2014a). Hence, the implementation of home-based palliative care is existing in the home care service and no specific care for the palliative stage of the dying elderly (Intarasombat, 2014).

Regardless of the level of home-based palliative care development, challenges related to palliative care in Thailand has rarely access to pain medications. There are fear of using opioids among public as well medical practitioners and misconception regarding the role and concept of palliative care among health-care professionals (Kitreerawutiwong, Mekrungrengwong., & Keeratisiroj, 2018). There is inadequate training for healthcare provider and healthcare volunteer for patients and the unsuitable management of the referral system from hospital to home to assure continuity of care (Pairojkul, 2016). Therefore, the caregiving role is mostly provided by family caregivers.

Family caregivers face the responsibility for many elements of terminal illness care such as monitoring treatment compliance, symptoms management, emotional support, meal preparation and providing financial support (Stenberg et al, 2010). However, these responsibilities usually occur with insufficient preparation in the provision of care (Rha et al, 2015). Family caregivers often neglect their own needs, stress, lacking of earnings, and suffering to their health and wellbeing (Panke & Ferrell, 2010). During the palliative stage, family caregivers face overwhelming issues associated with caring and death (Stajduhar, 2013). The efforts in caring for their loved ones induce burden to the family caregivers.

The caring burden is the negative outcome of caregiving stress. The task of the caregiving role puts high emotional, physical, social, and financial demands on caregivers (Aggar, 2012; Albers, Block & Stichele, 2014). Due to the high demands and poor mental health of caregivers, caregiving may affect suffering from poor health themselves, mood disorders, reduced quality of life, and loss of work (Nordtug, Krokstad & Holen, 2011).

Providing care during a critical period and facing stressful life events leads to the exacerbation of psychiatric illness (O'Hara, 2006). Caregivers may experience mood problems such as depression, anxiety, and fatigue (Panke & Ferrell, 2010; Toonsiri, Sunsern., & Lawang, 2011). According to a meta- analysis conducted by Pinquart and Sorensen (2003), caregivers were more stressed, depressed, and had lower levels of well-being, physical health, and self-efficacy than non-caregivers. The research showed that family caregivers who cared for terminally ill elderly had moderate to high stress level on the caring burden (Yotphet, 2005; Yotphet, 2006; Sritumrongsawat., & Boontamcharoen, 2010; Gray and colleague, 2013). The caring burden correlates with a decline of the physical and psychological health of caregivers in addition to the deteriorating health-related quality of life with compromised immunity and mortality (Garlo et al., 2010). The consequences of the caring burden impacts on decreasing the quality of care for the elderly (Toonsiri, Sunsern., &

Lawang, 2011; Limpawattana, et al., 2013). Quality of palliative care in all level of care has not yet been evaluated, whereas the evaluation of quality of palliative care mostly measures in some tertiary hospitals (Nantachaipan & Sroywong, 2015).

Currently, the palliative care service in Thailand is provided by four types of organizations (Wright et al, 2010): faith-based community organizations, tertiary hospitals, cancer centers, and private hospitals. Faith-based community organizations were the first to provide palliative care and the foundation for palliative service delivery in Thailand. For example, the temple of Wat Phrabat Nampu has provided hospice care for people living with HIV and AIDS. Tertiary hospitals mostly have specialists in palliative care and all patients receive palliative care specifically. Tertiary hospitals consist of King Chulalongkorn Memorial Hospital (Bangkok), Maharaj Nakhon Chiang Mai Hospital, Ramathibodi Hospital (Bangkok), Siriraj Hospital (Bangkok), Songklanagarind Hospital (Hat Yai), and Srinagarind Hospital (Khon Kaen). Wattanosoth Hospital, which is a private hospital on the Bangkok Hospital campus, provides palliative care for cancer people. However, all of these organizations are mostly concerned with the cancer patient group. A literature review found that the healthcare service system for the elderly with a terminal illness is sufficient in providing care (Milintarangul, 2014; Pairotkul, 2014). Regarding the convenience in adapting and integrating home-based palliative care programs within the nursing context, the literature review revealed few studies in which home-based palliative care programs in Thailand were implemented into nursing to achieve sustainable benefits.

Based on the evidence based practice, there are three types of programs to implement palliative care for the caregivers of the elderly at home, and these are case management (Aiken et al, 2006; Brumley et al, 2007; Chialli et al, 2013; Ciemins et al, 2006; Dhilliwai & Muckaden, 2015; Fernades et al, 2010; Finucane et al, 2013; Janse et al, 2014; Kerr et al, 2014; Specht et al, 2009), psychosocial interventions (Allen et al, 2008; Hall et al, 2011; Hudson et al, 2008; McMillan & Small, 2007; Walsh et al, 2007), and skills training (Healy et al, 2012; Kuo et al, 2013; Linstrom et al, 2013; Wang et al, 2012;).

Providing palliative care at home preserves the dignity in the final phase of life. In addition, home-based care allows the elderly to spend the terminal phase of their lives in their own homes, together with relatives who can offer them a more emphatic level of support (Hasegawa, 2011; Riolfi et al., 2013). The meta-analysis of Gomes, Calanzani, Curiale, McCrone and Higginson (2013) studied the comparison of palliative home care and routine care at home in 23 studies. They found that in the palliative home care group the elderly were likely to die at home and pain management was effective than that of the routine care at home group ($p< .01$). In addition, Behm (2015) synthesized home-based palliative care. The results found that fewer hospitalizations, fewer hospital days, and fewer physicians visit. The home-based palliative care can reduce the likelihood of readmission to a hospital within 30 days and increases the likelihood of completing an advanced directive. Home-based palliative care has shown to be cost-effective. Home-based care patients and their families report high levels of quality of life and satisfaction with their care.

Palliative care follows the perspective of holistic care: physical, psychological, social, and spiritual care (WHO, 2016). The National Health Security Office (2010) established and approved the “LIFESS” framework to guide healthcare providers for the assessment and implementation of care for people and their families who facing palliative stage. The LIFESS framework consists of six elements: L (Living will), I (Individual belief), F (Function), E (Emotional and Coping), S (Symptom), and S (Social and Support).

The literature review regarding the use of the ‘LIFESS’ framework found that the studies were conducted in developing practice guidelines and studying the family’s perspectives and support needs for caring. Suphansatit (2014) developed a nursing practice guideline for hospitalized patients with cancer. It is available to use and appropriate in the Thai hospital context. In addition, Pasri (2014) studied the family’s perspectives and support needs for caring in the end stage cancer patients. The purpose of Pasri’s study aimed to encourage health care providers to understand the perspectives and needs of advanced stage cancer patients and their families. These results can guide health care providers to care appropriately for patients and their families.

According to long term care service system, the challenge of developing home-based palliative care for the elderly in view of today's inaccessible system of care and it is not congruence with quality of service in population ages (Milintarangul & Thumtutaree, 2014). Hence, developing an ideal set of nursing care activity for home-based palliative care can help better service system of tomorrow to build a real and competent healthcare provider where the unique needs of elderly are reflected in the capacity of healthcare providers who serve them.

This study was developed based on two philosophical foundation for an ideal set of nursing care activity for home-based palliative care: 'LIFESS' framework (National Health Security Office, 2010) and participatory action research (PAR) (Kemmis & McTaggart, 1988). The LIFESS framework guided to construct an ideal set of nursing care activities for home-based palliative care covering holistic perspective. According to state of the art in home-based palliative care for Thai elderly, most of studies are conducted in hospitals specifically to cancer patients (Preedee, 2013; Sawasdeenarunat et al, 2015; Wisetchoonhasilp et al, 2013). Whereas, the Thai elderly wish to live and die at home (Pasri, 2014; Samaksaman, 2007; Srinakharin hospital, 2012) which deserve for promoting dignity at the end of life care (WHO, 2015). In addition, those studies did not reveal care activities regarding home-based palliative care (Pattniboon et al, 2012; Preedee, 2013; Tasprasit et al, 2013). As a result, the Thai elderly and their family caregivers are underserved for palliative care service (Intarasombat, 2014; Milintarangul, 2014). Hence, action research approach is chosen in this study because it helped in generating an appropriate set of nursing care activities for home-based palliative care in Thai context.

Action research acknowledges the nature of scientific literature on evidence-based practice, and yields knowledge based on studies conducted within practical contexts (Koshy et al, 2011). All participants who participate in this study can share views, perceptions and idea and contributed to change according to their expertise and knowledge (Friesen-Storms, Moser, van der Loo, Beurskens & Bours, 2014).

Technical action research is interested in offering way of developing practice-based knowledge that can improve of intervention on home-based palliative care.

Consequently, action research empowers the elderly and their caregivers to bring change through reflection on their personal experiences and situation (Glasson, Chang & Bidewell, 2008).

The process of action research can organize knowledge and structuring theoretical, including practical activities (Spirkin, 1983). Therefore, care activities and process for providing care in this study are occurred that derived from distinctions of action research methodology during the caring the Thai elderly. In addition, this study evaluated outcomes of an ideal set of nursing care activities for home-based palliative care, which was able to enhance care quality and reduce the caregiving burden for family caregivers of Thai elderly.

Objectives of the Study

1. To develop an ideal set of nursing care activities for home-based palliative care for the caregivers of Thai elderly.
2. To evaluate outcomes of an ideal set of nursing care activities for home-based palliative care on care quality and caregiving burden for the caregivers of Thai elderly.

Research Questions of the Study

1. What is an ideal set of nursing care activities for a home-based palliative care to enhance care quality and reduce caregiving burden for the family caregivers of Thai elderly?
2. How do an ideal set of nursing care activities for a home-based palliative care enhance care quality and reduce caregiving burden for the family caregivers of Thai elderly?

Philosophical Foundation of the study

An ideal set of nursing care activities for home-based palliative care was developed based on the ‘LIFESS’ framework of the Thai National Health Security Office (2010). Action research (Kemmis & McTaggart, 1988) at the level of technical action research (Grundy, 1982) was used as the method to develop an ideal set of nursing care activities for home-based palliative care.

LIFESS framework

The ‘LIFESS’ framework (the Thai National Health Security Office, 2010) was the base to develop an ideal set of care activities for home-based palliative care. There are six components: living will (L), individual belief (I), function (F), emotion and coping (E), symptoms (S), social and support (S). Firstly, a living will is a written document that specifies the kinds of medical treatment an elder person desires. It is a part of an advance directive, which may include documentation regarding a healthcare proxy and the power of a lawyer (Alfonso, 2009). Secondly, an individual belief is the beliefs of an elder person with an illness, in regards to the meaning of spirituality, religious beliefs, meaning in life, as well as death and dying. Thirdly, a function or functional status is the ability of the elderly to perform activities. The function of the elderly in palliative care is shown by decreased physical functioning which strongly indicates a deteriorating condition and imminent death (Gestsdottir et al, 2015). Fourthly, emotions and coping are the effects on the elderly and their family of illness and dying, and includes the effects of the caring provided by the caregivers to the elderly being at the end of life and after death. Next, symptoms are the signs and symptoms of the elderly, and how to manage the symptoms to reduce the signs and symptoms. Finally, social support is able to help caregivers to seek ways or resources from within the family and from outside the family, including accessing resources in the community (Dhiliwal & Muckaden, 2015).

The ‘LIFESS’ framework was used to base for developing an ideal set of nursing care activities for home-based palliative care under collaborate between the elderly, family caregivers, and a nurse. Five steps of action research: reconnaissance, and spiral of four steps (planning, acting, observing and reflecting) (see figure 1) was carried out in order to generate care activities that mutually initiated and evaluated through the following procedures.

1. The ‘LIFESS’ framework was used to explore the caring phenomena and assess care needs of the participants in reconnaissance step. Data from this step was analyzed to gain an understanding of current care situation and their context. All care needs were identified and analyzed to form mutual action plans.
2. Action plans were created. According to LIFESS concept, strategies for implementation was shared and discussed. In addition, evidence-based practice was considered to be their choices.
3. All mutually designed actions and strategies were implemented in acting and observing steps.
4. Reflecting on nursing care activities was performed and evaluated. Following the spiral of the four steps of action research, an ideal set of care activities were modified until an appropriative model.

Action research

Action research shares the goal of ways to enhance care quality and reduce caring burden by views, perceptions and ideas of participants and contributed to change according to their expertise and knowledge. Action research approach is compatible and possible with the participatory and development within implementation via the long term care service system. The developmental nature of this study was developed within critical theory.

The critical social theory has contributed towards action research since it proposes that researchers focus on the product of knowledge which is based on social, political, cultural, and economic contexts that inform the ways in which people act in daily situations (Kemmis, 2001). The critical social theory of Jurgen Habermas critiques modern society. Habermas identified philosophy anthropology in knowledge and human interest for an interdisciplinary critical social theory (Bohman & Rehg, 2014). This philosophy is adjusted toward critiquing and changing society as a whole.

Action research is the process to develop new ways of thinking and changing issues or problem needs in a family system (McIntyre, 2008). Action research aims to achieve this through a cyclical process of exploration, knowledge construction, and action at different moments throughout the research process (Kemmis, 2001).

Nowadays, development of innovation will be expected to apply in practice. Technology readiness levels (TRL) is to help management in making decisions concerning the development and transitioning of technology. It should be viewed to manage the progress of research and innovation within an organization and social. An ideal set of nursing care activities is formulated initially to develop, validate and analyzed by stakeholders (elderly and their family caregivers). In the future, this model will be developed towards TRL level 4 for practitioner such as nurse in primary care center to test and validate the model.

During the process of action research, technical action research was used as the method to construct an ideal set of nursing care activities for home-based palliative care (Grundy, 1982). The goal of the technical mode is to test a particular intervention based on a prespecific theoretical framework (Grundy, 1982). The relationship in the technical mode is between the elderly, family caregivers and researcher act as a nurse. Problematic is identified by all three parties. In addition, seeking involvement and agreement are shared and considered. The communication and the ideas may be communicated to the group (Grundy, 1982). The process of this mode induces the skill of action research, the idea being how the situation was occurred.

Technical action research was used in this study, and the reason for this can be described by following the characteristics of technical action research. Firstly, the study was stimulated by a person or family group because their experience or qualifications was regarded as expert knowledge (Holter & Schwartz-Barcott, 1993). Therefore, skillful family caregivers were help to construct the core activities in a program. Secondly, technical action research promotes efficient and effective practice. The model of the study was derived as the direct product, yet participants were improved the promotion of an ideal set of nursing care activities in personal participation in the process. The results of this level are shown in the accumulation of predictive knowledge, and the validation and refinement of existing theories which are deductive (Holter& Schwartz-Barcott, 1993).

The process of enhancing the caregivers of the elderly on care quality and reducing caring burden were simultaneous. ‘LIFESS’ was used to guide and clarify any problems and needs, including care activities of the participants toward implementation which covers the holistic perspective of care and each phase in the cycles of action research.

An ideal set of nursing care activities for home-based palliative care for the elderly and their family caregivers improved care quality. The specific aim of palliative care is to ensure that the elderly has the highest possible quality of life until they die, and to provide support for their nearest family caregivers (Hearn & Higginson, 1999). The emphasis of palliative care is not only on the relief of pain and symptoms but also on the resolution of emotional, social, psychological, and spiritual problems (WHO, 2014).

The caregiving burden experienced by the caregivers of the elderly in palliative care can be divided into physical, psychosocial, and financial burdens (Rha et al., 2015). The caregiving burden is reduced by nursing activities changing durably the process of action research. The caregivers had improved competency in their caregiving role from using evidence-based practice regarding home-based palliative care programs with the integration of the reflections of action research. The caregivers stress were assessed and managed before developing caregiving skill. The caregivers were reflected care outcome for continuing improvement and were promoted caregiving confidence for enhancing care quality at home.

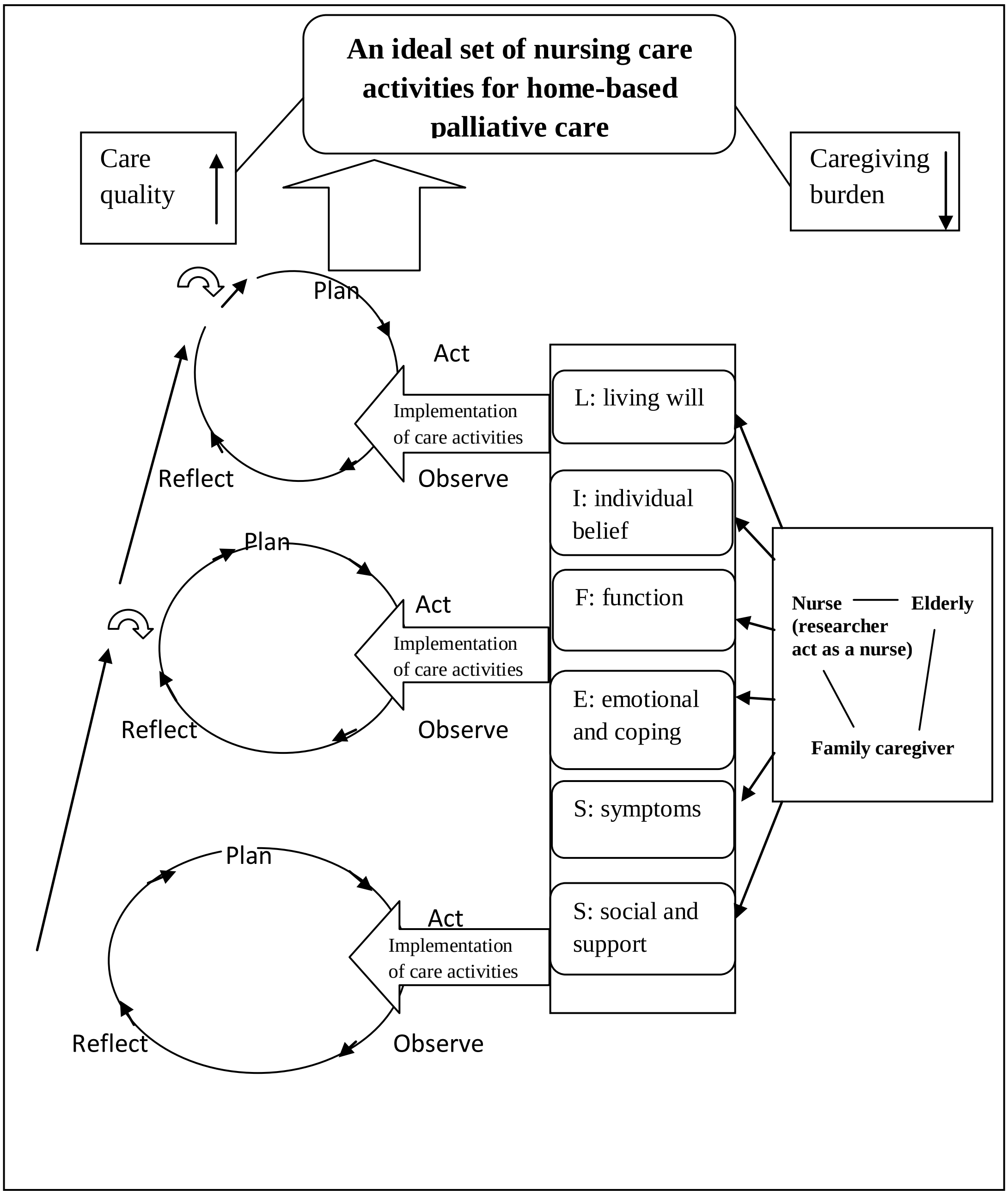


Figure 1 *Philosophical Foundation of the study*

Definition of Terms

An ideal set of nursing care activities for home-based palliative care

An ideal set of nursing care activities for home-based palliative care refers to a set of care activities emerging from two philosophical foundation: ‘LIFESS’ framework (National Health Security Office, 2010) and technical participatory action research (Kemmis & McTaggart, 1988) as a way to implement and collaboration between the elderly, their family caregivers and a nurse (researcher act as a nurse). The set of nursing care activities are revealed following five steps of action research: reconnaissance, and spiral of four steps (planning, acting, observing, and reflecting). During the research process, three parties of the study were generated care activities to enhance care quality and reduce caregiving burden. An ideal set of nursing care activities is proceeded initially to develop that validated and analyzed for stakeholders using. Thus, this model can be applied to be useful in primary care service system for nurses via long term care service system.

Palliative care

Palliative care is defined as caring that enhances comfort and quality of elder’s life and family during the terminal stage of life, and during the anticipation and release of suffering by indicates of early identification and impeccable assessment and treatment of pain, physical, psychosocial, and spiritual problems (World Health Organization (WHO), 2016). The goal of palliative care is based on elderly and their family caregivers’ needs.

Home-based care

Palliative care service in primary care for the elderly is implemented via the long term care service system (National Health Security Office, 2015). The elderly who received health services from the primary care centers. The criteria for home visiting the elderly followed by the activity of daily living (ADL) that divided into three levels: 0-4 scores (very low initial score, total dependence), 5-8 scores (low initial score, severe dependence), 9-11 scores (intermediate initial score, moderately severe dependence), 12-20 scores (intermediate high, mildly severe dependence, consideration discharge home). The elderly received palliative care from their home visit team (nurse, physical therapist, and healthcare volunteer).

Quality of care

Quality of care is defined as the outcome measures of palliative care on physical, psychological, and spiritual domains for the caregivers. The outcome was measured by three instruments, namely, 1) the Thai version of the Palliative care Outcome Scale (POS) (Sapinun, 2013) developed by Hearn and Higginson (1999), 2) the preferences of patients and of their surrogates for advance directives at the end of life (Suwannil, 2011), 3) the caregivers' capabilities in responding to the spiritual needs and the perceived caregivers' compassion to the spiritual needs (Issarapanit, 2005).

Caregiving burden

Caregiving burden is defined as the distress that caregivers feel as a result of caregiving. It is specific to the care and varied by emotional problems and general responses such as stress, anxiety, and depression. In addition, the caring burden includes the amount of time spent in caregiving and the type of caregiving provided. Evaluation on caring burden consists of physical, psychological, social, and financial domains which may result in caregivers neglecting their personal needs. The caregiving burden was measured by the Thai version of the Burden Interview (Toonsiri, Sunsern., & Lawang, 2011), which was developed by Zarit (1990).

Significance of the Study

This study is conducted with the objective of developing and evaluating of an ideal set of nursing care activities of home-based palliative care for healthcare providers in Thailand. The findings of this study are expected to be beneficial as follows.

The ideal set of nursing care activities were provided required knowledge and skill for home-based palliative care provision to promote the appropriate strategies enhance care quality and reduce caring burden among the caregivers of Thai elderly. In addition, it is enhanced quality of long term care service by providing accessible the home-based palliative care for Thai elderly and their family caregivers. The existing knowledge on the ideal set of nursing care activities can be further developed to be clinical practice guideline for quality control of the palliative care system.

Chapter 2
Literature review

The literature review in this chapter is organized into four parts. The first part is concerned with palliative care for the elderly in Thailand. The second part is related to home-based palliative care for the elderly. The third part is related to foundational concepts used to develop an ideal set of nursing care activities for home-based palliative care. The fourth part is concerned with the development of home-based palliative care for Thai elderly. The details of the review are organized as follows:

1. Palliative care for the elderly in Thailand
    1.1 Palliative care for the elderly
    1.2 Thai Policy on palliative care
    1.3 Palliative care services in Thailand
    1.4 Death, dying and cultural taboo from Thai perspectives within Thai society
2. Home-based palliative care for the elderly
    2.1 Evidences and outcomes of home-based palliative care programs
    2.2 Home-based palliative care for the elderly in Thailand
3. Foundational concepts in developing the home-based palliative care
    3.1 LIFESS
    3.2 Continuing care in home-based palliative care for the elderly
4. The development of home-based palliative care for Thai elderly
    4.1 Conceptual structure of home- based palliative care for Thai elderly
    4.2 Outcome measures of the home-based palliative care for Thai elderly
5. Action research

1. Palliative care for elderly in Thailand

Many nations of the world are facing a significant challenge in responding to palliative care for the elderly due to an aging society. One the one hand, Thailand is facing an aging society and challenges in addressing palliative care. There is now a growing acceptance of the value of early action in palliative care in a whole variety of diseases across a range of cancer and non cancer. Therefore, policy makers are aware of the need for palliative care for an aging population.

This part presents the information that is known about palliative care in the elderly, the national policy on palliative care, and palliative care services in Thailand.

1.1 Palliative care in the elderly

Definition of palliative care

Palliative care is treatment that improves comfort and the quality of a person's life and family during the terminal phase of life, and during the anticipation and release of suffering by indicates of early identification and impeccable assessment and treatment of pain, physical, psychosocial, and spiritual problems (World Health Organization (WHO), 2016). The work of palliative care deceits in the concurrence between the person, caregiver, physicians, nurses, and the team that the expected result is relief from distressing symptoms, the reduction of pain, and improving the quality of life (Coyle, 2010). The decision to proceed with vigorous palliative care is based on capability to meet stated goals that continue to be assessed as well as exploring and evaluating all treatment options in the context of the person's values and symptoms (Sepulveda et al, 2002). The person's choices and decisions concerning care are predominant and must be followed at all times (The National Hospice and Palliative Care Organization (NHPCO).

In recognition of the shifting trajectory of dying and the inferences for palliative care, the World Health Organization (WHO) (2016) defines the scope of palliative care beyond end of life care. WHO proposes that palliative care is an approach that can be integrated with life prolonging therapy and should be improved as death draws near. For example, the National Comprehensive Cancer Network (NCCN) has constructed guidelines to facilitate the “appropriate integration of palliative care into anticancer therapy”. The individual would have access to psychological counseling, nutrition services, pain management, fatigue management, and cancer rehabilitation. This model is appropriate for other diseases as well.

Palliative care for the elderly

The older population is growing older because of positive trends in medical treatment. This increase of the older segment of the population reinforces require for nurses, physicians, and healthcare team to understand the special palliative care requires of the elder people. Because of the increase in both life expectancy and the length of time living with illness conditions, there has been rising emphasis on providing supportive care through life-limiting illnesses and at the end of life. However, palliative care services often pay insufficient attention to the complex needs of individuals.

In elder persons, the palliative stage may be a steady process that is associated with the increasing effects of illness, frailty, and many interacting conditions, rather than a single cause. In many cases, a major medical situation, such as sepsis or a fractured hip, can cause the elderly to transition from a state of illness to a terminal state in which death occurs. Lunney and colleague (2003) described the patterns of function decline of illness trajectories: short period of apparent decline, long term restrictions with intermittent serious episodes, and prolonged dwindling. The researcher has described each of these three trajectories as follows.

Trajectory 1: short period of evident decline, typically cancer

This group depends on a conventional decline in physical problem over a period of weeks, months, years. This course may be interrupting by the effects of palliative cancer treatment. Most of the decrease in efficiency status and impaired capability for self care arises in the elderly in the last few months. There is normally time to predict palliative requires and plan for end of life care.

Trajectory 2: long term limitations with intermittent serious episodes

The elderly in this group experience organ failure due to non cancer chronic such as advanced heart failure, end stage renal failure and chronic obstructive pulmonary disease (COPD). They are generally ill for several months or years with irregular acute, frequently severe, exacerbations. Deteriorations are regarded by admission to hospital and intensive treatment. Each exacerbation may effect in death, and even the elderly frequently survive many such episodes, a steady deterioration in health and functional status is usual. However, the timing of passing away in this group stays uncertain.

Trajectory 3: prolonged dwindling

The elderly in trajectory 3 have a progressive disability from an already low baseline of cognitive or physical functioning. This third trajectory is the frail elderly and dementia/Alzheimer. The elderly in this group have a low level of ADL performance and show progressive reduce in physical capability in the terminal phase of their life. However, this trajectory may be breaking short by death after an acute situation such as a fractured femur or pneumonia.

Illness trajectory allows practical planning for a “good death”. All trajectories lead to death, but that death may be unexpected. Therefore, healthcare providers can make it evident that advanced planning is rational, and they can plan for terminal care in regards to the elderly and their families’ wishes.

Differences of palliative care for elderly and other groups

Clinical guidelines for palliative care are often applicable to patients of cancer. Whereas elderly who need palliative increase rapidly from being dependence and having multiple illness and disabilities. However, existing palliative care model is not suitable for elderly because the elderly need both palliative care and geriatric care (Goldstein & Meier, 2010; Jerant et al, 2004). Palliative care for elderly is different from younger patients because of the nature and duration of illness conditions during old age (Goldstein & Meier, 2010). Four main specific issues of palliative care for elderly are discussed as follows.

1. Geriatric syndromes

The geriatric syndromes are clusters of illness, often multifactorial in aetiology, that are prevalent among elderly (Goldstein & Meier, 2010). Most of geriatric syndromes are dementia, delirium, constipation, falls, frailty, and depression. Signs and symptoms of elderly with terminal illness are presented both symptomatic and geriatric syndromes (Chansirikan, 2014). Palliative care for the elderly engages treating the primary disease process (e.g. advanced heart failure, end staged renal failure), managing various chronic medical conditions and comobidities (e.g. diabetes mellitus, arthritis), and geriatric syndromes (e.g. cognitive impairment, frailty) (Goldstein & Morrison, 2005). Therefore, healthcare providers should concern to assess both physical and psychological symptoms to providing palliative care for the elderly.

2. Pharmacologic management of pain in the elderly

Pain in elderly is related with physical, psychological, and social aspects of pain. The elderly may have rose sensitivity to analgesic medications, smaller dosages may be efficient as compared with efficient dosages in younger people (Cavalieri, 2007). As a result, primary doses should be lower and proceed slowly to increase dose. Nonopioid medications are used to start for treating the elderly with mild pain, advancing to opioids for those with moderate to severe pain. Opioids are required when pain does not react to nonopioids only (Warring & Krieger, 2010).

Pharmacologic management should be defined by targeting the underlying pathophysiology. For example, if pain is caused by inflammation, anti-inflammatory medications should be known. However, if pain is neuropathic, anticonvulsant medications should be utilized. At time, associations of analgesics may be required. In addition, para-acetylaminophenol as the drug of choice for mild to moderate musculoskeletal pain (Cavalieri, 2007).

Healthcare providers should predict, avoid, and handle side effects. They should initiate prevention of constipation through the use of stool softeners whenever opioid is used in the elder persons, and sedation and delirium are commonplace when using opioids. Naloxone hydrochloride could be used to prevent respiratory depression and sedation (Cavalieri, 2007). It is advisable that elderly take a maintenance dose for several days. In addition, avoid the use of opioids that have regular adverse reactions in the older people such as propoxyphene, meperidine hydrochroride, and methadone hydrochroride, because of their high incidence of adverse effects on ataxia, dizziness, and neuroexcitatory, particularly psychosis (Warring & Krieger, 2010).

Management of pain in the elder person is very successful when based on a basic understanding of origins of pain and a systematic method to management. Different types of pain need different treatments. Occasionally, a combination of pain medication can be more therapeutic than each used alone.

3. Development of elderly in psychosocial aspect

Psychosocial theories try to give explanation elderly in terms of behavior, personality, and attitude change. Development is viewed as a lifelong process characterized by transitions. Psychological aspects are related with personality or ego development and accompanying challenges regarded with different life stages (Lange & Grossman, 2010).

According to Jung's theory of individualism (Jung cited in Lange & Grossman, 2010), the elderly engage in an "inner search" to critique their beliefs and accomplishments. Successful aging indicates recognition of previous times and an ability to handle with functional decline and loss of others. Elder's personality is viewed as being composed of an ego or self-identity (Jung, 1960 cited in Lange & Grossman, 2010). Self-identity of elder people depends on personality and perceptions surrounding persons or life events. Self-perception of personality continues stable overtime, including attitude and adaptation to old age are related to life satisfaction (Troll & Skaff, 1997). Hence, promoting on positive inner growth is described as a part of healthy aging (Erikson, 1986).

According to stage of personality development theory by Erikson (1963), there are three major issues related with old age (Erikson, Erikson & Kivnick, 1986): (1) meaningful life after retirement, (2) the empty nest syndrome (e.g.

a feeling of grief and loneliness when their children leave home for the first time), and (3) dealing with functional decline of aging. These tasks are related to develop of stage of ego integrity versus despair. Challenges of old age is adjusting to infirmity, developing satisfaction with one's lived life, and preparing for death.

4. Having multiple diseases and being longer periods of time

Most of elderly have multiple medical conditions (WHO, 2011). According to the report of the numbers of Thai elderly chronic conditions of the Office of the National Economic and Social Development Board (2011) found that Thai elderly normally have chronic conditions such as stroke, cancer, COPD, and dementia. In addition, one quarter of the elderly aged 85 years and older have dementia (Ferri et al, 2005). Therefore, they may have palliative care requires at any point in the illness trajectory and not just the life-threatening phase (WHO, 2011). Consequently, healthcare professionals need to attend to not on issues regarded with dying process, yet they need to concern on disease problems and fundamental problems related with joint pain, loss of hearing and vision, and perhaps fatigue (Amella, 2003). Healthcare professionals may not understand how dying might be handled differently in elderly (Amella, 2003). Thus, palliative care for elderly should incorporate between geriatrics and palliative care (Chansirikan, 2014).

Dying process may be lingering process in elderly. This may make prognostication of death very difficult (Amella, 2003). Current prognostic may fail to accurately predict the timing of death from illness (Chansirikan, 2014). According to figure 2, the elderly in a group of organ failure and prolonged dwindling group have slowly progressive illness. For example, the median length of survival from diagnosis to death is 8 years (Davies & Higginson, 2004). Hence, families caring with the elderly with dementia need a lot of support and assistance, and getting palliative care early is crucial.

In conclusion, most of existing palliative care services were designed to serve persons with cancer, whereas, the elderly are often untreated for palliative care. Because palliative care for the elderly needs to concern the cumulative effects of illness, frailty, and many medical conditions rather than a single cause.

Therefore, there are four specific issues of palliative care for elderly: (1) geriatric syndromes that leading to comprehensive assessment on care needs, (2) the elderly are sensitivity on medications, and pain is related with physical, psychological, and social aspects, thus, pharmacologic management of pain in the elderly can be considered initial lower dose and combination of pain medications, (3) each elderly have different individual believe, thus, the elderly need to be use palliative care program that appropriate designed for them (4) multiple diseases with long periods of time leading to fail in predicting the time of death, hence, the elderly need to receive palliative care early.

1.2 Thai Policy on palliative care

In this part, the researcher analyzes and identifies the global policy and the national policy in a time line of palliative care development and the barriers to implement palliative care policies into practice as follows.

Global policy on palliative care

Even though palliative care has been in place over the past 40 years in the developed world, many parts of the world still have no access to palliative care. Developed countries in palliative care are classified into three groups. Well-developed palliative care countries, such as Australia, Canada, Ireland, New Zealand and the UK, have well-developed services for dealing with palliative care. In developing counties, palliative care has not yet been integrated into the healthcare system. In the poorest nations, the most basic tools of palliative care for the relief of suffering are unavailable.

Policy guidance for palliative care can follow the palliative care model of the World Health Organization (WHO) developed in 1990. WHO developed a public health model to integrate palliative care into healthcare systems (Stjernsward, Foley, & Ferris, 2007). This model has four components: 1) appropriate policies, 2) adequate drug availability, 3) education of health care workers and the public, and 4) implementation of palliative care services at all levels throughout the society. However, the success of a palliative care service is based on the policies to drive it.

WHO stated that palliative care should be part of a national health plan and policies. Public funding needs to be available to support palliative care services. However, the key success of policy driven services depends on the awareness of the policy maker. For instance, the availability of opioid drugs is very crucial for cancer patients and people who need pain reduction. The accessibility of opioid drugs is only available through laws and bureaucratic procedure. In regards to the demand of palliative care, health care professionals need to be trained in palliative care, and this also includes family caregivers who need training and support. A curriculum of palliative care for health care professionals should be included in teaching programs. For example, the doctor of medicine program and bachelor of nursing science program need to include a section on palliative care. Implementation into society depends on leaders and the health care workforce in a community. Therefore, positive attitudes are needed by health care workers that palliative care can help patients and their families and how they can best utilize resources and increase quality of life and satisfaction of the patients and families that they are caring for.

National policy on palliative care

Since 2007 section 12 of the National Health Act approved the right of the terminally ill person to deny futile medical treatments to prolong natural death or to end the severe suffering from that illness by writing a living will (National Health Commission Office of Thailand, 2015). The National Health Act offers a legal tool for society to respect a person’s right to self determination. In addition, it allows the patient to decide what he/she wants regardless of what his/her family want in regards to the patient’s care and treatment (National Health Security Office, 2010). A living will is a part of the advance care planning of palliative care, and it should include any last wishes of the dying person.

Since 2012, the palliative care service in primary care has been organized by the National Health Security Office (NHSO). NHSO offers a budget for the palliative care service via two main activities: a promoting palliative care service network and offering morphine to reduce pain among patients at the end of life at home and in the community. The palliative care service system is worked from the provincial level service system to primary healthcare unit or one promoting hospital. The activity services include: 1) providing palliative care for patients and families that cover physical, psychological, social, and spiritual care, 2) counseling and advocating for setting goals of care between a patient and his/her family, including advanced care plan, 3) developing alternative treatments, 4) planning for discharge by case management for referral and continuity of care at home between a health care team and the patient and his/her family, 5) preparing for emergency care, 6) preparing of pain and symptom management in the primary care unit to relieve suffering at home, and 7) promoting palliative care at home and in the community, including preparing medical equipment for the patient at home.

In 2014, the National Health Commission approved the National Strategic Plan on Health Promotion for Good Death between 2014 and 2016 (National Health Commission Office of Thailand, 2015). The National Strategic Plan on Health Promotion for Good Death was made by the joint initiative of the Ministry of Public Health, the National Health Security Office, Thai Health Promotion Foundation, Health Systems Research Institute, Healthcare Accreditation Institute (Public Organization) and the Thai Palliative Care Society (THAPS). This plan concerns preparing and driving the means to provide palliative care for the older people. It is focused on care by the community and family support with close collaboration between health service facilities and local administration organizations. This policy purposes to strengthen long term care and palliative care to enhance the quality of life of the elderly and people at the end of life in community-based and family-based care (National Health Commission Office of Thailand, 2015).

The vision of the National Strategic Plan is that every person in Thailand can have well-being in the terminal phase of their life and experience a good death. The following are the three crucial strategies outlined in the plan (National Health Commission Office of Thailand, 2015): Firstly, to generate knowledge and positive attitudes about terminal well-being, good death and palliative care and to nurture the participation of all the stakeholders ranging between family and institution; secondly, to establish and organize quality, standard and comprehensive palliative care service to promote well-being in the last stage of life and support good death; finally, to create logistic systems to support the provision of care. This plan purposes to be used as a system-based tool that leads to promote health for good death or natural dying with quality of life and human dignity. It defines directing the strategic plan that aims to be effective at a practical level.

In 2015, the Thai government had concerns about the aging society in Thailand, particularly the dependent elderly. Therefore, the Thai government offered a budget of 600 million baht via a long term care service system by NHSO to provide care (National Health Security Office, 2015). The party network includes the Ministry of Public Health (MPH), NHSO and local government to cover every province in Thailand. The goal of this project is to provide access to palliative care for 100,000 dependent elderly in 1,000 sub-districts in Thailand in 2016. Therefore, the elderly will receive palliative care from a multidisciplinary team from a primary care unit and one sub-district promoting hospital at their home. In addition, the palliative care service in primary care via a long term care system is the collaboration between a patient, his/her family in the community and the local context. Moreover, a long term care service system can help to develop party networks with the Family Care Team (FCT) under the District Health System (DHS).

National policies play an essential role in extending access to palliative care. Nevertheless, implementation palliative care into practice is limited. The presence and effectiveness of palliative care services depend on the palliative care service of health system and the government throughout the country. There are several factors that are related to implementing palliative care policies into practice in Thailand.

Barriers to implement palliative care policies into practice

Five barriers to implement palliative care policies into practice are identified as follows.

1. Health care system

There is a government-led strategy for the development and promotion of national palliative care (The Economist Intelligence Unit, 2015). This has a broad vision, and no specific targets (Milintarangul, 2015). There are limited mechanisms in real practice (Pairotkul, 2014). In bureaucratic structure, it is not ordered to follow the national strategy (Nitikul, 2016). Palliative care is exiting under home care service system but it does not show specific in palliative care (Milintarangul & Thumtutaree, 2014; Pairotkul, 2014). For example, health care staff place more action on home care services such as home visits in regards to general care/no palliative care is provided, rehabilitation, and providing medical equipment (Intarasombat, 2014). Although the elderly who need palliative care can receive benefits from the universal coverage core package by a long term care service system but most of them do not know how to access palliative care in primary care setting (Nitikul, 2016).

On the other hand, primary care is not well developed in palliative care due to the national health policy which is still in the beginning stages for the primary care setting. Nowadays, the Minister of Public Health (MPH) sets the goal of palliative care for people who need palliative care can access the service anywhere in Thailand. The MPH states that palliative care units must be in 300 community hospitals by collaboration with 30,000 FCT (Rachatanawin, 2015). However, many community hospitals have no palliative care unit following this healthcare policy because many community hospitals lack nurses and professional staff to provide palliative care to those patients who need it.

The process of this study can empower the elderly and their family caregivers to gain awareness and to be able to act on the rights in accessing palliative care. In addition, a home-based palliative care program will be able to guide health care providers in primary care centers to plan and set the program in procedure to practice.

2. Human resources

There are three points in regards to the health care work force in palliative care on primary care: health care staff have less experience in palliative care in relation to knowledge and skills, there is a lack of health care professionals in palliative care, and less professionals in regards to the psychosocial approach such as psychiatric nurses and social workers. My study can improve this barrier by training healthcare providers and family caregivers who provide for the elderly at home in the philosophy of palliative care, knowledge, skill training, psychosocial approach and using community resources to help them, including collaborating with local staff and health care staff within their context.

3. Availability of opioid drugs

Opioid drugs are not simply accessible and/or access to them is limited through laws and bureaucratic red tape. In the long term service system, morphine based drugs are provided to the elderly to reduce their pain and symptoms under the universal coverage core package. Health care staff must report on the number of palliative patients who have received the pain killer morphine to treat for the relief of symptoms.

4. Funding

There are a limited number of government subsidies or programmes for the elderly accessing palliative care services. Where available, the qualification criteria are unclear, and funds and programs are difficult to access. However, a home-based palliative care program will work via the long term care service system for dependent elderly persons. This service system has more money to support dependent elderly persons. The Thai government offers a budget of 600 million baht via the long term care service system by the NHSO to provide care (National Health Security Office, 2015). Hence, all elderly persons who need palliative care can access home-based palliative care services effectively.

5. Public awareness of palliative care

The public has a limited understanding and awareness of palliative care services. Little to no information on palliative care is accessible from government portals and community mechanisms. It is culturally taboo in public to talk about palliative care such as talking about death and dying is not acceptable, it is disrespectful, creates bad luck or causes loss of hope, and damnation. The National Health Act offers a legal tool for society to respect a person's right to self determination in section 12 of the National Health Act 2007 which approved the right of the terminally ill person to deny futile medical treatments to prolong natural death or to end the severe suffering from that illness by writing a living will. Many healthcare staff, the elderly and their families do not like to talk about this issue. However, my study can guide as well as provide strategies on how to successfully communicate on this issue. In addition, this study can help people to form a positive attitude to palliative care, relieve suffering before death, and manage any tasks to provide for a good death.

In conclusion, there are challenges in the future implementation of the strategic movement to ensure the sustainability and quality of care in the national service systems. These are: public education, the integration of palliative care into the National Health Service system, the reorganization of the service structure and the promotion of community-based care towards dying at home or home-based care. However, there are many barriers to implement palliative care policies into practice: the health care system, human resources, the availability of opioid drugs, funding, and public awareness of palliative care.

1.3 Palliative care services

Palliative care services have evolved at an unequal rate across countries and all levels of care settings (tertiary, secondary, and primary levels). Thailand is classified as having a low level of palliative care development and services.

According to the Worldwide Palliative Care Alliance (WPCA) (WHO, 2014) report on the level of palliative care development in 2011, Thailand was among the level 3a countries. This group of countries are characterized by: the development of palliative care service that is inconsistent in possibility and not well supported; sourcing of funding that is often donor-dependent; limited access to opioids; and a small number of hospice-palliative care services that are frequently home-based in nature and relatively limited to the size of the people. However, at present the Thai government is concerned with the aging society and palliative care. Therefore, providing for older Thai people and palliative care are worked by the long term care service system. The party network includes the Ministry of Public Health (MPH), NHSO and local government to cover every province in Thailand.

Palliative care services in Thailand are classified by four types of organizations (Wright et al, 2010): faith-based community organizations, tertiary hospitals, cancer centers, and private hospitals. These types of organizations are described as follows.

Faith-based community organizations

Faith-based community organizations are the first to provide palliative care. The first faith-based palliative care organization is Pharbat Numpu temple in Lop Buri province. This temple provides care for people living with HIV and AIDS. People are cared for by Buddhist monks and volunteers (Krongyuth et al, 2014; Wright et al, 2010). The people who are cared for and those needing palliative care reside in the temple. Other faith-based organizations are Christian based. The Camillian Social Centre in Huay Pong, Rayong province. This organization provides for people living with HIV and AIDS (Wright et al, 2010). Another is St Clare's Hospice which is located in Phatum Thani province. St Clare's Hospice provides for people who are poor, homeless, and living in the final stage of AIDS (Wright et al, 2010). Finally, the Mercy Centre is a Christian charity run by the Human Development Foundation located in Bangkok. This organization aims to provide education, improve family health and welfare, and support children and adults living with HIV and AIDS (Wright et al, 2010).

Faith-based community organizations are the foundation for palliative care service delivery in Thailand. However, there are three weaknesses in these types of organizations providing palliative care (Krongyuth et al, 2014): there are a limited number of organizations that are able to provide care, people must leave their homes to receive palliative care, and there is a limited amount of funding to support the organizations.

Tertiary hospitals

There are many tertiary hospitals that provide palliative care services (Wright et al, 2010): King Chulalongkorn Memorial Hospital, Siriraj Hospital, Maharaj Nakhon Chiang Mai Hospital, Ramathibodi Hospital, Srinagarind Hospital (Khon Kaen), and Songklanagarind Hospital (Hat Yai).

King Chulalongkorn Memorial Hospital became interested in end of life care in 2003, leading to the beginning of a multidisciplinary committee which was recognized by the hospital administrator in 2005.

Siriraj Hospital developed a model which was incorporated into their structures and practices in 2007. There are three major clinics for patients who need palliative care: the pain unit, department of rehabilitation, and home care unit. Palliative care policy and implementation plans were recommended: a hospital-wide service delivered by departments and wards, supported by an instituted palliative care unit.

Maharaj Nakhon Chiang Mai Hospital has a well developed palliative care service in the North of Thailand. It uses the Suandok palliative care model as the guideline for practice. There are two major clinics for patients who need palliative care: the pain clinic and palliative care clinic.

Ramathibodi Hospital developed a palliative care unit in 2009. There are three community hospitals in Suphanburi province which are a part of a party network to develop the palliative care service.

Srinagarind Hospital in Khon Kaen has a well developed palliative care service in Northeastern of Thailand. It has Karunruk the Palliative Care Center. All patients who are recruited for consultation in Karunruk must have the following criteria: pain and symptom management, advanced directives, preparing for the end of life, assessment and care on psychosocial matters, solving family conflict, bereavement care, and a referral to the network.

Songklanagarind Hospital in Hat Yai, has a well developed palliative care service in the South of Thailand. It formed the palliative care development committee in 1999. The decision was taken to provide a hospital-wide palliative care service rather than have a separate ward or unit. The hospital-based palliative care unit was established in 2003.

Although tertiary hospitals provide palliative care services, there are many hospitals in Thailand and palliative care services which are not equally distributed throughout all levels of the country.

Cancer centers

Currently, there are two main cancer centers in Thailand: the National Cancer Institute and the Mahavajiralongkorn Cancer Centre. The National Cancer Institute works under the MoPH (Wright et al, 2010), and is located in Bangkok. A home care program was created by The National Cancer Institute as a demonstration in 1998. The Mahavajiralongkorn Cancer Centres are located throughout Thailand: Phatum Thani, Chonburi, Lampang, Lop Buri, Surat Thani, Ubon Ratchathani, and Udornthani. These cancer centers operate as a hospice facility and provide home care services for people and families.

Private hospital

Wattanosoth Cancer Hospital is one of the four hospitals on the campus of the private-run Bangkok Hospital Medical Centre. The palliative care unit opened in 2007 and extends the work of the former pain unit. There are 37 beds for inpatients, and 10-15 new patients have been recorded each month during the four months that the unit has been operational (Wright et al, 2010). Palliative care is provided for 10-20% of patients in two special oncology wards.

In conclusion, although palliative care has been developing over the past 10 years in Thailand, the health care service system is not developed for palliative care at all levels, particularly in primary care. Palliative care in Thailand is developed more in tertiary hospitals. However, palliative care for the elderly is going to develop under long term care service system. Therefore, health care professionals have a good opportunity to practice in palliative care.

1.4 Death, dying and cultural taboo from Thai perspectives within Thai society

Ninety percent of Thai people are Buddhist. Having a peaceful death is a common wish on Thai Buddhists (Ando, Somchit, Miyashita & Jamjan, 2016). Thought on death and dying the Thai society are based on Buddhist doctrine. When person performs good acts and thoughts, their minds are at peace and they believe they will go to a good place after death. In addition, performing religion activities for patient could help compensate bad karma (Wiseso, Fongkaew, Pinyokham & Spiers, 2017).

Thai cultural norm and value around responsibilities to each other created a strong context for caregiving beliefs and practices. Family beliefs are traditional or cultural values that are passed from generation to generation within Thai families (Wiseso, Fongkaew, Pinyokham & Spiers, 2017). In context of Thai family, religion played a crucial role in caregiving practice. Thai Buddhist belief meant that their family member was suffering as the result of his or her past deeds and that the illness was caused by karma.

Many people at the end of life prefer to stay and die at home (Pasri, 2014). Providing terminally ill person care at home preserves the dignity in the final phase of life, and it allows person to spend the terminal phase of their lives in their own homes, together with relatives who can offer them a more emphatic level of support. (Tipseankhum, Thongprateep, Forrester & Silpasuwan, 2016). A comforting environment was one that supported Buddhist spiritual bounds for a peaceful death.

Value-cultural related was consisted of issues of cultural norm and cultural taboo (Milintarangul, 2014). Talking about death and dying in Thai society has not been easy. This is challenging task for healthcare providers to carry out this task in

Thai culture where discussion about death and dying could be seen as a taboo topic. (Srinonprasert et al., 2014).

In summary, most Thai people are Buddhist and they thought on death and dying is based on Buddhist doctrine. Thai people belief illness is caused from karma. Families agreed to transfer their loved one to provide care at home for a peaceful death. Death and dying were avoided talking when patients being at the end of life because it is dam for patient. It is challenging task for healthcare providers when communicating this issue.

2. Home-based palliative care for the elderly

2.1 Evidences and outcomes of home-based palliative care programs

A systematic review of home-based palliative care programs which consists of a strategy to extract the data and a discussion on the type of interventions. This systematic review is analyzed and synthesized following PRISMA guidance (Moher et al., 2009). Evidences of home-based palliative care programs are described as follows.

Firstly, a systematic review was performed to search existing research evidence related to home-based palliative care programs in (1) CINAHL, (2) ProQuest, (3) PubMed, (4) Science Direct, and (5) ThaiLis. The key words consisted of home-based, homecare, home health care, hospice, palliative care, end of life, terminal, terminal care, terminally ill, dying, advanced disease, life-limiting, life-threatening, death, intervention, program, and experimental.

Secondly, systematic review eligibility was based on an initial screening of the title and abstract. Articles passing the first screening were retrieved for an additional check. The type of study, study design, number of samples recruited and completing the study, and study time-span were checked. Any type of home-based palliative care programs published in peer-reviewed journals were checked..

Finally, a systematic review was required following the type of study designs: randomized controlled trial (RCT); quasi experimental study, mixed-methods design, and cohort study (Joanna Briggs Institute, 2008). A systematic review was extracted by PRISMA flow chart (Moher et al, 2009). PRISMA flow chart consists of identification, screening, and eligibility (see Figure 2). According to Figure 2, the PRISMA flow chart shows the strategy used for screening the number of included and excluded articles. The researcher identified 2,551 records during searches of the databases, excluding duplicates. After screening the titles and abstracts, 2,490 studies were excluded. The researcher reviewed the full text of the remaining 61 records for a more detailed evaluation. A total of 19 studies were retrieved and met the inclusion criteria.

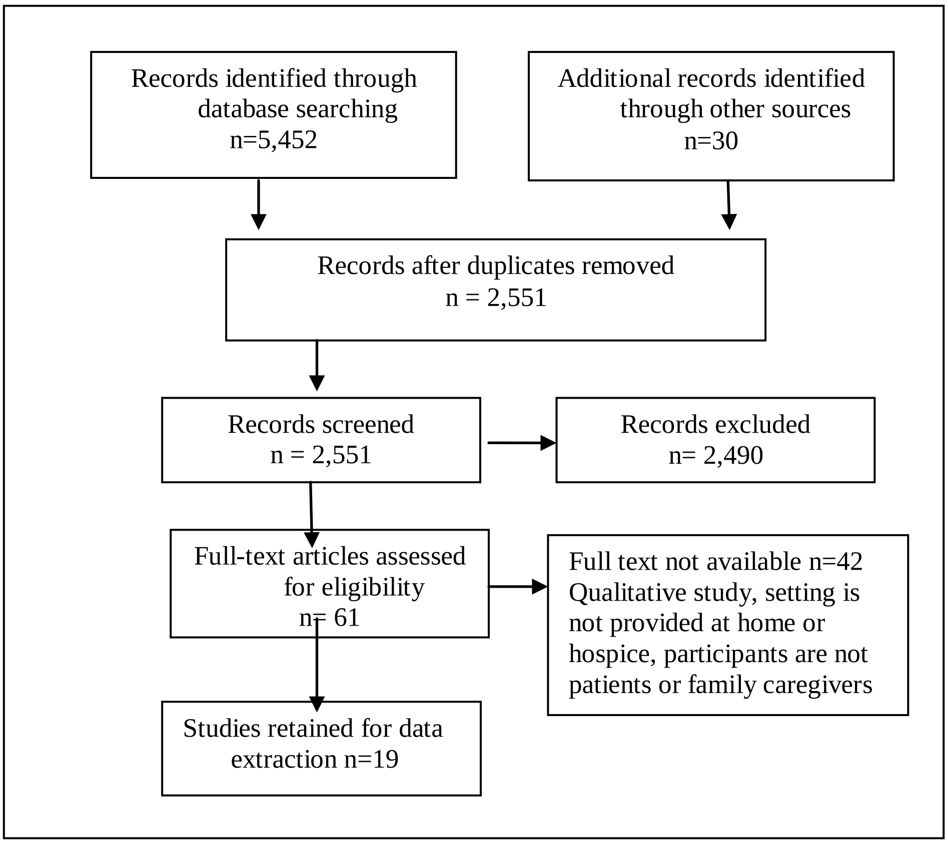


Figure 2 *PRISMA flow chart of search strategy*

According to a systematic review on home-based palliative care programs, the researcher identified 19 articles which dealt with interventions regarding case management, psychosocial, and skills training interventions. These interventions provided details of the characteristics in each intervention (Appendix A). Three types of interventions are classified for their strengths and weaknesses as follows.

Types of interventions

Case management interventions

Based on the literature review of 10 studies, a case management intervention is a collaborative process interaction between elder persons/ family caregivers, and case managers. Case management interventions use an interdisciplinary team approach, with the core team consisting of elder persons and their families plus physicians, nurses, social workers, and others. The steps of case management consist of the elderly person and caregiver classification and collection, assessment and problem classification, development of a case management preparation, achievement and management of care activities, evaluation of the case management plan and follow-up, and execution of the case management process. Assessment and implementation cover all domains of palliative care: physical, psychological, social, and spiritual needs of the elderly and their families. According to a systematic review, key success factors that influence home-based palliative care programs can be described in five factors. Key success factors can be described as follows.

Firstly, teams prepared death and end of life care. Case managers convened to develop a care plan following the wishes of the elder persons and their families. Case managers assisted persons and family/caregivers by addressing issues on understanding advanced directives or living wills. The case manager assisted with obtaining these documents (Spettel et al, 2009; Brumley et al, 2007). In addition, discussion and setting the goal of care took place between case managers and the elder person and the family caregivers.

Secondly, caregivers were trained on caregiver skill. The case manager educated the family caregivers on care and the management of symptoms control such as pain, dyspnea, nausea and vomiting, both in regards to pharmacological and non pharmacological therapy. Family caregivers were trained in the use of medications, disease process and prognosis, pain control (subcutaneous injections, hot and cold therapy) (Dhiliwal & Muckaden, 2015). Caregivers were empowered for elder care e.g. dressings, nasogastric tube feeding, tracheostomy care, back care, oral hygiene, etc (Dhiliwal & Muckaden, 2015).

Thirdly, psychosocial and spiritual support, psychosocial and spiritual support were provided in the form of counseling. Families were encouraged about the need for the person to have information about the illness as it would assist the person to cope with his/her illness better. Chialli and colleagues (2013) used many techniques to deal with the emotional problems faced by the family caregivers such as problem solving, reinforcing, and stress management training. Another approach found was consultation by a psychologist or pastor (Fernades et al, 2010).

Fourthly, finding facilitation resources in the community to help; case manager coordinated respite care to offer family caregivers support through volunteers (Kerr et al, 2014; Spettel et al, 2009), and on call palliative care support (Brumley et al, 2007; Chialli et al, 2013). In addition, case managers provided information about services offered by the National Health Service, municipal social services and local volunteer organizations.

Finally, approaching after death; after the death of a person, the care team provided bereavement support to families. Anticipatory grief was addressed through before home care visits. Family caregivers obtained a telephone bereavement call to evaluate their coping. Health care teams identified caregivers at high risk for emotional problems, and they offered family caregivers a bereavement home visit. Consequently, bereavement support monthly can help them to return to a normal life from the loss of their loved ones of grief and loss process (Dhilliwai & Muckaden, 2015; Finucane et al, 2013).

Additionally, some studies added specific methods to apply to the programs. The study of Aiken and colleagues (2006) and Brumley and colleagues (2007) used self-management to develop programs for persons with advanced chronic illness and their family caregivers. These programs aimed to increase a person's self-management of an illness and knowledge of health-related resources by providing information giving and teaching to persons with advanced chronic illness and their family caregivers. Chiatti and colleagues (2013) used technological device interventions to support the elder person and their caregivers. Technology can help in adapting to the home environment, including housing adaptations such as understandable paths, home leaving sensors, sensors to detect night fall, gas and water leak sensors, and automatic lights.

Strengths of case management interventions

The strengths of case management intervention were reaching to the goal of home-based palliative care: (1) caring covers all the domains of palliative care, (2) caring coordination, (3) using evidence-based practice, (4) accessing opioid drugs, (5) employing technique of psychosocial support, (6) facilitating resources in the community, and (7) continuity of care. These strengths of case management can be described as followings.

1. Caring covers all the domains of palliative care

The process of case management consisted of assessment, planning, implementation, evaluation, and follow up. Caring covers all the domains of palliative care consisted followed: physical, medical, psychological, social, and spiritual requires of the elderly and their families.

2. Caring coordination

Care coordination is the core strategy of case management to implement. Most case managers give additional services such as consultation and education on palliative care to other health care professionals.

3. Using evidence-based practice

Using evidence-based practice (EBP) helps case managers to identify and assess high-quality, clinically applicable research that can apply to clinical practice. EBP is a method to improve the quality of care because it involves basing decisions on several types of evidence to better ascertain that care requires are met in an effective manner.

4. Accessing opioid drugs

Patients and their family caregivers access to opioid drugs from health care service systems to control pain and symptoms. Hence, case managers can educate the family caregivers on care and the management of symptoms control effectively such as subcutaneous injections, hot and cold therapy.

5. Employing technique of psychosocial support

Case managers use technique of psychosocial support to provide patients and their family caregivers and families such as counseling, psycho-education, and problem-solving. Hence, case managers can early detect persons who are at risk from psychological problems.

6. Facilitating resources in the community

In the system of case management, a case manager can help patients and their family caregivers to find facilitation resources in the community. The services that are offered can be found in the National Health Service, municipal social services and local volunteer organizations.

7. Continuity of care

Continuity of care is featured in palliative care. Implementation starts from an assessment and continues until after death. Persons and their family caregivers are provided with many of the processes of palliative care. As a result, improvements of care and quality of life were found more in case management interventions than other types of interventions.

Weaknesses of case management interventions

Even the case management intervention can be able to improve all domains of palliative care, and patients and their family caregivers can access palliative care service. However, there is one weakness of case management intervention that barrier to reach the goal of palliative care.

Difficult to work as a team

In a primary setting, collaboration rose gradually because palliative care work was between nurse, physician, social worker, physical therapist, and psychologist or psychiatric nurse. Hence, implementation was difficult when patients living at their home, while collaboration was easy than when healthcare team work at hospitals. Hence, it is concern in implementation in Thai context. Few local and healthcare staffs can influence collaboration when conduct in this study.

Outcomes of case management interventions

There are three main outcomes that were measured in this review: successful outcome, using hospice care, and unimproved overall outcomes measurement.

1. Clients' service satisfaction and cost of care were concerned of successful outcome of case management intervention. The case management intervention showed a significant reduction in the cost of care overall and by average cost per day. Even though many of the studies found were conducted in Western countries, Eastern countries showed a significant improvement in good symptom control and improved patients and caregivers satisfaction.

2. Case management services can increase the number of patients in using hospice care at between 60%-70% (Ciemins et al, 2006; Spettel et al, 2009), but one study found an increase in total hospital deaths occurred (Finucane et al, 2013). Furthermore, some studies measured a person's preferences for site of death, but these data were not collected (Brumley et al, 2007).

3. Some studies found that interventions did not improve the overall outcomes measurement. For example, in frail elderly, the evaluation showed a significant decrease in the caring burden, but no effects were evaluated on quality of life (Janse et al, 2014). Some studies showed a significant improvement in ESAS scores but small significant changes in clinical symptoms (Kerr et al, 2014).

Case management interventions were designed to address the needs of persons and their families. The components of the interventions were aimed at increasing patient's understanding of his or her illness, including the family caregivers. Efforts were made to prepare persons for end of life management and care. This comprehensive nature of case management can be more effective than a system focused on facilitating communication with physicians. Most of the studies showed that the emphasis on family caregivers' sharing in care planning and provision resulted in a cooperation process between a case manager and the family caregiver. However, the family caregiver had to come to be more aware of his or her role in the care process.

Psychosocial interventions

Psychosocial interventions aim to reduce psychological distress and emotional problems both in elder persons and family caregivers. Based on the literature review of five studies, these studies had many types of interventions: psycho-education, coping skills, dignity therapy, and legacy.

Two studies included the psycho-education of family caregivers. Hudson and colleagues (2008) developed psycho-education in home-based palliative care in Australia. This program focused on preparing family caregivers for the role of supporting a dying person at home which had positive caregiver psychological outcomes. The program consisted of three sessions (1.5 hour/each) over a 3 week period. Counselors provide printed material about the illness, symptom management, and/or resources. Caregivers can participate in asking questions, providing comments, asking for clarification and take part in dialogue. The evaluation showed that a significant positive effect was found on the preparedness for the caring role, caregiving competence, and caregiving reward. One study was conducted by Walsh and colleagues (2007). The program consisted of six visits over a 6 week period. It consisted of seven domains for advice: (1) patient care, (2) physical health requires, (3) need for time away from the client in the short term and longer term, (4) need to plan to the future, (5) psychological health, relationship and social networks, (6) relationships with health and social service providers, (7) finances. A comprehensive assessment of the domains of needs was made on past, present, and future issues which were discussed, information and emotional support were provided. In the situation of a patient’s death during the intervention period, healthcare team continued to visit, up to a total of six times. Sometimes a telephone call took place of a visit. The evaluation showed a decrease on caregiver strain at all time points.

McMillan and Small (2007) developed a coping skills intervention for cancer patients and their family caregivers in America. The coping skills consisted of four components: creativity (developing new strategies for resolving), optimism (positive attitude), planning (caregiving goals were set to act), and expert information (caregivers were taught about the nature of any problems and how they can deal with the problems). Caregivers received the Home Care Guide for Advanced Cancer book for personal use to assist the patient. The evaluation showed a significant improvement in symptom distress in the intervention group (*p*=.009).

Hall and colleagues (2011) developed dignity therapy and brief palliative care psychotherapy for elder persons and their family caregivers in England. Sixty participants with no cognitive impairment were enrolled both in the intervention and control groups. The researchers approached the participants by inviting the elder persons to talk about what is most important to them and how they want to be remembered. The discussions were recorded, transcribed, and edited into a generativity document that was shared with the caregivers. Dignity therapy can reduce suffering and distress for caregivers. The evaluation found that this intervention had made participants’ lives more meaningful (*p*=.04).

The legacy intervention was developed by Allen and colleagues (2008). This intervention is designed to decrease caregiving stress and increase family communication. Participants were elder persons with a terminal illness and their family caregivers. Researchers constructed a personal legacy with scrapbooks with photographs, or audio-taped stories. The evaluation showed a decrease in caregiving stress in comparison with the control group caregivers.

Strengths of psychosocial interventions

The strengths of psychosocial intervention were specific approach of psychosocial technique. A psychosocial intervention has been implemented to directly approach persons who face psychosocial problems or distress. Hence, approach the person of psychosocial problems was considered under their symptoms occurred. Emotional problems were found on patients and caregivers include: anxiety, depression, hopeless, loneliness and stress. Caregivers were provided care differently according to the symptoms found.

Weaknesses of psychosocial interventions

Even psychosocial interventions can be improved distress or psychosocial problems of patients and their family caregivers. However, sufferings of persons come from physical problems such as pain and other symptoms. As a result, physical problems had major factors influence to suffering continuity both patients and family caregivers. Therefore, using psychosocial intervention only may not reduce emotional problems significantly. There are two weaknesses of psychosocial intervention.

1. **Inadequate psychosocial intervention to participants**

Persons who received home-based palliative care and their family caregivers met a variety of physical, psychological and spiritual, and socioeconomic problems. For each psychological intervention, there might be different empirically based approaches for older people and their family caregivers in the palliative stage and the end of life stage. These interventions might not help to relieve suffering from other domains.

2. **Inappropriate psychosocial technique to participants**

Some type of interventions did not approach or were inappropriate to deal with the psychological problems of older persons and family caregivers because the people who were at the end of life and their family caregivers had met a variety of psychosocial problems. The effective use of a psychosocial intervention should select an appropriate program to address the problems of persons and caregivers. According to the outcomes in the studies, some variables did not show improvement.

The researcher used some strategies and techniques in a psychosocial approach for the elderly person and the family caregiver. However, the use of strategies should be appropriate and feasible in the Thai context. Many caregivers need to have support in the psychological aspect, sharing and expressing emotions and feelings are the best ways that the researcher should use to approach the caregiver, including discussing the ways to deal with negative emotions.

Skills training

Skills training is focused on the development of coping, communication, and problem-solving skills with some focus on behavior change (Northouse et al, 2010). There were four studies concerned with skills training in home-based palliative care programs.

Two studies included skills training for the family caregivers of dementia people. These programs were conducted in China and Taiwan (Wang et al, 2012; Kuo et al, 2013). The activities that can improve outcomes: (1) identifying the targeted behavior problems and exploring the causative environmental stimuli, antecedents, and consequences of the targeted behavioral problems, (2) nurses coached caregivers by using the strategies of positive reinforcement to enhance the behavioral problems, (3) caregivers can reduce these stimuli and reduce the targeted behavioral problems by modifying the daily schedule and environment, and (4) nurses provided information concerning dementia care, confirmed the elders' behavioral problems, and finalized the plan for managing specific behavioral problems. According to the study by Wang and colleagues (2012), the evaluation showed a significant improvement in distress and quality of life compared to the control group ($p<.001$). Another result found that caregivers had better outcomes in bodily pain ($p < .05$), role disability due to emotional problems ($p < .05$), vitality ($p < .001$), mental summary score ($p < .05$), and reduced risk for depression (odds ratio = .15, confidence interval = .04-.65, $p < .05$).

Linstrom and colleagues (2013) developed a program for family caregivers of newly admitted hospice patients. This program is based on the self-regulation theory and role theory. The conceptual framework in this program can guide the development of a schema and skill building for caregivers. The program content consisted of four domains (1) information on symptoms pertaining to the dying person and his/her caregiver, (2) causes of the sensations and symptoms experienced by both the dying person and the caregiver, (3) temporal characteristics for dying persons and caregivers, and (4) possible environmental characteristics. The evaluation showed increasing preparedness, helpful beliefs, and confidence about the caregiving role.

Healy et al (2012) developed a package for caregivers to manage subcutaneous medications used for symptom control. Nurses educated and taught caregivers on: preparing, storing and administering subcutaneous medications at a clinically appropriate time, and gave instruction in injecting skills. The intervention was evaluated by the caregivers and the nurses. The result of this study revealed that the mean was high at above 5 on a 7 point scale.

Strengths of skills training intervention

Strengths of skills training intervention were having ability and competence of caregivers' skill and caregivers' role. Skills training were focused on the development of building caregiver skill and role, coping, communication, and problem-solving skills for family caregivers. The researcher viewed family caregivers as being centered and having latency in their role. Hence, the process of the development of skills building for them can improve a sustainable caregiving role. These interventions can help family caregivers to improve their confidence and preparation for their role, to plan any action to cope with problems from terminal illness caring, to set priorities for using resources, and to prepare for caring for their dying loved ones.

Weaknesses of skills training intervention

There are two weaknesses of skills training intervention: inappropriate approached on psychosocial problems and few sessions in programs and activities.

1. Inappropriate approached on psychosocial problems

Some outcomes did not show any significance in reducing psychological problems such as anxiety levels. Hence, to meet the needs of persons with psychological problems specific psycho therapy interventions should be selected.

2. Few sessions in programs and activities

Some studies had a few sessions in a program and a few sessions of activities. However, these are not appropriate for training family caregivers, because family caregivers need time to train. In order to provide comprehensive palliative care, all domains of palliative care need to be faced by a range of effective interventional strategies.

This intervention can help family caregivers to understand about the most important health needs for the elderly person and the family. The strategies of the caregiving role will involve the family caregivers. Therefore, increasing the family caregivers to feel the caregivers' role is not difficult. In the process of implementation, strategies are needed to increase the self-value of the caregivers as well as their understanding that the role of providing care is not difficult in the Thai context

In conclusion, the systematic review shows the different types of interventions and outcomes that were measured. In the case management interventions, these programs showed improving quality of care and cost outcomes. On the other hand, psychosocial and skills training interventions significantly reduced caregivers burden, improved coping behavior, increased self-efficacy (ie, perceived confidence and preparation), and enhanced aspects of quality of life. All of the studies showed the preparedness of health care services on home-base palliative care in different countries, however some of the methods need to be developed before they can be applied to the Thai context of this study such as living wills, spiritual needs, psychological problems, and facility resources to social support.

2.2 Home-based palliative care for the elderly in Thailand

Home-based palliative care particularly for elderly is not well developed in Thailand. Palliative care services are mostly provided to patients in hospital, particularly tertiary hospitals. Well developed palliative care and the best quality of care should have evolved at an equal pace across the country.

In the following part, three main points are discussed as: the benefits of home-based palliative care, the implementation of home-based palliative care, and the studies regarding home-based palliative care.

Benefits of home-based palliative care

Palliative care in Thailand is under the preliminary developed and there are two key success factors that are related to home-based palliative care. Two key success factors are discussed as follows.

Firstly, consistency with the Thai context of a strong extended family (Artsanthia et al, 2011). In Thailand, family caregiving is common practice- the traditional Thai culture of "filial piety" makes family members feel obliged to care for the elderly by themselves. Especially, women (daughters and the wife) take on the role to care, and are grateful to their parents (Intarasombat, 2014). Children think they are indebted to their parents who gave birth to them and raised them, and it is a natural duty to take care of their people in their old age. However, some women in this group express the burden of caring for a loved one (Yotphet, 2005; Yotphet, 2006).

Secondly, the elderly and their family caregivers are able to receive care from within their communities. The MoPH strongly supports the distribution of palliative care services at all government administrative levels such as funding mechanisms under the Universal Health Coverage (Hughes & Leethongdee, 2007). Currently, there is the national policy of development on a long term care service system for dependent elderly in a primary care setting under the Ministry of Public Health (National Health Security Office, 2015). The goal of the policy is that all older Thai people receive screening and the dependent elderly must receive standard of care. Thus, the elderly who need palliative care are part of the dependent elderly group. The strategies concerning providing palliative care at home under the health care work force is a major role to drive palliative care under the case management concept.

Implementation of home-based palliative care

Even though palliative care is not well developed in Thailand, the health care service system in primary care is well developed. According to the policy of development on a long term care service system for the dependent elderly in a primary care setting on 2016, the implementation of home-based palliative care will be able to be actioned via the long term care service system for dependent elderly persons. Key success factors regarding implementation are described as follows.

Firstly, focusing on integrating health care services and social services in community context are of concern Secondly, concern about sustainability and feasibility as well as the budgets in the future is considered. Thirdly, promoting participation in communities by the municipality or local government as a host to the management system, and supporting party networks in local settings that can help one promoting hospitals. Finally, developing and extending a long term care service system for the dependent elderly in primary care under a care manager and providing formal care giving.

The studies regarding home-based palliative care in Thailand

The literature review found that in Thailand the studies regarding the intervention of home-based palliative care for the elderly were mostly conducted in hospitals and all of the studies used action research as the methodology (Pattniboon et al, 2012; Preedee, 2013; Sawasdeenarunat et al, 2015; Tasprasit et al, 2013 Wisetchoonhasilp et al, 2013). The researcher has identified the strengths and weaknesses of these studies as follows.

Strengths of interventions

Strengths of interventions regarding home-based palliative care in Thailand were analyzed as follows.

1. Care activities covering all aspects of palliative care

Programs were developed to cover all the domains of palliative care needs (physical, psychological, spiritual, and socio-economic).

2. Appropriate to providing care for patient in hospital

The programs provided good practice for nurse practitioners at a hospital because most of the activities were shown in terms of palliative care in the hospital. The programs appropriately use in hospital because easy to work as a coordination and easy to access opioid drugs for patient.

3. Continuity of care

Most of the studies reported that they were undertaking continuity of care in the process of discharge planning and referral into the community by collaboration with party networks such as the community hospital, one promoting hospital, local government organizations, religious organizations, and health volunteers, including scheduling visits to the elderly person and visits to his/her family after the elderly member’s death.

Weaknesses of intervention

Even the studies regarding home-based palliative care in Thailand existed. But a few weaknesses were analyzed as followings.

1. Inadequate to identify activities designs

All studies reported palliative care at home after discharge, but they did not identify how the activities provided palliative and how collaboration with the party network in the community to support the elderly was undertaken.

2. Discontinuity of care between the settings

Programs had discontinuity in care from the hospital to the community and home.

3. Bleary care activities of home care and after death

Even though the programs were developed for providing patients from hospital to home care, the programs rarely showed the core activities of home care at home and after death.

In conclusion, the point of discontinuity in palliative care between after discharge and after death is the gap that this study will address to develop a model to fill this gap. This will be done by using strategies of collaborative care from western studies to integrate into my model concerning local government organizations, religious organizations and one promoting hospitals to drive this activity via the long term care service system. In addition, home-based palliative care is most likely to be care based on family beliefs and spiritual aspects. Hence, collaboration with context organizations is very crucial for the elderly at the end of life, including bereavement care which should identify clearly the activities to support the family caregivers.

3. Foundational concepts used to develop the home-based palliative care

Three foundational concepts will be used to develop an ideal set of care activities for home-based palliative care to enhance the quality of care and to reduce the caring burden of the caregivers of Thai elderly: LIFESS framework and continuing care.

3.1 LIFESS framework

Palliative care follows the perspective of holistic care: physical, psychological, social, and spiritual care. WHO (2016) stated that “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". The National Health Security Office (2010) established and approved the LIFESS framework to guide healthcare providers for the assessment and implementation of people and their families facing life threatening illnesses. The LIFESS framework consists of six elements: L (Living will), I (Individual belief), F (Function), E (Emotional and Coping), S (Symptom), and S (Social and Support). It can seen that the LIFESS framework follows the holistic perspective of care among people and families who need palliative care. These elements can be described as follows.

Living will

The term "living will" was coined by Luis Kutner in 1969 to explain a document in which a capable adult sets forth directions about medical treatment in the situation of his or her future incapacitation (Kutner, 1969). The document is a will in the sense that it spells out an individual's directions. It is "living" as it takes effect before death. Over the past twenty years, a living will has become of interest and concern for many dying persons (Annas, 2010). Society for the Right to Die, concurrently dedicated its primary efforts to encouraging states to pass legislation giving formal legal recognition to the living will (Annas, 2010).

A living will indicates how the elderly person makes decisions about planning his/her future healthcare. It records the elder person's wishes for medical treatment imminent death. It may specify the extent of life sustaining treatment and major healthcare the elder person wants. It may help the elder person die with dignity. These may specify how much discretion the elder person gives to his/her proxy about end of life decisions (Derby, O'Mahony & Tickoo, 2010).

In addition to the aforementioned living will, there are other medical and legal planning documents that are coupled to advance care plans. Some such medical documents are: proxy directive and do not resuscitate (DNR) form (Warring, & Krieger-Blake, 2014). A proxy directive is a document authorizing a specific person to make healthcare decisions on behalf of an elder person only after that elder person loses decision making capacity. A DNR instructs healthcare professionals not to perform cardiopulmonary resuscitation in the case of an elderly person whose heart has stopped or he/she has stopped breathing. A DNR order is signed by a doctor and is put in an elder person's medical chart.

Furthermore, instructive directives specify what life sustaining treatment the elder person would or would not want in various health situations. They often state the elder person's wishes about life sustaining treatment in various clinical situations. The elder persons with decision making capacity have the right to refuse any treatment, and instructive directives extend that right when the decision making capacity is compromised (Aging with Dignity, 2016).

A living will involves an individual to predict accurately his or her last illness, and a living will requires physicians to make decisions on the basis of their interpretation of a document, rather than a discussion of the treatment options with an individual acting on behalf of the client (Annas, 2010). The proposed solution of these problems is not modifying the living will but to replace it with another form, one assigning a durable power of attorney to a designated person (Singha, 2015).

A living will is important in the elder persons who are living with terminal illnesses. A living will depends on several factors, including communication topics, value differences, cultural issues, ethnicity, and mental capacity. A living will would ensure that the elder person's preferences are honored. However, the expression of a living will in the Thai elder person is rarely used at present.

Individual belief

Loses in life frequently face our faith and philosophical systems. Those who experience loss and grief may differ concerning religious and spiritual perspectives from which they seek answers, look for meaning, and to which they turn for ritual, comfort, and support (Sherman, 2002). Understanding the methods that individual belief facilitates the adjustment to loss and grief is a critical task to those involved in palliative care.

Many elder persons and their families are concerned about their individual beliefs. They may only know about how to demonstrate their individual beliefs as well as spirituality through religious expression. Palliative care should always support the elder person and his/her family in the expression of their specific religious beliefs. In this part, the researcher describes individual belief in two aspects of palliative care: spirituality and religion.

Spirituality

The conceptualizations of spirituality comprise the following as aspects of spirituality: the requisite for purpose and meaning, forgiveness, love and relatedness, hope, creativity, and religious faith and its expression. A well-accepted explanation for spirituality authored by Reed (1992) suggested that spirituality involves meaning-making through intrapersonal, interpersonal, and transpersonal relation. A recent meaning that incorporates themes found in nursing literature is Narayanasamy's explanation of spirituality as the heart of our being and it gives meaning and purpose to our existence. In addition, Narayanasamy's description of spirituality is a "guide force", an "inner source of power," and "source of wisdom": it drives us to search for meaning and purpose, and begin positive and trusting relationships with others. There is a mysterious nature to our spirituality and it gives peace and tranquility during our relationship with 'something other' or things we value as supreme. However, the elderly person and the family caregiver's definition of spirituality may differ from the nurse's assumption about it. Therefore, spiritual assessment is important to the researcher for implementation in each case.

Spiritual awareness rises as one faces an imminent death (Chio et al, 2008). There is growing empirical evidence to propose that individual with terminal illness consider spirituality to be one of most crucial contributors to quality of life (Taylor, 2010). Studies imply that awareness to the spirituality of terminally ill persons and their family caregivers is of significance. Spiritual resources assist them in coping and awareness and concerns of spirituality can help them to view spiritual health as most crucial to their quality of life in the near death process (Byrne, 2007). Therefore, spiritual assessment and approach that initiates a process promoting spirituality is very important to successful palliative care.

The study of Taylor found spiritual well being functioned to protect terminal cancer persons against end of life despair. Spiritual well being was shown to have strong inverse relationships with the desire for a hastened death, hopelessness, and suicidal ideation. Family caregivers of terminally ill persons find strength from their spirituality that helps them in coping (Nolan et al, 2006). In addition, spiritual well being had an important positive relationship with persons who received palliative care, and a negative relationship with symptom distress (Get-Kong, 2009).

Religion

Religion is a belief and respect for a supernatural power or powers regarded as a author and governor of the universe and it is a personal or institutionalized system grounded in such belief and worship (Potter, Durette & Kazanowski, 2012). In addition, religion can be described as a set of beliefs, values, and practices based on the teaching of a spiritual leader (American Heritage Dictionary, 2006).

Religion can give answers and help provide meaning to circumstances regarded to suffering and dying (Greenstreet, 2006). When persons face with others of similar beliefs and values or share in similar faith-based communities, they typically are provided with a supportive social network (Potter, Durette & Kazanowski, 2012). Religious traditions give people with community, companionship, and support. Companionship and support assist people transcend the suffering experience, regularly by helping them reach peace (Beeston, 2011).

Spiritual and religious beliefs and practices can play a considerable role in the lives of those who are dying, and for their families. As well as providing a foundation for the decisions that the elderly and their families make, spiritual and religious traditions often provide a conceptual framework for understanding the human experience of death and dying, and for making meaning of illness and suffering (Beeston, 2011).

The importance of individual belief in coping with illness, suffering, and dying is outlined by various studies. The elderly and their families can derive comfort from their individual beliefs as they face the end of life.

In conclusion, individual belief is an element and pervading dimension for persons, particularly those for whom death is imminent. Individual belief assessment is essential to effective and sensitive individual belief care. Individual belief assessment is the beginning of individual belief care. Nurses are indicating to the elderly and their family caregivers that grappling with individual belief issues are normal and valuable. Nurses may be in a position to help the elderly and their families to obtain access to the rituals that may be crucial as a person is nearing death.

Function

The elderly have many comorbid medical conditions that contribute an added symptom burden to this palliative care population (Derby, O'Mahony, & Tickoo, 2010). The presence of existing comorbidities and disabilities make them vulnerable to the complications of a new illness and its treatment. The presence of illness medical conditions is associated with disability and increased healthcare use and hospitalization in the elderly.

Seventeen percent of community-dwelling adults older than 65 years report impairment in their daily activities (The Office of the National Economic and Social Development Broad, 2011). The elderly report impairment in daily activities such as walking, the ability to eat, and the ability to use the toilet (Dumrikarnlert, 2012).

Three general stages in the progression of a medical illness have been identified and are: the early stage; diagnosis and preliminary management, the middle stage; disease modification and adjustment to functional decline, the late stage; preparation for dying (Aday, 2001).

An understanding of some of the common geriatric syndromes should be understood by the palliative care providers. The geriatric syndromes that can be found in the elderly are those such as dementia, delirium, urinary incontinence, and falls (Assantachai, 2010). These syndromes further complicate end of care planning, and end of life symptoms management in this population.

Symptoms

In palliative care for the elderly, good symptoms management is crucial and relief from distressing symptoms is important. However, symptom relief should be managed differently for each major illness. The elderly have different experiences of illness before death by illness trajectories (Beeston, 2011). Watson and colleagues (2009) offer a detailed account of the assessment and management of different symptoms.

Even the end of life process is individualized and unpredictable, some symptoms commonly occur (Miller, 2015). A systematic review of the prevalence of symptoms during the last 2 weeks of life identified the following as the most commonly occurring ones: dyspnea (56.7%), pain (52.4%), respiratory secretion (51.4%), and confusion (50.1%) (Kehl & Kowalkowski, 2013). Additional symptoms that are often addressed at the end of life include fatigue and weakness, constipation, nausea and vomiting, dehydration, and decreased appetite. On the one hand, the study of Hockley and colleagues (2004) found that the most common symptoms occurring in dying elders at home are: agitation (58%), respiratory secretion (32%), and pain (29%).

When symptoms during the active dying process become apparent, it is important that nurses work with the elderly and their families to help them understand the dying process and anticipate changes. Characteristic physical signs show the active dying process. The elderly person has become dependent on others for all aspects of care. Physiological changes occur in little or no interest in the oral intake of food or fluids, breathing patterns, and circulation slows down, sensory awareness decreases, and there is muscle weakness. The overall focus of nursing care at this point is to go on to promote physiological and psychological comfort, while assisting the elderly in achieving a peaceful, dignified death (Miller, 2015).

Emotional and coping

In this part, there are three elements of discussion: psychosocial, emotional, and coping elements.

Psychosocial

Family members face role changes when they are the primary caregivers of the elderly with a terminal illness. Family caregivers provide increasing physical care. The elderly may resist and resent the need for the increased level of care due to more limitations and inabilities in their level of independence. Family caregivers may not understand the emotional changes and resistance of their relative. Therefore, family caregivers become frustrated with the rising tasks of care and with the emotional burdens.

Nurses may be helpful for family caregivers to view the last year of an individual's life. This perspective helps family caregivers see that the elderly person is not intentionally increasingly helpless. The areas that may be affected are the areas of mobility, activities of daily living, cognition, and individual care needs.

Emotional

When the elderly face imminent death, they look back upon his/her life and reflects upon his/her experiences. There is an effort to emotionally integrate all the aspects of one's life, including the determination of its meaning and acceptance of its uniqueness (Rando, 1984). On the one hand, family caregivers face many feelings when providing care to the elderly, because they provide complex care. Thus, a caring intervention should continue to facilitate an appropriate death for the aged person. In this part of the emotional element, the researcher describes loss and grief at death as follows.

Loss

The term is applied to the passing away of a person, and it is the bereaved person who is considered to have experienced a loss (Corless, 2010). Robinson and McKenna (1998) described three attributes of loss:

1. Loss refers that somebody or something one has had, or ought to have had in the future, has been taken away.
2. That which is taken away must have been valued by an individual experiencing the loss.
3. The meaning of loss is decided individually, subjectively, and contextually by an individual experiencing it.

The psychological concern of the elderly and families facing death is reaction loss. The elder people are confronted with a diversity of losses in various aspects of their lives, not just with the death of a spouse, family members, or long-time friends. The elderly face many losses. For example, the loss of bodily functions that occurs as an illness progresses, the loss of roles, decreases assumed in the relationship, and loss of independence (Warring & Krieger-Blake, 2014). On the one hand, family caregivers may experience several types of losses: loss of independence, loss of control, loss of the future as it had been imagined; loss of financial security, loss of freedom, sleep, and family harmony; loss of somebody to share chores and other tasks with, or simply the loss of someone to talk things over with.

The feelings of loss are ambiguous. Family caregivers may be physically present but psychologically absent, physically absent but psychologically present, or in transient relationships. Feelings of confusion, hopelessness, and ambivalence may accompany ambiguous loss (Corless, 2010).

Grief

Grief is defined as an individual's emotional response to the situation of loss (Stephenson, 1994), as the state of mental and physical pain that is experienced when the loss of a significant point, individual, or part of the self is realized (DeSpelder & Strickland, 1987), and as the highly personal and subjective set of responses that a person makes to a real, perceived, or anticipated loss (Doka, 1989). There are numerous definitions of grief, and these are illustrative of variations on a theme. The process of grief has been studied and reformulated, phases identified, types proposed (anticipatory, complicated, disenfranchised), and expressions of grief described (Corless, 2010).

Anticipatory grief is a process of adjustment through the course of the terminal ill that is faced by the elderly as well as by the family/caregivers. When caring for the elderly over time, family caregivers may start to grieve for the elderly long prior to they die. Experiencing loss on a daily basis, as well as anticipating the loss at an imminent death, knowing what is coming, can be just as painful as the loss associated with a death. Anticipatory grief is a method of allowing us to prepare emotionally for the predictable. Preparing for the death of a loved one can allow family caregivers/members to consider and make end of life plans for the funeral. Sometimes, when someone has grieved a death over a long period, there is less grief when the elderly person dies or sometimes there is more pain when the elderly person dies.

Coping

According to Lazarus and Flokman (1984), they conceptualized that coping is a process-oriented phenomenon, and they make it clear that such effort is different from automatic adaptive behavior that has been learned. The outcome of coping strategies can be considered as either a positive or negative effect. It depends on the equality between the secondary appraisal of resources and the flow of situations.

According to the cognitive theory of emotion, Lazarus and Flokman (1984) presented rational arguments for the explanatory power of stress, coping, thoughts and emotions. These are related processes and include anxiety, fear, anger, guilt, and sadness. In the same vein, Kubler-Ross (1989) defined five stages of grief as follows:

Stage 1: Denial

Persons have trouble accepting the fact of death, the diagnosis or new reality, and experience numbness. They have an inability to do their usual activities.

Stage 2: Anger

Persons feel anger at themselves, others, professionals (particularly doctors), God, or life. They are feeling helpless and powerless, and abandoned.

Stage 3: Bargaining

Persons are making “deals” with God or friends hoping to change the situation. They think about “what could have been” or what they “should have done differently”.

Stage 4: Depression

Persons feel overwhelmed with loss and change, sadness, regret, fear, and anxiety. In addition, they are feel lonely, isolated, self-pity, empty, and lost.

Stage 5: Acceptance

Persons are adjusting to the new reality, starting to move on and have a sense of hope, and healing.

According to the conceptualization of coping by Lazarus and Flokman and the stages of grief by Kubler-Ross, an individual will find the effort needed to deal with situations. In addition, a person should tend to cope by seeking support, solving problems, or maintaining positive thinking.

Social support

Many older people and their families have socio-economic concerns. The concerns are greater, of course, for persons or families with few resources, or with only some resources. Even though subsidies for some services are available, many people may not have the capability to access them. The palliative care team may be helpful in linking the elderly person and his/her family with suitable resources. Nurses can help them to have basic information obtainable for possible referrals when access to other team members is not accessible, including advocate and inform about the individual’s rights in regards to medical services. There are people available to augment the family’s capability to provide care. However, if the elderly and their families do not receive social support, they may not be able to avoid problems. In this part, social support is a source to help and support elderly persons and their family caregivers to the right of access to medical services and community support. The researcher describes social support in terms of the definition and the types as follows.

Definitions of social support

There are several definitions for social support. Kaptein and Weinman (2004) defined social support as the function and quality of social relationships, such as the perceived accessibility of help or support actually received. Social support is the functional content of the relationship, such as the level to which the relationship entails affect or emotional concern, instrumental or tangible aid, information, and the like (House & Klan, 1985; Kahn, 1979). In addition, House and Kahn stated that social support must be considered part of the general domain of social support including social support (type, source, and quantity or quality), social relationship (existence, quantity, and type), and social network (size, density, durability, intensity, frequency, homogeneity, and dissension). These three part of social support influence emotional and physical well being, whether an individual experiences stress or health.

Types of social support

Social support can be divided into four types: emotional support, instrumental support, information support, and appraisal support. These types are described as follows.

1) Emotional support is related to illustrating care involving the provision of empathy, love, trust, caring, esteem, affect, concern, and listening.

2) Instrumental support, is related to the provision of tangible aid and services which directly assist an individual in need involving help in the form of money, labor, time, and modifying the environment.

3) Information support is related to providing information involving the provision of advice, suggestions, and information which can be used to handle individual and environment problems.

4) Appraisal support, is related to the provision of information which is useful for self-evaluation purposes including affirmation, constructive feedback, and social comparison.

In conclusion, based on the definitions, social support can be viewed as a perceived social support and received social support. The types of social support include emotional support, instrumental support, information support, and appraisal support.

3.2 Continuity of care for home-based palliative care for the elderly

Continuity of care is a multidimensional term used to describe a variety of relationships or outcomes between people and healthcare professionals. This care can help people over an extended period of time. In this part, the concept of continuing care is reviewed in order to apply this to the care for the elderly receiving palliative care and their family caregivers. This includes a definition and the components.

Definition of continuing care

According to a review of the definitions of continuity of care, this care is described in different healthcare domains. The definition of continuity of care is described as follows.

Continuity of care in primary care is viewed as the relationship between a single practitioner and a patient that extends beyond specific episodes of illness or disease (Hjortdahl, 1990; Rogers, & Curtis,1980). Continuity implies a sense of coordination between patients and their practitioners.

The nursing literature emphasizes information transfer and coordination of care over time. The emphasis is on communication between nurses (Keenan & Aquilinois, 1998). The purpose is to continue a constant approach to care between nurses and to personalize care to a client's changing needs during an illness (Sparbel & Anderson, 2000).

Freeman and colleagues (2000) propose that continuity needs to be maintained within and between teams as well as between practitioners. This is particularly relevant for palliative care persons, because care for them is often delivered simultaneously by several multidisciplinary teams.

In summary, the concept of continuity of care is becoming a "core value" in the organization of health services; it entails coordination and communication with reassurance linkages across time, settings, providers, and consumers of healthcare. Even its definition is various, normally it is defined as a method in which a series of healthcare situations are experienced as coherent and sequentially related with a person's needs and personal context.

Components of continuity of care for home-based palliative care for the elderly

The concept of continuity of care for home -based palliative care for the elderly is comprised of three major components, namely relationship, communication, and comprehensive integrated care (D'Angelo et al., 2015). These components are described as follows.

Relationship

The relationship with the elderly is central care, either in contract with a person provider or in an institutional alliance in which the elderly develop closeness with more than one service provider at a time (van der Plass et al, 2012). The elderly is able to rely, over time, on having associations with an individual or individuals who are interested in them and who respond to them on an individual level. During the illness progression, the elderly need stable and honest relationships that may be affected by a number of factors (Dumont et al, 2005). The challenge of maintaining stable relationships, particularly with the healthcare staff, grows directly as the number of healthcare professionals involved increases (Michiels et al, 2007). The elderly with a terminal illness often involve treatment from multiple health care providers, which could guide to fragmented and uncoordinated care (Back et al, 2010). However, health care providers may have difficult in relaying bad news, and the approach may affect the relationship with the elderly and their families (Finlay & Casarett, 2009).

Communication

Communication is a very important tool of healthcare providers. The success of health care depends on effective therapeutic relationships between a person and healthcare professional. Communication is very important to create a comfortable relationship which represents a crucial part of the ongoing care planning process (Joshua & Hauser, 2009). There are three levels of communication for the palliative care approach (D’Angelo et al., 2015). Firstly, the simple passage of information to the final negotiation is the primary step to approach the elderly and their caregivers. During the transition from curative to palliative care, there is requisite of preparation based on what to expect during this type of transition (Fox, 2005). The elderly and their families need information regarded the setting such as disease progression, treatment, prognosis, and symptoms management (Michiels et al., 2007). Secondly, dialogue offers the possibility to discuss difficult aspects of terminal illness such as what illness means to the elderly and their caregivers, their hopes, beliefs, and needs (Hanson & Ersek, 2006; Peppercorn et al., 2011). In addition, encouraging the person to express his or her feelings is very important to the approach (Aubin et al., 2012; National Consensus Project for Quality Palliative Care, 2009).

Comprehensive integrated care

Comprehensive integrated care is care that helps the elderly obtain a diverse arrangement of care and support according to their requisites and wishes. Comprehensive integrated care is a cross-sectional dimension; it is comprehensive in a sense that it consists of a variety of services regarded the many needs of the elderly. It is a distinctly interdisciplinary quality (van der Plass et al, 2012). Comprehensive integrated care can help the elderly to relief of physical and psychological symptoms, and to have their spiritual and social needs met (Hall et al, 2007). D'Angelo and colleagues (2015) stated that a quality of palliative care should anticipate, prevent, improve, or relieve symptoms for as long as possible. Thus, the coordination of a team can help with providing adequate treatment for the elderly in regards to complex care needs (Wiebe & Von Roenn, 2010).

In conclusion, the continuity of care for the elderly in the palliative stage demonstrates which factors may affect the continuity reaching (deficient communication and relationship), and provides advice to facilitate care planning (attention to reduce of symptoms, and preparing for death).

4. The development of home-based palliative care for Thai elderly

Through reviewing previous studies in Thailand, these were mostly to implement in hospital. The majority of the elderly and their families received general care by home care service systems, and poor provision of specifically based palliative care at home. This is due to the health care system which is not ordered to follow the national strategy. Hence, developing of an ideal set of care activities can support the national policy and strategy plan of palliative care into implementation for palliative care in primary care. The development of an ideal set of care activities for home-based palliative care for Thai elderly in this study is described in two main points: the conceptual structure of home-based palliative care and the outcomes measure of home-based palliative care.

4.1 Conceptual structure of home-based palliative care for Thai elderly

In this part, the researcher describes the conceptual structure of home-based palliative care in regards to definition, purpose, and the major elements of home-based palliative care.

Definition of home-based palliative care

Many definitions of home-based care are provided by many professional and trade associations that address the home-based issue (National Association for Home Care, Consumer's Union, American Hospital Association, American Medical Association, Center for Medicare and Medicaid Services, etc.). Common to all of the definitions is the recognition that home-based care is the care of the sick and well in the home by professionals and teams.

Buch and Nies (2015) proposed the term home-based care as a system in which health care and social services are offered to homebound or disabled persons in their homes rather than in medical facilities (Buch & Nies, 2015). The U.S. Department of Health and Human Services (USDHHS) set forth a definition of home-based care that an interdepartmental work group developed, in which home-based care is a component of a continuity of comprehensive health care by which health services are provided to persons and families in their places of residence (Buch & Nies, 2015).

Home-based care nursing is defined as the provision of nursing care to acutely illness, chronically illness, terminally illness and well clients of all ages in their homes. Home-based care nursing focuses on health promotion and care of the sick whilst integrating environmental, psychosocial, economic, cultural, and personal health factors affecting a person's and family's health status (American Nurses Association, 2008).

Purpose of home-based palliative care

Common to all purposes of home-based care is to improve health, enhance comfort, and improve the quality of life of clients (National Association for Home Care, Consumer's Union, American Hospital Association, American Medical Association, Center for Medicare and Medicaid Services, etc.). The primary purpose of home-based care is to allow persons to stay at home and receive health care services that would otherwise be offered in a health care institution, such as a hospital, public health center and health promoting hospital (Buch & Nies, 2015). The U.S. Department of Health and Human Services (USDHHS) proposes the goal of home-based care as promoting, maintaining or restoring health, or maximizing the level of independence, whereas reducing the effects of disability and illness, including terminal illness.

Major elements of home-based palliative care

A home-based palliative care serves as a case manager for the elderly who receive care either from a staff member of the contract services or others. The success of a case management plan is related to the nurse's ability to use the nursing process to develop a plan of treatment that best fits the needs of the elderly and their families or caregivers.

In this study, the researcher will develop an ideal set of care activities for home-based palliative care for family caregivers of Thai elderly based on the conceptual framework of Albrecht nursing model for home-based care (Albrecht, 1990). There are three major elements of the home-based care model: structural, process, and outcome elements.

The structural elements consist of the elderly, family caregiver, and case manager. The process elements include the type of care, coordination, and intervention. Outcome elements consist of elderly and family satisfaction with care, quality of care, caring burden, and cost effectiveness of care.

In conclusion, establishing appropriate patterns of home-based palliative care for family caregivers of Thai elderly are problematic because of the small amount of home-based care, and lack of healthcare professionals to provide palliative care (Peter et al, 2008). However, developing of an ideal set of care activities for home-based palliative care for family caregivers of Thai elderly is feasibility for implementation under the long term care service system. It is equal implementation across the country for all dependent elderly and their family caregivers.

4.2 Outcomes and outcomes measure of the home-based palliative care for Thai elderly

Care quality for the elderly who need palliative care depends on the family system. Quality of all level of palliative care has never been evaluated, whereas the evaluation of quality of palliative care mostly measures in tertiary hospitals (Nantachaipan & Sroywong, 2015). In addition, lacks of home visit plan for the elderly who are discharged home from hospital. As a result, poor quality of palliative care at home exists. Moreover, family caregivers take major caregiving role to care for the elderly and face many problems in providing care. The task of the caregiving role puts high emotional, physical, social, and financial demands on caregivers. They face overwhelming problems associated with caring and death. These efforts to care for their loved ones burden the family caregivers. The outcomes measure of an ideal set of care activities for home-based palliative care will measure care quality and the caring burden among family caregivers. Two outcomes are discussed as follows.

Quality of palliative care

The definition, domains of care quality in palliative care, and instrument to evaluate quality of care in this study are identified as follows.

Definition of quality of care

The National Quality Forum, a national not-profit membership organization created, developed and implemented a national strategy for health care quality measurement and improvement, which defines quality as high quality care that depends a great deal more on effective systems than person behavior. It looks for to develop standards, best practice, and guidelines. The evidence makes clear that palliative care delivers high quality care in terms of benefit to clients, is client-centered focus, and efficient.

1. Patient-centered

A palliative care plan is based on the goals and wishes of clients and families.

2. Beneficial

Many studies have demonstrated decreased symptoms and enhanced satisfaction among clients and their families receiving palliative care as compared with similar clients who are not.

3. Efficiency

It is sufficient, as demonstrated by reductions in health care utilization and resulting cost savings.

Domains of care quality in palliative care

The National Consensus Project for quality palliative care developed a framework that has identified eight domains of quality palliative care (Ferrell et al, 2007). The domains are listed in table 1, with the key elements described within the guidelines.

In this table, the domain of the structure and process of care provides guidance for developing programs. Guidelines for an interdisciplinary team of palliative care encourage these professionals to obtain advanced training and certification in palliative care. The five domains consist of four aspects, which are physical, psychological/psychiatric, social, and spiritual/religious aspects. The cultural domain is very crucial in influencing terminally ill and death. Another domain recognizes that the dying person becomes even more important as death is coming up. The last domain listed in the table is the ethical and legal aspects of care that relate to clinical outcomes.

All domains and recommendations for improving quality palliative care can be used to develop an ideal set of care activities for home-based palliative care in this study. In addition, this guideline will be updated to assure a current and evidence-based foundation upon which a palliative care program. The guideline is integrated within the Thai context.

Care quality measure of the home-based palliative care

In this study, care quality will be measured by three instruments, namely, 1) the Thai version of the Palliative care Outcome Scale (POS) (Sapinun, 2013) developed by Hearn and Higginson (1999), 2) the preferences of patients and of their surrogates for advance directives at the end of life (Suwannil, 2011), 3) the caregivers' capabilities in responding to the spiritual needs and the perceived caregivers' compassion to the spiritual needs (Issarapanit, 2005).

1. The Thai version of the Palliative care Outcome Scale (POS)

Hearn and Higginson (1999) developed the Palliative care Outcome Scale (POS) to measure care quality of palliative care. The POS is widely used in Europe, Australia, America, and Asia. The POS covers the physical, psychological, and spiritual domains of life within the remit of palliative care. The tool is proposed for use in evaluating the palliative care for a person with a terminal illness such as cancer, HIV/AIDS, and chronic illness. The POS can be used for measure in various settings such as a hospital, day care center, and home.

Table 1 *Domains and recommendations for improving quality palliative care*

Domains	Recommendations
1. Construction and process of care	- Comprehensive interdisciplinary evaluation of client and family - Attend to identified and expressed requisites of client and family - Interdisciplinary team reliable with preparation of care - Teaching and training - Psychological impact of work - Relationship with hospices - Physical environment requisites of client and family
2. Physical of care	- Pain, symptoms, and management side effects by using best practices - Documents and communicates treatment choices permitting client/family to make informed choices - Family is taught and supported to give safe/appropriate comfort measures to client
3. Psychological and psychiatric of care	- Psychological and psychiatric topics are assessed and managed - Team utilizes pharmacological, non-pharmacological, and alternative care as appropriate - Grief and bereavement plan is available to clients and families
4. Social of care	- Interdisciplinary social evaluation - Care plan developed - Referral to suitable services

Table 1 *(continued)*

Domains	**Recommendations**
5. Spiritual, religious/faith, and existential of care	- Assesses spiritual concerns - Recognizes and respects religious/faith beliefs and gives religious/faith support - Builds relationships with community and spiritual/religious/faith groups or persons as desired by client/family
6. Cultural of care	- Assesses and purposes to meet the culture-specific requisites of clients and families - Respects and contains range of language, dietary, habitual, and ritual practices of clients and families
7. Care of the dying person	- Signs and symptoms of imminent death are concerned and communicated - As clients decline, team introduces or reintroduces hospice - Signs/symptoms of approaching death are developmentally, age, and culturally suitable
8. Ethical and legal of care	- Client's goals, preferences, and alternatives are respected and form basis for preparation of care - Team is attentive of and addresses complex ethical topics - Team is informed about relevant federal and state statutes and regulations

The Thai version of POS consists of three identical measures, one of which is completed by staff, one by patients, and another is completed by the caregivers. In the Thai version, the nursing department of Maharaj Nakhon Chiang Mai Hospital (2010) translated the POS from the English language to Thai language, and the POS are tried the translated version out on cancer patients at Maharaj Nakorn Chiang Mai Hospital (Sapinun, 2013). The POS was used in evaluating various setting in Chiang Mai province. The Cronbach alpha of the POS was .93.

The POS for caregivers consists of 10 questions, which cover the physical, psychological, and spiritual domains of life within the remit of palliative care. It is measured using a 5 points Likert scale. Two questions are open ended questions on the patient’s significant problems in the past 3 days, and another question asks for the patient’s functional activities. The overall scores are summarized from each of the 10 questions. The overall score is ranging between 0 and 40.

POS is designed to be approachable to change. It can identify clinically significant changes over time that are regarded the course of the disease. POS item scores of zero or one require less clinical consideration than items that score 3 or 4. For example, if an elder person scores a 4 for question one when rating their pain this means the elder person is reporting pain that is overwhelming to them and hinders their ability to think of anything else. A score of zero indicates that the person isn’t affected at all by pain, and a score of one means they are a little impacted upon by pain but not bothered by it.

Changes in scores over time are significant to detect as they may specify disease progression or a change in perception, circumstances or priorities. For example, a pain score that changes from 1 to 2 may specify that something has changed in the person’s profile to the degree that it is now impacting on their activities. A timely clinical reaction is required when items are scored with 3 or 4, or when scores change.

2. The preferences of elderly and their surrogates for advance directives at the end of life

The instrument of preferences of elderly and their surrogates for advance directives at the end of life was developed by Suwannil, 2011. This instrument consisted of two parts: 1) the preferences of elderly for advance directives at the end of life and 2) the preferences of surrogates for advance directives at the end of life

These instruments consist of 32 items for which the responses are scored on a 6-point Likert scale. Each item is scored from 0 to 5 ranging from “no need under the term of that” to “very much to need”. This instrument enables the measurement of advance directives at the end of life with subscales of need for information about illness and treatment (7 items), need for information regarding advance directive (10 items), requirements regarding the use of advance directive (9 items), and decision needs to terminate or prolonging medical treatments that prolong the lives of patients being at the end of life (6 items).

The level of needs of elderly and their surrogates can be classified as follows.

3.34 – 5.00	the needs for advance directive at high level
1.67 – 3.33	the needs for advance directive at moderate level
0.00 – 1.66	the needs for advance directive at low level

The preferences of patients and their surrogates for advance directives at the end of life are tried out on patients being at the end of life at community hospitals in the southern of Thailand. Cronbach's alpha reliability coefficients were .82 and .85 respectively.

3. The caregivers' capabilities in responding to the spiritual needs and the perceived caregivers' compassion to the spiritual needs

The instrument of the caregivers' capabilities in responding to the spiritual requisites and the perceived caregivers' compassion to the spiritual requisites was developed by Issarapanit, 2005. This instrument consisted of two parts: 1) the caregivers' capabilities in responding to the spiritual requisites and 2) the perceived caregivers' compassion to the spiritual requisites.

3.1 The caregivers' capabilities in responding to the spiritual requisites

The caregivers' capabilities in responding to the spiritual requisites consist of 30 items for which the responses are scored on a 6-point Likert scale. Each item is scored from 1 to 6 ranging from "least capabilities in responding to the spiritual requisites" to "very much capabilities in responding to the spiritual requisites". This instrument subscales include: 1) ability to predict (12 items), 2) ability to adjust (6 items), and 3) ability to act (12 items). The last item is related with overall of caregivers' capabilities in responding to the spiritual requisites.

The level of caregivers' capabilities in responding to the spiritual requisites can be classified as follows.

4.35 – 6.00	caregivers' capabilities in responding at high level
2.68 – 4.34	caregivers' capabilities in responding at moderate level
1.00 – 2.67	caregivers' capabilities in responding at low level

3.2 The perceived caregivers' compassion to the spiritual requisites

The perceived caregivers' compassion to the spiritual requisites consist of 30 items for which the responses are scored on a 4-point Likert scale. Each item is scored from 1 to 4 ranging from "no perceived caregivers' compassion to the spiritual requisites" to "always perceived caregivers' compassion to the spiritual requisites". This instrument subscales include: 1) meaning or purpose needs in life (10 items), 2) relationship need (10 items), and 3) hope need (10 items). The last item is related with overall of perceived caregivers' compassion to the spiritual requisites.

The level of perceived caregivers' compassion to the spiritual requisites can be classified as follows.

3.01 – 4.00	perceived caregivers' compassion to the spiritual requisites at high level
2.01 – 3.00	perceived caregivers' compassion to the spiritual requisites at moderate level
1.00 – 2.00	perceived caregivers' compassion to the spiritual requisites at low level

The caregivers' capabilities in responding to the spiritual requisites and the perceived caregivers' compassion to the spiritual requisites are tried out on clients with cancer and their family caregivers who receiving service from Radiology Department, Songklanagarind Hospital. Cronbach's alpha reliability coefficients were .97 and .75 respectively.

Caregiving burden

The dying process is an uncertain situation in regards to what will happen, how long it will take, and how to meet an individual's physical, psychological, emotional, and spiritual needs (Makhija et al, 2011). Family caregivers are faced with increasing distress when they provide care (Waldrop & Kirkendall, 2013). Caring near the end of life is described as unpredictable, intense, complex, frightening, and a period of suffering (Phillips & Reed, 2010). Therefore, these factors can involve increasing the risk of the caring burden for family caregivers.

The caregiving burden of family caregivers for the elderly with a terminal illness is widely used to describe the negative physical, psychological, or emotional, social, and financial effects that are experienced by family caregivers (Rha et al, 2015). In this part, the definitions, aspects of caring burden, and instrument used to measure caring burden in this study are described as follows.

Definitions of caregiving burden

According to the literature review, the term caring burden was first defined by Grad and Sainsbury (1966) as negative effects on a family caused by providing care for a person with an illness. The caregiving burden consists of two views: objective burden and subjective burden (Hoenig & Hamilton, 1966 as cited in Rafiyah, 2011). Hoenig and Hamilton (1966) described objective burden as a situation or activities related with negative caregiving experiences, while subjective burden was negative feelings caused by the caregiver's duties.

On the other hand, Zarit, Reever, and Bach-Peterson (1980) defined caregiving as the extent to which caregivers perceived negative physical, emotional, social, and financial aspects as a consequence of caring for their relatives. They proposed the caregiving burden as a result of the subjective perception of caregivers. The dimensions of the caring burden as defined by Zarit are: 1) caregiving burden in the relationship: caregivers' perceptions on the impact of caregiving on the present relationship with the care-recipient, 2) emotional well-being: caregivers' perception on the impact of caregiving on their psychological well-being, 3) social and family life: caregivers' perception on the impact of caregiving on their social life, financial: caregivers' perception on the impact of caregiving on their financial wellbeing, 5) loss of control over one's life: caregivers' perception on the impact of caregiving on their health.

In conclusion, the caregiving burden can be defined as the negative impact of caring for an impaired person which is experienced by the caregiver. In addition, the caregiving burden is distress that caregivers feel as a result of providing care. The components of the caregiving burden are compounded by physical, psychological, social, and financial burdens. These components are described as follows.

Aspects of caring burden

There are four aspects of the caregiving burden that have been identified: physical, psychological, social, and financial burdens.

1. Physical burden

Many studies show that many family caregivers have their own health problems. Recently, Stenberg and colleagues (2010) found that the most prevalent physical problems reported by caregivers included sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss.

Up to 82% of caregivers of female cancer patients reported that sleep disturbance was significantly associated with depression and anxiety (Flaskerud, Carter & Lee, 2000). In contrast, Limpawattana and colleagues (2013) found that the health status among caregivers were uncomplicated illnesses and slight reporting of physical health problems. However, the study showed that caregivers had a high caregiving burden level of dementia, advanced cancer, and cerebrovascular patients.

2. Psychological burden

Psychological distress is a multifactorial, unpleasant emotional experience of psychological (cognitive, behavioral, emotional) (Stajduhar, 2013), social and/or spiritual nature that may interfere with effective coping (Remedios et al, 2011). Caregivers report emotional distress from feelings of stress, exhaustion, worry (Rodger, O Neill., & Nugent, 2015) loneliness, fear, guilt, helplessness and lack of control in everyday life (Mosher, Bakas & Champion, 2013). These factors affect emotional problems such as anxiety and depression.

About 41- 62% of family caregivers providing palliative care had a high level of psychological distress compared with 19% of the general population (Stajduhar, 2013). In caregivers of older people under palliative care, depression and anxiety symptoms accounted for 48.3% (Hebert., & Schulz, 2006). Lambert and colleague (2013) studied the prevalence of clinical depression and anxiety among caregivers of cancer patients, which showed 13.3% and 13.5 % at 6 and 12 months respectively, after diagnosis (p<.01). In Thailand, family caregivers report that they had feelings of stress, low self esteem, lack of freedom in their life, and burden (Yodphet, 2006; Sombat, 2006; Sritumrongsawat., & Boontamcharoen, 2010).

3. Social burden

Several studies reported that social dysfunction is one of the most widely self-reported problems related to family caregiving (Stenberg, Ruland & Miaskowski, 2010). Caregivers often report trying to participate in social activities but they feel like giving up as a result of concern for the elderly while they are absent (Girgis et al, 2013). On the other hand, Thai family caregivers reported that they have social support and can manage their daily lives (Limpawattana et al, 2013).

4. Financial burden

The financial burden experienced by family caregivers of elderly is strongly documented. Caregiving appears to reduce a person’s chance of being employed. Many caregivers are unable to work and have fewer work hours.

Reduction in paid work contributes to social isolation. The long-term financial impacts of caregiving include a loss of savings for retirement (Girgis et al, 2013). In Thailand, eighty-six percent of family caregivers showed self-reported income as not enough, and they work from home (Limpawattana et al, 2013).

In conclusion, family caregivers play a critical role in the overall care of elderly. All types of care affect family caregivers' physical and psychological well-being, social and personal relationship, and financial circumstances. Health care professionals will be able to identify caregivers who may be at risk from a caregiving burden and support them through direct care or by referral to appropriate services to help meet their needs. Hence, using a standard tool to screen the caring burden is very crucial.

Caregiving burden measure of the home-based palliative care

In this study, the researcher will use the Thai version of the Burden Interview (Toonsiri, Sunsern., & Lawang, 2011) developed by Zarit (1990) to evaluate the caregiving burden on family caregivers from the pre-test and post-test of the study.

The Thai version of the Burden Interview consists of 22 items for which the responses are scored on a 5-point Likert scale with total score ranging from 0 to 88 (higher scores indicating higher burden). The Thai version of the Burden Interview enables the measurement of the caregiving burden with subscales of burden in the relationship (6 items), emotional well-being (7 items), social and family life (4 items), financial (1 item), and loss of control over one's life (4 items). The level of caring burden can be classified as follows.

0-20	little or no burden
21-40	mild to moderate burden
41-60	moderate to severe burden
61-88	severe burden

The Thai version of the Burden Interview was translated by Toonsiri, Sunsern and Lawang (2011). This tool was measured in the caregivers of patients with chronic illness. The Cronbach alpha of the Burden Interview was .92.

In this study, these instruments will be used to evaluate care quality in palliative care and caring burden among the caregivers of Thai elderly.

5. Action research

Action research is attention in flexibly and sustainably translating theory into practice by the process of research. Action research was designed to bridge between theory, research and practice and incorporates both humanistic and naturalistic scientific method (Holter & Schwartz-Barcott, 1993). Kemmis and McTaggart (1988) proposed that action research was method in connecting theory and practice into one whole as “idea-in-action”. Streubert and Carpenter (2003) stated that action research transcends the traditional dichotomy of researcher and participant to understand human experience through democratizing the research process. Therefore, action research is strong vitality in generating individual, organizational, and social changes in explicit events. In this part, action research was reviewed on philosophic foundations, definitions, characteristics, levels and process.

Philosophic foundations

Three major paradigms serve as the philosophical foundation for different types of action research: positivism, interpretive theory, and critical theory. In the past, positivism was popular foundation for American action research in 1950, but it is not popular in action research today. Nowadays, interpretive theory and critical theory are popular with many different model and approaches to action research (Willis & Edwards, 2014).

The paradigm wars were three different paradigms that social scientists proposed as foundations for research. Post-positivism is a modern version of positivism. Critical theory is a modern version of traditional Marxist/neo-Marxist theory. Interpretive theory is roots in several different ways of knowing including pragmatism, progressivism, and constructivism. Several scholars used critical theory as a foundation for action research models, and there are a number of models based on the interpretive paradigm (Willis & Edwards, 2014).

In Marxist philosophy, Habermas described human actions are on the basis of cognitive interests and needs which motivate persons to acquire three categories of knowledge: technical, practical, and emancipatory. The technical interest seeks the explanation of cause and effect for obtaining the power of control over nature and guaranteeing effective actions. People need to capture the meanings of life for understanding each other during inter-subjectively interpreting social situations, and obtain practical knowledge. Human actions are influenced by board social, political, economic and cultural context. People need emancipator knowledge to liberate themselves from eventual constraints for growing freedom and autonomy (Holloway & Wheeler, 2010).

In critical social theory, the Frankfurt school of Germany in the 1920s is its starting point, in which intellectuals reappraised Marxist theory and explained the notion of domination exceeding economic and class struggle (Kim & Holter, 1995). Many critical theorists consider the democratic participation of participants in the entire process to be an essential element of action research. Action research is used by critical researchers who practice to describe what they do. This insistence on broad and equitable participation is crucial to critical theorists because of their view of how change must be facilitated in social systems.

Definition of action research

Kemmiss and McTaggart (1988) defined action research as a form of collective self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out.

Holloway and Wheeler (2010) described action research as a type of inquiry undertaken by practitioners who become researchers, or who work in partnership with researchers, to examine issues and problems in their own settings; it is carried out during a cyclical process in which each cycle depends on the one before.

De Chesnay (2014) described action research as a form of research that includes the research subjects in a meaningful way in every step of the research process. Research subjects are called “participants” in action research because they are included as members of the team in every phase of the research process.

Action research is a type of participatory and corporative inquiry which is a holistic and egalitarian and stands out for its connection with political aspects of producing knowledge (Reason, 1994 cited in De Chesnay, 2014). One the one hand, action research is a highly practical, contemporary because it allows researchers to involve participants in every step of the research process and give them a voice and meaningful role in the actions that emerge from the research study (De Chesnay, 2014).

Characteristic of action research

Borgia and Schuler described the characteristics of action research as the “Five Cs”: commitment, collaboration, concern, consideration, and change.

Commitment. Action research takes time. The participants need time to get to know and trust each other and to observe practice, consider changes, try new approaches, reflect, and interpret the results. Those who agree to participate should that they will be involved with the project for some time and the time commitment is a factor that all participants should consider carefully.

Collaboration. The power relations among participants are equal during action research; each individual contributes and each individual has a stake. Collaboration involves a cyclical process of sharing, giving, and taking. Ideas and suggestions of each individual should be listened to, reflected on, and respected.

Concern. The interpretive nature of action research refers as participants will develop a support group of “critical friends”. For example, the interpretive of action research will be relied on individual dialogue and a close working relationship. Trust in each other and value of the project is crucial.

Consideration. Reflective practice is mindful review of one’s action specifically, and one’ professional action. Reflection involves concentration and careful consideration as one seeks patterns and relationships that will generate meaning within investigation.

Change. Growing and changing are part of developmental cycle of life. Chang is ongoing.

Levels of action research

The levels of action research are classified in many terms of the different levels of action research. Grundy (1982) classified three modes of action research: technical, practical, and emancipatory. Holter and Schwartz-Barcott (1993) discussed three types of action research: a technical collaborative approach, a mutual collaborative approach and an enhancement approach. McKernan (1991) listed three types of action research: the scientific-technical view of problem solving, practical-deliberative action research, and critical-emancipatory action research. The different levels of action research are classified to demonstrate the relationship between the models of action research and the types of reflective process. There are three modes in action research which have different goals that influence the development of specific reflective processes in the participant(s).

Grundy (1982) discussed three levels of knowing. Technical action research is knowing-how, the source of skillful action. Practical action research is knowing-that, the source of scientific action. Emancipatory action research is knowing-why, the source of moral action or what is called practical judgment. The characteristics of the three modes are described as follows.

In technical action research, the goal of the technical mode is to test a particular intervention based on a prespecific theoretical framework. The relationship in the technical mode is between the research and the practitioner. For example, a relationship might come from between a researcher working with a family caregiver and an elderly person. The researcher serves as a collaborator and a facilitator to the role of nurse case manager. The researcher identifies the problem and a specific intervention, after that the researcher will involve and they agree to facilitate with the implementation of the intervention. The communication is primarily between the facilitator and the group, and the ideas may be communicated to the group (Grundy, 1982). The process of this mode induces the skill of action research, the idea being how the situation will occur.

In practical action research, the goal of the practical mode is more understanding in the practice and solving immediate problems. In this mode, the researcher and practitioners come together to identify potential problems and issues (Holter& Schwartz-Barcott, 1993). The research problem is defined after the researcher and practitioner assess the situation, and reach a mutual understanding. The practitioners involved in the mutual collaborative approach to action research gain a new understanding of their practice. The design of practical action research is a more flexible approach than technical action research as it adapts for empowering and emancipating stakeholders working with the practitioner. The communication in the modes of practical and emancipatory starts between each member of the group and the facilitator (Grundy, 1982). Practical action research fosters the development of professionalism by emphasizing personal judgment in decisions to act for the good of the client (Grundy, 1982).

In emancipatory action research, there are two goals in this level. The first goal is to increase the closeness between real problems dealt with by practitioners in a specific setting and using the theory to explain and solve the problem. The second goal is to assist practitioners in identifying and making explicit fundamental problems by raising their collective consciousness (Holter& Schwartz-Barcott, 1993). Emancipatory action research is often the change in a power relationship within a group that causes a shift from one mode to another. The development of the process of this mode has three phrases: theory, enlightenment, and action (Grundy, 1988). According to the critical social theory by Jurgen Habermas, he presents a framework within which social critique may be developed, and he stated that it is through the development of critique that the mediation of theory and practice is possible. Emancipatory action research promotes a critical consciousness which exhibits itself in political as well as practical action to promote change.

The differences in each level of action research can be classified in the relationship between the participants and the source and scope of guiding ideas can be traced to the question of power. In technical action research, the idea is the source of power for action, and ideas often come from a facilitator who controls power in the study. In practical action research, the power is shared between groups of participants.

In emancipatory action research, power resides wholly within the group, not with the facilitator and not with a person within the group.

The researcher used technical action research in this study, and the reason to use this level can be described by following the characteristics of technical action research. Firstly, the study was stimulated by a person or family group because their experience or qualifications was regarded as expert knowledge. Therefore, skillful family caregivers were helped to construct the core activities in an ideal set of care. Secondly, technical action research promotes efficient and effective practice. The model was derived as the direct product. The results of this level are shown in the accumulation of predictive knowledge, and the validation and refinement of existing theories which are deductive (Holter& Schwartz-Barcott, 1993).

Process of action research

According to Kemmis and McTaggart (1988) proposed “a thematic concern and four moments” of action research. A thematic concern means a problematic part perceived and identified by group, that could be enhanced through group members working together. Four stages of action research are planning, acting and observing, and reflecting. Theses stages can be described as follows.

Planning is a potential construction of future action, which can be flexibly adjusted to emerging confinements and unpredicted effects. Prescription action proposed critically informed on the basis of considering the authentic material and political limitations, possible risks in subsequent social change, and maximization of actions’ effectiveness. The acting may facilitate actors to get during current constrictions and to be empowered for acting effectively in the actual situation.

Acting is practice guided by planning yet not entirely manipulated by planning. Acting is dynamic, requesting immediate decision, virtual judgment, fighting for enhancement, negotiation and necessary compromise. Each planning can be developed next acting in the spiral of action research.

Observating provide a reasonable foundation of critical reflecting, and it should be planned of further reflecting. While, it should be captured the unexpected data. Contents of observating comprise the acting process, acting effects, circumstances in which acting is achieved, the constraints on acting, and other arising issues.

Reflecting proposes to understand process, problems and constraints in strategic acting during recalling records in observating. Reflecting is interpretive (reconstructing the meaning of event and providing basis for revising the planning), evaluative (appraising the effects of acting and advising further strategies), and descriptive (obtaining a vivid understanding on life in the event).

In conclusion, action research is a dynamic process by the spiral of four moments. Through the cycle of planning, acting, observating, and reflecting are improvement in understanding the event triggers more appropriate rationale for omplemetation.

Considering of technology readiness levels (TRL) and social readiness levels (SRL) in this study

Technology readiness levels: TRL

The purpose of using TRL is to help management in making decisions concerning the development and transitioning of technology. It should be viewed to manage the progress of research and development activity within an organization. According to development an ideal set of nursing care activities, this model is arranged in TRL level 3 (see table 13). The model is proceeded initially to develop the model that validated and analyzed for stakeholders using. In the future, this model will be developed towards TRL level 4 by stakeholders testing and validating. However, concerning on social readiness levels (SRL) is an essential for applying the model.

Social readiness levels: SRL

Societal readiness level (SRL) is a way of assessing the level of societal adaptation, social project, a technology, a product, a process, an intervention, or an innovation to be integrated into society. If the societal readiness for the social or technical solution is expected to be low, suggestions for a realistic transition towards societal adaptation are required. According to the result of this study claim that it is arranged on SRL 3 (see table 14). This model was developed with stakeholders (elderly and their family caregivers). In the future, this model will be validated through pilot testing in a relevant setting to qualify proposed impact and societal readiness.

Summary

Palliative care in the elderly needs to concern the cumulative effects of illness, frailty, and many interacting conditions rather than a single cause of diseases as other aged groups. Palliative care for the elderly can be divided into three groups: short period of evident decline, end-stage organ failure, and prolonged dwindling. Palliative care services in Thailand are classified by four types of organizations: faith-based community organizations, tertiary hospitals, cancer centers, and private hospitals. Currently, the elderly with terminal illness at home receive palliative care service via long term care system. Based on the evidence based practice, there are three types of programs to implement palliative care for the caregivers of the elderly at home: case management interventions, psychosocial interventions, and skills training.

The foundational concepts underpinning the study are based on LIFESS framework, case management, and continuing care. According to state of the art in home-based palliative care, most studies which conducted in hospitals specifically to cancer patients. However, most Thai elderly wish to live and die at home. Hence, action research approach will help in generating an appropriated set of care activities for home-based palliative care in Thai context by using the LIFESS as framework of the study. In addition, the conceptual of case management will be integrated for designing comprehensive palliative care that focusing on continuous care process, aiming at providing ongoing holistic care process.

Chapter 3

Research methodology

This chapter describes the methodology used for this action research. The purpose of this study is to develop and evaluate an ideal set of nursing care activities for home-based palliative care. This chapter is divided into research design, research setting, participants, ethical consideration, instruments and data collection, research procedures, data analysis and trustworthiness of the study.

Research design

The research design was action research as proposed by Kemmis and McTaggart (1988). An ideal set of nursing care activities for home-based palliative care was developed and refined through active participation among the elderly, their family caregivers, and the researcher who acted as a nurse. This study was carried out from May to December 2017.

Research setting

This study was conducted in the contracted areas of 14 primary care centers located in Hat Yai city, Songkhla Province. The participants were those who received health services from the primary care centers via the long-term care service system. The participants received palliative care from their home visit team (nurse, physical therapist, and healthcare volunteer).

Participants

Purposive sampling was used to select the participants. The number of participants depended on the saturation of the emerged data on nursing care activities. The inclusion criteria of the participants are as follows.

Elderly

The criteria for choosing the elderly were: (1) Thai elderly; (2) 60 years of age or over with a terminal illness which was divided into three groups: (2.1) the elderly with cancer in stage III through to IV, (2.2) the elderly with end-stage organ failure as assessed by the Palliative Performance Scale (PPS) (Appendix C9) less than or equal to 50%, (2.3) frail elderly as assessed by the Palliative Performance Scale (PPS) less than or equal to 50% and 70 years of age or over (Grossman, Rootenberg, Perri, Yogaparan, DeLeon, Calabrese & Mazzotta, 2014) and dementia/Alzheimer with moderate to severe levels as measured by the Palliative Performance Scale (PPS) less than or equal to 50%.

Family caregivers

The selection criteria were: (1) being over the age of 18 and able to give informed consent; (2) being a family caregiver to the elderly person at home (relative or partner (or spouse) who is involved in the care of the elderly); (3) providing to the elderly person at present and willing to continually provide care for the elderly person and (4) being able to understand the Thai language.

Ethical consideration

Ethical approval for the study was granted by the Institutional Review Board from the Faculty of Nursing, Prince of Songkla University (PSU IRB 2017-NSt 003) (Appendix B3). Following screening, informed written consent was obtained from the participants who met the inclusion criteria and were willing to participate in this study (Appendix B1-1/B1-2). Each of the participants was assured of confidentiality and had the option to decline participation or withdraw from the trial at any time. The participants were guaranteed anonymity in the published results. The process of this study brought up sensitive subjects which could be a strain for the participants. The researcher collaborated with staff at the primary care centers to follow the participants even after the study had finished. Before the interviews the researcher reviewed the clinical background of the participants as it was important for enabling an assessment/follow-up of any reaction among the participants. In addition, anticipated harm and considerations that were of concern are outlined as follows.

1. Psychological harm

The researcher confronted with the ethical dilemma to continue with the interview and gain more insight about the topic understudy or to stop the interview and give advice or refer the participant to an appropriate treatment or counseling service (Richards & Schwartz, 2002). Stopping the interview and searching for possible solutions for a participant's distress indicates that the researcher was aware of the vulnerability of the participants and their rights. The moral obligation of the researcher was to refer participants to counseling or ensure that they regained control of the situation by talking. In some cases, a follow-up phone call or visit was appropriate.

2. Physical harm

The researcher identified and explained in informed consent that there would be no physical threat or abuse to the participants during the trial (Tarawanich, 2016). If participants had severe symptoms, they would be referred in a timely manner to an appropriate health professional in the primary care centers (the National Health and Medical Research Council, 2011).

Instruments and data collection

The researcher

The researcher was a crucial instrument in the action research. The roles of the researcher were: (1) the catalyst in helping the participants discover and identify their thematic concerns, current problems, causes and the possibilities of solving these; (2) the facilitator to improve communication and mutual support between the elderly persons and their family caregivers through discussions, sharing information, and recommending useful resources and (3) the tool for collecting and analyzing data by asking questions, conducting observations and reviewing documents.

The instrument for data collection in this study comprised of two categories.

1. Interview guideline and field notes.

1.1 The Thai version of interview guidelines was used for conducting in-depth interviews with the elderly and their family caregivers (Appendix C10).

1.2 Field notes helped in recording observations (what is heard or seen, thoughts, and/or narratives about the researcher's perception) (Speziale & Carpenter, 2007). The field notes consisted of a reflection guideline that was used by the researcher to record and make notes on the self reflection of the participants and as well as the researcher's self-reflection. The field notes described the setting, actions and behavior of the participants (Appendix C2).

Equipments for collecting the qualitative data collection were as follows.

1) Digital voice recorder. The equipment was utilized to collect narrative data during in-depth interviews.

2) Researcher's diary. The diary was used to write down the progression of this action research and the researcher's observations and self-reflection during three stages of action research approach: preparation, action and evaluation.

3) Camera. The equipment was used to capture and record the significant figures, actions, scenes, events, and situations.

2. Demographic and outcome evaluation questionnaire

2.1 A demographic data form was developed for use in this study. This instrument was used to collect the demographics and health data of the elderly, as well as the personal data of the family caregivers (Appendix C1).

2.2 Outcome evaluation questionnaire was used to measure the change in an ideal set of nursing care activity for home-based palliative care.

2.2.1 Quality of care was measured by three instruments as follows.

2.2.1.1 The Thai version of the Palliative Care Outcome Scale (POS) (Sapinun, 2013) (Appendix C3). Cronbach's alpha reliability of the POS was .93. The overall score is ranging between 0 and 40, and the POS item scores of zero or one require less clinical consideration than items that score 3 or 4.

2.2.1.2 The preferences of elderly and their surrogates for advance directives at the end of life (Suwannil, 2011) (Appendix C4-5). Cronbach's alpha reliability coefficients of these instruments were .82 and .85 respectively. These instruments are scored on a 6-point Likert scale. Each item is scored from 0 to 5 ranging from "no need under the term of that" to "very much to need". The level of needs of elderly and their surrogates can be classified as follows.

3.34 – 5.00	the needs for advance directive at high level
1.67 – 3.33	the needs for advance directive at moderate level
0.00 – 1.66	the needs for advance directive at low level

2.2.1.3 The caregivers' capabilities in responding to the spiritual requisites and the perceived caregivers' compassion to the spiritual needs (Issarapanit, 2005) (Appendix C6-7). Cronbach's alpha reliability coefficients were .97 and .75 respectively.

The caregivers' capabilities in responding to the spiritual requisites are scored on a 6-point Likert scale. Each item is scored from 1 to 6 ranging from "least capabilities in responding to the spiritual requisites" to "very many capabilities in responding to the spiritual requisites". The level of caregivers' capabilities in responding to the spiritual requisites can be classified as follows.

4.35 – 6.00	caregivers' capabilities in responding at high level
2.68 – 4.34	caregivers' capabilities in responding at moderate level
1.00 – 2.67	caregivers' capabilities in responding at low level

The perceived caregivers' compassion to the spiritual requisites is scored on a 4-point Likert scale. Each item is scored from 1 to 4 ranging from "no perceived caregivers' compassion to the spiritual requisites" to "always perceived caregivers' compassion to the spiritual requisites". The level of perceived caregivers' compassion to the spiritual requisites can be classified as follows.

3.01 – 4.00	perceived caregivers' compassion to the spiritual requisites at high level

2.01 – 3.00	perceived caregivers’ compassion to the spiritual requisites at moderate level
1.00 – 2.00	perceived caregivers’ compassion to the spiritual requisites at low level

2.2.2 Care burden was measured by the Thai version of the Burden Interview (Toonsiri, Sunsern., & Lawang, 2011) (Appendix C8). The Cronbach’s alpha of the Burden Interview was .92. Total score of the Thai version of the Burden Interview is ranging from 0 to 88 (higher scores indicating higher burden). The level of caring burden can be classified as follows.

0-20	little or no burden
21-40	mild to moderate burden
41-60	moderate to severe burden
61-88	severe burden

Research procedures

This research employed the participatory action research approach of three stages: preparation, action and evaluation. These stages are described as follows.

Preparation stage

This stage aimed to recruit participants, introduce the research study, protect ethical human rights, build rapport, and appoint times to visit participants. The procedures and outputs on the preparation stage can be described as follows.

*Procedure*s

1. Contacting the directors of fourteen primary care centers which located in Hat Yai city to introduce the research project and its objective. As a result, the directors of two primary care centers suggested which elderly participants to approach for this study. One located in the center of Hat Yai city, while another one

located in suburban zone. Both of primary care centers lie with municipality of Hat Yai city.

2. The two directors of primary care centers gave the participants from the name list and medical records to gather the basic information about the elderly and their family caregivers who are met the inclusion criteria. The participants included 4 organ failures, 3 cancer patients, 2 dementia/Alzheimer and 1 frailty, and 10 family caregivers. Their family caregivers were recruited by the method of one elder to one caregiver as a dyad. All participants were willing to be recruited in this study.

3. The participant was contacted by telephone and a home visit with the directors, and they were invited to participate as a key informant.

4. The participants who willing to be recruited into this study explained the criteria of the participants, including the protection of participants' rights. Participants had to sign the consent form for participation in the study. After that, an appointment for an interview was made and they were asked for permission to visit their homes.

Action stage

Integration of those scheduled home visits with spiral of action research was made through four phases of action research: (1) reconnaissance, spiral phases of action research (2) planning, (3) acting and observing, and (4) reflecting. Aim and procedures of each phase and its output are presented as follows.

1. Reconnaissance phase

The reconnaissance phase aimed to explore the situation of care needs and the performance of thematic concerns among the nurse, the elderly and their family caregivers in order to gain mutual understanding. The participants expressed their feelings, including perceptions and meaning of problems or concerning issues. In addition, the participants explored care needs and inhibiting factors influencing care.

Procedures

1. Reconnaissance phase was conducted in the first visit. Elderly and their family caregivers or family were involved to explore care needs, and assess on care activities. Care needs and care activities were mutual analyzed and discussed regarding strength, weaknesses, opportunities, and obstacles.

2. The care needs of the participants were in-depth interviews following the Thai version of interview guidelines (Appendix C 10). In addition, care activities were observed and recorded in the field notes.

3. Mutual summarizing regarding the ways to improve care from the guideline questions. For example, family caregivers were asked the following interview guideline questions.

What do you want to make better?

What are the ways that you think this problem can be solved?

How do you feel about the opportunity you have to care for the elderly family member in this stage?

How do you provide care?

What are the problems/obstacles?

What do you expect or need help with to care for the elderly family member?

4. Providing opportunities for participants to find ways to resolve any problems or improving care activities.

5. The data were verified by the participants, and triangulated by the family. In addition, methodology triangulation was used for validity such as interviews, using a questionnaire, observing care activities, and the member checking.

6. The recorded data from the participants were transcribed verbatim. Content analysis was used to analyze the data in order to understand the situation, care needs, cultural norms, and other associated problems in the field. After analyzing the data, member checking was used by presenting the findings to the participants for reviewing and reflecting in order to ensure qualitative research rigor.

2. Planning phase

Planning phase aimed to set a priority on any problems and care activities that needed improvement. Participants were stimulated in the ways and opportunities that could develop their care activities.

Designing and developing a tentative model was in accordance within the Thai context. Developing a tentative model was performed by two methods: (1) evidence based practice and (2) pilot study. The process to develop the tentative model is described as follows.

*Procedure*s

1. A systematic review of literature was performed to search existing research evidence related to home-based palliative care programs by (1) CINAHL, (2) ProQuest, (3) PubMed, (4) Science Direct, and (5) ThaiLis. The key words consisted of home-based, homecare, home health care, hospice, palliative care, end of life, terminal, terminal care, terminally ill, dying, advanced disease, life-limiting, life-threatening, death, intervention, program, and experimental.

2. A tentative model was developed by integrating the literature review, and qualitative data from the reconnaissance phase. The qualitative data was derived from the pilot study in 3 cases of elderly persons who needed palliative care and their family caregivers.

3. A mutual communication and discussion to plan were implemented. For example, questions to stimulate planning:

What needs to be resolved?

Why activities need to be revised or developed?

What is your expectation with these activities?

What are the ways to improve/develop each activity?

4. Providing an opportunity for the participants to discuss, and nurse offer help to elderly and their family caregivers. For example, stimulating questions for discussion:

Do you need more help?

Is there anything more to develop?

5. Using evidence based practices regarding home-based palliative care were selected and applied to implement care activities.

6. A mutual summarizing on planning to implementation. In addition, the elderly persons and their caregivers consulted the nurse on care implementation via telephone.

3. Acting and observing phase

This phase aimed to: (1) improve care activities; (2) conduct and adopt a tentative process model; (3) improve the development of an ideal set of nursing care activities for home-based palliative care.

Procedures

1. Implementation of care actions was involved after gathering the data in reconnaissance phase in the process of spiral of action research: planning, acting, observing, and reflecting (the first loop).

2. Twelve visits were scheduled to interview the elderly and their caregivers in their homes. Each interview took about 60-90 minutes. The participants were visited weekly, however, the times of follow up and outcome evaluations of the participants depended on the situation and data saturation.

3. Nine elders were visited following planned while one passed away before the final outcome evaluation. However, the nurse visited after the death and found that the caregiver was proud to fulfill the elderly member’s needs and wishes. All of the participants were visited on average 10 times, which less than planned scheduled of 12 times because the care outcomes had been mutually achieved.

4. Developing an ideal set of nursing care activities took about eight months. The number of times participants was visited was from 3 to 12 times, with duration of between 2 weeks and 8 months.

5. The following approaches were performed for changing care activities strategies.

5.1 Using evidence based practice regarding home-based palliative care among the elderly to motivate the participant to apply the implementation.

5.2 Advising and counseling participants during implementation by both home visits and telephone. In addition, an application line was used to report care outcomes.

5.3 Facilitating mutual goal setting, summarizing and discussion on the problems that need to revise and develop.

5.4 Giving the participants an opportunity to express opinions, and request assistance when they needed to via telephone.

5.5 Promoting caregivers confidence in their caregiving skills to care for the elderly in the palliative stage at home.

5.6 Providing continued support by telephone follow-up, line application and home visits.

5.7 Applying supportive communication techniques to provide emotional support to elderly and caregivers.

6. Observing situations that occurred to collect data by recording field notes. Observations for collecting data were: (1) daily activities, care activities, including care behavior for both the elderly and their family caregiver/families, (2) routine care activities, (3) meaning of care activities, (4) relationship between the elderly person, family caregiver, family and community, and (5) participating in the community.

Question guidelines to stimulate implementation

What are mutual activities?
Does planning work well or not?
How do the activities follow the plan?

7. A tentative model was implemented with 10 elderly persons and their family caregivers over eight months. In this phase, formulating an action, observing actions, collecting and analyzing data on actions were done together. A tentative model was synthesized. Data were collected through observation, taking field notes and in-depth interviews. Analysis of a variety of data was used on theme development

and componential analysis, which was used throughout the study to classify and group data.

8. Conducting an ideal set of nursing care activities based on mutual action research method (planning, acting and observing, reflecting, and revising plans). Data collection continued until saturation. In the mean time, the data and findings were derived from filed analysis.

4. Reflecting phase

Reflecting phase aimed to (1) mutual reflects care activities; (2) analyze lessons learned; (3) feasibility to implement care activities; (4) evaluate care action toward recommend next acting.

Procedures

1. Reflecting phase was evaluated in the second visit onwards, and it was performed by mutually summarizing the care activities, and reflecting on each activity by using stimulating questions as outlined in the following.

What are the problems? And how do you solve them?
What are the supportive factors to the care activities?
What are the consequences of the activities?
What have you learned?
Do the activities follow a plan or not?
What are the activities that need to be developed?

2. Reflective data were recorded on reflection of the activity from the observation record form (Appendix C2). The details of this form consisted of: *what to do, with whom, when to do it, where to do it, how to do it*. In addition, participants self reflected on the reasons for doing an activity, including self-reflection on care activities and the outcomes that occurred.

3. Participants were encouraged to identify the methods that can help in the successful performance of the care activities.

4. The information obtained from the reflection of the participants was used to revise the plan for developing care activities in an ideal set of nursing care activities. The research process moved to re-planning, re-acting, and reflecting in three cycles.

5. Reflective field notes were analyzed by the content analysis method. The description of reflection included feelings, problems, ideas, attitudes, conflicts, influencing factors, analysis, self management capability, action plan for future inquiry and other ideals about participation in this phase.

To summarize, reflection was performed with all the participants to evaluate the outcomes of the implementation of this model, and identify the factors influencing the development of the model. Following the spiral of the four phases of action research, this model was constantly modified until an appropriative model was generated for enhancing the quality of care for the elderly and for reducing the caring burden for family caregivers.

Evaluation stage

This stage aimed to evaluate the outcome of care as a result of implementation in this study. The outcomes that were measured: (1) quality of care and (2) caregiving burden.

Procedures

1. The process evaluation investigated the elderly persons and their family caregivers' care needs in the process of executing an ideal set of nursing care activities for home-based palliative care via observation, in-depth interviews, and the outcome evaluation questionnaire.

2. Care quality and caregiving burden were evaluated by the family caregivers. These outcomes were measured by the POS scale, the preferences of elderly and their surrogates for advance directives at the end of life, the caregivers' capabilities in responding to the spiritual needs and the perceived caregivers' compassion to the spiritual needs, and the Thai version of the Burden Interview. The post-test was evaluated in the final visit. The evaluation was performed at different time-points involving the first-visit, and the final visit (Figure 3).

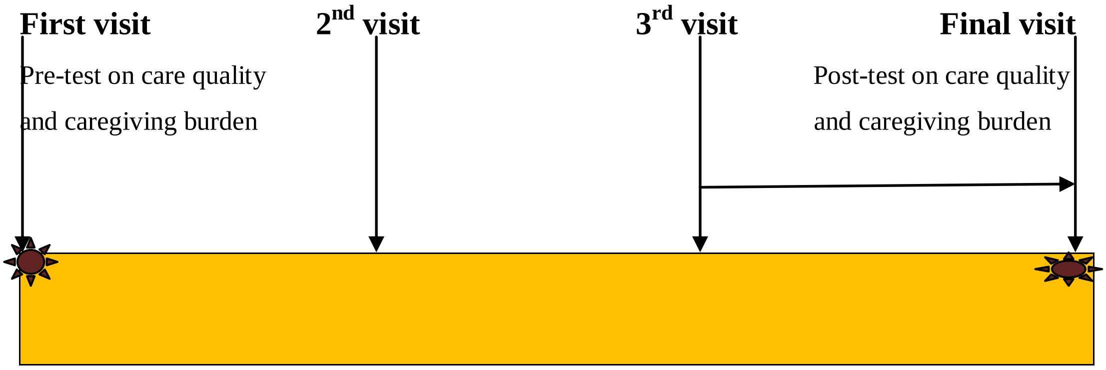


Figure 3 *Time frame of the outcomes evaluation*

Data analysis

Qualitative data were analyzed using a systematic procedure for the data analysis, descriptive statistics and inferential data analysis. The analysis of the data was used for theme development and component analysis throughout the study. Content analysis was used to analyze the qualitative data following guidance by Hsieh and Shannon (2005). All narrative data were transcribed verbatim. The researcher read word by word the narrative data to gain a sense of whole. The next step involved breaking the data into analytic units, coding each unit, naming the units, grouping into categories into a hierarchical structure. The process of analysis helped the researcher to obtain necessary information to develop an ideal set of nursing care activities for home-based palliative care.

Descriptive statistics including frequency was used to describe the demographic data. Wilcoxon matched pair and signed rank test were used to compare the quality of care and caregiving burden for the caregivers of the Thai elderly before and after model implementation.

Trustworthiness

In this study, trustworthiness was evaluated following the criteria for qualitative research. This can be supported by four elements: credibility, transferability, dependability and conformability (Lincoln & Guba as cited in Speziale & Carpenter, 2007).

Credibility

The credibility was established using four methods: prolonged engagement, triangulation, member checking, and peer debriefing. Firstly, prolonged engagement was used to build the elderly and their family caregivers' trust. Trust allowed the researcher to get the real in-depth information. In addition, the study procedures and answering all questions was explained before consent was given. Twelve visits were scheduled to interview the participants in their homes. Each interview took about 60-90 minutes. Secondly, triangulation was performed via multiple methods of data collection including in-depth interviews, observations, and field notes. The researcher used reflective commentary in each time after home visit. This used to record the researcher’s initial impression of each data collection session, pattern appearing to emerge in the data collected. Thirdly, the member checking method was carried out in which the transcripts and interpretations with participants were guaranteed by the participants in regards to the authenticity of the data. Themes and sub-themes were checked by elderly and family caregivers to accuracy of the data. Checking validity of data was verified by elderly, family caregivers, advisers, peer-reviews, and the researcher. Finally, advisory member read the findings and confirmed or questioned the categories and sub-categories. In addition, the credibility was accomplished through this process of data collection and data analysis by using the constant comparative method.

Transferability

The strategy is used to be sure of transferability and was performed using a thick description about the participants, the context and the entire process of this study. A thick description was provided from the beginning to the end of the process in this present study. In regards to a thick description, collected sufficiently detailed were described of the data in the context, and this was reported with sufficient detail and precision to allow judgments about transferability to be made by the reader. In addition, the research methods, settings, and the participant’s characteristics were described clearly. Coding is labeled in both Thai and English language.

Dependability

Dependability is guaranteed by an audit trail. Details of all procedures, data collection, data analysis and synthesis are explained. All data from digital recordings, transcriptions, field notes, and photos were kept as documents to ensure accuracy and to facilitate the audit trial. Detailed descriptions of the data provide enough information for the reader and the participants to judge the key elements, clusters, categories, and themes of the analysis.

Confirmability

Member checking was performed at every phase of this study after completing the action research process. All the information was recorded in an orderly and clear way so as to confirm understanding with the participants. The data has been verified for accuracy and validity. In addition, selecting diverse participants was used to ensure the confirmability of this study. Participants with various personal characteristics and different situations were recruited, e.g. age, gender, education level, income level, religion, illness, family relationship with the elderly person. Importantly, appropriate quotes of the participants' statements were reported to support the findings from the obtained data rather than the researcher's preconceptions.

Overcome limitations through data collection and analysis

The researcher solved limitations through data collection and analysis as follows.

Considering iterative questions and adaptive question. The participants cannot express some questions because they did not understand/unclear in these questions. These ways can help the use of probes to elicit detailed data. The researcher returned to matters previously raised by participants and extracts related data through rephrased question.

Negative case analysis. One form of negative care analysis may see the researcher refining a hypothesis until it addresses all cases within the data. In completing initial categories, the researcher revisited the data in order to confirm that these construct s do indeed account for all instances of the phenomenon involved, even if some of the types embrace only one instance.

Summary

This study was designed to develop an ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce the caregiving burden for the caregivers of Thai elderly persons using participatory action research. The participants were the elderly with a terminal illness and their family caregivers. They were recruited from the catchment of the two primary care centers located in Hat Yai city. The process consisted of three steps: preparation, action and evaluation. The step of preparation aimed to recruit the participants by purposive sampling, building rapport with the elderly persons and their family caregivers and to gain an understanding of their context of living with a terminal illness. In addition, care quality and caregiving burden were measured in this step as a pretest on the first visit. The multiple steps of action were based on the spiral of action research (planning, acting, observing, and reflecting) in order to develop an ideal set of nursing care activities for home-based palliative care and to refine it. The evaluation step covered both the process and outcomes evaluation of the care model. In-depth interviews, observations, and structural questionnaires were used to collect data. The data analysis was guided by the techniques of constant comparison including using descriptive statistics and inferential data analysis. Trustworthiness was evaluated following the criteria of qualitative research. This is supported by four elements: credibility, transferability, dependability and conformability.

Chapter 4

Results and discussion

The study aimed to develop an ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce caring burden among the caregivers of Thai elderly persons. Action research was used as design to develop an ideal set of nursing care activities for home-based palliative care. The findings are presented as following.

1. Characteristics of the participants
2. The findings of technical action research
    2.1 Reconnaissance phase
        2.1.1 Situation analysis of home-based palliative care for Thai elderly
        2.2.2 Caregivers' perspective on improving care for Thai elderly in the palliative stage
        2.2.3 Caregiving burden among family caregivers
    2.2 An ideal set of nursing care activities for home-based palliative care
    2.3 Factors influencing the ideal set of nursing care activities
    2.4 Outcome evaluation
3. Discussion of the results

Characteristics of the participants

Among the ten elderly participants (see table 2), there were five men and five women aged 60-91 years. All of them were Buddhist. The elderly participants can be divided into two groups: cancer patients (lung, breast, ovarian) and non-cancer patients (COPD, renal failure, CVA, diabetes, frailty, and dementia/Alzheimer). Five were divorced/ widowed/ separated, four were married, and only one was single. One had no formal education, eight participants had completed elementary school, and one had a bachelor degree. Their family average monthly income varied from 5,000 to more than 30,000 baht/month. All of the participants were covered by medical insurance: nine were in universal health care coverage, and only one had social security.

Among the ten family caregivers (see table 3), there were four men and six women aged 38-75 years. All of them were Buddhist. Seven family caregivers were elderly. Most of the caregivers were the elderly person’s wife or husband (3 cases), followed by sibling (3 cases), and an adult child (3 cases). More than half (6 cases) of the family caregivers were women. Seven were married, two were single, and one was widowed. Six had completed elementary school, three had a bachelor degree, and one had a master degree. Eight were unemployed, and two had their own business.

Table 2 *Characteristics of the elderly (n = 10)*

Characteristics		n
Gender	Male	5
	Female	5
Age (years)	60-70	5
	> 70-80	4
	> 80	1
Religion	Buddhist	10
Health problems	Cancer (lung, breast, ovarian)	3
	End-stage of organ failure (COPD, renal failure, CVA, diabetes)	4
	Frailty and dementia/Alzheimer	3
Marital status	Single	1
	Married	4
	Divorced / widowed/separated	5
Education	No formal education	1
	Elementary	8
	Bachelor	1
Family monthly income (Baht)	5000-10,000	4
	>10,000-20,000	1
	>20,00-30,000	2
	>30,000	3
Health insurance	Universal health care coverage	9
	Social security	1

Table 3 *Characteristics of the family caregivers (n = 10)*

Characteristics		n
Gender	Male	4
	Female	6
Age (years)	<60	3
	60-70	4
	>70	3
Religion	Buddhist	10
Relationship with the elderly	Spouse (husband=2, wife=1)	3
	Adult child (son=1, daughter=2)	3
	Sibling (older sister=1, younger sister=2)	3
	Grandson	1
Marital status	Single	2
	Married	7
	Widowed	1
Education	Elementary	6
	Bachelor	3
	Master	1
Occupational status	Unemployed	8
	Business person	2

The findings of mutual action research phase

The ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce the caregiving burden for the caregivers were developed through three phases: 1) reconnaissance, 2) spiral action research process to develop an ideal set of nursing care activities for home-based palliative care, and 3) outcomes evaluation.

Reconnaissance phase

The findings in the reconnaissance phase were consisted of: 1) situation analysis of home-based palliative care for Thai elderly, 2) caregivers' perspectives on improving care for Thai elderly persons in the palliative stage, and 3) caregiving burden among family caregivers.

Situation analysis of home-based palliative care for Thai elderly

In this part of the study, the nature of the caregivers' who provided care for the elderly at home is described as (1) general care and (2) special care. The results were explained as follows.

Strengths

Strengths are internal positive aspects on caring for the elderly. The strengths can be divided into 1) family and 2) caregivers.

The strengths of the family

A very warm family was shown in the nature of love and support among family members. Family members were ready and willing to help and support the elderly and the caregivers in all matters.

The strengths of the caregivers

The strengths of the caregivers were (1) well adapted to caring, (2) positive attitude towards care, (3) deep understanding of the nature of the elderly, and

(4) always practicing religious activities. The strengths of the caregivers are described as follows.

Firstly, well adapted and modified to caring is referred to as trying to provide the best care for the aged family members. Secondly, positive attitude towards care was based on the role of children to care for their parents, therefore, positive thoughts on care affected good care, respectively. Thirdly, a deep understanding of the nature of elderly was expressed from the caregivers as knowing the elder’s emotions and characteristics. When caregivers were affected by the elderly for whom they were providing care for, they were able to solve and manage the problems. Finally, most Thai people are Buddhist, therefore, religious practice helps the caregiver to enhance mental attachment. For example, two caregivers expressed experience of care for the elderly:

The first example of a 36-year-old man, the caregiver of a 94-year frail grandmother, “I need to have an understanding on elder’s condition. I must have a deep understanding. I tell her please calm down”

The second example of a 42-year-old woman, the caregiver of a 74-year-old man with COPD, “I make merit and dedicate offerings to the monk every Friday. I pray that this merit is for persons who may have been offended in a previous life of my dad. I must do these for him because he cannot do it”

Weaknesses

There were internal negative aspects of providing palliative care for the Thai elderly at home. Three weaknesses were categorized into 1) lacking of knowledge to care for a dying person, 2) facing barrier from chronic diseases, and 3) communicating conflict from cultural taboos.

Lacking of knowledge to care for a dying person

Many family members were not preparing to provide care for a dying person, and they did not know how to provide care for their loved one. They lacked knowledge on palliative and end of life care.

Facing barriers related to chronic diseases

Most of the caregivers were elderly with the role of husband, wife, older sister, and younger sister. Hence, most often had chronic diseases such as hypertension, diabetes mellitus, and osteoporosis. Caregivers expressed that having a chronic disease was a barrier in caring for the elderly because they were also suffering a disease and thought that they worried that no person as a caregiver will care for the elderly in the future.

Communicating conflict from cultural taboos

In Thai culture, talking about death and dying are like a curse. Hence, Thai people avoid talking about death. As a result, many families were not preparing themselves for death and the dying process or arranging to care for a dying person. For example, two caregivers reflected their opinion:

> “Please teach me to care for my wife; we do not know how to manage symptoms such as shock, severe pain. I am worried my wife cannot eat rice, I need to take her to the hospital to get intra-venous saline” (A 66-year-old man, the caregiver of a 68-year-old wife with lung cancer)

> “I have chronic diseases: diabetes mellitus, hypertension, and osteoporosis. I am weak, sick, am not comfortable and experience dizziness, pain in my back/legs and pain many pains in my body.” (A 75-year-old woman, the caregiver of a 66-year-old husband with CVA)

Opportunities

Many opportunities supported the elderly and their family caregivers: 1) visiting by health care volunteers, 2) receiving health services as needed, 3) participating in religious practices, and 4) getting help from the neighborhood.

Visiting by health care volunteers

In the community, the elder persons and their family were visited at their home by health care volunteers. Health care volunteers visited home regarding coordinating for the elder's benefit and the person's rights. If the older persons had severe and symptoms or any health needs, the health care volunteers reported this immediately to healthcare staff.

Receiving health services as needed

Since palliative care has been existed under the home care service system, the Thai elderly have been receiving benefits from the universal coverage core package through long term care services such as rehabilitation, and the provision of medical equipment.

Participating in religious practices

Most Thai people are Buddhists; therefore, there are a lot of temples in the community. Thus, it is easy for Thai people to always practice religious activities.

Getting help from the neighborhood

In suburban zone, neighborhood had willing to help and support elders in many aspects such as go to hospital/primary care center follow-up or emergency situations, cut the hair, buy food, and help elders to walk. Two caregivers expressed receiving health care services at home:

> "Neighbors take me to the hospital. One time, I did not stand up, they helped me, someone bought food, and sometimes they cut my hair for me." (A 63-year-old man with renal failure)

> "The staff and healthcare volunteer visit every month. They pay money for dependent elderly." (A 72-year-old woman, the caregiver of a 77-year-old husband with dementia)

Threats

There are three threats to home-based palliative care among older people: 1) discontinuity of care, 2) unclear guideline, and 3) lack of primary care provider.

Discontinuity of care

Family caregivers expressed that the elders received home care from health services from the primary care centers by home visit teams (nurse, physical therapist, and healthcare volunteer). However, most of them only received health services sometimes, no continuity of care. In addition, the finding found that most non-cancer elders and their family caregivers did not receive regular home visits for palliative care, but received chronic care.

Unclear guideline for palliative care

As mentioned, the elders did not receive a schedule plan for palliative care visits at home. Even though many of the elders were in the palliative and end of life stage, some cancer elders received home-based palliative care following the guideline from the Palliative Care Center, Hat Yai Hospital, and non cancer elders did not receive any home-based palliative care guideline from staff such as illness progression, advance care plan, and pain and symptom management. Because many elders in general resided in the area receiving health services from the primary care centers.

Lack of primary care provider

Many people resided in the area which receiving health services from primary care centers. Hence, primary care provider had many cases to visit home. Therefore, people who needed receiving home visit particularly elder people rarely receive this service.

Routine care activities for home-based care among the elderly

In order to understand the ways the elderly are cared, there were two main care activities related to home-based palliative care for the Thai elderly: 1) general care and 2) special care.

1. General care

General care was the care activity for the elderly who had partial dependence or total dependence or those who were bed ridden. These activities were provided in three aspects: 1) performing routine activities, 2) preventing complications, and 3) preparing for emergencies.

1. 1 Performing routine activities

Family caregivers performed routine activities for the elderly for maintaining the elders' abilities to prevent physical decay. They provided close support to the elderly with partial dependence, while, the elderly who were totally dependent or bed ridden were provided with complete care. Performing routine activities of caregivers were feeding, moving, toileting, and bathing. For example, two caregivers expressed performing routine activities to elder persons.

> "She can wash by herself, I support her to toilet. I wait for her to rub her face, change her diaper." (A 36-year-old man, the caregiver of a 94-year- old frail grandmother)

> "I prepare rice for him; he can eat rice by himself. I support him to toilet." (a 71-year-old woman, the caregiver of a 63-year-old husband with renal failure)
> "I provide care by routine: rub his body, give medicine, feed him, change his diaper, and observe his excretion." (A 75-year-old woman, the caregiver of a 66-year-old brother with CVA)

1.2 Preventing complications

Complications contribute to functional decline, and these induced an elder’s suffering such as pain from pressure sores, severe cough and dyspnea from respiratory infection. Therefore, these effects can reduce care quality before an elder’s death. Preventing complication can be divided into three aspects: infection, immobility, and skin care. Two caregivers explained their activities to prevent complication for elder persons.

> “I must try to stretch to her hand. If she does not use this side, it will bend up. The muscles are not used. I try to always tell her, she’s angry, but I must tell her.” (A 36-year-old man, the caregiver of a 94-year-old frail grandmother)

> “When I rub and shower him, I apply ointment to his skin, and lift his body. I do not do like the hospital that toss and turn his body every 2 hours. I use a pillow to support his back and hip, I switch the pillow to move on his left and right.” (A 42-year- old woman, the caregiver of a 74-year-old father with COPD)

1.3 Preparing for emergencies

Preparing for emergencies was part of the family system plan to deal with situations of uncertainty. It was important that caregivers understood how to interact with their community emergency resources. The activities of preparing for emergencies were: observe signs and responses, assess for causative factors, and prepare facility. For example, two caregivers explained activities to prepare for emergencies situation to their loved one.

> “I already prepare a bed, I plan step by step. When she will be bedridden, I will adapt the plan depending to the situation, I have to plan. I do not know

> what will happen. I will consult my uncle, and my house is near the hospital. If the elderly family member has serious symptoms, I will take her to hospital." (A 36-year-old man, the caregiver of a 94-year-old frail grandmother)
>
> "Last week, he lost consciousness. I helped him, after that he woke, and then I called my brother quickly." (A 70-year-old women, the caregiver of a 74-year-old brother with dementia)

2. Special care

Special care was care activities that provided support for an elder's beliefs, psychosocial aspect, and to relieve aspects of suffering. The five activities of special care are described as following.

2.1 Fulfilling elderly needs

Fulfilling elderly needs were shown by having family members' respect for the elderly wishes for care at the end of life. The fulfillment of the needs of the elderly is the ways that the family caregivers ascertained the best actions given the elder's wishes about his or her preferences. This activity was divided into two parts: 1) spiritual needs and 2) psychological needs.

2.1.1 Spiritual needs

Spiritual needs were often provided near death or when the elderly knew that they would die soon. Caregivers expressed that the providing of spiritual needs can fulfill the elderly in order to fulfill the elderly wishes. Activities of spiritual needs to the elderly were: prepare clothes, winding sheet and garland when elder persons die. For example, one caregiver expressed their belief and their opinion of fulfill the elderly wishes after their loved one pass away:

> "This dress you will put on me, the dress is pink silk, with a yellow winding sheet to give respect, to be beautiful and to go to heaven. She ordered a garland to be placed on her chest and her wrist." (A 68-year-old woman, the caregiver of a 79-year-old sister with ovarian cancer)

2.1.2 Psychological needs

Caregivers expressed that when the elderly received psychological needs from family. It makes the elderly happy. Activities of psychological needs to the elderly were: support reminiscence, sing a song, travel, and listen to music. For example, one caregiver expressed their support psychological needs to elder person.

> "She is happy to be here (original house is located in Kim Yong Market), she has been here all her life. She has many relationships here. A house where she stayed at near Prince of Songkla University is not familiar like here. Because of the people who stayed living separately but here is joyful. Here are a lot of shops, and many acquaintances and people she knows stay in here. When she was a girl, she sold goods. But now, she cannot do that. While, she can look at the possibilities, meet the acquaintances and people she knows. It is her happiness." (A 36-year- old man, the caregiver of a 94-year-old frail grandmother)

2.2 Expressing love

This activity was expressing love between family members and the elderly. Family members expressed that they let the elderly know their child or children loved him or her. In addition, expressing love shows a good relationship between a child and a parent. For example, three persons reflected their expressing love to their loved one:

> “I peck her on her cheek before she sleeps at night. She is shy, I can do it openly. For example, I can peck her on her cheek when I cut her fingernails.” (A 36-year- old man, the caregiver of a 94-year-old frail grandmother)

> “Saying I love you, and saying it often. I tell my husband I love you. For my children, children hug him, everybody hugs him, for me, I touch his hand often.” (A 72-year-old woman, the caregiver of a 77-year-old brother with dementia)

> “I love you (and she touch her son)” (A 94-year-old frail mother and a 66-year-old son with stroke)

2.3 Supporting emotion

Most family members needed and tried to help the elder persons to be happy before they died. They tried to avoid doing anything that caused harm for the elderly. They attempted with willingness to do everything that caused pleasure for the elders. Activities of supporting emotion were: communicate positively and receive visits from family member. For example, one caregiver expressed:

> “All relatives visit her, gave her touch and talk positively” (A 66-year-old man, the caregiver of a 68-year-old wife with lung cancer)

2.4 Practicing religion/faith

The activities of practicing religious/faith can be divided into two parts: 1) elderly practice and 2) caregivers practice. In the elderly practice, the elderly were very decrepit at the end of life. Therefore, they did not practice religion/faith by themselves; all the elderly did was to pray only. Meanwhile, all caregivers practiced religion/faith for the elderly. These activities can help the elderly who were suffering, particularly to serve for an elderly peaceful passing.

> "Even though she did not pray loudly she ordered me to chant for her, and she chanted in her heart. In addition, she practiced meditation all the time. I think that she had more merit, she was not suffering." (A 68-year-old woman, the caregiver of a 79-year-old sister with ovarian cancer)

> "I make merit every morning. I go to make merit at Hat Yai Nai Temple every Buddhist holy day. I pray for my family to be happy, for my husband to be comfortable, for improvement in his memory, to be healthy and to have happiness." (A 72-year-old woman, the caregiver of a 77-year-old brother with dementia)

> "I chant Bahum worshipfully to her normally, (worship Buddha), Chinnabanchon (protection from evil) and Itipiso (worship Three Gems). She remembered all worships" (A 68-year-old woman, the caregiver of a 79-year-old sister with ovarian cancer)

2. 5 Comforting and pain management

Most symptoms occurring in the elderly were pain, dyspnea and confusion. In addition, fatigue and weakness, constipation, nausea and vomiting, dehydration, and decreased appetite occurred during the last one month of life. Comforting and pain management were separated into two groups: 1) pharmacological intervention and 2) non-pharmacological intervention. These interventions can be described as following.

2.5.1 Pharmacological intervention

Pharmacological intervention consisted of: 1) non-opioid analgesics, and 2) opioid analgesics. The most commonly used non-opioid analgesics in the elderly are (1) acetaminophen, (2) hydrating agents group, and (3) bronchodilator. On the other hand, the most commonly used opioid analgesic in the elderly is morphine.

2.5.2 Non-pharmacological intervention

The activities of non-pharmacological interventions are based on caregivers' knowledge. A non-pharmacological intervention is an essential component of a comprehensive approach for all types of pain. In addition, there are rarely any adverse effects, and this type of intervention often has various benefits, such as enhances comfort, reduces anxiety, and improves quality of care. Non-pharmacological interventions are divided as follows.

2.5.2.1 Massage: manipulation of soft tissue by using rubbing, kneading, rolling, pressing, slapping and tapping movements.

2.5.2.2 Cold therapy: use of cold pads and baths.

2.5.2.3 Meditation: using deep relaxation to calm the body and mind and focus on the present.

2.5.2.4 Touch: touch is a form of energy healing in which the caregiver places hands over various parts of the elderly's body to manipulate the elder's energy field.

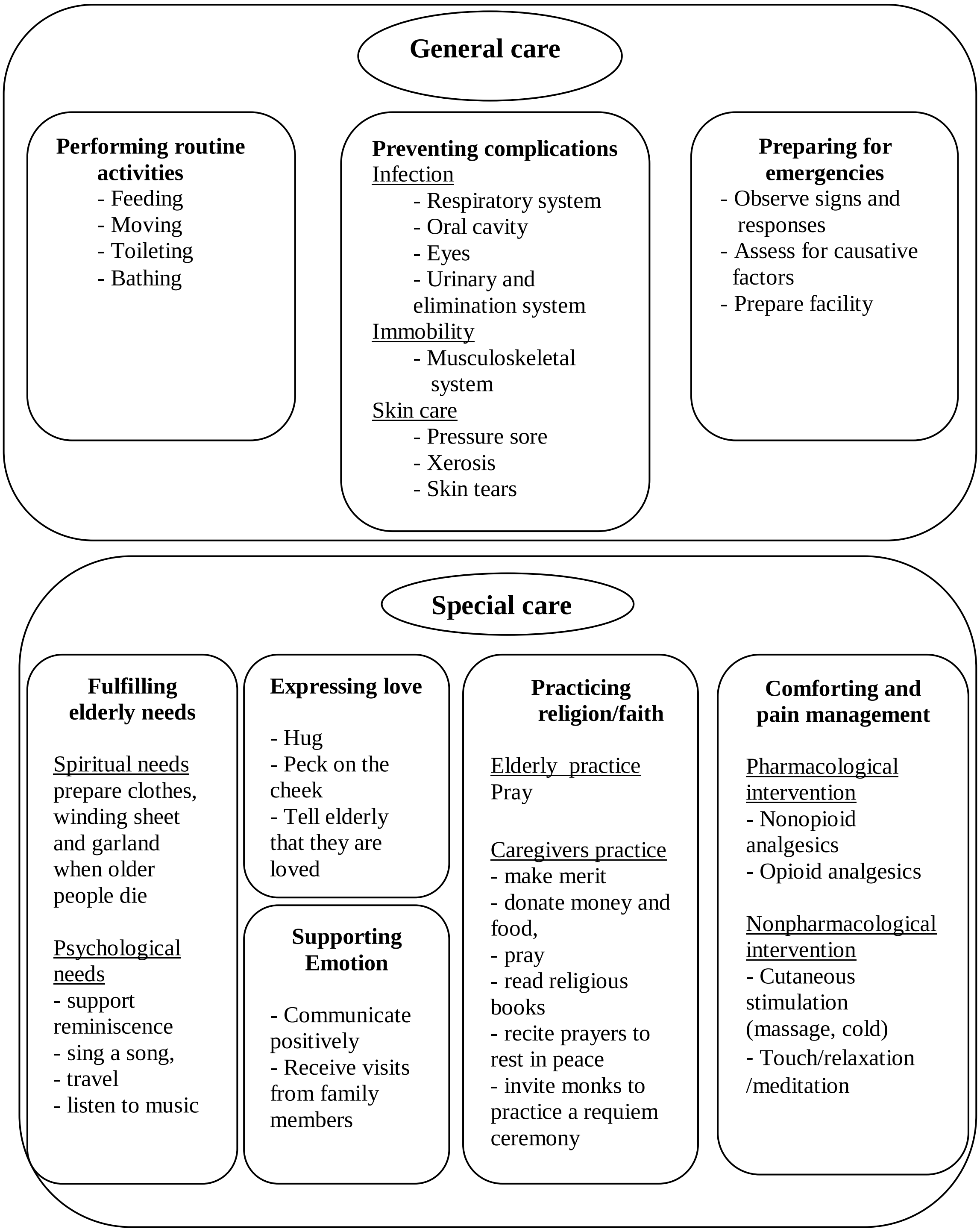


Figure 4 *Home-based palliative care activities for Thai elderly*

Caregivers' perspective on improving care for Thai elderly in palliative stage

Family caregivers expressed their opinions on improving care for the elderly in the palliative stage. Three themes and 6 sub-themes emerged as described in the following.

1. Caring to repay elders' kindness

  1.1 Giving care unlimitedly
  1.2 Providing unconditional care

2. Caring to minimize elders' perception of being abandoned/a burden

  2.1 Doing something for what has never been done
  2.2 Caring better than the past

3. Following the ancestral tradition for the elderly to die peacefully
  3.1 Strictly performing religious activities based on an elderly person's condition
  3.2 Making merit for the elderly for reducing suffering from illness

1. Caring to repay elders' kindness

In Thai culture, parents are crucial persons who give life, care and love to their children. In the life span of ages, they are always willing to help and support their children without any expectation. Thus, caring to repay an elder's kindness is the role of a child and it expresses their gratitude. Two sub-themes supported this theme: 1) giving unlimited care and 2) providing unconditional care.

1.1 Giving care unlimitedly

Caregivers worked hard in providing care to the elderly. They tried to serve the best care to their loved one and they did not consider themselves exhausted. For example, two caregivers expressed the best providing care for their loved one:

> "My mom did not eat rice for 2 years. I tried to force water but she did not drink it because she choked on the water and she said that water is bitter, thus I tried to serve ice instead of water. In the morning, I prepared a steamed stuffed bun and dim sum for my mom, I expect that she would not eat more, even when she eats a little, I am satisfied. Another day, I prepared soft noodles with sugar for her. If I prepare noodles only, she would not eat it." (A 72-year-old man, the caregiver of a 100-year-old frail mother)

> "What is happiness? I will make it. I take care of my grandma almost 24 hours. I sleep bedside her, in an emergency situation, I can handle it immediately." (A 36-year-old man, the caregiver of a 94-year-old frail grandmother)

1.2 Providing unconditional care

Most caregivers gave care without expecting anything in return. Because they are providing care with love, and they think that this caring cannot repay the elders' kindness completely.

> "I find what she likes to eat. For example, she likes black crab but she does not like flower crab. In the past, when she could walk, I stabbed black crabs to death for cooking. One day, I worshiped in the temple, I felt sudden chest pain. Since that day, I have not killed black crabs for cooking. Yep, when she cannot walk and she needs to eat, I will do it again." (A 72-year-old man, the caregiver of a 100-year-old frail mother)

2. Caring to minimize elders' perception of being abandoned/a burden

Feelings of abandonment and being a burden among the elderly always occurred. Caregivers can feel that the elders' perception of being abandoned and of being a burden which they can see from an elder's sad eyes, listlessness, and of the elder being uncommunicative. Thus, the caregivers tried to strengthen their relationships with their elders by maintaining their trust, confidence, and satisfaction. Two sub-themes were described (1) doing something for what has never been done and (2) caring better than the past.

2.1 Doing something for what has never been done: Expression of love

Caregivers felt that the elderly deserved the practice of care received from their children such as expressing love or concern; however in the past they had never did it. Therefore, they were willing to do this for the elderly to reduce the elder's perception of abandonment and of being a burden. For example, two caregivers expressed love as followings:

> "Telling him I love him often, saying that I love you and I touch his hand often, everybody (children) hugs the elderly person." (A 72-year-old woman, the caregiver of a 77-year-old husband with dementia)

> "He loves to sing a song, so I invite him to sing, and I sing a song with him. I turn on the music on YouTube for father to sing. 'Saw Pug Hai' is his favorite song (country music). Because my mom's name is Wilai, Wilai is the main actress in this music video." (A 42-year-old woman, the caregiver of a 74-year- old father with COPD)

2.2 Caring better than the past: Promotion of better care

Caregivers expressed that they were not satisfied in the level of caring they provided care to the elderly. They thought that they needed to provide better care than they had in the past.

> "Is not that the best care? I do it fully. But sometimes there are deficiencies as well because I have others to do some things. If I can, I should care more." (A 72-year-old man, the caregiver of a 100-year-old frail mother)

> "What do you want to eat? What do you want to do? Please tell me. I can make anything just you tell me, please decide and tell me." (A 36-year-old man, the caregiver of a 94-year-old frail grandmother)

3. Following the ancestral tradition for the elderly to die peacefully: Promotion of peaceful death following the ancestral tradition for the elderly

Family members expressed that practicing religion/faith is an original tradition in their family. All religion/faith ceremonies are practiced by ancestors or all generations.

3.1 Strictly performing religious activities based on an elderly person's condition

Most families rigorously practiced religious/faith activities, and they explained that Buddhist people should practice such activities. In addition, these activities affect the life of the elder in each phase. In the palliative stage, religious activities can help them get free from the cause of illness or beliefs related to their karma. In the dying phase, religious activities affect their mind such as providing comfort, satisfaction, and maintaining consciousness.

> “I invited 5 monks to pray for the elderly family member. The ceremony is called be successful in aging (jum rern a yu). If she lives, she stays alive. If she has not life, she will die. I prepare this ceremony completely. She needs to make merit and to lay a robe (tod pha bung su gul). I practice following my ancestors, there is a traditional ceremony. This ceremony is made for a dying person, for supporting her mind and to relieve suffering.” (A 68-year-old woman, the caregiver of a 79-year-old sister with ovarian cancer)

> “We make merit and give the offering dedicated for the monks every Friday at the temple, because I and my sister were born on a Friday. When we go to the temple, we give money to the monk for praying. We chant for the persons with previous deeds who have offended others from a previous life. Please be pleased and forgive him up until now.” (A 42-year-old woman, the caregiver of a 74-year-old father with COPD)

> “The elderly family member did not eat last week. My brother makes merit by offering food to the monk at 6.05 AM every day. For me, I pour water of dedication at 6.15 AM every day. My brother lights 3 incense sticks to pay respect to Buddha and lights 16 incense sticks to pay respect to the Thao Wessuwan (King of the Giants and wraith) for the elderly family member’s soul. We will do this until he dies. He has karma. After that, he can eat rice and he can walk to the toilet. His symptoms relief better.” (A 70-year-old woman, the caregiver of a 74-year-old brother with dementia)

3.2 Making merit for the elderly for reducing suffering from illness

Many caregivers prefer to make merit because it is related to their belief. They believe that making merit can help the elderly person by reducing his/her suffering such as the pain and symptoms of the elder’s illness.

> “His illness is caused by old karma. I don’t know what he was doing in his previous life. The fortune teller said that the persons with previous deeds on

> each other who have been offended from a previous life are monkeys. As a result, I make merit by offering bananas or fruit to the monkeys.” (A 72-year-old woman, the caregiver of a 77-year-old husband with dementia)
>
> “We want to sacrifice this merit for the persons with previous deeds on each other who have been offended from the previous life of my father, to reduee suffering, please forgive him. I hope that my father will not be like this again.” (A 42-year-old woman, the caregiver of a 74-year-old father with COPD)
>
> “My father believes in karma, old karma or karma from a previous life. This illness is caused by karma. I make merit by releasing the fish/birds, and by donating money. We make merit for the persons with previous deeds on each other who have been offended from their previous life.” (A 38-year-old man, the caregiver of a 66-year-old father with CVA)

Caregiving burden among family caregivers

Caregiving burden on family caregivers was divided into two aspects: 1) feeling not being burden and 2) feeling being burden. Caregiving burden on family caregivers is shown in the following figure 4. Two aspects can be described as following.

1. Feeling not being burden

Four caregivers were 3 adult children and 1 grandson. They expressed that care giving for their loved one was not a caregiving burden. Because caring for the elderly was providing loving care and repaying the kindness of the elder. Thus, they provided care with willingness. However, during the care provided, the main concerns of the caregivers were as follows: 1) worry about infection and complications, and 2) inadequate care giving skills.

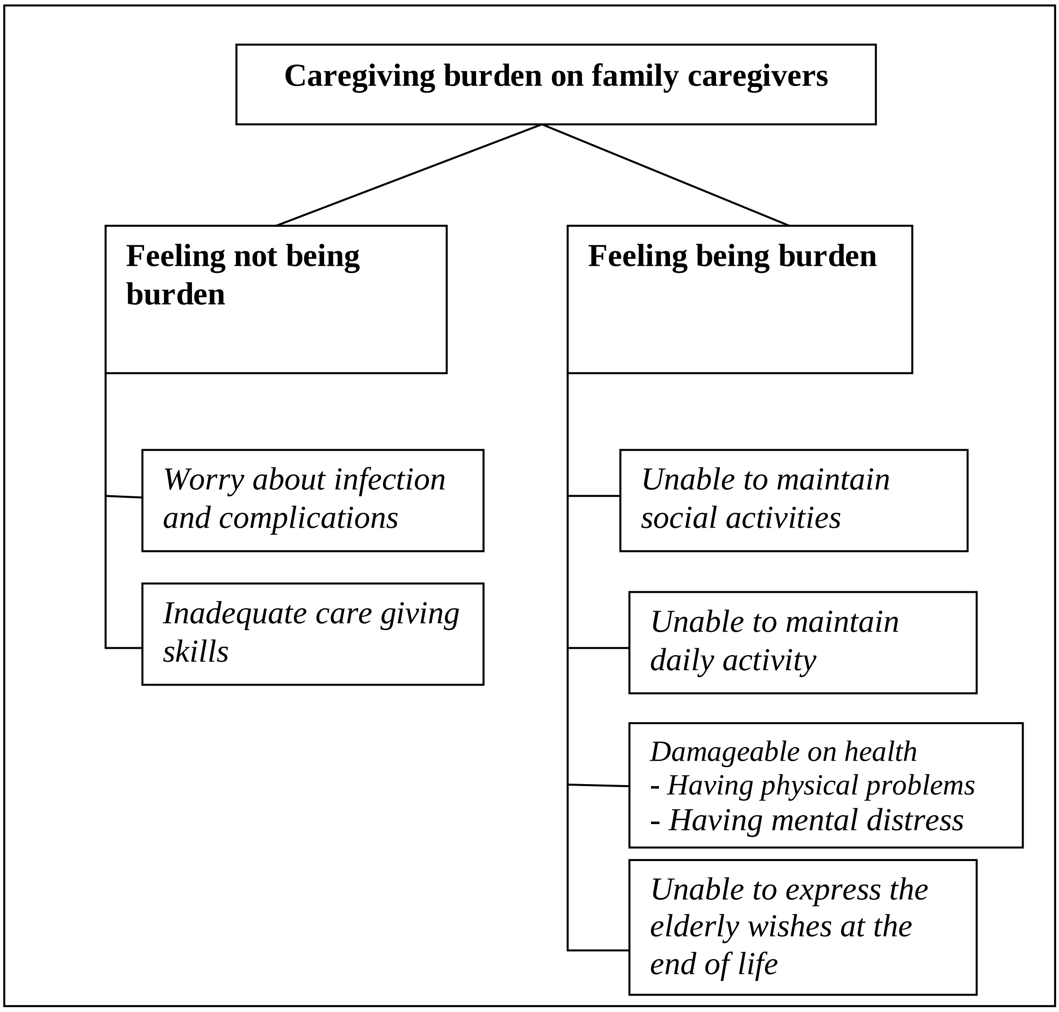


Figure 5 *Caregiving burden among family caregivers*

1.1 Worry about infection and complications

Some caregivers were anxious to prevent infection in the elderly family member. There were a number of reasons for this. If the elderly were infected, they suffered from many symptoms and may die early. As one caregiver reflected:

> "I want to change my house so it looks cleaner than this; I hire a cleaner to clean my house once a week. I'm afraid my father will be infected, because he has a tracheostomy tube. I cannot manage something such as a clean house,

> because we are living with the brother, and he is a psychiatric patient, I cannot solve the condition. I have been with him since childhood. I did not change much. I have to live this way" (A 38-year-old man, the caregiver of a 66-year-old father with CVA)

> "Why when changing his nasogastric tube that is on the left side there is a lot of secretion more than the right? Every time, it is always in the early time period, I worry about the secretion, what effect will it have?" (A 38-year-old man, the caregiver of a 66-year-old father with CVA)

1.2 Inadequate care giving skills

Even though the caregivers provided complete care, they needed to learn how to care for the elderly in the following situations. Importantly, some elderly family members and their caregivers were unable to manage symptoms and comfort.

> "I do not know what to do when she has symptoms such as severe pain and dyspnea. I quickly take her to the hospital" (A 66-year-old man, the caregiver of a 68-year-old wife with lung cancer)

> "I have severe dyspnea, what do I do?" (A 63-year-old man with renal failure)

2. Feeling being burden

For some of the caregivers in the group, the role of caregiver was an unacceptable role. They did not modify their self-concept as a caregiver for the elderly. Six caregivers were a spouse or a sibling. All of them were elderly and had illness themselves. They were unwilling to provide care for the elderly family member or take on the role of caregiver. The craegiving burden in their view was: 1) unable to maintain social activities, 2) unable to maintain daily activities, 3) damageable on health, and 4) unable to express the elderly family member's wishes at the end of life.

2.1 Unable to maintain social activities

Providing care for the elderly reduced social activities for the caregiver. Caregivers gave up some of their previous social activities. It made them feel separated from social events such as meeting friends, making merit, and traveling. Thus, caregivers needed to try to participate in their previous social activities. As two caregivers reflected:

> "I cannot go to any places or take part in social activities, my friend invited me to join a tour to make merit but I cannot" (A 72-year-old woman, the caregiver of a 66-year-old brother with CVA)

> "In the past, I always gave food to monks and made merit at the temple but now I cannot do this, and I cannot go any places that I need to go. I have stress because I cannot go to other places" (A 70-year-old woman, the caregiver of a 75-year-old husband with dementia)

2.2 Unable to maintain daily activities

Five caregivers were living with their family members, and one was living with the elderly family member. They provided care for the elderly by themselves involving: hygiene care, dressing, feeding, preparing food, cooking, and housekeeping (e.g. washing clothes and cleaning the home). As two caregivers explained as followings:

> "I have to do all the housekeeping, my family members cannot help me to provide for the elderly family member and do the housekeeping. I have severe

> pain from osteoporosis in my back and my legs. I do not know what day I will die. (A 72-year- old woman, the caregiver of a 66-year-old brother with CVA)

> “I am overwhelmed because of dialyzing his kidneys after that I saw the clock oh time passes quickly, I have to wash the dialysis towel” (A 71-year-old woman, the caregiver of a 63-year-old husband with renal failure)

2.3 Damageable on health

Most caregivers were the elderly. Thus, they have chronic diseases and may be suffering from deterioration of health due to aging. Persons who have served as caregivers of the elderly being at the palliative stage and end of life phase worked hard and they did not get enough rest. As a result, providing care for the elderly impacted on their health: 1) having physical problems and 2) having mental distress. These health problems were expressed by the caregivers in the following.

2.3.1 Having physical problems

Providing care for the elderly all the time exacerbated symptoms from illness such as high blood pressure and osteoporosis pain. Therefore, symptoms from physical illness caused the caregivers to suffer. As three caregivers explained:

> “Normally I was healthy but since my brother is a dependent person, I am weak, sick, not comfortable experience dizziness, pain in my back/legs and pain many pains in my body. I have chronic diseases: diabetes mellitus, hypertension, and osteoporosis” (A 75-year-old woman, the caregiver of a 66-year-old brother with CVA)

> “I walk rarely, my legs are bending, I cannot walk. If I am healthy, I would be able to help and provide for him fully” (A 71-year-old woman, the caregiver of a 63-year-old husband with renal failure)

> “I have pain in my chest and back because of when I lift him, I use a lot. 5 months ago, I could not raise my hand because of serve pain in my hand and edema of my hand” (A 42-year-old woman, the caregiver of a 74-year-old father with COPD)

2.3.2 Having mental distress

The caregivers had not fully accepted the role as caregiver. Most caregivers for this group explained that the caregiver role was given by family members and they were not willing to fully accept this role. Mental distress was found in the caregivers and this included: depression and stress. For example, three caregivers explained:

> “I have hypertension and I must provide for him. Sometimes I feel overwhelmed and think that providing for the elderly family member is a care burden. I need someone else to care for the elderly family member. Sometimes, I have suicidal thoughts” (A 72-year-old woman, the caregiver for a 77-year-old husband with dementia)

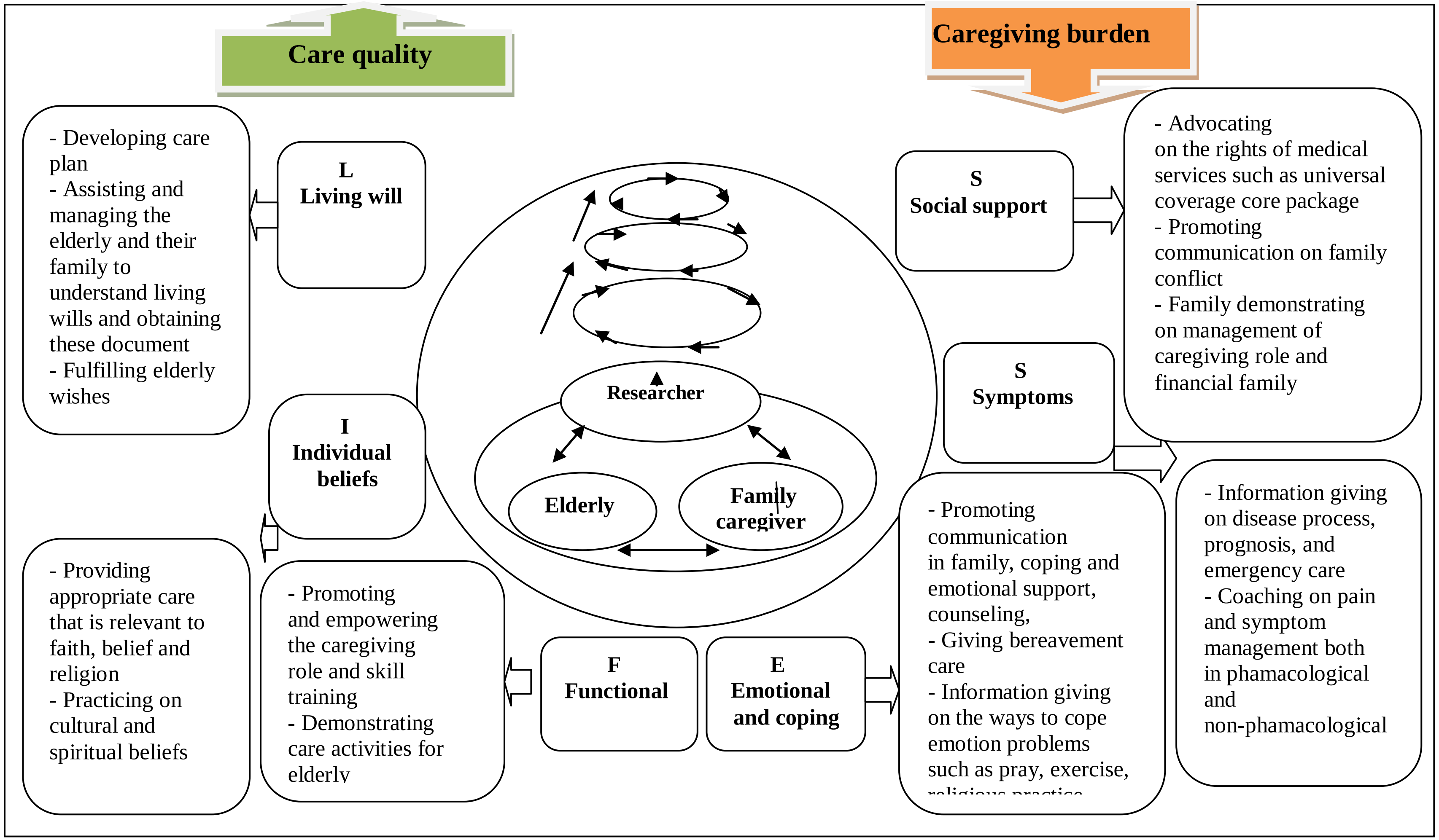
> “Providing for my brother makes me stressed. I am very tired and depressed. I feel neglected why is it only me that takes on the caregiver role? Why does anyone not understand me” (A 72-year-old woman, the caregiver of a 66-year-old brother with CVA)

> “Our life is hard, we have no children. I and my husband help together. This is like a canal that we must swim across the canal, even I cannot swim but I try to swim” (A 71-year-old woman, the caregiver of a 63-year-old husband with renal failure)

2.4 Unable to express the elderly person's wishes at the end of life

Even though the family caregiver understood completely to fulfill the elderly family member's wishes at the end of life, some families did not understand or accept the elderly family member's wishes particularly the issue of advanced directive treatment that the elderly person had ordered. Thus, this issue caused family conflict. Opposing an advanced directive among family members caused the wishes of the elderly family member to go unexpressed at the end of his/her life. As caregivers explained:

> "His hand is restrained, a tracheostomy tube, and nasogastric tube were put in and he has intravascular injections, while my sister did not agree with me on these treatment. She is afraid of dad suffering. But when he had severe symptoms, I feel sorrow" (A 42-year-old woman, the caregiver of a 74-year-old father with COPD)



- Developing care plan
- Assisting and managing the elderly and their family to understand living wills and obtaining these document
- Fulfilling elderly wishes

- Providing appropriate care that is relevant to faith, belief and religion
- Practicing on cultural and spiritual beliefs

- Promoting and empowering the caregiving role and skill training
- Demonstrating care activities for elderly

- Advocating on the rights of medical services such as universal coverage core package
- Promoting communication on family conflict
- Family demonstrating on management of caregiving role and financial family

- Promoting communication in family, coping and emotional support, counseling,
- Giving bereavement care
- Information giving on the ways to cope emotion problems such as pray, exercise, religious practice

- Information giving on disease process, prognosis, and emergency care
- Coaching on pain and symptom management both in phamacological and non-phamacological

Figure 6 *A tentative model of an ideal set of nursing care activities for home-based palliative care*

An ideal set of nursing care activities for home-based palliative care

The process of developing an ideal set of nursing care activities for home-based palliative care was studied following the spiral participatory action research process, consisting of planning, acting and observing, and reflecting. The model was developed through three activities (see figure 6): 1) mutual understanding on care requirements, 2) skill building in caregiver roles, and 3) enabling the family environment to promote spiritual well being.

Firstly, **mutual understanding on care requirements** refers to creating understanding on care demands between the nurse and the elderly patient or/and caregivers. It derives from the experience of care at home among elderly family members and caregivers. Secondly, when the elderly family member and caregivers understood what care demands needed to be responded to, they were involved in participating in the activity called **skill building in the caregiver role**. Finally, all the activities in skill building in a caregiver role were evaluated resulting in mutual satisfaction and the elderly family member and the caregivers were moved to engaging in **enabling the family environment to promote spiritual well being**. Two activities of skill building in a caregiver role and enabling the family environment to promote spiritual well being were evaluated by reflecting on the care outcome for continuing improvement and promoting care giving confidence to enhance care quality. The perspective of care requirements in this study can be divided into two groups: 1) the elderly who had normal cognition and 2) the elderly who had cognitive impairment and such care demands were met by the caregivers' group. Each activity can be described as in the following.

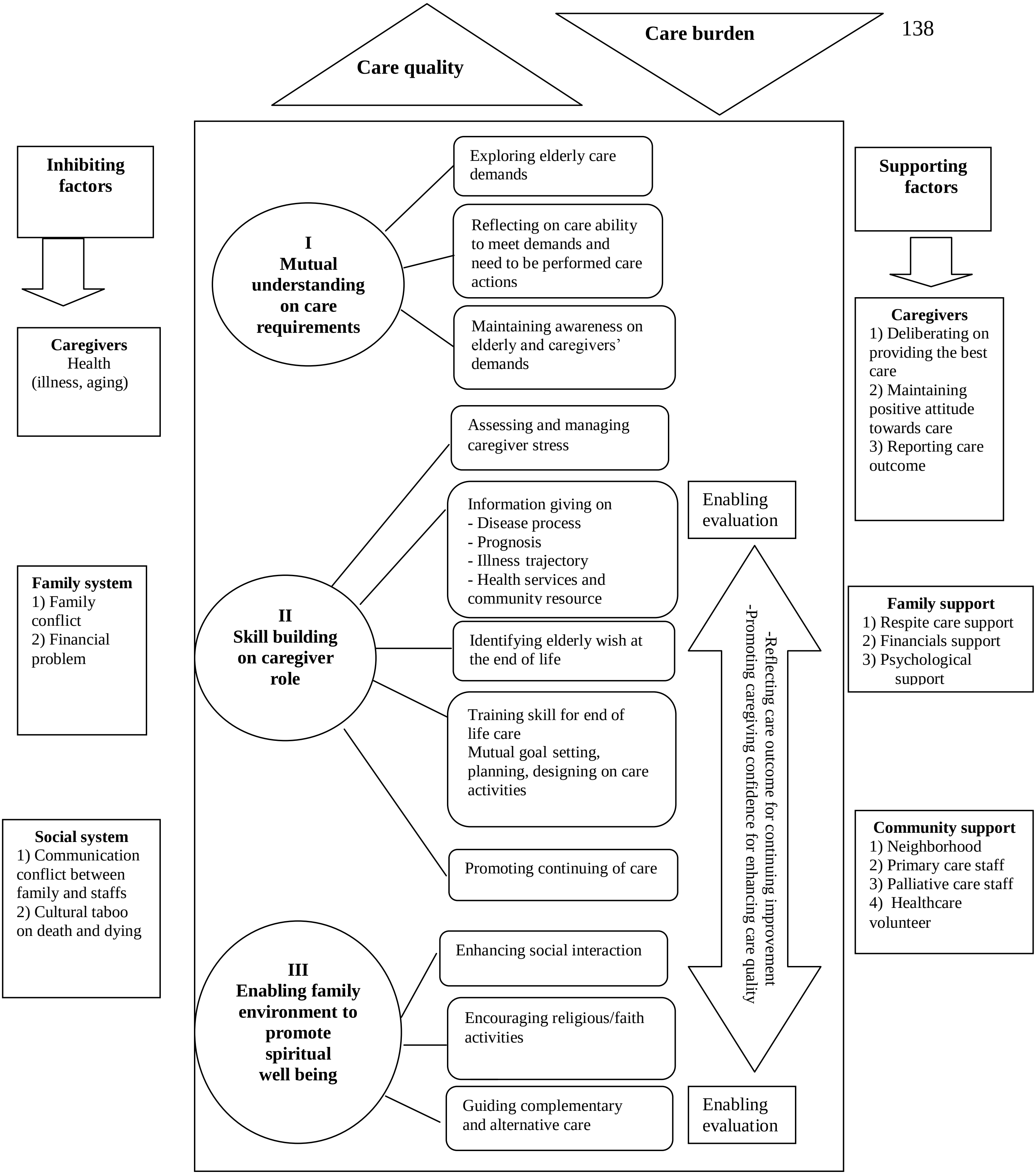


Figure 7 *An ideal set of nursing care activities for home-Based palliative care to enhance care quality and reduce caregiving burden among the family caregivers of Thai elderly persons*

Activity I Mutual understanding on care requirements

Mutual understanding seems to be the first activity because providing care should be taken to ensure improved quality of care and reduced care giving distress for caregivers. According to the main problems in caregivers' situations, mutual understanding on care requirements was developed for prioritizing problems and activities that need to develop. The strategies to guide achievement of this activity involving:

1. Building rapport of relationships with participants
2. Facilitating mutual goals setting, summarizing and discussion on the problems that need to revise and develop
3. Giving opportunity the participants express opinions, and they can request assistances when they need via telephone

Mutual understanding on care requirements can be divided into three activities: 1) exploring elderly care demands, 2) reflecting on care ability to meet demands and need to perform care actions, and 3) maintaining awareness on elderly and caregivers' demands. Nurses' questions to mutual understanding on care requirements are shown in the table 5. Three activities can be described as follows.

1. Exploring elderly care demands

Exploring care demand was the activity that the nurse asked for understanding about the participants' needs before provided a nursing intervention. This activity can be explained as follows.

1. Nurse explored the elderly persons' demands by asking general questions and using opened end questions (see table 4).
2. After that, the elderly care demands were explored by in-depth interview to identify care demand that needed to improve.

2. Reflecting on care ability to meet demands and need to be performed care actions

The nurse reflected on the care demands for the participants to acknowledge. This activity can be explained as follows.

1. All care demands were discussed and mutual summarized toward performed care actions.

2. Reflecting techniques was used to reflect care demand, including feeling of elderly and their family caregivers that expressed. In addition, non verbal and verbal of the elderly and their family caregivers were observed to detect their feeling.

3. Maintaining awareness on elderly and caregivers' demands

Maintaining awareness on elderly and caregivers' demands were activities that helped participants to aware on care demand for improving their care giving ability. This activity can be explained as follows.

1. The nurse informed the participants of the effect of the care demands on their life, and care actions were developed to improve their life.

2. The nurse followed up care demands that changed because care demands depended on the illness situation changing.

Table 4 *Nurses' questions for mutual understanding on care requirements*

Action	Asking questions
1. Exploring elderly care demands	1. Are there any problems that you are facing? 2. How to care for the elderly? 3. Did you see the doctor yesterday? 4. What are your symptoms in this period?
2. Reflecting on care ability to meet demands and need to perform care actions	1. How to participate in caring for your father? 2. How do you feel about this illness? 3. Do you think you can do it? 4. Do you have the opportunity to do what you need to

Action	Asking questions
	do?
3. Maintaining awareness on elderly and caregivers' demands	1. What do the elderly need to know about treatment? 2. When the elderly person stays in home or hospital is this different? How?

The nurse should understand the present situation, for understanding the elderly persons and caregivers' needs. In addition, the nurse should understand the participants before exploring, by observing and asking general questions. For example, the elderly person just came back from follow-up treatment, and the nurse asked to explore their needs that are important to them at this time (Did you see the doctor yesterday?). After that, the nurse explored the participants' needs and future needs in the next step.

According to the reconnaissance phase, most of the elderly family members and their caregivers felt that staff did not provide the information they should know. Caregivers who had not experienced caring for the elderly expressed that they needed home visits, and they needed to develop the new care giving role. They did not know about providing palliative care for the dying person at home. While for the caregivers who had experience, they still needed some information or needed to develop some skills for the elderly family member. From 10 participants, everyone expressed mutual understanding, for example in table 5.

Table 5 *Caregivers' quotes expressing mutual understanding*

Key informant	Quotes expressing mutual understanding
1	"The staff and volunteer came to help but they didn't give knowledge about the disease" (A 72-year-old woman, the caregiver of a 75-year-old husband with dementia)
2	"The staff came to draw blood, check blood pressure and bring medicine to me, but they did not give information on the palliative stage to me" (A 65-year-old with renal failure)

Key informant	Quotes expressing mutual understanding
3	“The staff visited, no one asked about or looked at the wound, I want your cheerfulness and recommendations” (A 68-year-old man, the caregiver of a 69-year-old husband with lung cancer)
4	“The staff came at the beginning to help, they do not come regularly, I need to know the way to prevent infection” (A 38-year-old man, the caregiver of a 61-year-old father with stroke)

According to the table 5, the data on the quotes expressing mutual understanding can be summarized into five issues: 1) mutual assessment on the elder’s problem, 2) giving knowledge of the disease, 3) educating in care giving skills for the elderly family member in the palliative stage, 4) mutual understanding on the disease and caring in the palliative stage, and 5) visiting the home.

Most caregivers are elderly persons who needed to know what the recommendations were for taking care of their elderly family member as well as having some knowledge about the disease because they lacked knowledge and understanding due to their educational background. On the other hand, adult children were concerned with preventing complications.

Activity II Skill building in caregiver’s role

The second stage of the model was skill building in the caregiver’s role. The strategies were used in this stage:

1. Using evidence based practice regarding home-based palliative care among the elderly to promote the participant for applying implementation.
2. Promoting caregivers’ confidence in the care giving skill to care the elderly with a palliative stage at home.
3. Providing continued support by telephone follow-up, line application and home visit.
4. Encouraging family caregiver to provide the elderly proper assistance and support.

5. Applying supportive communication techniques to provide emotional support to caregivers.

The step into implementing the skill building in the caregiver’s role were divided into four activities: 1) assessing and managing caregiver’s stress before skill building in the caregiver’s role, 2) information giving on disease process, prognosis, illness trajectory and health services and community resource, 3) mutual goal setting, planning, designing on care activities, and 4) promoting continuing of care. These activities can be described as the following.

1. Assessing and managing a caregiver’s stress before skill building in the caregiver role

This activity was used nurses’ questions guideline (see table 6) and acting of nurse can be described as follows.

Assessing on caregiver stress. Assessing on caregiver stress was divided into two parts: 1) evaluating by tool and 2) interviewing and observing.

By evaluating the tool. Caregivers were assessed stress by the Thai version of the Burden Interview. In case of depression symptoms occurred, caregivers were evaluated by 2Q and 9Q depression screening questionnaire.

Interviewing and observing. Caregivers were encouraged the expression of feelings. Thought emotional and behavior of caregivers who had stress from care giving were expressed. Techniques were used to assess caregiver stress as listen carefully, use of eye contact, open end question, exploring, reflecting and summarizing. These techniques can help nurses to emphatic understand caregivers and toward for managing caregiver stress.

Managing caregiver stress. All caregivers had various emotional problems. Needs and problems in each family had different. Hence, caregivers were provided psychological support differently. The methods to solve caregiver stress were divided into two parts as followings.

Caregivers were ensured fulfillment of physical needs. Most caregivers were older adults. Caregivers had health problems from chronic disease, body destroy by age, and taking care of the elderly. Caregivers had chronic diseases, such as hypertension and osteoporosis. Health care problems were caused from taking care of the elderly, such as back pain and chest pain. Pay attention to assess health problems of caregivers was crucial. Caregivers are advised their health care and follow up their health were concerned.

Managing to solve emotional distress of care giving was occurring. Emotional problems were found on caregivers include: depression and stress. Caregivers were provided care differently according to the symptoms found.

Depression

Helping to develop positive self esteem. Caregivers were guided opportunities for success, mutual setting new goals, and how to form. Nurses' quotes such as "You take the best care of your mom, she has not pressure sore, how do you do?" "Wow, you are a son, you can wash your mom's stool, you are a very good child, she is very lucky to have a child like you"

Encouraging the expression of feelings. Anger, guilt, frustration and other feelings were expressed. Caregivers were afforded time to listen and guide caregivers through these feelings, and the nurse actively listen.

Avoiding minimizing feelings. Nurses' quotes such as "Don't worry, things will get better"

Stress

Exploring feelings that care the elderly was stress. Caregivers expressed all feelings, and needs were explored. Most caregivers needed time to rest and they required other family members to help them to care the elderly. Encouraging caregivers to rest was selected and family members supported by family communication. The way that the rest was traveling, leaving vacation, making merit at other provinces. Other activities and methods of support were used such as exercising (running, jogging, swimming, and yoga), deep breathing, and relaxing.

Table 6 *Nurses' questions and quotes*

Actions	Questions and quotes of nurses
Assessing caregivers' stress	1. How do you feel about the opportunity to care for the elderly person in this phase? 2. How do you feel in having the role to care for your mother? 3. Do you think providing care to your mother is a burden?
Managing caregivers' stress	1. When you feel dim, stressed, what do you think are the ways to handle this? 2. I have ways to manage these emotional problems such as deep breathing, exercises, and muscle relaxation. 3.Using reassurance, admiration, and reflection techniques on the interaction between the nurse and caregiver (You have done a very good job in your role as a son, you can see, no bed sores, you take her to pee and poo, this is a very rare for a son to take care of his mother in Thai culture, when you say that when you were young, the elderly person took care of five children with difficultly because your father passed away, now you care for your mom in the same very good way as your mom took care of you when you were a kid.)

2. Information giving on disease process, prognosis, illness trajectory and health services and community resource

The nurse informed about disease process, prognosis and illness trajectories for the elderly. For many older people, the end of life may be a gradual process that is associated with the cumulative effects of disease and may interacting conditions rather than a single cause. For example, sepsis or a fractured hip were induced the elderly to transition from a state of chronic disease to end of life state. Hence, many family caregivers and family member needed to know how long their elderly live, and they needed to plan for caring. The process to implement in this activity can be showed in table 7.

The situation of the caregivers who asked on the prognosis of the disease in regards to the health of their elderly family member represented the need of comforting in regards to worrying about the elderly parent. After that, the nurse explained in general about illnesses of the elderly that is divided into three groups: 1) elderly with cancer, 2) elderly with organ failure, and 3) elderly with dementia and frailty. The nurse pointed out the differences in each group. For example, the disease progression of the elderly with cancer is faster than in other groups, however, all groups will end up the same. It means that the elderly people face the same death, regardless of the disease. As a result, this description helped to comfort the elderly caregiver. In addition, other techniques were used to approach such as touching, listening actively, and ventilating.

According to the reconnaissance phase, elderly and their family had faced problems in caring. For example, most elder cancers had very painful from physical symptoms, but the family did not have the ability to access painkiller for using at home. They reduced pain by themselves, such as rubbing the body with refreshing towel, making appropriate position, and turning on the music. However, these methods did not reduce pain at all. Thus, the nurse informed caregivers that they can request pain killer at hospital such as Hat Yai Hospital. On the one hand, caregivers can request medical service at primary care centers such as bed, suction machine and oxygen tank.

3. Identifying elderly wishes at the end of life

The elderly and their family caregivers were identified the desire in the end of life when the elderly entering the final phase. The elderly are expressed on their wishes in advance of serious illness, that are the elderly would like to do when they come to the end, and intended to through the medical care for specific person if they become unable to express their health care choices at a future date. The main point of elderly wishes was identified as following.

3.1 The elderly expressed wishes by verbal or writing document such as need to death and stay at home, no sustain life, and divide the inheritance. However, the participants were explored in the following point.

3.1.1 Asking on how fulfilling the elderly wishes and what cannot be done reason and the ways to help.

3.1.2 The elderly who can communicate, they were encouraged to express their wishes at the end of life, including signing document.

3.2 The elderly did not express wishes when they near died. Thus, the elderly and their family caregivers were identified elderly wishes at the end of life as follows.

3.2.1 Ask for meaning and understanding about the elderly wishes at the end of life.

3.2.2 Ask for the elderly wishes at the end of life.

3.2.3 Ask for the point of the elderly wishes at the end of life.

3.2.4 In case the elderly wishes with verbal, promoting to write on document, and how to apply.

4. Training skill for end of life care and mutual goal setting, planning, designing on care activities

Training skill for end of life care and mutual summarizing and discussing on demands for improving and mutual planning, designing on care activities based on evidence based practice. Each care activities can be described as follows.

Teaching caregivers' skills in managing elderly symptoms and comfort. The activities to enhance comfort and control symptoms at the end of life can be described as follows.

Fatigue

1. Informing elderly and family of the normality of fatigue at the end of life.

2. Promoting optimal sleep, with regular time of rest.

Constipation

1. Preventing with emphasis on fiber (e.g. prune juice, fruit juice), fluid intake, and activity
2. Massaging to abdomen for intestine movement

Dyspnea

1. Promoting to rest
2. Providing oxygen canula usually 2-4 L per min
3. Providing calm comfort
4. Using a fan to circulate air and helping to reduce the feeling of breathlessness
5. Comforting to position for optimal respiratory function (e.g. on the side with head slightly high for unresponsive elderly)
6. Teaching elderly to use pursed-lip breathing and encourage relaxation techniques to reduce muscle tightness.

Nausea and vomiting

1. Offering small meals; serving foods cold (e.g. ice water)
2. Applying cool cloth to face when nauseated
3. Providing oral care after vomiting

Dehydration

1. Performing fluids, offering ice chips
2. Providing frequent oral care; using swabs to clean

Pain

1. Pain assessment by using visual analog scale
2. Considering the impact of psychological factors on elder’s physical pain (anxiety, boredom, or other psychosocial factors). Some psychosocial

discomforts were induced from a listening ear or more frequent visits from their family.

3. Recommend on pain killer (paracetamol per oral, morphine syrup per oral or/and drip via subcutaneous).

4. Cold therapy: using cold pads packs and baths

5. Massage: using rubbing, kneading, rolling, pressing, slapping and tapping movements

6. Meditation: using deep relaxation to calm the body and mind and focus on the present

7. Touch: caregivers placed hands over various parts of the elderly body to manipulate the elderly field

Monitoring and early detect on physical symptoms. Most elderly and caregivers did not know that physical symptoms occurred affected on health and care. Physical symptoms were occurred such as complication, infection, and symptoms that need urgent help (e.g. dypsnea, cyanosis, and severe cough). Activities on monitoring and early detect on physical symptoms can be explained as follows.

Facilitating on care of complication and prevention. Family caregivers needed skill training, knowledge, and managing regarding complication prevention and caring. The activities of care of complication and prevention were divided into two groups:

Infection

Firstly, the majority of eyes infections were caused by their nails. The nails were dirty from scratching. Therefore, the eyes were characterized by green discharge. To prevent eyes infections, family caregivers were instructed about using cloth bag to put the elderly hands. To caring eyes infections, family caregivers were instructed using wipe the eyes by sterile technique that used cotton ball with boiled water is cold, wiping from beginning of the eye lid to end of the eye lid.

Secondly, most respiratory infection was found in the elderly who had tracheostomy tube. The elderly were infected from family member who had common cold or influenza. When the elderly become infected, the symptoms are more severe such as pneumonia and bronchitis. Therefore, the elderly were suffered from this complication such as high fiver and severe cough. To prevent respiratory infection, family member were advice on wearing mask and separating from the elderly for who had common cold or influenza. In addition, family caregivers were instructed about education on medication and management such as nebulizer, percussion, and being aware on cyanosis or lacking of oxygen when suction.

Finally, skin infection always found in the elderly had dementia, and it caused by long nails and scratching. To prevent skin infection, cutting the nail for short all the time is important, as well as using cloth bag to put the elderly hands.

Skin care

In older people, the skin tends to be very thin, fragile, often transparent, and very dry. The skin of the elderly with palliative and end of life phase was damaged by trauma, pressure, or medication induced as in the elderly taking corticosteroids. Most skin damage in the elderly was pressure injury, xerosis, skin tare, and rash. The activities to prevent and care skin damage were instructed to caregivers as following.

Pressure injury

To prevent pressure injury, caregivers and family member were instructed about pressure injury as follows.

1. Assessing for risk of pressure injury.
2. Using mild cleansing agents for bathing, avoiding hot water, harsh soaps, and friction.
3. Moisturizing after bathing and minimize environmental factors that lead to dry skin such as coconut oil, Vaseline and baby lotion.
4. Massaging bony prominences.
5. Assessing for compromised nutrition, particularly protein and caloric intake.

6. Maintaining the elderly mobility and activity level.

7. Turning bed-bound the elderly at least every 2 hours.

8. Using pillows to keep bony prominence from direct contact with each other (e.g., knee, ankles).

To manage pressure injury, caregivers and family member were instructed of dressing changes as following.

1. Cleansing the wound with saline during each dressing change.

2. Performing wound care using topical dressings determined by wound and availability.

3. Reassessing the wound with each dressing changes to determine whether treatment plan modifications were needed.

4. Identifying wound infections.

The common skin problems in the elderly were found in xerosis, skin tears, and rash. Maintenance of optimal nutrition and hydration is a crucial intervention in the skin care of the elderly. The activities to teach caregivers on improving skin health can be described as following.

Maintaining healthy skin

1. Including adequate amounts of fluid in the daily diet.

2. Maintaining environmental humidity.

3. Using unscented soap or use a mild when bathing.

4. Maintaining water temperatures for bathing at about 32-37 °C

5. Applying moisturizing lotions immediately after bathing, when the skin was still moist.

6. Avoiding skin care products that contain perfumes or isopropyl alcohol.

Preventing injury from abrasive forces

1. Using soft towel or cotton washcloths.

2. Making sure that an adequate amount of soft, absorbent material is place near the body

Developing caregiving skills for other family members. Some caregivers explained that they wanted the family members who living together had caregiving skill to care elderly. Because caregivers were elderly and had chronic disease, and when caregivers sick or rest family members will be able to have competency to care the elderly.

Caregivers taught care giving skill to care the elderly for family members, and researcher facilitated and assisted care giving skill. Topics taught include: hygiene care, feeding, dressing, and massage.

5. Promoting continuing of care

All activities to build skill on caregiver role were promoted continuing of care. Example of promoting continuing of care can be explained in table 7.

Activity III Enabling family environment to promote spiritual well being

The perspective of Thai people on spiritual well being could lead to peace, happiness and enlightenment. The set of care activities of an enabling environment to promote spiritual well being can be divided into three groups: 1) enhancing social interaction within the family, 2) encouraging caregivers to practice religious/faith activities, and 3) promoting complementary and alternative medicine. These activities are described as follows (see table 8).

1. Enhancing social interaction within the family. This activity can be divided into two topics.

Promoting positively family communication and expressing love. Communication includes auditory, visual, and tactile stimulation to appropriately care for while dying. Verbal and nonverbal communications are essential to express positive communication. Hand-holding, touching hands and placing an arm around the shoulder or sitting on the edge of the bed as appropriately conveys to the dying person. In verbal communication, positively communication was brought to use for expressing with the elderly. Family caregivers and family members discussed and shared positive memory try to make the elderly know. There were some tips of sharing by family, e.g. viewing worthy photos, taking to go a valuable place, and going to the sea.

Table 7 *The quotes and questions asked for skill building in the caregiver's role*

Actions	**Assessment**	**Implementation (quotes of nurse)**	**Evaluation**
Information giving 3 topics -*Disease process* -*Prognosis* -*Illness trajectory*	1. What is your father's disease? 2. What do you know about your father's illness? 3. Do you know the duration of the disease (and getting well from the disease? are you talking about recovery from the disease?) 4. How is it?	"The illnesses of the elderly can be divided into three groups: 1) cancer, 2) organ failure, and 3) dementia and frailty, In cancer, the disease prognosis is faster than in other groups, life is short. In group 2, we cannot predict the situation of the symptoms of acute illness when it is acute; the projection of life is longer than the cancer. However, if there is a chance of acute symptoms. In the last group, graphs are shorter and longer than all groups; the prediction of survival is longer than in both groups. In the nature of the elderly, the elderly is the age of the deterioration of the body, so when an illness occurs, there may be a more severe disease, and the risk of infection and complications is easier"	1. According to the explanation, do you understand? 2. Are you worried?

Actions	Assessment	Implementation (quotes of nurse)	Evaluation
Information giving on health services and community resources	Do they know that they can loan medical devices?	1. “Can we borrow the suction machine from the primary care center? 2. “We can borrow a patient’s bed by contacting the staff, the staff will coordinate with Hat Yai hospital and they will bring the patient’s bed to our home”	Following 3 days later, the elderly family member had a bed and suction machine at home
Mutual goal setting, planning, designing care activities	Nurse: “What will you teach your sister?” Caregiver: “I’m concerned about hygiene care; I don’t know how to brush his teeth when I go to Bangkok. I am concerned about hygiene care on oral cavities and tracheotomy tube, (I don’t’ know what she does” (A 75-year-old woman, the caregiver of a 63 year-old brother with CVA) Caregiver: “She has a family, I	1. “The topic you will teach your family member is on hygiene care such as oral cavities and tracheotomy tube” (nurse) 2. “You are able to teach fluently and skillfully” (nurse)	“This week my sister will go to Phuket, I and my nephew will take care of our elderly family member, I can do it, I can remove the tracheotomy tube to clean it, last time, I could not do it” (A 72 year-old woman whose family member is a 63 year-old brother with CVA) “You can do hygiene care for the elderly family member fluently and correctly” (nurse)

Actions	Assessment	Implementation (quotes of nurse)	Evaluation
	think that teaches hygiene care, she will come for a short time, if I get sick, she will help me" (A 75 year-old woman, the caregiver of a 63 year-old brother with CVA)		
Promoting continuing care	*Complication* "I don't know that this is a bedsore" (A 65 year-old man, the caregiver of a 69 year-old wife with lung cancer)	In the situation of a bedsore on an elderly family member with lung cancer, the nurse visited 4 times to follow up on the bedsore progression. In the first time, caregivers were educated on wound dressing, prevention, causes and influencing factors. In the second time, the elderly family member's bedsore showed good progression, and the nurse reassured the caregivers on dressing care. In the third time, the elderly family member had a bedsore again, the nurse looked for the influencing factor that caused the	"Please I can see the bedsore on the right hip of the elderly person" (nurse)

Actions	**Assessment**	**Implementation (quotes of nurse)**	**Evaluation**
		bedsore “Your wife is lying on her right side to the wall all the time. The TV in the room might be noisy and disturb her, you can play a song that your wife likes, however, your wife should rest” (nurse) In the fourth time, the nurse followed up on the bedsore, and the bedsore had healed well.	
	Infection “The elderly family member has conjunctivitis, his eyes have green excretion, you can see” (nurse)	In the situation of the elderly family member with conjunctivitis, the nurse visited 3 times to follow up on the conjunctivitis. In the first time, caregivers were educated on eye cleansing by sterile technique, including prevention. In the second and the third times, the elderly family member had no excretion from his eyes.	“Your father does not have any excretion” (nurse)

Reducing social separation of the elderly. Families were advised to understand the stages of dying process, particularly depression stage. The families should require reassurance for the helplessness elder's feeling at this time. Depression was necessary for a person to be approach death in a stage of acceptance and peace. During acceptance stage, the elderly received benefit more from nonverbal than verbal communication. Touching, comforting, and being near the elderly were valuable actions. Some families were not known what they do when the elderly move into depression and acceptance stages.

2. Encouraging religious/faith activities

The nurse must understand the art of attentive listening and focused presence, which can be used for both assessment and interventions in spiritual care. The nurse can gain insights into elderly and their families' spiritual concerns and needs, while the elderly gained new insights about their own lives, which may lead to affirmations and acceptance. Hence, attentive listening and focused presence were foundational to all spiritual care intervention. In addition, nurses should not have bias towards the caregivers' belief such as counseling with spiritual counselor and practicing rituals of faith.

Most family caregivers were always religious practiced to their elderly. However, some elderly and caregivers had a different opinion to religious practice. For example, the elderly needed to listen to the tape Dharma, but their caregivers thought that the elderly did not need to hear it. Hence, the nurse was opportunity for both to talk together, after that, caregiver understood concerning on the religious practice of the elderly, and they did it. On the one hand, some families missed to concern religious needs of the elderly. Exploring religious of the elderly, and encouraging family to support were occurred.

Recognizing of elderly and their families' spirit is essential. Therefore, emphatic understanding of an individual's experience provides for understanding the human experience of death and dying. Moreover, the elderly were derived comfort from their religious or spiritual belief as they faced the end of life.

3. Guiding complementary and alternative care

Most situations found that the caregivers tried to give the elderly as much food as possible. In addition, one Thai cultural belief is that if a sick person is still able to eat this shows that their health is recovering. However, everyone who was at the end of life had problems with the symptoms in their body, and this made the caregivers worry. Hence, other members of the family provided alternative care which helped to ease the worry of the family members who dealt directly with the elderly family member in the palliative stage. Complementary and alternative cares were implemented, including: prayer, meditation, therapeutic arts (music), humorous talk, reminiscence therapy, herbal medicine, and nutritive food.

Factors influencing the ideal set of nursing care activities

The main factors influencing the ideal set of nursing care activities for home-based palliative care were described in two parts: (1) supporting factors and (2) inhibiting factors.

Supporting factors

Several supporting factors influencing the development of an ideal set of care activities for home-based palliative care were described as involving: (1) caregivers; (2) family support; (3) community support.

1. Caregivers

Caregivers’ factors to support developing an ideal set of nursing care activities for home-based palliative care were described as involving: (1) deliberating on providing the best care; (2) maintaining positive attitude towards care; (3) reporting care outcomes.

1.1 Deliberating on providing the best care

In Thai culture, a previous review found that an extended family with strong family ties is a unique aspect of Thai families (Nilmanat, 2016). And most caregivers are direct relatives of the family such as adult child and grand children. However, many families in this study were a single family. Yet, the relationship between the elderly family member and family caregivers remains as ever a social kinship relationship that is knitted by loving kindness and compassion. Hence, family caregivers were deliberating on providing the best care for their loved one. Because they believed that proving care for a parent was to repay the elder's kindness.

1.2 Maintaining positive attitude towards care

As mentioned, family caregivers deeply understood the nature of their loved one regarding the elderly patients. Hence, family caregivers were emphatic to the reason and cause regarding any behaviors that occurred because of the elderly family member's behavior towards them. Providing the care was based on love, acceptance, and an understanding of the characteristics of the elderly family member. These involved caregivers maintaining a positive attitude toward care.

1.3 Reporting care outcome

In each visit, the elderly family member and their family caregiver reported symptom progression, the ability to manage problems, including overall care outcomes. Being disciplined was progressively reported as being involved in the care activities each time. Moreover, caregivers' awareness on improving the quality of care for the elderly family member was also reported, which is due to the hope of relieving the suffering of their elderly family member.

Table 8 *Nursing care activities for enabling family environment to promote spiritual well being*

Action	Quotes of nurse enabling family environment to promote spiritual well being	Evaluation
Enhancing social interaction	The situation of the female elderly who isolated herself from the family # 9 “Did you see someone else calling your wife, she did not open her eyes, but when you call once, she open her eyes immediately” (nurse)	“Today I made soup for my wife, she ate a lot and she can smile” (A 62-year-old man, the caregiver of a 69-year-old wife with lung cancer)
	The situation of the female elderly person who is crying all the time is from knowing about the diagnosis of cancer # 6 “You can touch her hands and arms, she needs your support” (nurse)	“They came to talk to my husband almost every day after going back to school” (A 72 year-old woman, the caregiver of a 75-year-old husband with dementia)
Encouraging religious/faith activities	The situation of the elderly need to listen to prayers as well as pray in their faith “Your wife needs to listen to the prayers of Guan Yin” “If possible, you can pray to Guan Yin to your wife”	Family caregiver fulfilled faith activities for the elderly family member. For example, family caregivers put a talisman of Guan Yin on her chest, for her safe health, and he prayed and brought beads for her for praying.
Guiding complementary	The situation found the caregiver is worried about the nutritional status of the elderly family member. Nurse educated the family caregiver as following. 1. Educated on the digestive mechanism system in the end of	One week later, the caregiver sought a herb and a soup for the elderly family member. “I took the fish soup for my wife; it can help her eat rice more. This is from a monk (Green

Action	Quotes of nurse enabling family environment to promote spiritual well being	Evaluation
	life for the family caregiver's understanding. 2. Recommended not forcing as much food as possible on the elderly person. 3. Explained that in the end of life, getting a saline solution intravenously cannot help. On the other hand, the body's chemical systems create the body to sleep, relax and reduce pain. 4. Asked questions about the foods that the elderly family member eats, as well as recommended foods or foods that the family thinks can help the elderly family member eat. "What types of food does the elderly person have?" "You can ask your wife. What do you want to eat? What other food has the family arranged for your wife?	bottle in green and back color, this medicine is good for my wife as it will help her to sleep well and reduce her pain, it is tongue drops to use" (A 62-year-old man, the caregiver of a 69- year-old wife with lung cancer)

2. Family support

Family support factors influencing the development of an ideal set of nursing care activities for home-based palliative care were described: (1) respite care support; (2) financial support; (3) psychological support.

2.1 Respite care support

Sometimes, the caregivers were not able to take time out such as when they got sick, or needed a rest, and/or joined in with social activities, and other family members being available to take care of the elderly person.

2.2 Financial support

Other family members who were not involved in providing care to the elderly family members worked in other places or they were not able to care for the elderly family member for many reasons. However, they were willing to pay monthly money to support the caregivers and the elderly family member. Moreover, the family members supported payments for medical supplies such as diapers, nutrient supplements, and suction tubes.

2.3 Psychological support

Psychological support was perceived by the family. Caregivers were overwhelmed from providing care over time. It helped caregivers had a high amount of energy. Sometimes they cried, felt tired, and depressed. However, they perceived this support from their families such as encouragement, positive communication, counseling and travel.

3. Community support

Community support factors influencing the development of an ideal set of care activities for home-based palliative care were described: (1) neighborhood; (2) primary care staff; (3) palliative care staff; (4) healthcare volunteer.

3.1 Neighborhood

According to the single families, most of them did not have an adult child to provide care for the elderly family member. The spouse was the caregiver and the elderly family member's care was dependent on the ability of their spouse to do that. Some care activities they could not do. For example, they should see the doctor at the hospital to follow-up the treatment, but they did not have family members to help them to get there, and their spouse had physical problems so that they could not go to the hospital. Hence, the neighbors were willing to help them to receive treatment both at the hospital and the primary care center. Moreover, when the elderly family member stayed at home and they needed some help, neighbors were available to help out such as with a haircut, help the elderly family member keep walking, and with kidney dialysis.

3.2 Primary care staff

Primary care staff support for the elderly at home is provided by the universal health coverage package (National Health Security Office, 2015) and this includes health care services and social services. Health care services consisted of screening and the assessment of care needs and home-based care, nursing care, rehabilitation, and medical equipment. While, social services consisted of helping with housework and assisting in daily care activities.

Even though there are many patients patients at the palliative stage received health services from primary care staff at home such as health assessments, home visits, and treatment. In addition, primary care provider had to service the medical devices such as the hospital bed, suction machine, and oxygen tank.

3.3 Palliative care staff

Even though the primary care center did not have palliative care staff, primary care provider visit people who had needed palliative care at home. Palliative care staff that came from Hat Yai Hospital had the ability and privilege to provide advanced nursing. For example, they used a syringe driver of morphine in patients who had severe pain.

3.4 Healthcare volunteers

Healthcare volunteers took care of patients in their own area of responsibility. The duty of the healthcare volunteers was to visit the home to assess in helping on the care needs of patients. They tried to service community resources and patients' right such as disability rights and elderly rights.

Inhibiting factors

Inhibiting factors influencing the development of an ideal set of nursing care activities for home-based palliative care were described as: (1) caregivers; (2) family system; (3) social system.

1. Caregivers

Most caregivers were of an older age, and they had an illness. The age range of the caregivers was from 66 to 75 years old. On the one hand, they had illnesses such as hypertension, diabetes mellitus, and osteoporosis. Therefore, aging and their illness affected the quality of care and induced care burden. Because, providing care for the elderly particularly palliative care at the end of life stage made the caregivers feel overwhelmed, overworked, and the activities upset daily life because of providing care around the clock.

2. Family system

The family systems related to the development of an ideal set of nursing care activities for home-based palliative care were: (1) family conflict; (2) financial problems.

2.1 Family conflict

Some families had conflicts between the caregivers and family members. These conflicts were: disagreement on treatment and unhappiness in the commissioned role of a caregiver. Firstly, caregivers agreed on using medical treatment to sustain life, while family members disagreed. Caregivers explained that they wanted to live with their loved one for as long as possible but other family members did not want to see the suffering of the elderly family member. Secondly, the caregiver role was selected by most family members and considered by the ability to provide for the elderly family member such as the daughter role, care giving skills, and having a good relationship with the elderly family member.

2.2 Financial problems

Financial problems were found in some families. It was a barrier to providing care at home because some medical supplies were not free to use such as dippers, gauze, and suction tubes. In addition, daily expenses were a financial problem such as going to the primary care center/hospital, cooking, and excessive treatment.

3. Social system

The social system influenced the development of an ideal set of nursing care activities for home-based palliative care and was described as: (1) communication conflict between family and staff; and (2) cultural taboos on death and dying.

3.1Communication conflict between family and staff

In the initial phase, there was a lot of communication conflict between the family and staff. Caregivers did not know the prognosis and they feared their elderly family member’s symptoms would cause suffering including not being able to manage the symptoms when they occurred. The nurse should give information on disease process, prognosis, symptoms, and educate in symptoms management. The worry about symptoms and the suffering of the caregivers and their family should be dealt with by using communication techniques such as emphatic understanding, and support which can help to reduce conflict between family and staff.

3.2 Cultural taboos on death and dying

Talking about death and dying has not been easy in Thai culture. Using questions regarding death and dying were avoided. A Thai cultural belief is that talking of death and dying is curse to a patient. However, opening discussion of this issue can help the nurse to get the participant to talk with an open mind.

Evaluation of the ideal set of nursing care activities for home-based palliative care

The evaluation of the ideal set of nursing care activities for home-based palliative care was measured by using outcome evaluation questionnaires, which consisted of the Palliative Care Outcome Scale, the preferences of the elderly and their surrogates for advance directives at the end of life, the caregivers' capabilities in responding to the spiritual needs, and caregiving burden. The aforementioned outcome evaluation questionnaires were measured both before and after the implementation of an ideal set of nursing care activities, and were compared.

1. Care quality

The findings revealed that the mean score on care quality was 19.66 (SD=6.10) before the model's implementation, and this was improved to 10.56 (SD=5.00) after the model's implementation. Details are presented in the table 9 and figure 8.

Table 9 *Comparison of care quality for caregivers before and after the implementation*

	N	Mean	SD	Median	Interquartile Range	*Z*	*p*
Before implementation	10	19.66	6.10	18	9	-2.668	.008*
After implementation	9	10.56	5.00	10	8.5		

*Wilcoxon matched pair and signed ranks test

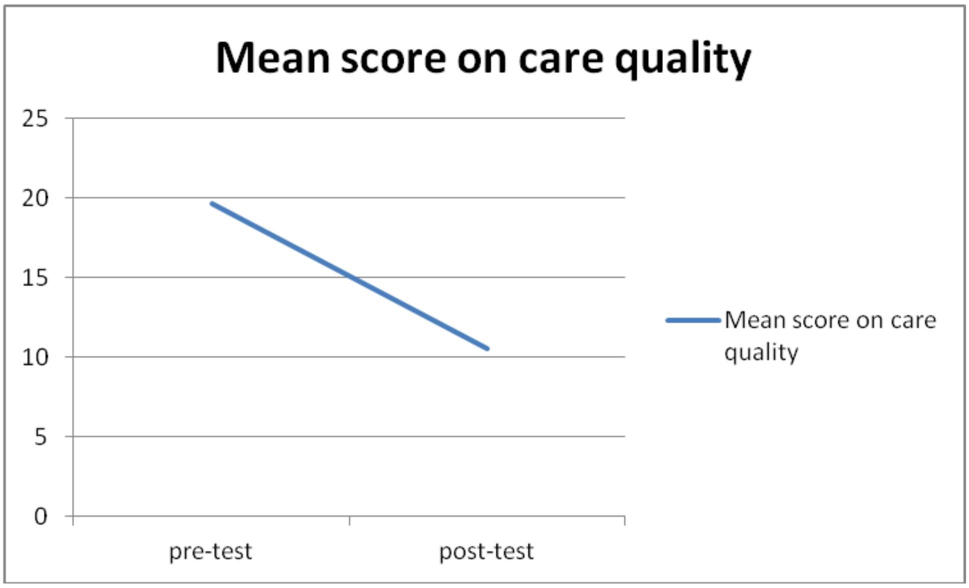


Figure 8 *Comparison of care quality for caregivers before and after the implementation*

2. The preferences of the elderly and their surrogates for advance directives at the end of life

The findings revealed that the mean score on the preferences of the elderly and their surrogates for advance directives at the end of life was 3.60 (SD= .61), the need for an advance directive was at a high level before the model’s implementation, and this was improved to 2.06 (SD= .5), and the need for an advance directive was at a moderate level after the model’s implementation. Details are presented in table 10 and figure 9.

Table 10 *Comparison on the preferences of the elderly and their surrogates for advance directives at the end of life before and after the implementation*

	N	Mean	SD	Median	Interquartile Range	*Z*	*p*
Before implementation	10	3.60	0.61	3.47	.96	-2.805	.005*
After implementation	10	2.06	0.50	2.09	.85		

*Wilcoxon matched pair and signed ranks test

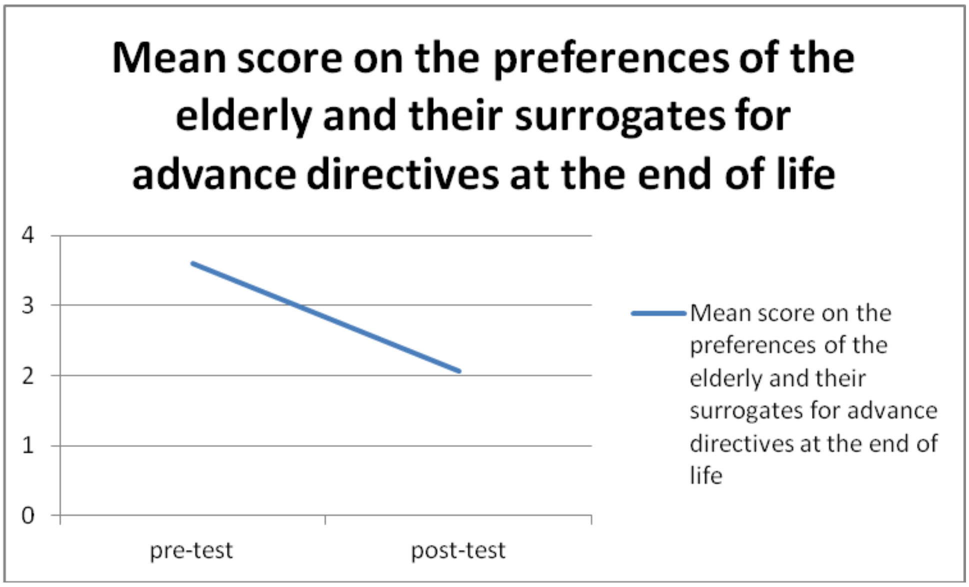


Figure 9 *Comparison on the preferences of the elderly and their surrogates for advance directives at the end of life before and after the implementation*

3. The caregivers' capabilities in responding to the spiritual needs

The findings revealed that the mean score on the caregivers' capabilities in responding to the spiritual needs was at a high level both before and after implementation. The mean score before implementation was 4.27 (SD=0.93) and this was improved to 5.25 (SD=0.49) after the model's implementation. Details are presented in table 11 and figure 10.

Table 11 *Comparison on the caregivers' capabilities in responding to the spiritual needs before and after the implementation*

	N	Mean	SD	Median	Interquartile Range	*Z*	*p*
Before implementation	10	4.27	.93	4.42	1.60	-2.603	.009*
After implementation	10	5.25	.49	5.29	.94		

*Wilcoxon matched pair and signed ranks test

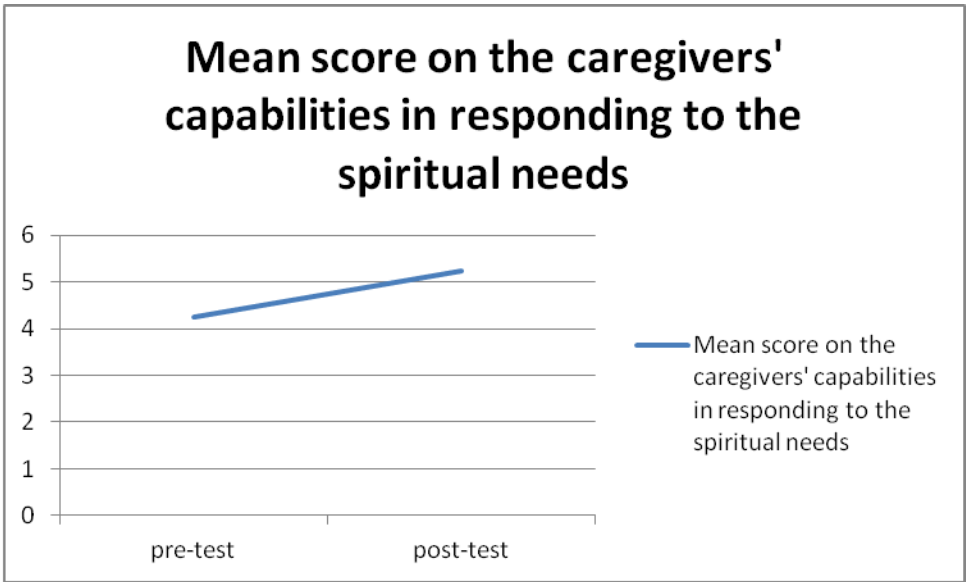


Figure 10 *Comparison on the caregivers' capabilities in responding to the spiritual needs before and after the implementation*

4. Caregiving burden

The findings revealed that the mean score on caregiving burden was 31.40 (SD=20.96) (mild to moderate caregiving burden) before the model's implementation, and this was improved to 17.80 (SD=18.06) (little or no caregiving burden) after the model's implementation. Details are presented in table 12 and figure 11.

Table 12 *Comparison on caregiving burden before and after the implementation*

	N	Mean	SD	Median	Interquartile Range	*Z*	*p*
Before implementation	10	31.40	20.96	30.00	31.50	-2.803	.005
After implementation	9	17.80	18.06	11.00	27.00		

*Wilcoxon matched pair and signed ranks test

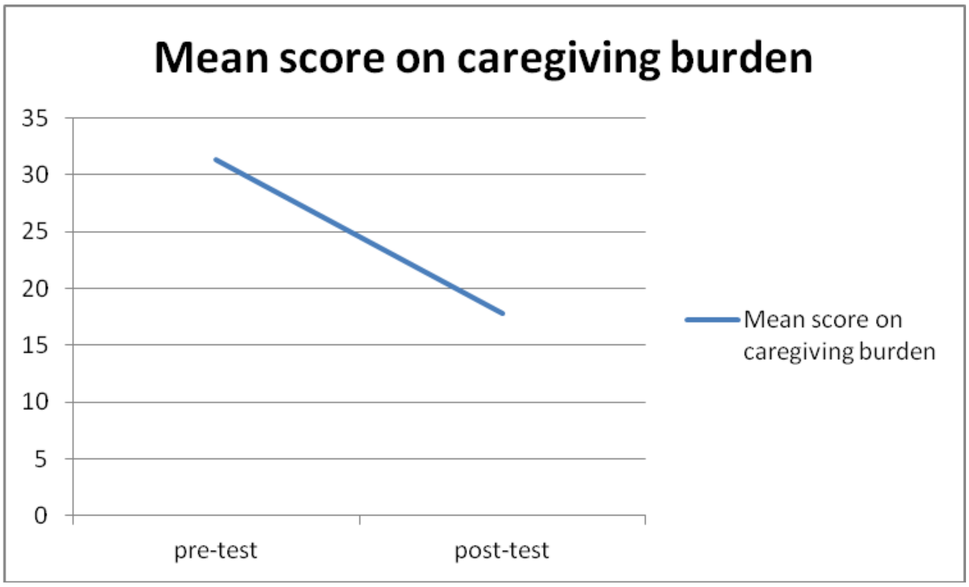


Figure 11 *Comparison on caregiving burden before and after the implementation*

Discussion

The discussion section is divided into five parts: 1) context of study 2) caregiving burden on family caregivers 3) set of nursing care and care activities for the elderly, 4) outcomes of care and 5) lessons learned.

Context of study

The elderly in palliative stage The elderly participants were cancer patient, end-stage organ failure, and frail elderly/dementia/Alzheimer. Their monthly family incomes came from family members who had high income. The majority of elderly participants were covered by universal health care coverage. Their monthly family incomes came from family members who had high income. According to reconnaissance phase found elderly and their family caregiver expected that home visits from health care providers for fulfilling their needs.

The elderly with organ failure and prolong dwelling lived with their illness long time than cancer group, therefore, they familiar with their illness and accepted death when being at the end of life than cancer group. However, some organ failure and prolong dwelling elder persons perceived death when into a crisis situation, while, cancer elder persons perceived death since they had been diagnosed.

The family caregivers More than half of the family caregivers were women (daughter, wife, and sibling). Four were men (adult child, grandson, and husband). According to reconnaissance phase found all family members agreed that this person was the most suitable to provide their loved. 1) good relationship with the elderly and 2) provide better can than others.

According to reconnaissance phase, the themes of caring to repay elders' kindness that emerged from the data were giving unlimited care and providing unconditional care. Family caregivers were adult children providing unconditional care rather than a spouse or sibling because they expressed that parents and grandparents gave life.

A key finding was that family caregivers providing care considered their role e.g. child role, wife role. However, providing care with love and bonds was significant more than their role. In addition, good care was depended on good relationship between the elderly and caregivers in the past.

This theme of repaying elders' kindness was congruent with the study of Hemman Nilmanat and Matchim (2017). The result of the study described Muslim caregivers' experiences in caring for patients with end-stage renal disease receiving palliative care. The theme of the living relations were categorized on 1) taking care on the basis of love and bonds, 2) repaying gratitude, 3) those surrounding the patient are important, and 4) being a bridge between God and the patient.

Seven were elderly (wife/husband, sibling), and most often had deteriorated health and chronic diseases. They had feeling care burden and impact to quality of care. Three of them were in adulthood and they left a job to take care their loved one. Caregivers lost incomes and occupational role. Some caregivers can be able to maintain both caregivers' role and occupational role. Most family caregivers had a higher educational up to a master's degree. Therefore, they can be able to find caring resources and information to help them to provide the elderly.

The caregiving burden on family caregivers

The caregiving burden of caregiver was revealed in two patterns: well and poor adaptation to the care burden. These patterns can be explained as follows.

Firstly, most well adaptation group were adult child and they had more experience on care giving skill. They expressed that they cared to repay an elder's kindness is the role of a child and it expresses their gratitude. In addition, they cared to their loved one because of providing unconditional care by love. However, some caregivers felt losing their role. For example, they left a job to take care their loved one and some caregivers maintain both caregivers' role and occupational role together. Even all family members agreed that this person was the most suitable to provide the elderly but some caregivers were not willing to accept in their role.

Secondly, according to reconnaissance phase, the burden on family care burden usually found in the elderly caregivers. Most often had health problems and chronic diseases. Caregivers had chronic diseases such as hypertension and osteoporosis. Health problems were caused from taking care to the elderly such as back pain and chest pain. They had feeling care burden and impact to quality of care, because they undertook caregiver role that overwork.

This result was consistency with study of Limpawattana and colleagues (2013) found that health statuses among caregivers were affected on caregivers' physical health problems and care burden. That study also found that caregivers had a high caring burden caused by as a result of caring for dementia, advanced cancer, and cerebrovascular patients. In financial burden, this result was congruence with the study of Girgis and colleagues (2013) which found that long-term financial impacts of care giving include a loss of savings for retirement of family caregivers. On the one hand, eighty-six percent of family caregivers reported that their incomes were not enough, and they had to find the work that created at home (Limpawattana et al, 2013).

Set of nursing care and care activities for elderly

There are three sets of nursing care activities for elderly in this study: 1) mutual understanding on care requirements, 2) skill building in caregiver roles, and 3) enabling the family environment to promote spiritual well being. These can be discussed as following.

Mutual understanding on care requirements.

The home-based palliative care services have been developed to meet the needs of the patients in terminally ill at home with physical symptoms and distress (Dhiliwal & Muckaden, 2015). The outcome of home-based palliative care was differing from hospitalization through patients and their family counseling, empowering the family and performing simple palliative care procedure.

Mutual understanding must be established first because elderly and caregivers would be known about what needs to be done (Loghmani, Borhani & Abbaszadeh, 2014). Performed mutual understanding would help nurse and caregiver to design nursing care activities and improve quality of care (Loghmani, Borhani & Abbaszadeh, 2014). King (1981) proposed that mutual understanding on care requirements were nurse-client interaction, which their shared perceptions or understanding will influence on the interaction process.

There are evidences to support using mutual understanding which involved both the nurse and patient in planning of their care on goal achievement by Cheng (2017) and Cheng (2018).

Care activities of mutual understanding on care requirements

Nursing care activities for enabling mutual understanding on care requirements are 1) exploring elderly care demands, 2) reflecting on care ability to meet demands and need to perform care actions and 3) maintaining awareness on elderly and caregivers' demands.

1. Exploring elderly care demands

Exploring elderly care demands must be done first because nurse needs to be able to understand the elderly person's and caregivers' perspective requirements to improve care (Riessman, 2008). During the process of dying, time is limited and there is only one time (death) of life. The participants in this study were vulnerable group. Hence, exploring elderly care demands should be done with caution. Participants were asked by asking general question first because it made developing trust and respect of person (Sukmak, 2014). After that, in-depth interviews were done later and care demands were identified towards spiral phases of action research.

2. Reflecting on care ability to meet demands and need to perform care actions

Care demands were reflected for participants to acknowledge, and they could view that their demands can be performed as by the actions (Bainbridge, Bryant, & Seow, 2017). Reflecting can be help participants continue to be responsible for continuing to know and the meeting of appropriate nursing care action (Thiamwong & Pungchompoo, 2018).

Reflection helped participants to understand the process of care in the palliative phase by mutually defining and identifying problems and needs. This should help to identify what is important here. Reflection is understood as an assessment of *how* or *why* participants should have perceived, thought, felt, or acted, it must be differentiated from the assessment of *how best* to perform care actions which is guided by what we have learned before (Silva & Santana, 2009).

3. Maintaining awareness on elderly and caregivers' demands

Maintaining awareness on elderly and caregivers' demands were done finally on *the mutual understanding on care requirements*. Participants got to know why they were performing care actions. Participants were informed of the effect of care demands on their lives (Berlin, 2017). Hence, crucial factors that related to improving care activities should be derived from participants' needs, therefore, the continuity of deliberate care occurred and sustainable (Cheng, 2017).

According to the theory of self-care (Orem, 2001), Orem was concerned that the awareness of a person is related to a person performing self-care in two sets: 1) estimate or investigate what can and should be done, and 2) decide what can be done, and produce the care. Two sets were a complex action of knowing and seeking information on specific care that should be done because the elderly and the caregivers' demands have an impact and are necessary for the life, health, and well being of the elderly and family caregivers.

Skill building in caregiver roles.

Care giving role for the elderly in palliative stage is a secondary role (Gitlin & Wolff, 2012). The role can be acquired through learning on caring skills responding to the care requirements (Johnson, Fieler, Jones, Walasowicz, & Mitchell, 1997). Caregiver role assist the elderly and they help every day in big tasks. They understand to provide comfort and dignity to their loved one at end of life phase. Role of family caregivers are continual problem solving, decision making, communication with other (family members and health care providers), and constant vigilance over the care elder's well being (Gitlin & Wolff, 2012).

Develop care giving skill can improve patient's symptoms, and it has potential to decrease care giving burden related to role changes and improve caregiver quality of life (Waldron, Janke, Bechtel, Ramirez & Cohen, 2013). In addition, caregiving skill can improve caregiver knowledge, confidence and self-efficacy, in turn, benefits both caregivers and patients (Mollica, Litzelman, Rowland & Kent, 2017).

The set of nursing care activities of skill building in caregiver roles is congruent with the study of Linstrom and Melnyk (2013). This study revealed increases in caregiver activity, caregiving preparedness, and family confidence. Wang and colleagues (2012) conducted skills training program for the family caregivers of dementia people. The evaluation showed improvement in distress and quality of life compared to the control group. Another result found that caregivers had better outcomes in bodily pain, role disability due to emotional problems, vitality, mental summary score, and reduced risk for depression.

Care activities of skill building in caregiver roles.

The care activities of skill building in the caregiver's role can be divided into four stages: 1) assessing and managing caregiver's stress before skill building in the caregiver's role, 2) information giving on disease process, prognosis, illness trajectory, health services and community resources, 3) mutual goal setting, planning, designing care activities, and 4) promoting continuing of care. Each stage can be discussed as followings.

1. Assessing and managing caregiver stress

Before building caregivers' skills, caregiver stress was assessed and managed. Caregivers' psychological problems should be solved, because learning to develop caregiver skills requires concentration. The ability to develop skills in caregivers who are solved on psychological problems is better. Therefore, skill building can be able to improve quality of care and reduce care burden (Babara & Reinhard, 2017).

The caregiver role may lead to increased psychological and physical morbidity. Caregivers' responses to providing care depend on the complexity of care, and changes in the elder's condition. Stressful situations and extensive sets of tasks and changes, plus emotional stressors, can cause caregiver exhaustion (Given and Reinhard, 2017). As well, distress from realizing the elderly family member is at the end of life may interfere with caregivers' abilities to make decisions and convey quality care for their loved ones (Kramer and Boelk, 2015). Caregivers need to effectively assess and manage their caregiving stress for quality of care.

Caregivers are expected to perform quality of care. Many caregivers reported low preparedness for end-of-life care and often indicated they did not have the knowledge and skills needed for providing care. Caregiving stresses related to the end of life, and this phase becomes an especially difficult time for caregivers who may be at risk of becoming ill as care demands exceed their resources and capacities (Given and Reinhard, 2017).

Theory of stress and coping by Lazarus and Folkman (1984) has laid out the ground for understanding caregivers and families' responses to supporting the elderly with palliative and end of life stages. This theory has been used to understand the issues' related to end-of-life care from the psychological point of view. It has been used to detect caregiving stress that impacts on caregivers. It has been encouraged to be used as evidence based practice in palliative care research for implication to caregivers which are diverse and their various appraisals, which is how they perceive their caregiving role and the recourses available to them.

The activity of assessing and managing caregiver stress is congruent with the study of Empeno and colleagues (2011), in which they provided for family caregivers to reduce caregiver stress. The result of the study revealed that family caregivers experienced decreases in caregiver stress. In addition, Janse and colleagues (2014) used a case management intervention to reduce care burden and increase quality of life among family caregivers of frail elderly persons, and the result revealed that care was reducing burden between group, and there was improvement of quality of life in the intervention group.

2. Information giving on disease process, prognosis, illness trajectory, health services and community resources

Bereaved family caregivers are more likely to rate highly if they were regularly informed about their loved one's condition such as cancer and end of life phase. If they were informed about the disease process, prognosis, and illness trajectory, their emotions were supported and they were able to readily manage their loved one's care (Fine & David, 2017). Elders' and family caregivers' readiness to discuss disease process, prognosis and illness trajectory was variable; depending on factors which included exposure and adjustment to the disease, coping style and spirituality (Walczaka, Butowa, Tattersalla, Davidsonc, Youngd, Epsteine, & Claytona, 2017).

The majority of the patients agreed that it is crucial to talk and discuss the prognosis with the patients in practice. The core reason for doing so is a belief that it is honest and equally crucial to inform both patients and families on illness trajectories and treatment possibilities and limitations so that they can adjust their expectations (Siouta, Clement, Aertgeerts, Beek., & Menten, 2018).

The care activity was congruent with the study of Walczak and colleagues (2017). They encouraged a communication support program to discuss the prognosis of the patient being at the end of life. The result revealed giving significantly more cues that they wished to discuss prognosis, end of life care, future care options and general issue during consultation. However, the family caregivers expected that the elderly can get well if their loved one received advanced treatment. This issue was congruent with the study of Walczak and colleagues (2015). They reported that despite discussion with the nurse about the benefit of early discussion of prognosis and end of life issues even when death is not immediately imminent, participants may have believed that they were still too well or had additional treatment avenues to explore before end-of-life issues were relevant.

Giving information on health services and community resources were established to help the elderly stay in the comfort of their own homes during the final stage of life, as it improves elders' quality of life, increases satisfaction and reduces the burden on the healthcare system (Yu, Guerriere., & Coyte, 2015). Information giving on health service and community resource is congruent with the study of Sangjune, Yunak and Tangkawanich (2015). They developed village health volunteers' potentiality program. The program was provided for stroke patient at home. The stroke patient was informed about caring for stroke patient and accessibility emergency health service. The study showed that village health volunteers' assisting behaviors scale in caring stroke patient higher than the score before the program started.

Recently, resources to support the elderly at home are provided by the universal health coverage package (National Health Security Office, 2015) includes health care services and social services. Health care services consisted of screening and assessment of care needs and home-based care, nursing care, rehabilitation, and medical equipment. While, social services consisted of helping with housework and assisting in daily care activities.

However, the home-based palliative care was not enough cover in some things, and most of the elderly and their caregivers did not know about the right of the universal health coverage package at home. Hence, they were informed and encouraged on health services in order to be treated equally and they were entitled to get these rights.

3. Mutual goal setting, planning, designing care activities

Mutual goal setting, planning, and designing care activities were agreed to by the participants which may lead to improved quality of life and goal attainment (Parsons, Rouse, Robinson, Sheridan, & Connolly, 2012). These are required care activities between nurses and participants in communicating the explicit goal of care. Importantly, the goal of care that is mutually agreed to by both nurses and participants was defined as a clear direction for both parties to make success easier. Therefore, the process of setting mutual goals encouraged the discussion of personal strengths, abilities, and the needs of the participants. On the one hand, mutually agreed goal setting facilitates the prioritization of concern and resources for nurses and participants to achieve the care goal (Yuri, Takabatake, Nishikawa, Oka, & Fujiwara, 2016).

The finding suggests that the participants achieved improved care quality, since the achievement of care goals reflects a state of improved care activities. The results are consistent with previous studies that setting goals in agreement with patients brought about positive change in self-care behaviors of older people (Cheng, 2017), and pain management strategies of older people with rheumatic disease (Davis & White, 2008).

Solari and colleagues (2015) develop home-based palliative care program for people with severe multiple sclerosis and their caregivers. Participants in an intervention group were visited by home-based palliative approach team 2/month, more if need in the first phase. The team visited participants 3 month follow up (based on dyad need). In 6 month follow up, participants were interviewed semi-structure and met focus group by physicians. Home visiting depended on the intensity of care and type of symptom (for example physician for pain management, nurse for bed sore treatment). The findings revealed that reducing on symptoms and increasing quality of life of patient, reducing care burden and increasing quality of life on caregivers.

4. Promoting continuing of care

Promoting continuity of care can help the elderly to reduce costs and have better health outcomes. It is associated with lower rates of emergency department visits (Simmonds, Glogowska, McLachlan, Cramer, Sanders, Johnson & Purdy, 2015), decreased hospital deaths (Almaawiy, Pond, Sussman, Brazil & Seow, 2014), and supportive needs being met (Husain, Barbera, Howell, Moineddin, Bezjak & Sussman, 2013). Continuity in palliative care gives roles in providing comprehensive and compassionate full personal care for the elderly who are terminally ill.

The three major attributes of continuity of care described by D’ Angelo and colleagues (2015) are namely relationship, communication and comprehensive integrated care. According to the concept of continuity of care (Freeman, Sheppard, Robinson, Ehrich., & Richards, 2000), management continuity was crucial to the practices. Nurses emphasized sharing information, good communication within parties and establishing healthcare service systems that supported effective elder person management.

The result of this study is congruent with the study of Eerden and colleagues (2017), in that they found the needs of patients and their family caregivers to maintain relational continuity, however, at primary care level services few health care professionals were readily available to collaborate. Additionally, both hospital/palliative care specialists and physicians should take that responsibility. Furthermore, this finding demonstrated that although the elderly and family caregivers needed and expected to receive multidisciplinary collaboration, informational and management continuity (Richardson, Wagland, Foster, Symons, Davis, Boyland & Addington-Hall, 2015).

Promoting continuing of care is congruent with the study of Man ng and Wong (2018). They developed home-based palliative heart failure program. The program was based on four transitional care features: comprehensiveness, collaboration, coordination, and continuity of care. The structure of the program included post-discharge home visits and telephone calls delivery by nurse case manager. The findings revealed that significantly increase quality of life in experimental group than the control group. The experimental group had higher satisfaction and lower caregiver burden than the control group.

Enabling family environment to promote spiritual well being.

For persons with end of life phase, even though their physical health continue to decline, but their psychological health is still able to recover from illness and agitation, and they can remain claim even at the end of life (Visalo, 2014). Promoting spiritual well being helps to develop patients' wisdom in order to understand the law of nature and the truth of life in order to accept what is happening of that moment, being able to let everything go, and being able to perceive their value (Chimluang, Thanasilp, Akkayagorn, Upasen, Pudtong, & Tantitrakul, 2017).

According to reconnaissance phase, promoting spiritual well being needs to enable in the family environment because family members emphatic understand on elders' need and they can be able to provide the best spiritual care than others. When illness or dying occurs in family, it can impact on all other parts of family. Family member can share cultural belief and have been shown to be effective in meeting the needs of elderly (Tan, Wilson, Olver & Barton, 2017).

Spiritual belief can provide to comfort elder person who are struggling with terminally ill, and it offers hope of life after death, which can be comforting (Hilton &Child, 2014). Spirituality related to the end of life was addresses by the international Work Group for Death and Dying (1990). The principle of spirituality is related the transcendental, inspirational and existential ways to live one’s life. The spirituality can be control over aspects of health. Spirituality is a crucial dimension of humanity. Every person has a spiritual dimension in addition to physical, psychological and social dimensions. No dimension can be influenced without affecting the whole person, and the whole includes spiritual aspects (Loseth, 2002).

The finding from this study was congruent with Chimluan and colleague (2017) and Rattanil and Kespichayawattana (2016), who found that Buddhist spiritual care could increase spiritual well being among elderly patients. Additionally, Sankhe Dalal Agarwal and Sarve (2017) evaluated the effect of spiritual care on the spiritual well being of cancer patients and their family caregivers, and they found that there were significant increases in the score at all the follow up times when compared to the control group.

Care activities of enabling family environment to promote spiritual well being.

The care activities of enabling environment to promote spiritual well being can be divided into three parts: 1) enhancing social interaction within the family, 2) encouraging caregivers to practice religious/faith activities, and 3) promoting complementary and alternative medicine. In each care activities were discussed as followings.

1. Enhancing social interaction

In Thai culture, Thai males often do not talk or express love. However, encouraging the expression of love between the elderly and their family caregivers can reduce the isolation between them. Promoting social interaction can help to foster hope and self-fulfillment and this means the elderly were enabled to improve their mood and foster a sense of achievement and belonging (Payne, Hartley., & Heal, 2008).

Social interaction relates to the fundamental and universal needs of belonging (Patrick, Knee, Canevello., & Lonsbary, 2007). The importance of feeling connected to other persons is strongly relayed to safety and basic physiological needs (Maslow, 2011). In addition, social interaction is defined as the ongoing momentary affective experience of belonging, based on awareness (the sense of being in touch and sense of involvement and sharing) and appraisals of social relationships and interactions (van Bel, Smolders, Ijsselsteijn., & de Kort, 2009). Social interaction helps people to feel as if they belong and have a part to play in a society, and it makes people feel safe and promotes well being in their lives (van Bel, Smolders, Ijsselsteijn., & de Kort, 2009).

2. Encouraging religious/faith activities

The activity of encouraging religion/faith contributed to making the elderly people have more peace and self-worth, as well as a better understanding of the truth of life. Consequently, the elderly were ready to use their wisdom to understand the truth of life, accept their illness, and accept whatever unpredicted circumstances arose. As a result, the elderly had spiritual contentment and enhanced spiritual well-being (Chimluang, Thanasilp, Akkayagorn, Upasen, Pudton & Tantitrakul, 2017). Hence, the nurse should understand the basic religious/faith principles of practice to facilitate, and the nurse should encourage practicing religious/faith activities that the elderly need.

People being at the palliative stage need psychological care as much as physical care because even their physical health continues to decline but their psychological health is still able to recover from illness, and they can remain calm even at the end of their lives (Visalo, 2014). Hence, during the last phase, religious/faith practices may help to promote spiritual well-being, and these practices must develop the elderly family member's wisdom in order to understand the law of nature and the truth of life in order to accept what is happening at that moment, the letting go of everything, and perceiving their value.

All of the participants were Buddhist. Thoughts about death were based on the Buddhist doctrine (Nimanat & Street, 2007). Hence, the nurse promoted dignified dying by providing opportunities for the elderly and their families to discuss and manage family affairs. After that, the nurse encouraged the elder's family to say good bye, to show gratitude for the elder's life, and show their love to the dying elderly family member such as a kiss, touch, and positive talk.

The findings from this study were congruent with Rattanil and Kespichayawattana (2016), they found that Buddhist spiritual care could increase spiritual well-being among the elderly with terminal cancer. This research can help the elderly prepare and accept reality in the present and in the future, including learning about death and the dying process. Besides this, the findings were consistent with Suwanampa, Kespichayawattana and Chimluang (2016). The study revealed increased personal faith and spiritual contentment through merit precept and meditation to gain spiritual well-being in patients newly diagnosed with cancer.

3. Guiding complementary and alternative care

According to feeding the elderly at the end of life, Thai people believe that being able to eat is healthy. Hence, the important role of a nurse is promoting life satisfaction and dignified dying appropriately by providing physical, psychological, and spiritual comfort (Kongsuwan & Touhy, 2009). Guiding complementary and alternative care is one of the ways that was used to help the elderly family member feel comfortable and helped family caregivers to reduce feelings of worry, anxiety, and it promoted self-care and compliance.

Several reasons were identified as why patients used complementary and alternative care: hope to improve physical symptoms, support emotional health, stimulate the immune system, improve quality of life, and reduce side-effects of conventional treatment (Poonthananiwatkul, Howard, Williamson & Rosemary, 2016). Hope to improve physical symptoms was a major reason as why patients use complementary and alternative care (Poonthananiwatkul, Howard, Williamson & Rosemary, 2016). Hope helps patients to cure their illness as well as to make them feel better, and it is fundamental in each one of these reasons (Puataweepong, Sutheechet & Ratanamongkol, 2012).

Complementary and alternative care was a positive attitude towards using it for the self-management of relieving symptoms. The finding of this study regarding diets derived from the use of herbs and soups was congruent with Place's (2005) description. Beside this, the dietary approaches that family caregivers provided to the elderly family members were congruent with the study of Pokpalagon and colleagues (2012). The family caregivers sought vitamins or dietary supplements for the patients.

Care outcomes

After implementation on three nursing care activities: 1) mutual understanding on care requirements, 2) skill building in caregiver roles, and 3) enabling the family environment to promote spiritual well being. Findings were emerged to evaluate by observing as: 1) fulfilling the elderly family member's needs and 2) improving the ability of care giving skills.

Fulfilling elderly needs

At the beginning of the research project, it was not easy to involve the caregivers and their families to fulfill the elderly family member's needs. In practice, different strategies must be used in each family depending on a family's perspective on dying. The process of three nursing care activities promoted awareness on a certain situation which would trigger proper rationales towards how to enhance their loving peace and to promote the elderly family member's good death. Encouraging dying at home by communication was not effective, proving and self-learning ability and confidence was how they could reduce the suffering of their loved one which is more important. If the family caregiver could get this point of relieving the suffering of the elderly family member, they could fulfill the elderly family member's needs and wishes completely.

Improving ability of caregiving skills toward end of life stage

Improving the ability of caregiving skills to pass the end of life stage must include: physical and psychological skills. The problems which family caregivers were confronted a complicated and dying process either solving problems or supporting decisions regarding care giving. The complications and dying were associated with family care giving result in increasing family burden with a significant impact on quality of care. Implication on three nursing care activities can help family care givers to systematic manage caregiving tasks. For example, one caregiver reflected on the evaluation of the intervention:

> "I learned how to provide care and gained knowledge from you, your knowledge improved the care for my mom, my experience may not be the best care, you are the professional but I am not, I have only experience to care. I gained new knowledge which improves the quality of care for my mom" (72 year son who is the caregiver of a 99 year old frail woman)

Lessons learned

While conducting this action research study, the researcher gained meaningful experiences. These occurred at all stages-while situation analysis, entering the research setting, starting the project, collecting and analyzing the data, and finalizing the findings. These valuable lessons are described as followings.

Conducting an action research study.The process of choosing the elderly, who were in the palliative stage and end of life and their family caregivers as the participants, was based on elderly family members who had different diseases and who were of various ages. The elderly family members were classified into three groups: cancer, organ failure, frailty and dementia/Alzheimer. Hence, palliative care in the elderly was not focused on cancer patients only but other groups were of equal concern. Many cases of elderly persons with organ failure, frailty and dementia/Alzheimer show that they also can pass away rapidly. The factors surrounding palliative and end of life care are often unforeseeable. These made the researcher realize that caring for the elderly is very complicated, and is influenced by many factors such as cultural, economic, family and personal factors.

Subsequently, the process of conducting this action research study among the three parties (elderly person, family caregiver/family and nurse) provided the researcher both challenges and opportunities to: emphatically understand the elderly family member and their family caregivers being at the palliative stage and end of life, concern, needs, expectations, problems and difficulties; to meet the participants together to find possible solutions, manage actual problems and coping with caregivers stress; facilitate communication and interaction among the participants that was very difficult in the dying process; enhance their self-care actions, nurse empowering actions by personal and critical reflection; follow the procedures of action research methodology; finally, help and coordinate with the elderly to fulfill their needs at the end of life.

Self-development of the researcher. Even though it was difficulty work for the researcher to conduct this action research study, she had acquired professional and personal interest in: palliative and end of life care competency, research competency and personality development.

Palliative and end of life care competency. Before the formal data collection, the researcher learned about palliative care and the palliative stage by various ways, for example, reading literature, training and participating in workshops on palliative care, being involved in the research project of the research center for caring of Thai elders. In the reconnaissance phase of this study, the researcher observed and learned caregivers' activities of caring for the elderly under their context in each family. In the subsequent phase, the researcher was able to constantly develop competency in palliative and end of life care.

Research competency. During data collection and analysis, the researcher was overwhelmed by the huge amount of qualitative data. Starting from verbatim transcripts of interview audio-recordings, and comments from critical advisors helped the researcher to overcome the barriers in data analysis.

Personality development. In reflecting on the process of conducting this study, the researcher had a huge learning curve in the study. Thanks to the inspiration, guidance and support from the advisors as well as support from family and friends, the researcher has gained in the development of her personality with more patience, and grit, to successfully achieve this study.

Development of nursing science knowledge. The nursing science knowledge gained from this study reflects the need to conduct action research to actual practice with the purpose of developing technical knowledge and evidence-based knowledge into practice and to improve practice. Action research focuses on taking action to resolve problems and needs through the cycle of planning, acting, observing and reflecting. In addition, the knowledge gained in this study assists in the development of suitable care for the elderly and their family caregivers according to the cultural context of the present society.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents the conclusion, implications of nursing, recommendations for future research and limitations of the study.

Conclusion

The action research method was applied in this study to develop an ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce caregiving burden among the family caregivers of Thai elderly persons. The study proposed to describe the process of the development of an ideal set of nursing care activities model and its influence on care quality and caregiving burden. There were 10 elderly persons and their family caregivers involved in this study.

The findings in the reconnaissance phase were presented as: 1) situation analysis of home-based palliative care for Thai elderly, 2) caregivers' perspective on improving care for Thai elderly persons in the palliative stage, and 3) caregiving burden among family caregivers. The home-based palliative care context were revealed in two aspects: (1) general care, including: performing routine activities, preventing complications, and preparing for emergencies; and (2) special care, including: fulfilling elderly needs, spiritual needs, psychological needs, expressing love, supporting emotions, practicing religion/faith, comforting and pain management.

The caregivers' perspective on improving care was emerged into three points of view: (1) caring to repay an elder's kindness, including: giving unlimited care, and providing unconditional care; (2) caring to minimize an elder's perception of being abandoned/a burden, including: doing something for what has never done, and caring better than the past; and (3) following the ancestral tradition for the elderly person to die peacefully, including: strictly performing religious activities based on the elderly person's condition, and caregivers making merit for the elderly for reducing their suffering from their illness.

The caregiving burden on family caregivers was revealed in two patterns: 1) feeling not being burden and 2) feeling being burden. The feeling not being burden expressed their major characteristics on: 1) worry about infection and 2) complications, and inadequate care giving skills. The feeling being burden expressed their major characteristic on: 1) unable to maintain social activities, 2) unable to maintain daily activities, 3) caring for the elderly has damageable on health, and 4) unable to express the elderly person's wishes at the end of life.

The ideal set of nursing care activities for home-based palliative care was formulated in three steps: 1) mutual understanding on care requirements, 2) skill building on caregiver roles, and 3) enabling the family environment to promote spiritual well being. Mutual understanding on care requirements consisted of: exploring elderly care demands, reflecting on care ability to meet demands and the need to perform care actions, and maintaining awareness on the elderly and caregivers' demands. Secondly, skill building in the caregiver roles consisted of: assessing and managing caregiver stress, information giving on disease process/prognosis/illness trajectory/health services and community resources, mutual goal setting, planning, designing care activities, and promoting continuing care. Finally, enabling the family environment to promote spiritual wellbeing consisted of: enhancing social interactions within the family, encouraging caregivers to practice religious/faith activities, and promoting complementary and alternative medicine.

Furthermore, the influencing factors that affected the development of an ideal set of care activities consisted of supporting factors and inhibiting factors. In supporting factors, there are three aspects that are related to these factors: (1) caregiver, including: deliberating on providing the best care, maintaining positive attitude towards care, and reporting care outcome; (2) family support, including: respite care support, financial support, and psychological support; (3) community support, including: neighborhood, primary care staff, palliative care staff, and healthcare volunteers. While, there are three parts that are related to the inhibiting factors: (1) caregivers, including: health (aging and illness); (2) family system, including: family conflict, and financial problems; (3) social system, including: communication conflict between family and staff, and cultural taboo on death and dying.

Finally, the outcome of this model had a significant effect on several variables: care quality, the preferences of the elderly and their surrogates for advance directives at the end of life, the caregivers' capabilities in responding to the spiritual needs, and caring burden.

Implication for Nursing

The implication of this study included nursing practice, nursing education, and nursing management.

Implication for nursing practice

This study provided essential care in the use of nursing care for the elderly and their caregivers in the palliative stage at home in Thai culture. The study proposes and assists the nurses in a primary care center in providing for the elderly and their family caregivers. It is encouraged that other primary care centers should develop similar care activities to serve as guidelines for nurses on their practice for patients and caregivers with palliative and end of life care. Currently, palliative care service in primary care for the elderly has been implemented via the long term care service system since 2015 (National Health Security Office, 2015). Hence, the ideal set of nursing care activities can be applied via long term care service system in primary care centers and one health promoting hospitals by nurses and care managers to visit home.

Implication for nursing education

In nursing education, professors can use an ideal set of nursing care activities for home-based palliative care to apply for teaching student nurses and academic services to the community and society. Therefore, there will be an improvement in the ability of caregiving skills for caregivers of the elderly at the palliative stage at home.

Implication for nursing management

Nurse managers in hospital and directors in primary care centers can encourage their colleagues to improve their knowledge on palliative care at home regarding an ideal set of nursing care activities for the elderly and their family caregivers. Health care provider will be trained to enhance their knowledge and skills of palliative care, which can then be applied to the knowledge in the area appropriate for improving service quality and patients' quality of life.

Recommendations for future research

The interview guideline is of concern and needs to be adapted further for better use in both the elderly patients and their elderly caregivers, for example, clearer language as well as symbols for easier understanding. According to reconnaissance phase, communicating conflict from cultural taboos is weakness point to discuss between elderly, their family caregiver, and nurse. Nursing strategies in interview guideline for talking about death and dying issues will be amended. Nurses should be trained communication technique about this issue carefully.

Beside, nurses visit patients at home, health care volunteers are team to assist patients in community. In this study, visiting by health care volunteers was an opportunity to develop care activities for home-based palliative care. health care volunteers will be involved in the future research, and they will be trained for gain palliative knowledge and skill.

Nurses and a researcher can use this model to apply to other groups of participants such as caregivers of children and adults with a terminal illness. In addition, a quasi-experimental study will be conducted in a future study. An ideal set of nursing care activities will be applied developing the program to provide accurate evidence on the effects of the model on care quality and caregiving burden.

Considering of technology readiness levels (TRL) and social readiness levels (SRL) in this study

Technology readiness levels: TRL

The purpose of using TRL is to help management in making decisions concerning the development and transitioning of technology. It should be viewed to manage the progress of research and development activity within an organization. According to development an ideal set of nursing care activities, this model is arranged in TRL level 3 (see table 13). The model is proceeded initially to develop the model that validated and analyzed for stakeholders using. In the future, this model will be developed towards TRL level 4 by stakeholders testing and validating. However, concerning on social readiness levels (SRL) is an essential for applying the model.

Social readiness levels: SRL

Societal readiness level (SRL) is a way of assessing the level of societal adaptation, social project, a technology, a product, a process, an intervention, or an innovation to be integrated into society. If the societal readiness for the social or technical solution is expected to be low, suggestions for a realistic transition towards societal adaptation are required. According to the result of this study claim that it is arranged on SRL 3 (see table 14). This model was developed with stakeholders (elderly and their family caregivers). In the future, this model will be validated through pilot testing in a relevant setting to qualify proposed impact and societal readiness.

Limitations of the study

An ideal set of nursing care activities was emerged from the relationship between the elderly, family caregivers and researcher act as a nurse. Hence, it may not be directly used for nurses in primary care centers. In the future, nurses will be involved to participate for developing this model. Moreover, some care activities in this model were not specific for elderly being at the end of life. Therefore, nursing interventions for this group should be improved for specific needs. In addition, all elder persons and their family caregivers were Buddhist, therefore, nursing intervention was not seen on the cultural diversity of death and dying approach.

Table 13 *TRL definitions, descriptions, and supporting information*

TRL	Definitions	Descriptions	Supporting information
1	Basic principles observed and reported	Lowest level of technology readiness. Scientific research begins to be translated into applied research and development (R&D). Examples might include paper studies of a technology's basic properties.	Published research that identifies the principles that underlie this technology. References to who, where, when.
2	Technology concept and/or application formulated	Invention begins. Once basic principles are observed, practical applications can be invented. Applications are speculative, and there may be no proof or detailed analysis to support the assumptions. Examples are limited to analytic studies.	Publications or other references that outline the application being considered and that provide analysis to support the concept.
3	Analytical and experimental critical function and/or characteristic proof of concept	Active R&D is initiated. This includes analytical studies and laboratory studies to physically validate the analytical predictions of separate elements of the technology. Examples include components that are not yet integrated or representative.	Results of laboratory tests performed to measure parameters of interest and comparison to analytical predictions for critical subsystems. References to who, where, and when these tests and comparisons were performed.
4	Component and/or breadboard validation in laboratory environment	Basic technological components are integrated to establish that they will work together. This is relatively “low fidelity” compared with the eventual system. Examples include integration of “ad hoc” hardware in the laboratory.	System concepts that have been considered and results from testing laboratory-scale breadboard(s). Reference to who did this work and when. Provide an estimate of how breadboard hardware and test results differ from the expected system goals.
5	Component and/or	Fidelity of breadboard technology increases	Results from testing laboratory breadboard

TRL	Definitions	Descriptions	Supporting information
	breadboard validation in relevant environment	significantly. The basic technological components are integrated with reasonably realistic supporting elements so they can be tested in a simulated environment. Examples include “high-fidelity” laboratory integration of components.	system are integrated with other supporting elements in a simulated operational environment. How does the “relevant environment” differ from the expected operational environment? How do the test results compare with expectations? What problems, if any, were encountered? Was the breadboard system refined to more nearly match the expected system goals?
6	System/subsystem model or prototype demonstration in a relevant environment	Representative model or prototype system, which is well beyond that of TRL 5, is tested in a relevant environment. Represents a major step up in a technology's demonstrated readiness. Examples include testing a prototype in a high-fidelity laboratory environment or in a simulated operational environment.	Results from a laboratory testing of a prototype system that is near the desired configuration in terms of performance, weight, and volume. How did the test environment differ from the operational environment? Who performed the tests? How did the test compare with expectations? What problems, if any, were encountered? What are/were the plans, options, or actions to resolve problems before moving to the next level?
7	System prototype demonstration in an operational environment	Prototype near or at planned operational system. Represents a major step up from TRL 6 by requiring demonstration of an actual system prototype in an operational environment (e.g., in an aircraft, in a vehicle, or in space).	Results from testing a prototype system in an operational environment. Who performed the tests? How did the test compare with expectations? What problems, if any, were encountered? What are/were the plans, options, or actions to resolve problems before moving to the next level?
8	Actual system	Technology has been proven to work in its	Results of testing the system in its final

TRL	Definitions	Descriptions	Supporting information
	completed and qualified through test and demonstration	final form and under expected conditions. In almost all cases, this TRL represents the end of true system development. Examples include developmental test and evaluation (DT&E) of the system in its intended weapon system to determine if it meets design specification.	configuration under the expected range of environmental conditions in which it will be expected to operate. Assessment of whether it will meet its operational requirements. What problems, if any, were encountered? What are/were the plans, options, or actions to resolve problems before finalizing the design?
9	Actual system proven through successful mission operations	Actual application of the technology in its final form and under mission conditions, such as those encountered in operational test and evaluation (OT&E). Examples include using the system under operational mission conditions.	OT&E reports.

Table 14 *Definition of social readiness level*

SRL	**Definitions**
1	Identifying problem and identifying societal readiness
2	Formulation of problem, proposed solution (s) and potential impact, expected societal readiness; identifying relevant stakeholders for the project
3	Initial testing of proposed solution (s) together with relevant with stakeholders
4	Problem validated through pilot testing in relevant environment to substantiate proposed impact and societal readiness
5	Proposed solution (s) validated, now by relevant stakeholders in the area
6	Solution (s) demonstrated in relevant environment and in co-operation with relevant stakeholders to gain initial feedback on potential impact
7	Refinement of project and/or solution (s) and, if needed, retesting in relevant environment with relevant stakeholders
8	Proposed solution (s) as well as a plan for societal adaptation complete and qualified
9	Actual project solution (s) proven in relevant environment

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Appendices

Appendix A

Summary of studies included in the review

Appendix A

Summary of studies included in the review

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
Aiken et al (2006) USA Case management	RCT	- Physical symptoms (pain, most troublesome symptom), quality of life, general health and vitality, physical, psychological and social functioning, self management of illness and knowledge of resources, advance care planning (preparation for end of life) - Disease and symptom management, patient and caregiver education (included self monitoring, home safety, equipment and medication), counseling and helping community resources - Memorial Symptom Assessment Scale, the Surrogate Integrated Care System After death Interview, SF-36 - Patient empowerment model and behavior change theory - All participants in the intervention group received telephone interviews every 3 months (time 0, time 1, time 3)	192	Significant on self-management of illness, awareness of illness-related resources, and legal preparation for end of life (higher scores on the SF-36 Social Functioning Scale, F (1,189) = 3.45, p = .07, g = 0.27, and on the SF-36 Mental Health Scale, F(1,190) = 3.35, p = .07, g = .26).	I
Brumley et al (2007)	RCT	- Death at home, patient satisfaction with care, Survival	298	Baseline differences in care satisfaction scores	I

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
USA Case management		- Symptom management, education, training patients and caregivers on use of medication, self management and crisis intervention at home - The Reid-Gundlach Satisfaction with Services instrument, the Palliative Care Performance Scale - Interviews were conducted via telephone within 48 hours of study enrollment and every 30, 60, 90, and 120 days to measure satisfaction with services and site of death.		(intervention higher satisfaction; *p* = .03) Patients preferred to die at home than those who were receiving usual care (*p*<.001). In-home palliative care patients were less likely to visit the emergency department (*p*=.01) or be admitted to the hospital than those receiving usual care (*p*<.001), resulting in significantly lower costs of care for intervention patients (*p*=.03).	
Ciemins et al (2006) USA Case management	Cohort study	- Symptom status (pain, confusion, shortness of breath, cognitive function), anxiety, depression - Nurse managers educated patients and caregivers about disease process and prognosis, advance care planning, avoidance of unnecessary emergent care and hospitalization, pain and symptom management, goal clarification, and facilitation of hospice enrollment. - The Center for Medicare and Medicaid Services (CMS)'s Outcome and Assessment Information	435	28% difference was observed in the number of hospice referrals between patients who received the intervention and usual care (47% intervention; 33% usual care, *p* = .003). Differences persisted after controlling for symptom status,	IIIA

Authors Country Intervention	**Design**	**Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration**	**Sample**	**Results**	**Evidence level**
		Set (OASIS) - Advance illness management philosophy and methodology - Between January 2003 and September 2005.		and home health length of stay.	
Dhiliwal and Muckaden (2015) India Case management	Prospective non-randomized	- Physical symptoms, out of hours care, bereavement - Symptom control, education on care activities for caregivers, psychosocial support (counseling, support group meeting on patients and caregivers), health‑related communication, home‑based death, ESAS scale	506	All participants who received intervention had good relief of physical symptoms (*P* < .005). 83.2% patients received out of hours care through liaising with local general practitioners; 42.68% received home based bereavement care and 91.66% had good bereavement outcomes.	IIIA
Chiatti and colleagues (2013) Italy Case management	RCT	- Caregiver burden and number of days spent at home - 1) individual face to face counseling, focusing on topics on housing arrangements,disease awareness and problem solving, 2) reinforcement on those, 3) stress management training, 4) information about service/aid by the Italian national health service, municipal social service	450 dyads	Result of this study did not show reducing caregiver burden and number of days spent at home, but the study reported that analysis of different interventions were expected to provide evidence of the effectiveness and cost of	I

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
		and local volunteer organization, 5) coordination of professionals working in different care settings, and between hospital and community doctors in the case of hospital discharge./ Technology device intervention for virtual information counter for technological aids and adapting to the home environment. - Caregiver Burden Inventory (CBI) - Concept of case management - 4 and 8 months		programs supporting AD patients in the community.	
Janse and colleagues Natherlands (2014) Case management	Quasi-experiment	- Burden and quality of life - Single entry point, multidisciplinary care plan, multidisciplinary consultations and meetings, a steering group, task specialization and an integrated information system support - Objective Burden of Informal Care Instrument, CareQoL, the Self-Rated Burden (SRB) Scale, Cantril's Self-Anchoring Ladder	377	- Significance on reducing burden (within group, p=.007/ between group, p=.087), - Significant improvement of quality of life in an intervention group (p=.008)	II
Finucane and colleagues (2013) UK	Pilot study	- DNACPR, proposition of elderly with any form of anticipatory care plan, proposition of elderly know to have died on the adapted Liverpool Care Pathway	elderly who live on 3 care homes	*Elderly who die in hospital* -30 of 132 elderly died in hospital (23%). -over 50% did not have	IIIA

Authors Country Intervention	**Design**	**Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration**	**Sample**	**Results**	**Evidence level**
Case management		- Communication, pain and symptom management, bereavement - From November 2009 to June 2011: 35 workshops were carried out during the study, and 2.5 hr was each workshop		DNACPR -80% had experienced some form of anticipatory care plan *Elderly who die in care home* -97% have DNACPR -99% had anticipatory care plan -57% have been on Liverpool Care Pathway before death	
Fernandes and colleagues (2010) USA	Prospective design	- Symptom relief, quality of life, use of community resources, hospitalization and emergency department visits, advanced care planning, and satisfaction with home-based palliative care -Improving accessibility of home-based palliative care and deliver culturally sensitive palliative care to home -Missoula-Vitas Quality of Life Index, the Edmonton Symptom Assessment Scale, and PPS Scale - Over 12 months	91	There was a decrease in hospitalization (p=.02), discussion and documentation of end of life wished increase from 50% to 90%, p <.01). Caregiver satisfaction was high.	IIIA
Allen and colleagues	Quasi-experiment	-Caregiving stress, well-being, pain and symptoms, religious meaning, and depression	42 families	-Caregiver group showed significantly reduced	II

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
(2008) USA		-Discuss positive memories: patient and family generating and sharing positive memories, brainstormed potential meaning to portray the life story - Life review, Chochinov's Dignity Therapy, Cognitive Behavioral Therapy (CBT) - Caregiver Stressors Scale-Revised, Subjective-well being (SWB), Edmonton Symptom Assessment Scale, Brief Multidimensional Measure of Religion and Spirituality (BMMRS), CES-D) - Three sessions (the first averaged 82 minutes, the second averaged 66 minutes, the third averaged 70 minutes		caregiving stress F(1, 29)= 4.93, p= .034 -Significantly decreased breathing difficulty, F(1,26)=5.54, p=.026 - Social interaction between patient and caregiver, family communication improved, F(1, 29)=6.52, p=.016 -Increasing religious meaning on patient, F(1,26)=5.10, p=.032.	
Hall et al (2011) England Psychosocial	RCT	- Dignity-related distress, depression, hopefulness, and quality of life - The program based on dignity therapy and brief palliative care psychotherapy (transcribed verbatim, a narrative using a formatted editing process, edited and suggestion transcript from participants) - Patient Dignity Inventory, Geriatric Depression Scale, Herth Hope Index, Quality of life (EQ-5D)	60	-Reducing dignity-related stress across both groups (p=.026). -Significance on feeling their life more meaningful at 2-week follow-up (p=.04).	I

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
		- Chochinov's dignity model - No telling about duration of session, data collected outcomes in face to face interviews at baseline (T1) and at 1 week (T2) and 8 weeks (T3) follow up			
Healy et al (2012) Australia Skill training	RCT	- Usefulness and relevance of the package components - Managing subcutaneous medications used for symptom control among caregivers - Questionnaires to test usefulness of the package components - Two sessions (session 1 (T1)) (session 2 four weeks after)	76	The result of this study revealed that the high means were above 5 on a 7 point scale (ranging from 1-7, 95% CI).	I
Hudson et al (2008) Australia psychosocial	Single group	- Preparing family caregivers for the role of support - A group education program: preparing primary caregivers for the role of supporting a relative receiving home-based palliative care - Session evaluation tool, program evaluation form(including measure for participants, lives),	74	Significant on preparedness(p<.001), competence (p<.001), distress (p<.001), rewards (p<.05), and having needs met (p<.001), over times. Multivariate effects within groups was found for	II

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
		DDQ, self –report instruments to assess the effectiveness of the program, semi-structure interviews, facilitators' journals - Transactional model of coping - 3 sessions (1.5 h each) over a 3-week period		time (p<.001). 25 caregivers were interviewed: program had a positive impact in lives.	
Kuo et al (2013) Taiwan Skill training	Mixed method	- Health-related quality of life (HRQoL) and depressive symptoms - Emphasized the caregivers' knowledge about managing patients' behavioral problems, to plan for the patient's individual care - Family caregivers' HRQoL by the Thaiwan version of the Medical Outcomes SF-36, The Center for Epidemiological Studies-Depression (CES-D) - Progressively Lowered Stress Threshold model, the concept of partnership with family caregivers, The Antecedent Event-Behavior-Consequence (ABC) Skiner's theory - 2 sessions each session 1 week apart	129	Significantly better in health related outcome: bodily pain (p<.013), emotional problems (p<.013), vitality (p<.001), mental summary score (p<.013) than control group Decreasing risk for depression (p<.013).	IIIA
Linstrom and Melnyk	RCT	- The feasibility and preliminary effects of the intervention	18	Significant increase of caregiver activity restriction	I

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
(2013) USA skill training		- Development of a schema and skill building to provide caregivers with information and caregiving skills for their new caregiver role - The Center for Epidemiological Studies-Depression (CES-D), the State-Triat Anxiety Inventory, Caregiver Activity Restriction Scale (CARS), Family Preparedness Scale, the adapted Family Beliefs Scale for Caregivers of Hospice patients (FBS-CH) - Self-regulation theory and role theory - 2 sessions: session one 30 minute CD, session two 18 minute CD		(p<.10), preparedness (p<.10), and family beliefs/confidence (p<.01) Trend to decrease anxiety level	
McMillan and Small (2007) USA psychosocial	Single group	- To determine significance of patients receiving standard care plus the COPE problem-solving intervention - Teaching caregiver's skills in managing patient symptoms, helping caregivers to appraise stressors, caregivers to use problem-focused coping techniques, - Pain score, Dyspnea Intensity Scale, Constipation Assessment Scale, Memorial Symptom Assessment Scale Hospice Quality-of-Life Index	480	Significant interaction on symptom distress scores in COPE intervention group (p<.01), greatest declines over time.	II

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
		- Problem-solving therapy approach - Over 9 days after admission			
Specht et al (2009) USA Case management	RCT	- On elderly: cognitive status, stage of dementia, functional status, functional ability, behaviors, health status/on caregivers: health status, well being, stress, endurance potential - Dementia management and assessment, developing the service plans to promote communication, collaboration, and cooperation within and between community service providers, caregivers, and other informal supports, meeting needs and finding ways of coping with mutually identified problems between nurse and elderly and caregiver. - Mini-Mental Status Exam (MMSE), Global Deterioration Scale (GDS), Functional Assessment II, Modified IADL/ADL's from Lawton and Brody, Behavior rating checklist, SF-36, Nursing Outcomes Classification (NOC). - Case management model - No report on duration of the intervention, the outcome measures were taken at baseline, first and second follow-up. The first follow-up	252	For caregivers: significantly lower stress, and better endurance potential & well-being in the intervention group during different follow-up periods (P= .014 for stress; P = .002 for well being; and p = .006 for endurance potential).	I

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
		occurred between months 3 and 6 of enrollment and the third follow-up occurred between months 9 and 15 of enrollment.			
Spettell et al (2009) USA Case management	Quasi-experiment	- Hospice using, mean hospice days - Comprehensive assessment of elderly and caregivers needs, developing individual plans of care, education of disease process for elderly and caregiver, discussion of advanced directives and documents, identifying community resources for support, social support, pain control, medical management, helping respite care. - Case management model - In this program, participants were calculated between stating program and last day of life (death).	8,650	Hospice use increased for all groups receiving case management than control group (p<.0001). Mean hospice days increased from 15.9 to 28.6 days (p<.0001). and from 21.4 to 36.7 days in (p<.0001) for these group.	II
Walsh et al (2007) UK Psychosocial	RCT	- Anxiety, depression, carer burden, quality of life, satisfaction with care, strain in caregivers - Psycho-education and support, bereavement support - GHQ-28, Carer Strain Index, Caregiver Quality of Life Index (cancer), Core Bereavement Items (CBI)	271	Mean scores in the intervention group were lower at all time points but these differences were not significant.	I

Authors Country Intervention	Design	Intended outcome +Characteristic of intervention+ Tool + Theory/conceptual framework + Duration	Sample	Results	Evidence level
		- Six visits over 6 week period			
Wang and colleagues (2012) China skill training	Experiment-study	-Caregiver stress, quality of life, family support service - Family support group: development of group as a support system, emotional impact of caregiving (sharing of emotions and feeling about caregiving;discussion of ways to deal with negative emotions), learning about self-care (empowerment on individual self-efficay), improvement of interpersonal relationships (learning of effective communication and interpersonal skills with client and family members), establishing support outside the group (discussion about a continuation of the support group after intervention), and improvement of home care skills. -The neuropsychiatric inventory-caregiver distress scale, World Health Organization Quality of Life Measure-Brief Version, Family support services index - 12 sessions by 24- week group intervention	78 family caregivers	Significantly greater improvements in distress levels (p<.005) and quality of life (p=.001) than control group.	I

Appendix B

Ethical Consideration

Appendix B1

Informed consent form

B1-1 For the elderly

Dear participant,

I am Kanyanat Supaporn, a lecturer of Faculty of Nursing of Srinakharinwirot University. Now, I am a Ph.D. student in Faculty of Nursing, Prince of Songkla University. Currently, I am undertaking a research project entiled "Development of an ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce caregiving burden among the family caregivers of Thai elderly". You are an important participant who has the experience of home-based palliative care. The study will develop appropriate care activities to serve the needs of the elderly and their family caregivers in order to enhance care quality and reduce caring burden among Thai elder's caregivers.

I would like to ask you to complete the relevant forms, participate in the interviews with the researcher. The aim of the interviews is to understand (1) your experience of palliative care at home, (2) your needs and expectations about palliative care at home, (3) your opinion about this developed care activities. Several interviews will take about 60-90 minutes for each interview. I would like to get your permission to record the interviews by digital voice recorder and take photos for important occasions. All information provided will be treated in a confidential manner and no name will appear in the transcripts of the interviews. In addition, you will be guaranteed anonymity in the published results.

You have the option to decline participation or withdraw from the trial at any time. The process of this study will bring up sensitive subjects which could be a strain for you. You will be given advice or refer you to an appropriate treatment or counseling service, and you will be followed-up phone call or visit may be appropriate. In addition, the researcher will collaborate with staff at the primary care centers to follow you even after the study has finished.

Thank you for your collaboration

…………………………………

(Miss Kanyanat Supaporn)

Agreement to participate in this study

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

( ) I am willing to participate in this study.

( ) I am not willing to participate in this study.

Participant’s signature…………………………………………..Date……………….

If you have any questions regarding this study, please do not hesitate to contact me.

Contact address:

Kanyanat Supaporn, a PhD student, Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla, Thailand, 90112. Mobile: 062-0535597**.**

B1-2 For family caregiver

Dear participant,

I am Kanyanat Supaporn, a lecturer of Faculty of Nursing of Srinakharinwirot University. Now, I am a Ph.D. student in Faculty of Nursing, Prince of Songkla University. Currently, I am undertaking a research project entiled “Development of an ideal set of nursing care activities for home-based palliative care to enhance care quality and reduce caregiving burden among the family caregivers of Thai elderly”. You are an important participant who has the experience of caring the elderly with terminal illness at home. The study will develop appropriate care activities to serve the needs of the elderly and their family caregivers in order to enhance care quality and reduce caring burden among Thai elder’s caregivers.

I would like to ask you to complete the relevant forms, participate in the interviews with the researcher. The aim of the interviews is to understand (1) your experience of caring the elderly with terminal illness at home, (2) your needs and expectations about palliative care at home, (3) your opinion about this developed care activities. Several interviews will take about 60-90 minutes for each interview. I would like to get your permission to record the interviews by digital voice recorder and take photos for important occasions. All information provided will be treated in a confidential manner and no name will appear in the transcripts of the interviews. In addition, you will be guaranteed anonymity in the published results.

You have the option to decline participation or withdraw from the trial at any time. The process of this study will bring up sensitive subjects which could be a strain for you. You will be given advice or refer you to an appropriate treatment or counseling service, and you will be followed-up phone call or visit may be appropriate. In addition, the researcher will collaborate with staff at the primary care centers to follow you even after the study has finished.

Thank you for your collaboration

…………………………………

(Miss Kanyanat Supaporn)

Agreement to participate in this study

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

( ) I am willing to participate in this study.

( ) I am not willing to participate in this study.

Participant’s signature…………………………………………..Date……………….

If you have any questions regarding this study, please do not hesitate to contact me.

Contact address:

Kanyanat Supaporn, a PhD student, Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla, Thailand, 90112. Mobile: 062-0535597**.**

Appendix B2

Informed Consent Guideline

1. Clinical integrity

1.1 Participants are given the best available continuing treatment and care as their health care change due to terminal conditions.

1.2 If the participants have exacerbation of illness, the participants are referred in timely to appropriate health professional.

2. Respect for persons

2.1 The researcher seeks to discover the participants are willing and able to be informed about their conditions and prognosis.

2.2 participants are given accurate and timely information that enable them to understand the objective of this study, including understanding the prognosis for their terminal condition and available care and treatment options.

2.3 Participants' wish about their care and options are sought and respected.

2.4 Participants are given appropriate support to adapt to the changes in their condition, to plan for their future needs, and to appoint a representative if they wish.

2.5 A person's right to refuse additional treatment that they believe having a negative impact upon their comfort and quality of life is recognized and respected.

2.6 The cultural and spiritual beliefs and practices of the participants are acknowledged and respected at all time.

3. Justice

3.1 The researcher avoids any kind of actual unjust discrimination against the participants such as their spiritual beliefs or disadvantage situation

3.2 The participants’ preference about where they are cared or interviewed for (e.g. in private room) are sought and implemented

3.3 The relevant legal protections and government resources should be made available to the participants.

4. Beneficence

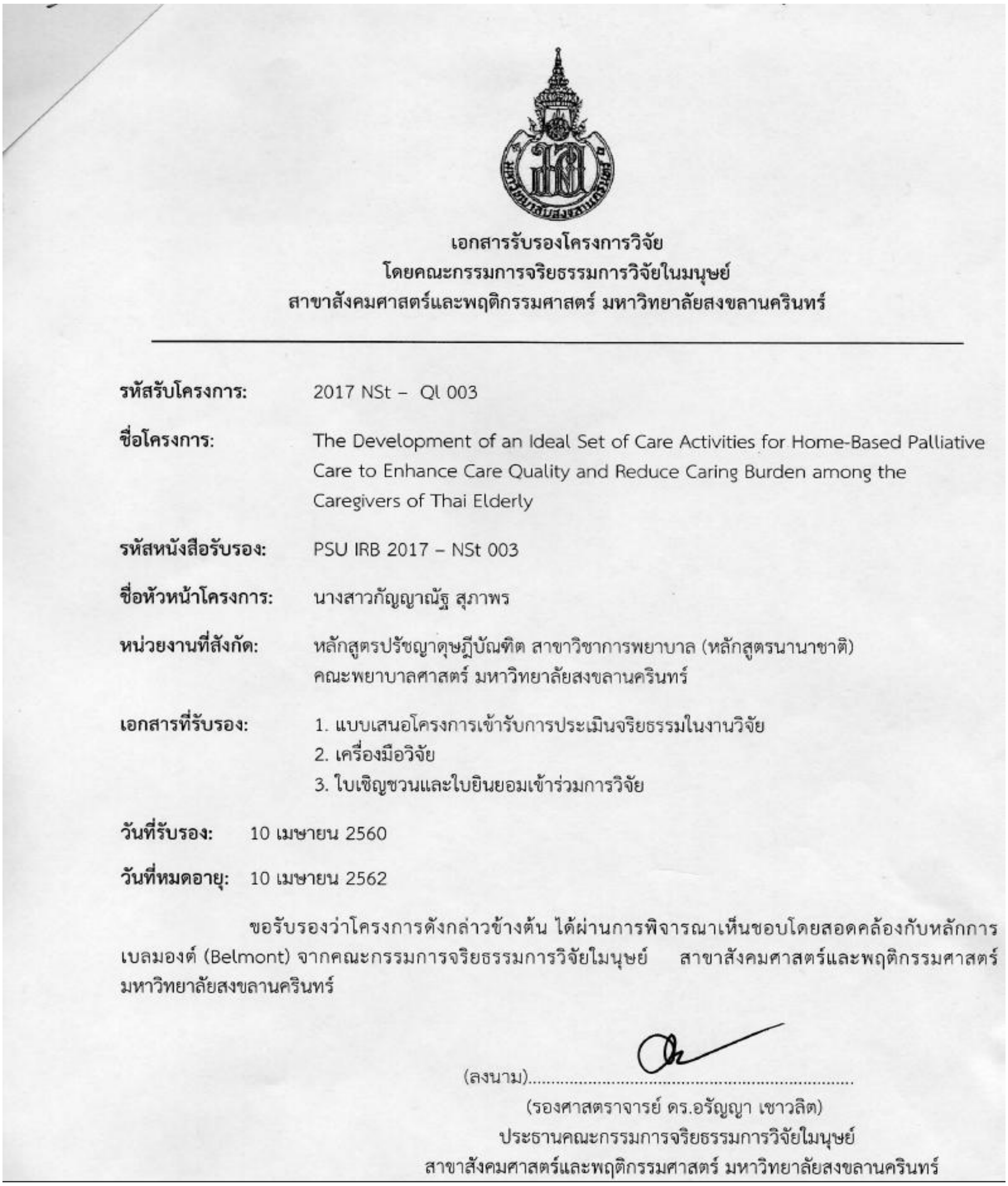
1. The goals of care are clearly identified and evaluated of the participants’ overall needs and preferences.
2. Palliative care principles are introduced into a person’s care as early as appropriate.
3. When it s relevant, the inevitability of death and its likely timing are discussed with the elderly concerned (or the culturally appropriate person), and their family, in a way that respects cultural and spiritual values.
4. Decisions to withdraw are informed wherever possible by presumed wished of the participants.
5. Any disagreement about treatment and care decisions are acknowledged honestly.

Appendix B3

IRB Approval Document

Of the Instrument Ethics Research Committee,

Faculty of Nursing, Prince of Songkla University



เอกสารรับรองโครงการวิจัย
โดยคณะกรรมการจริยธรรมการวิจัยในมนุษย์
สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

รหัสรับโครงการ: 2017 NSt – Ql 003

ชื่อโครงการ: The Development of an Ideal Set of Care Activities for Home-Based Palliative Care to Enhance Care Quality and Reduce Caring Burden among the Caregivers of Thai Elderly

รหัสหนังสือรับรอง: PSU IRB 2017 – NSt 003

ชื่อหัวหน้าโครงการ: นางสาวกัญญาณัฐ สุภาพร

หน่วยงานที่สังกัด: หลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (หลักสูตรนานาชาติ)
คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

เอกสารที่รับรอง:
1. แบบเสนอโครงการเข้ารับการประเมินจริยธรรมในงานวิจัย
2. เครื่องมือวิจัย
3. ใบเชิญชวนและใบยินยอมเข้าร่วมการวิจัย

วันที่รับรอง: 10 เมษายน 2560

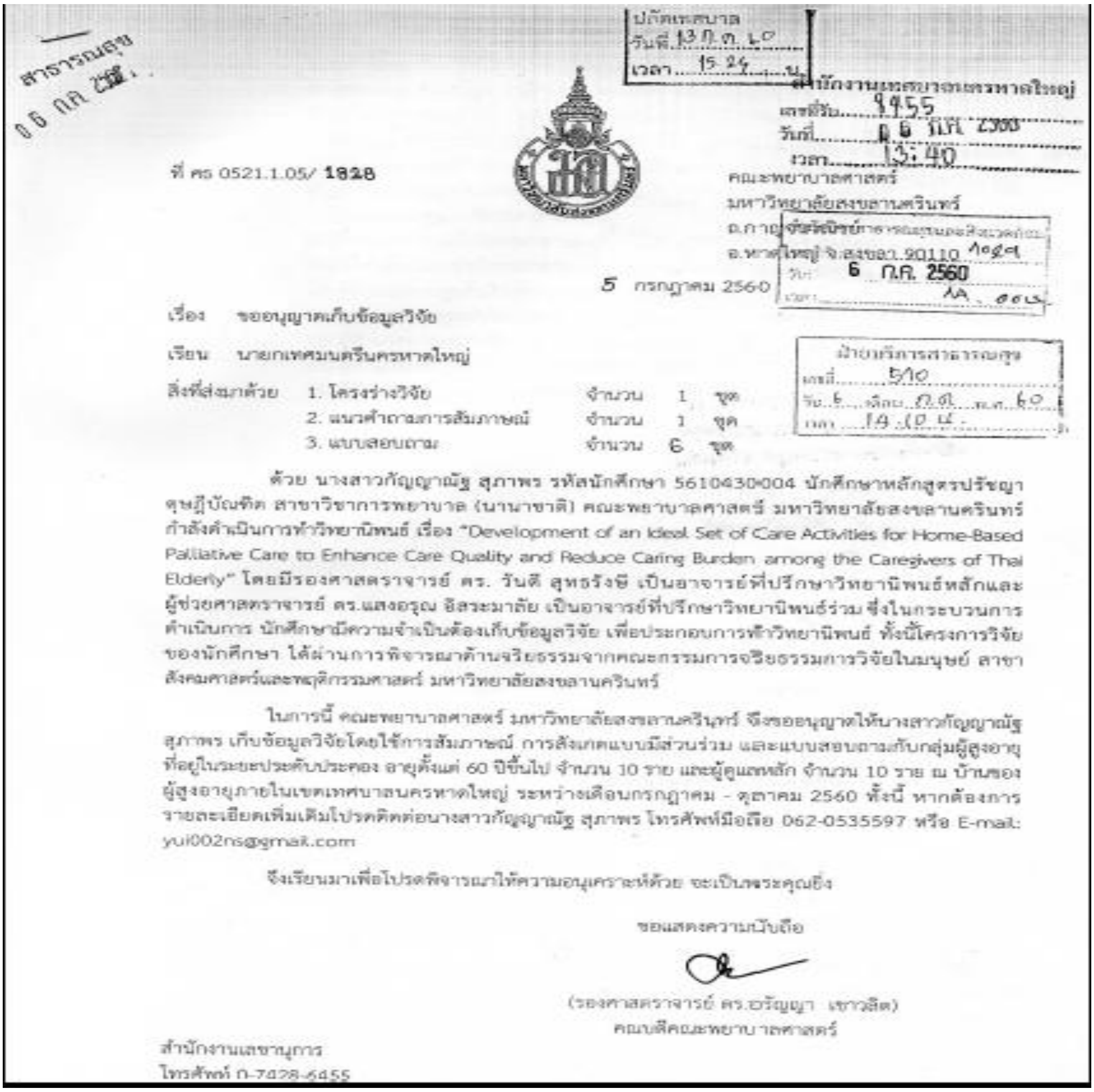
วันที่หมดอายุ: 10 เมษายน 2562

ขอรับรองว่าโครงการดังกล่าวข้างต้น ได้ผ่านการพิจารณาเห็นชอบโดยสอดคล้องกับหลักการเบลมองต์ (Belmont) จากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

(ลงนาม)...
(รองศาสตราจารย์ ดร.อรัญญา เชาวลิต)
ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์
สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

Appendix B4

Permission letter for collecting data



สาธารณสุข
06 ก.ค. 2560

ปลัดเทศบาล
วันที่ 13 ก.ค. 60
เวลา 15.24 น.

สำนักงานเทศบาลนครหาดใหญ่
เลขที่รับ 1455
วันที่ 06 ก.ค. 2560
เวลา 13:40

ที่ ศธ 0521.1.05/ **1828**

คณะพยาบาลศาสตร์
มหาวิทยาลัยสงขลานครินทร์
ถ.กาญจนวณิชย์
อ.หาดใหญ่ จ.สงขลา 90110

[illegible] 1029
วันที่ 6 ก.ค. 2560

5 กรกฎาคม 2560

ฝ่ายบริการสาธารณสุข
เลขที่ 510
วันที่ 6 เดือน ก.ค. พ.ศ. 60
เวลา 14.10 น.

เรื่อง ขออนุญาตเก็บข้อมูลวิจัย

เรียน นายกเทศมนตรีนครหาดใหญ่

สิ่งที่ส่งมาด้วย
1. โครงร่างวิจัย จำนวน 1 ชุด
2. แนวคำถามการสัมภาษณ์ จำนวน 1 ชุด
3. แบบสอบถาม จำนวน 6 ชุด

ด้วย นางสาวกัญญาณัฐ สุภาพร รหัสนักศึกษา 5610430004 นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (นานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ กำลังดำเนินการทำวิทยานิพนธ์ เรื่อง "Development of an Ideal Set of Care Activities for Home-Based Palliative Care to Enhance Care Quality and Reduce Caring Burden among the Caregivers of Thai Elderly" โดยมีรองศาสตราจารย์ ดร. วันดี สุทธรังษี เป็นอาจารย์ที่ปรึกษาวิทยานิพนธ์หลักและผู้ช่วยศาสตราจารย์ ดร.แสงอรุณ อิสระมาลัย เป็นอาจารย์ที่ปรึกษาวิทยานิพนธ์ร่วม ซึ่งในกระบวนการดำเนินการ นักศึกษามีความจำเป็นต้องเก็บข้อมูลวิจัย เพื่อประกอบการทำวิทยานิพนธ์ ทั้งนี้โครงการวิจัยของนักศึกษา ได้ผ่านการพิจารณาด้านจริยธรรมจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

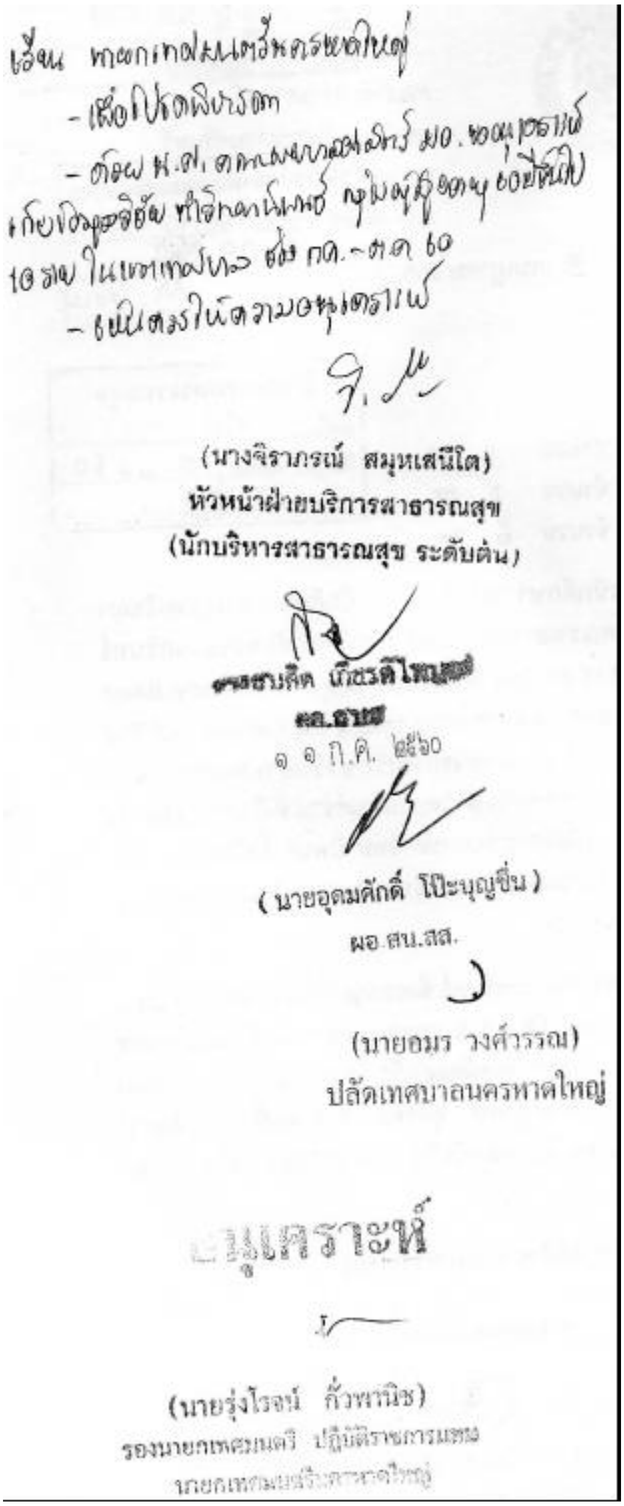
ในการนี้ คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ จึงขออนุญาตให้นางสาวกัญญาณัฐ สุภาพร เก็บข้อมูลวิจัยโดยใช้การสัมภาษณ์ การสังเกตแบบมีส่วนร่วม และแบบสอบถามกับกลุ่มผู้สูงอายุที่อยู่ในระยะประคับประคอง อายุตั้งแต่ 60 ปีขึ้นไป จำนวน 10 ราย และผู้ดูแลหลัก จำนวน 10 ราย ณ บ้านของผู้สูงอายุภายในเขตเทศบาลนครหาดใหญ่ ระหว่างเดือนกรกฎาคม - ตุลาคม 2560 ทั้งนี้ หากต้องการรายละเอียดเพิ่มเติมโปรดติดต่อนางสาวกัญญาณัฐ สุภาพร โทรศัพท์มือถือ 062-0535597 หรือ E-mail: yui002ns@gmail.com

จึงเรียนมาเพื่อโปรดพิจารณาให้ความอนุเคราะห์ด้วย จะเป็นพระคุณยิ่ง

ขอแสดงความนับถือ

(รองศาสตราจารย์ ดร.อรัญญา เชาวลิต)
คณบดีคณะพยาบาลศาสตร์

สำนักงานเลขานุการ
โทรศัพท์ 0-7428-6455



เรียน นายกเทศมนตรีนครหาดใหญ่
- เพื่อโปรดพิจารณา
- ด้วย น.ศ. คณะพยาบาลศาสตร์ มอ. ขออนุเคราะห์
เก็บข้อมูลวิจัย [illegible] กลุ่มผู้สูงอายุ 60ปีขึ้นไป
10 ราย ในเขตเทศบาล ช่วง กค.-ตค 60
- เห็นควรให้ความอนุเคราะห์

(นางจิราภรณ์ สมุหเสนีโต)
หัวหน้าฝ่ายบริการสาธารณสุข
(นักบริหารสาธารณสุข ระดับต้น)

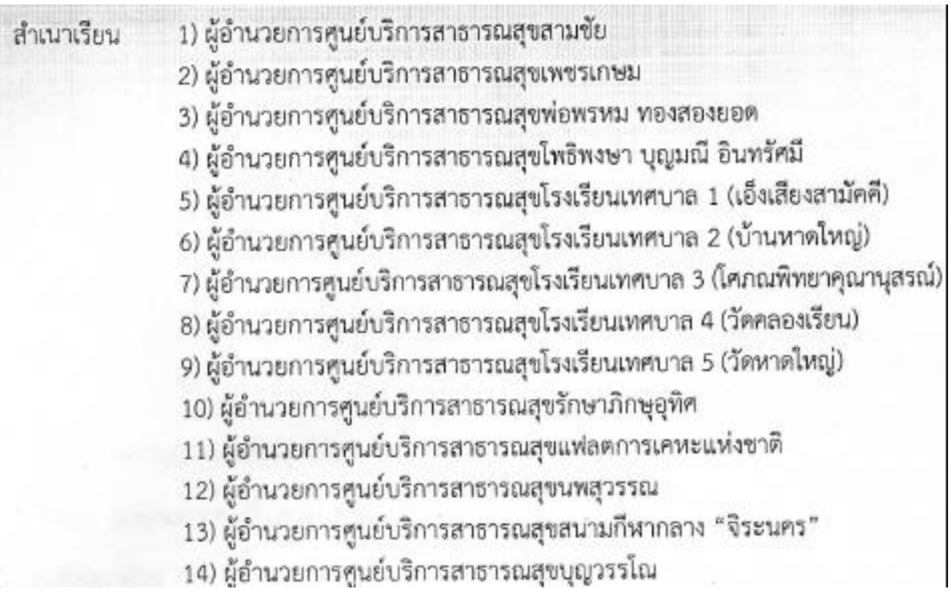
[illegible]
ผอ.[illegible]
๑ ๑ ก.ค. ๒๕๖๐

(นายอุดมศักดิ์ โป๊ะบุญชื่น)
ผอ.สน.สส.

(นายอมร วงศ์วรรณ)
ปลัดเทศบาลนครหาดใหญ่

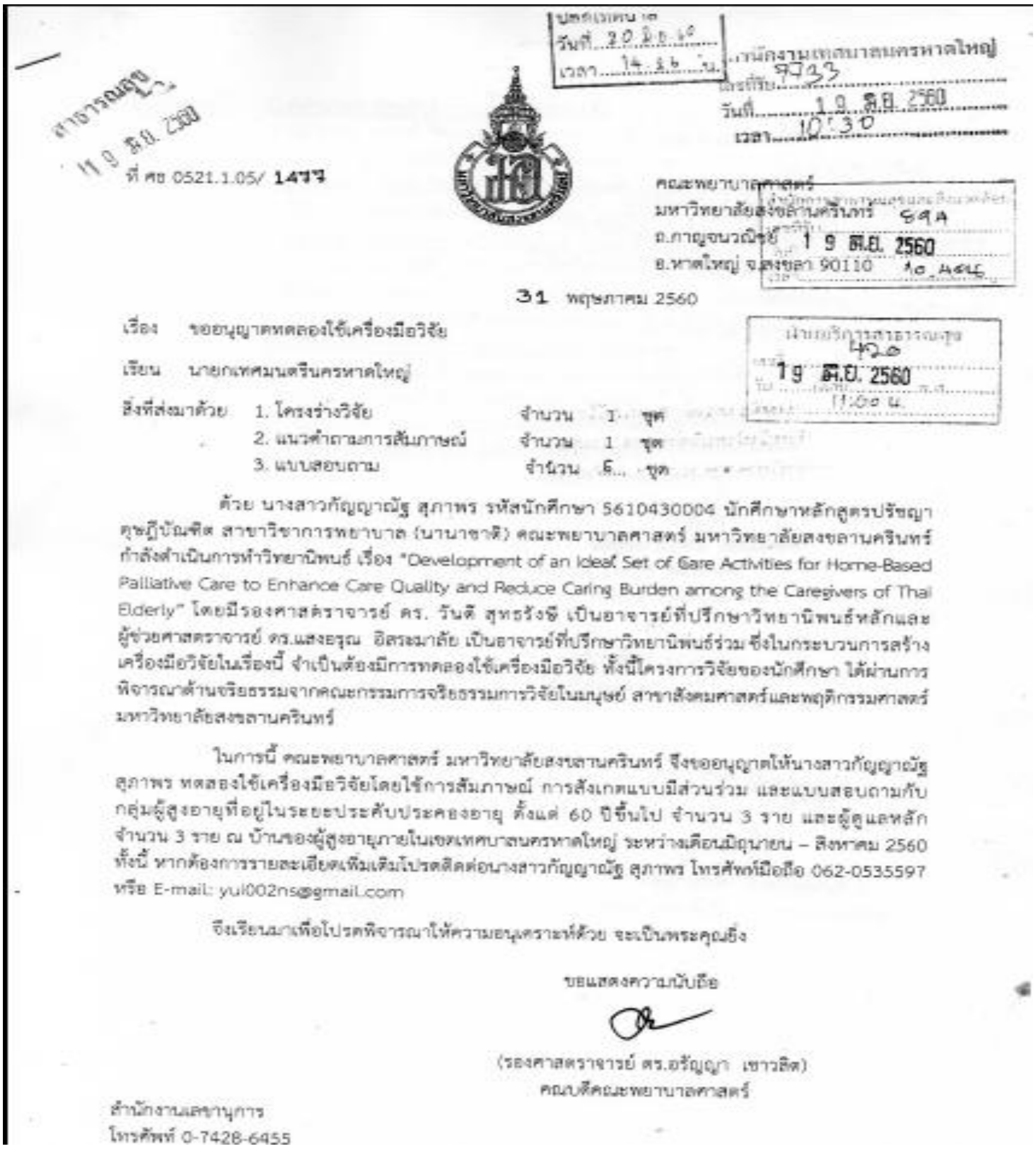
อนุเคราะห์

(นายรุ่งโรจน์ กั้วพานิช)
รองนายกเทศมนตรี ปฏิบัติราชการแทน
นายกเทศมนตรีนครหาดใหญ่



สำเนาเรียน

1) ผู้อำนวยการศูนย์บริการสาธารณสุขสามชัย
2) ผู้อำนวยการศูนย์บริการสาธารณสุขเพชรเกษม
3) ผู้อำนวยการศูนย์บริการสาธารณสุขพ่อพรหม ทองสองยอด
4) ผู้อำนวยการศูนย์บริการสาธารณสุขโพธิพงษา บุญมณี อินทรัศมี
5) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 1 (เอ็งเสียงสามัคคี)
6) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 2 (บ้านหาดใหญ่)
7) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 3 (โศภณพิทยาคุณานุสรณ์)
8) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 4 (วัดคลองเรียน)
9) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 5 (วัดหาดใหญ่)
10) ผู้อำนวยการศูนย์บริการสาธารณสุขรักษาภิกษุอุทิศ
11) ผู้อำนวยการศูนย์บริการสาธารณสุขแฟลตการเคหะแห่งชาติ
12) ผู้อำนวยการศูนย์บริการสาธารณสุขนพสุวรรณ
13) ผู้อำนวยการศูนย์บริการสาธารณสุขสนามกีฬากลาง "จิระนคร"
14) ผู้อำนวยการศูนย์บริการสาธารณสุขบุญวรรโณ



ปลัดเทศบาล ๓
วันที่ 20 มิ.ย. 60
เวลา 14.56 น.

สำนักงานเทศบาลนครหาดใหญ่
เลขรับ 9733
วันที่ 19 มิ.ย. 2560
เวลา 10.30

สาธารณสุข
19 มิ.ย. 2560

ที่ ศธ 0521.1.05/ **1477**

คณะพยาบาลศาสตร์
มหาวิทยาลัยสงขลานครินทร์
ถ.กาญจนวณิชย์
อ.หาดใหญ่ จ.สงขลา 90110

สำนักการสาธารณสุขและสิ่งแวดล้อม
เลขรับ 694
วันที่ 19 มิ.ย. 2560
เวลา 10.45

31 พฤษภาคม 2560

ฝ่ายบริการสาธารณสุข
เลขรับ 420
วันที่ 19 มิ.ย. 2560
เวลา 11.00 น.

เรื่อง ขออนุญาตทดลองใช้เครื่องมือวิจัย

เรียน นายกเทศมนตรีนครหาดใหญ่

สิ่งที่ส่งมาด้วย
1. โครงร่างวิจัย จำนวน 1 ชุด
2. แนวคำถามการสัมภาษณ์ จำนวน 1 ชุด
3. แบบสอบถาม จำนวน 6 ชุด

ด้วย นางสาวกัญญาณัฐ สุภาพร รหัสนักศึกษา 5610430004 นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (นานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ กำลังดำเนินการทำวิทยานิพนธ์ เรื่อง "Development of an Ideal Set of Care Activities for Home-Based Palliative Care to Enhance Care Quality and Reduce Caring Burden among the Caregivers of Thai Elderly" โดยมีรองศาสตราจารย์ ดร. วันดี สุทธรังษี เป็นอาจารย์ที่ปรึกษาวิทยานิพนธ์หลักและผู้ช่วยศาสตราจารย์ ดร.แสงอรุณ อิสระมาลัย เป็นอาจารย์ที่ปรึกษาวิทยานิพนธ์ร่วม ซึ่งในกระบวนการสร้างเครื่องมือวิจัยในเรื่องนี้ จำเป็นต้องมีการทดลองใช้เครื่องมือวิจัย ทั้งนี้โครงการวิจัยของนักศึกษา ได้ผ่านการพิจารณาด้านจริยธรรมจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

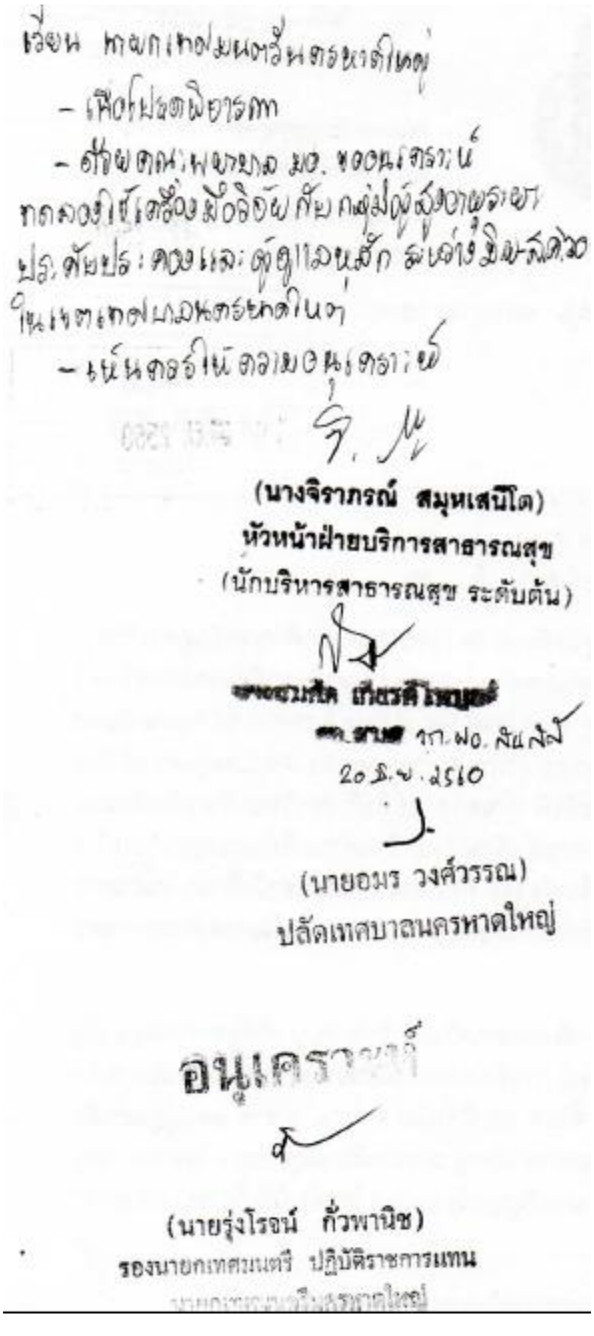
ในการนี้ คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ จึงขออนุญาตให้นางสาวกัญญาณัฐ สุภาพร ทดลองใช้เครื่องมือวิจัยโดยใช้การสัมภาษณ์ การสังเกตแบบมีส่วนร่วม และแบบสอบถามกับกลุ่มผู้สูงอายุที่อยู่ในระยะประคับประคองอายุ ตั้งแต่ 60 ปีขึ้นไป จำนวน 3 ราย และผู้ดูแลหลัก จำนวน 3 ราย ณ บ้านของผู้สูงอายุภายในเขตเทศบาลนครหาดใหญ่ ระหว่างเดือนมิถุนายน – สิงหาคม 2560 ทั้งนี้ หากต้องการรายละเอียดเพิ่มเติมโปรดติดต่อนางสาวกัญญาณัฐ สุภาพร โทรศัพท์มือถือ 062-0535597 หรือ E-mail: yui002ns@gmail.com

จึงเรียนมาเพื่อโปรดพิจารณาให้ความอนุเคราะห์ด้วย จะเป็นพระคุณยิ่ง

ขอแสดงความนับถือ

(รองศาสตราจารย์ ดร.อรัญญา เชาวลิต)
คณบดีคณะพยาบาลศาสตร์

สำนักงานเลขานุการ
โทรศัพท์ 0-7428-6455



เรียน นายกเทศมนตรีนครหาดใหญ่

- เพื่อโปรดพิจารณา
- ด้วย คณะพยาบาล มอ. ขออนุเคราะห์ ทดลองใช้เครื่องมือวิจัย กับกลุ่มผู้สูงอายุระยะ ประคับประคอง และผู้ดูแลหลัก ระหว่าง มิ.ย.-ส.ค. 60 ในเขตเทศบาลนครหาดใหญ่
- เห็นควรให้ความอนุเคราะห์

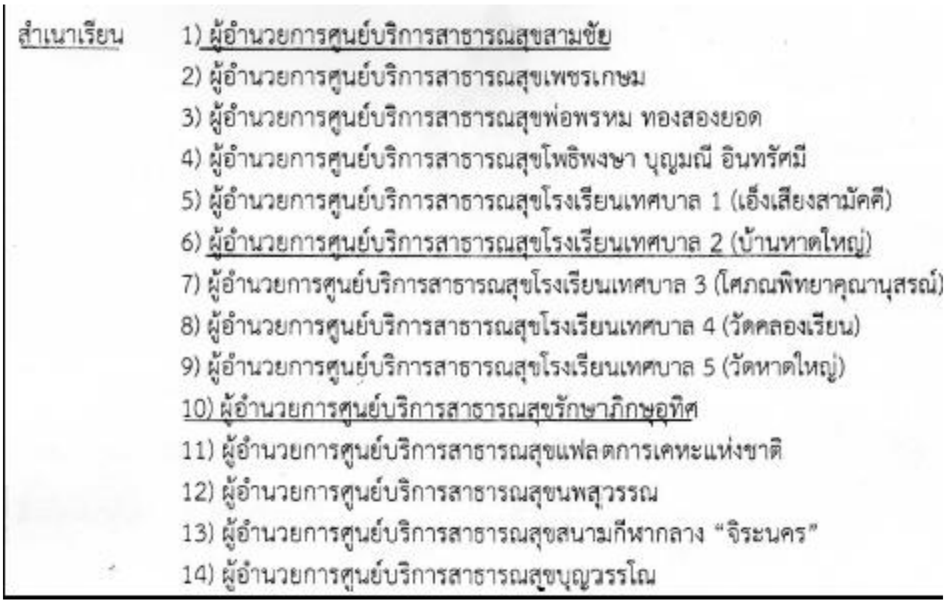
(นางจิราภรณ์ สมุหเสนีโต)
หัวหน้าฝ่ายบริการสาธารณสุข
(นักบริหารสาธารณสุข ระดับต้น)

[illegible] เกียรติไพบูลย์
ผอ.ส่วน รก.ผอ.สนส.
20 มิ.ย. 2560

(นายอมร วงศ์วรรณ)
ปลัดเทศบาลนครหาดใหญ่

อนุเคราะห์

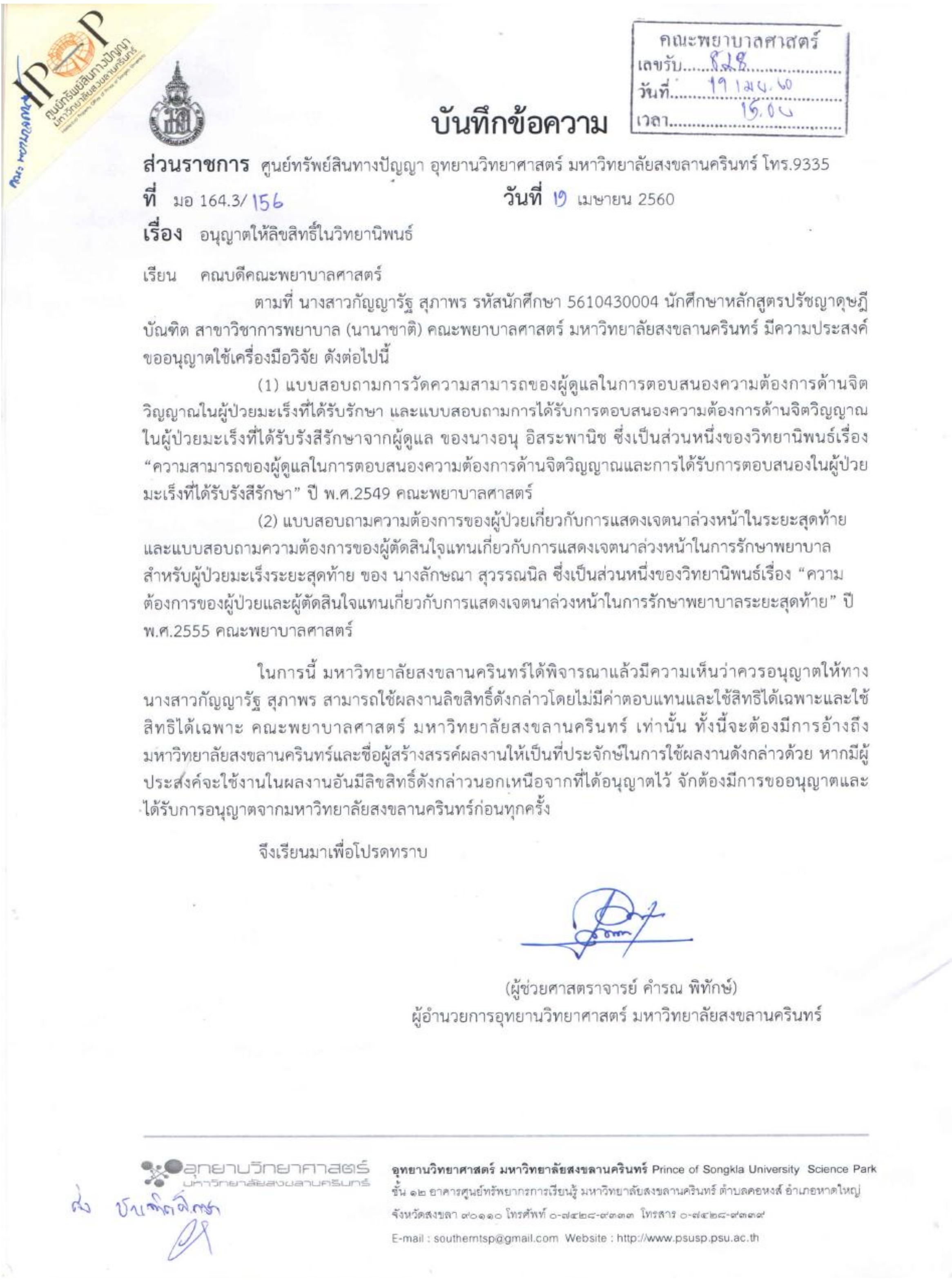
(นายรุ่งโรจน์ กั้วพานิช)
รองนายกเทศมนตรี ปฏิบัติราชการแทน
นายกเทศมนตรีนครหาดใหญ่



สำเนาเรียน
1) ผู้อำนวยการศูนย์บริการสาธารณสุขสามชัย
2) ผู้อำนวยการศูนย์บริการสาธารณสุขเพชรเกษม
3) ผู้อำนวยการศูนย์บริการสาธารณสุขพ่อพรหม ทองสองยอด
4) ผู้อำนวยการศูนย์บริการสาธารณสุขโพธิพงษา บุญมณี อินทรัศมี
5) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 1 (เอ็งเสียงสามัคคี)
6) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 2 (บ้านหาดใหญ่)
7) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 3 (โศภณพิทยาคุณานุสรณ์)
8) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 4 (วัดคลองเรียน)
9) ผู้อำนวยการศูนย์บริการสาธารณสุขโรงเรียนเทศบาล 5 (วัดหาดใหญ่)
10) ผู้อำนวยการศูนย์บริการสาธารณสุขรักษาภิกษุอุทิศ
11) ผู้อำนวยการศูนย์บริการสาธารณสุขแฟลตการเคหะแห่งชาติ
12) ผู้อำนวยการศูนย์บริการสาธารณสุขนพสุวรรณ
13) ผู้อำนวยการศูนย์บริการสาธารณสุขสนามกีฬากลาง “จิระนคร”
14) ผู้อำนวยการศูนย์บริการสาธารณสุขบุญวรรโณ

Appendix B5

Permission letter for using instrument



คณะ พยาบาลศาสตร์

คณะพยาบาลศาสตร์
เลขรับ ๘๒๘
วันที่ ๑๙ เม.ย. ๖๐
เวลา ๑๕.๐๖

บันทึกข้อความ

ส่วนราชการ ศูนย์ทรัพย์สินทางปัญญา อุทยานวิทยาศาสตร์ มหาวิทยาลัยสงขลานครินทร์ โทร.9335

ที่ มอ 164.3/156 **วันที่** 19 เมษายน 2560

เรื่อง อนุญาตให้ลิขสิทธิ์ในวิทยานิพนธ์

เรียน คณบดีคณะพยาบาลศาสตร์

ตามที่ นางสาวกัญญารัฐ สุภาพร รหัสนักศึกษา 5610430004 นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (นานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ มีความประสงค์ขออนุญาตใช้เครื่องมือวิจัย ดังต่อไปนี้

(1) แบบสอบถามการวัดความสามารถของผู้ดูแลในการตอบสนองความต้องการด้านจิตวิญญาณในผู้ป่วยมะเร็งที่ได้รับรักษา และแบบสอบถามการได้รับการตอบสนองความต้องการด้านจิตวิญญาณในผู้ป่วยมะเร็งที่ได้รับรังสีรักษาจากผู้ดูแล ของนางอนุ อิสระพานิช ซึ่งเป็นส่วนหนึ่งของวิทยานิพนธ์เรื่อง “ความสามารถของผู้ดูแลในการตอบสนองความต้องการด้านจิตวิญญาณและการได้รับการตอบสนองในผู้ป่วยมะเร็งที่ได้รับรังสีรักษา” ปี พ.ศ.2549 คณะพยาบาลศาสตร์

(2) แบบสอบถามความต้องการของผู้ป่วยเกี่ยวกับการแสดงเจตนาล่วงหน้าในระยะสุดท้าย และแบบสอบถามความต้องการของผู้ตัดสินใจแทนเกี่ยวกับการแสดงเจตนาล่วงหน้าในการรักษาพยาบาลสำหรับผู้ป่วยมะเร็งระยะสุดท้าย ของ นางลักษณา สุวรรณนิล ซึ่งเป็นส่วนหนึ่งของวิทยานิพนธ์เรื่อง “ความต้องการของผู้ป่วยและผู้ตัดสินใจแทนเกี่ยวกับการแสดงเจตนาล่วงหน้าในการรักษาพยาบาลระยะสุดท้าย” ปี พ.ศ.2555 คณะพยาบาลศาสตร์

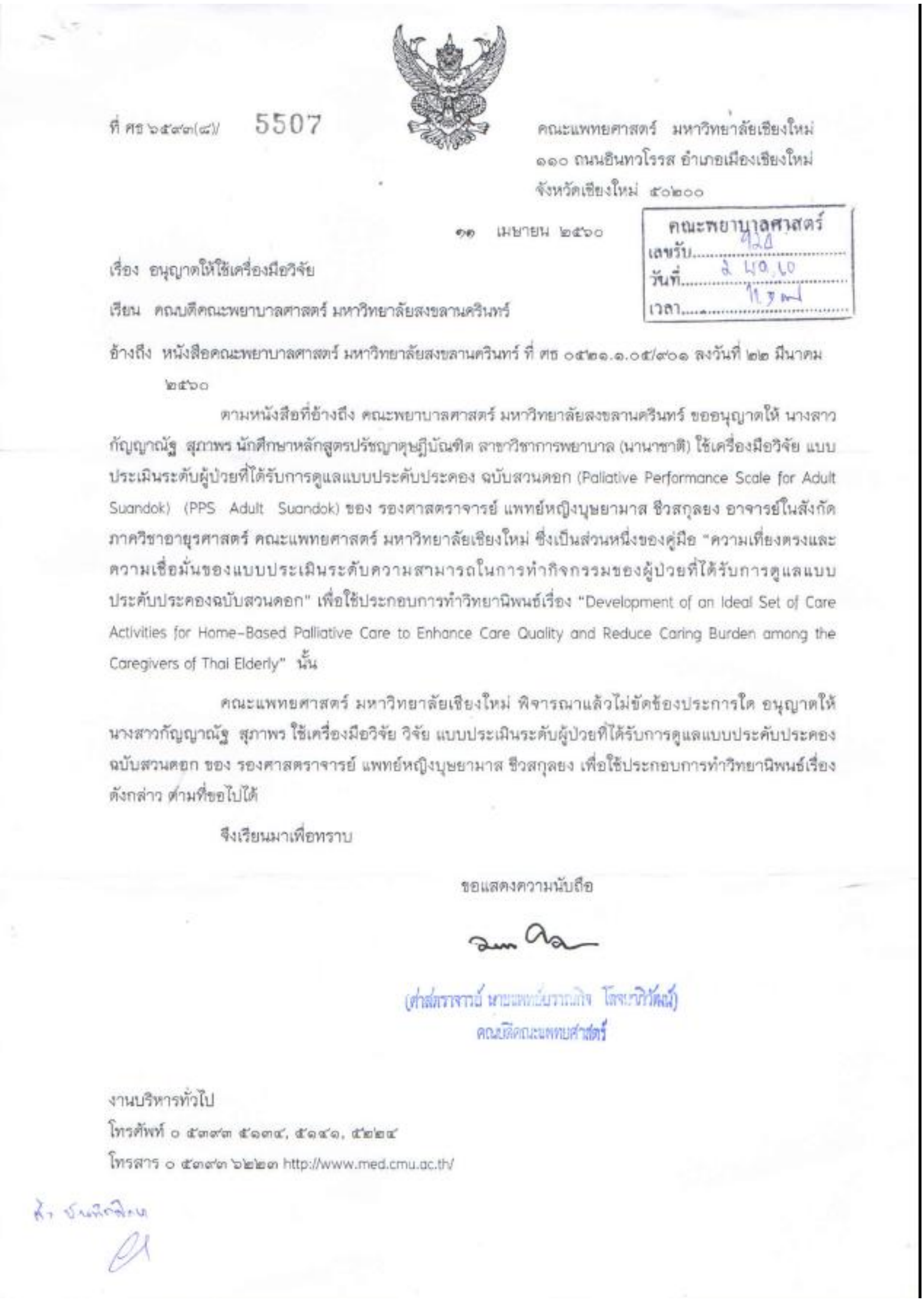
ในการนี้ มหาวิทยาลัยสงขลานครินทร์ได้พิจารณาแล้วมีความเห็นว่าควรอนุญาตให้ทาง นางสาวกัญญารัฐ สุภาพร สามารถใช้ผลงานลิขสิทธิ์ดังกล่าวโดยไม่มีค่าตอบแทนและใช้สิทธิได้เฉพาะและใช้สิทธิได้เฉพาะ คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ เท่านั้น ทั้งนี้จะต้องมีการอ้างถึงมหาวิทยาลัยสงขลานครินทร์และชื่อผู้สร้างสรรค์ผลงานให้เป็นที่ประจักษ์ในการใช้ผลงานดังกล่าวด้วย หากมีผู้ประสงค์จะใช้งานในผลงานอันมีลิขสิทธิ์ดังกล่าวนอกเหนือจากที่ได้อนุญาตไว้ จักต้องมีการขออนุญาตและได้รับการอนุญาตจากมหาวิทยาลัยสงขลานครินทร์ก่อนทุกครั้ง

จึงเรียนมาเพื่อโปรดทราบ

(ผู้ช่วยศาสตราจารย์ คำรณ พิทักษ์)
ผู้อำนวยการอุทยานวิทยาศาสตร์ มหาวิทยาลัยสงขลานครินทร์

อุทยานวิทยาศาสตร์ มหาวิทยาลัยสงขลานครินทร์ Prince of Songkla University Science Park
ชั้น ๑๒ อาคารศูนย์ทรัพยากรการเรียนรู้ มหาวิทยาลัยสงขลานครินทร์ ตำบลคอหงส์ อำเภอหาดใหญ่
จังหวัดสงขลา ๙๐๑๑๐ โทรศัพท์ ๐-๗๔๒๘-๙๓๓๓ โทรสาร ๐-๗๔๒๘-๙๓๓๙
E-mail : southemtsp@gmail.com Website : http://www.psusp.psu.ac.th

ส่ง บัณฑิตศึกษา



ที่ ศธ ๖๕๙๓(๘)/ 5507

คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่
๑๑๐ ถนนอินทวโรรส อำเภอเมืองเชียงใหม่
จังหวัดเชียงใหม่ ๕๐๒๐๐

๑๓ เมษายน ๒๕๖๐

คณะพยาบาลศาสตร์
เลขรับ ๙๒๘
วันที่ ๒ ๔๐.๖๐
เวลา 11.[illegible]

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน คณบดีคณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

อ้างถึง หนังสือคณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ ที่ ศธ ๐๕๒๑.๑.๐๕/๙๐๑ ลงวันที่ ๒๒ มีนาคม ๒๕๖๐

ตามหนังสือที่อ้างถึง คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ ขออนุญาตให้ นางสาวกัญญาณัฐ สุภาพร นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (นานาชาติ) ใช้เครื่องมือวิจัย แบบประเมินระดับผู้ป่วยที่ได้รับการดูแลแบบประคับประคอง ฉบับสวนดอก (Paliative Performance Scale for Adult Suandok) (PPS Adult Suandok) ของ รองศาสตราจารย์ แพทย์หญิงบุษยามาส ชีวสกุลยง อาจารย์ในสังกัดภาควิชาอายุรศาสตร์ คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่ ซึ่งเป็นส่วนหนึ่งของคู่มือ "ความเที่ยงตรงและความเชื่อมั่นของแบบประเมินระดับความสามารถในการทำกิจกรรมของผู้ป่วยที่ได้รับการดูแลแบบประคับประคองฉบับสวนดอก" เพื่อใช้ประกอบการทำวิทยานิพนธ์เรื่อง "Development of an Ideal Set of Care Activities for Home-Based Palliative Care to Enhance Care Quality and Reduce Caring Burden among the Caregivers of Thai Elderly" นั้น

คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่ พิจารณาแล้วไม่ขัดข้องประการใด อนุญาตให้นางสาวกัญญาณัฐ สุภาพร ใช้เครื่องมือวิจัย วิจัย แบบประเมินระดับผู้ป่วยที่ได้รับการดูแลแบบประคับประคองฉบับสวนดอก ของ รองศาสตราจารย์ แพทย์หญิงบุษยามาส ชีวสกุลยง เพื่อใช้ประกอบการทำวิทยานิพนธ์เรื่องดังกล่าว ตามที่ขอไปได้

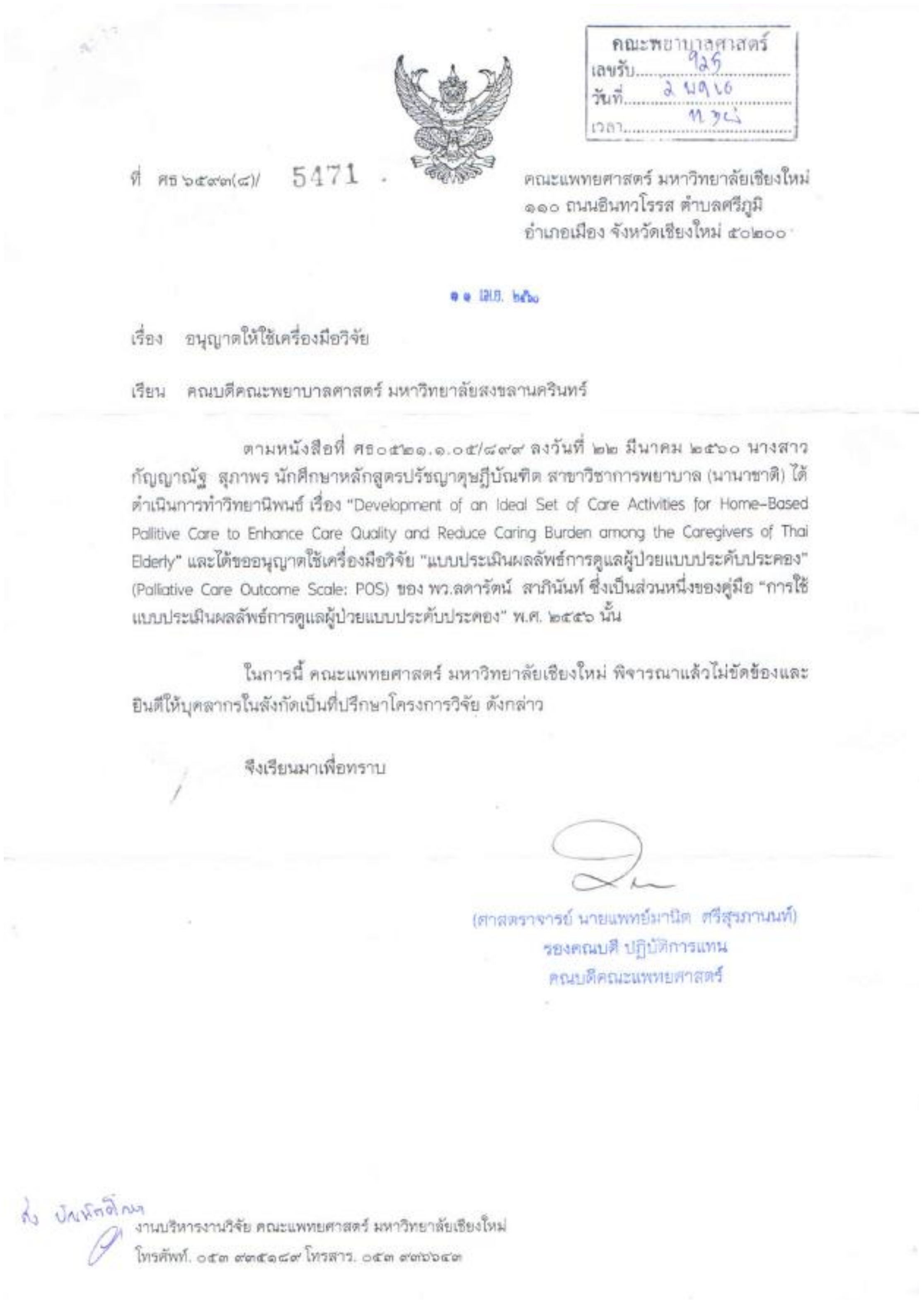
จึงเรียนมาเพื่อทราบ

ขอแสดงความนับถือ

(ศาสตราจารย์ นายแพทย์บรรณกิจ โลจนาภิวัฒน์)
คณบดีคณะแพทยศาสตร์

งานบริหารทั่วไป
โทรศัพท์ ๐ ๕๓๙๓ ๕๑๓๔, ๕๑๔๑, ๕๒๒๔
โทรสาร ๐ ๕๓๙๓ ๖๒๒๓ http://www.med.cmu.ac.th/

ส่ง บัณฑิตศึกษา



คณะพยาบาลศาสตร์
เลขรับ ๙๒๕
วันที่ ๒ พค ๖๐
เวลา ๑๑.๒๕

ที่ ศธ ๖๕๙๓(๘)/ 5471

คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่
๑๑๐ ถนนอินทวโรรส ตำบลศรีภูมิ
อำเภอเมือง จังหวัดเชียงใหม่ ๕๐๒๐๐

๑๑ เม.ย. ๒๕๖๐

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน คณบดีคณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

ตามหนังสือที่ ศธ๐๕๒๑.๑.๐๕/๘๙๙ ลงวันที่ ๒๒ มีนาคม ๒๕๖๐ นางสาวกัญญาณัฐ สุภาพร นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (นานาชาติ) ได้ดำเนินการทำวิทยานิพนธ์ เรื่อง "Development of an Ideal Set of Care Activities for Home-Based Pallitive Care to Enhance Care Quality and Reduce Caring Burden among the Caregivers of Thai Elderly" และได้ขออนุญาตใช้เครื่องมือวิจัย "แบบประเมินผลลัพธ์การดูแลผู้ป่วยแบบประคับประคอง" (Palliative Care Outcome Scale: POS) ของ พว.ลดารัตน์ สาภินันท์ ซึ่งเป็นส่วนหนึ่งของคู่มือ "การใช้แบบประเมินผลลัพธ์การดูแลผู้ป่วยแบบประคับประคอง" พ.ศ. ๒๕๕๖ นั้น

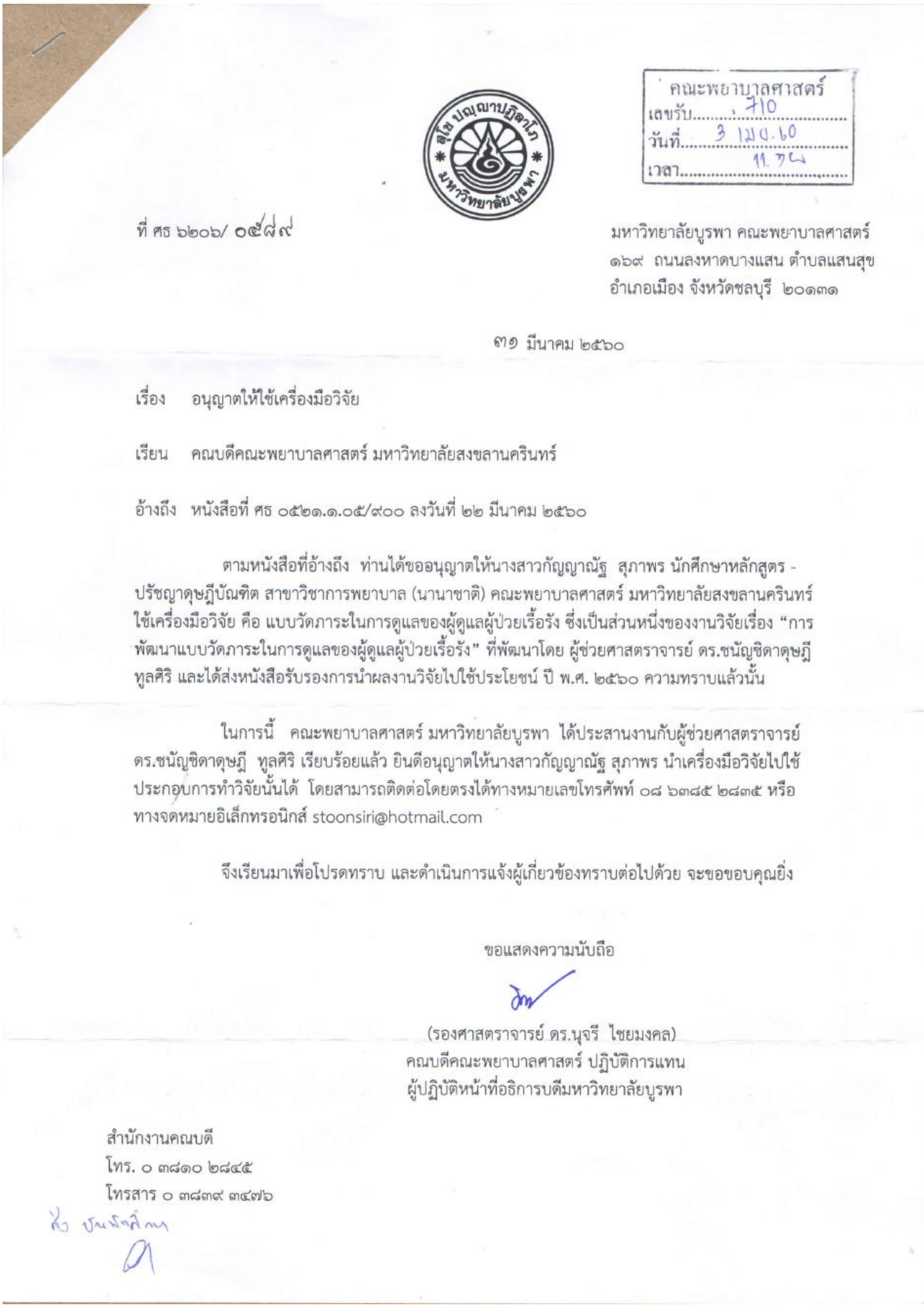
ในการนี้ คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่ พิจารณาแล้วไม่ขัดข้องและยินดีให้บุคลากรในสังกัดเป็นที่ปรึกษาโครงการวิจัย ดังกล่าว

จึงเรียนมาเพื่อทราบ

(ศาสตราจารย์ นายแพทย์มานิต ศรีสุรภานนท์)
รองคณบดี ปฏิบัติการแทน
คณบดีคณะแพทยศาสตร์

ส่ง บัณฑิตศึกษา

งานบริหารงานวิจัย คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่
โทรศัพท์. ๐๕๓ ๙๓๕๑๘๙ โทรสาร. ๐๕๓ ๙๓๖๖๔๓



คณะพยาบาลศาสตร์
เลขรับ 710
วันที่ 3 เม.ย.60
เวลา 11.75

ที่ ศธ ๖๒๐๖/ ๐๕๘๙

มหาวิทยาลัยบูรพา คณะพยาบาลศาสตร์
๑๖๙ ถนนลงหาดบางแสน ตำบลแสนสุข
อำเภอเมือง จังหวัดชลบุรี ๒๐๑๓๑

๓๑ มีนาคม ๒๕๖๐

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน คณบดีคณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

อ้างถึง หนังสือที่ ศธ ๐๕๒๑.๑.๐๕/๙๐๐ ลงวันที่ ๒๒ มีนาคม ๒๕๖๐

ตามหนังสือที่อ้างถึง ท่านได้ขออนุญาตให้นางสาวกัญญาณัฐ สุภาพร นักศึกษาหลักสูตร - ปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (นานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ ใช้เครื่องมือวิจัย คือ แบบวัดภาระในการดูแลของผู้ดูแลผู้ป่วยเรื้อรัง ซึ่งเป็นส่วนหนึ่งของงานวิจัยเรื่อง “การพัฒนาแบบวัดภาระในการดูแลของผู้ดูแลผู้ป่วยเรื้อรัง” ที่พัฒนาโดย ผู้ช่วยศาสตราจารย์ ดร.ชนัญชิดาดุษฎี ทูลศิริ และได้ส่งหนังสือรับรองการนำผลงานวิจัยไปใช้ประโยชน์ ปี พ.ศ. ๒๕๖๐ ความทราบแล้วนั้น

ในการนี้ คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา ได้ประสานงานกับผู้ช่วยศาสตราจารย์ ดร.ชนัญชิดาดุษฎี ทูลศิริ เรียบร้อยแล้ว ยินดีอนุญาตให้นางสาวกัญญาณัฐ สุภาพร นำเครื่องมือวิจัยไปใช้ประกอบการทำวิจัยนั้นได้ โดยสามารถติดต่อโดยตรงได้ทางหมายเลขโทรศัพท์ ๐๘ ๖๓๘๕ ๒๘๓๕ หรือทางจดหมายอิเล็กทรอนิกส์ stoonsiri@hotmail.com

จึงเรียนมาเพื่อโปรดทราบ และดำเนินการแจ้งผู้เกี่ยวข้องทราบต่อไปด้วย จะขอบคุณยิ่ง

ขอแสดงความนับถือ

(รองศาสตราจารย์ ดร.นุจรี ไชยมงคล)
คณบดีคณะพยาบาลศาสตร์ ปฏิบัติการแทน
ผู้ปฏิบัติหน้าที่อธิการบดีมหาวิทยาลัยบูรพา

สำนักงานคณบดี
โทร. ๐ ๓๘๑๐ ๒๘๔๕
โทรสาร ๐ ๓๘๓๙ ๓๔๗๖

ส่ง บัณฑิตศึกษา

Appendix C

Instruments

Appendix C1

Demographic Forms

C1-1 For the elderly

Code:
Date:

Instruction: The questions ask for information about your personal data and disease related data. Please fill in the available space that is appropriate for you and answer the best choice by putting a mark √ in the box.

Gender ☐ Male ☐ Female

1. Age …….years
2. Religion ☐ Buddhist ☐ Islamic ☐ Christian ☐ Other………
3. Marital status ☐ Single ☐ Married ☐ Divorced / widowed/separated
4. Living with ☐ Spouse ☐ Children ☐ Others…………
5. Health insurance ……………………………………………..
6. Educational level ☐ No formal education ☐ Elementary school
   ☐ Junior high school ☐ Senior high school ☐ Diploma
   ☐ Bachelor ☐ Above
7. Family average monthly income………….baht/month
8. Disease …………………
9. Current medication ……………………………………..
10. Your hospital treatment ……………………………..
11. Your contact address ……………………………..
12. Your telephone number ……………………………..
13. Other ……………………………..

C1-2 For family caregiver

Code:
Date:

Instruction: Please fill in the available space that is appropriate for you and answer the best choice by putting a mark √ in the box.

1. Relationship with the elderly ……………………………..
2. Age ……. Years
3. Gender ☐ Male ☐ Female
4. Religion ☐ Buddhist ☐ Islamic ☐ Christian ☐ Other………
5. Educational level ☐ No formal education ☐ Elementary school ☐ Junior high school ☐ Senior high school ☐ Diploma ☐ Bachelor ☐ Above
6. Marital status ☐ Single ☐ Married ☐ Divorced / widowed/separated
7. Occupational status ……………………………..
8. Your telephone number ……………………………..
9. Other ……………………………..

Appendix C2

Observation Record Form

Instruction: the researcher should use this form to make field note during the process of participant observation.

Observation Record No……………………………………………………Page……

Date……………………………………………………Time…………………….

Location………………………………………………………………………………

Participants…………………………………………………………………………...

Observed data	Reflection

Appendix C3

The Thai version of the Palliative care Outcome Scale (POS)

แบบประเมินผลลัพธ์การดูแลผู้สูงอายุแบบประคับประคอง ฉบับใช้ถามผู้ดูแลหลักของผู้สูงอายุ

กรุณาตอบคำถามต่อไปนี้ โดยทำเครื่องหมาย √ ให้ตรงกับคำตอบที่ท่านคิดว่าตรงกับความรู้สึกของผู้สูงอายุที่สุด

1. ในช่วงสามวันที่ผ่านมา ผู้ป่วยมีอาการปวดหรือไม่

☐ 0 ไม่มีอาการปวดเลย

☐ 1 ปวดเล็กน้อยแต่ไม่รบกวน จึงไม่ต้องจัดการกับความปวด

☐ 2 ปวดปานกลาง ความปวดทำให้ไม่สามารถทำกิจกรรมบางอย่างได้

☐ 3 ปวดรุนแรง จนมีผลกระทบอย่างมากต่อการใช้สมาธิในการทำงานหรือการทำกิจกรรมต่างๆ

☐ 4 ปวดอย่างมากมายท่วมท้น จนคิดอะไรไม่ออก

2. ในช่วงสามวันที่ผ่านมา ผู้สูงอายุมีอาการอื่นที่มีผลต่อความรู้สึกของผู้สูงอายุ เช่น รู้สึกไม่สบาย ไอ ท้องผูก หรือไม่

☐ 0 ไม่เลย

☐ 1 เล็กน้อย

☐ 2 ปานกลาง

☐ 3 รุนแรง

☐ 4 มากมาย ท่วมท้น

3. ในช่วงสามวันที่ผ่านมา ผู้สูงอายุรู้สึกหงุดหงิดหรือกังวลใจเกี่ยวกับความเจ็บป่วยหรือการรักษาหรือไม่

☐ 0 ไม่กังวลเลยหรือไม่หงุดหงิดเลย

☐ 1 กังวลใจบ้างหรือหงุดหงิดนานๆครั้ง

☐ 2 กังวลใจบ้างหรือหงุดหงิดเป็นบางครั้ง เป็นบ้างไม่เป็นบ้าง

☐ 3 กังวลใจหรือหงุดหงิดตลอดเวลา ส่วนมากแล้วมีผลกระทบกับความคิดหรือสมาธิของผู้ป่วย

☐ 4 กังวลใจหรือหงุดหงิดตลอดเวลาจนไม่สามารถคิดอะไรออกเลย

4. ในช่วงสามวันที่ผ่านมา สมาชิกในครอบครัวของผู้สูงอายุ มีความวิตกกังวลเกี่ยวกับผู้สูงอายุหรือไม่

☐ 0 ไม่วิตกกังวลเลย

☐ 1 นานๆครั้ง

☐ 2 เป็นบางครั้ง มีผลกระทบบ้างต่อความคิดหรือสมาธิของสมาชิกในครอบครัว

☐ 3 วิตกกังวลเป็นส่วนมาก

☐ 4 วิตกกังวลตลอดเวลา

5. ในช่วงสามวันที่ผ่านมา ผู้สูงอายุและท่าน และสมาชิกในครอบครัว หรือเพื่อนของผู้สูงอายุ ได้ทราบข้อมูลเกี่ยวกับการดูแลรักษามากน้อยเพียงใด

☐ 0 ได้รับทราบข้อมูลเต็มที่ รู้สึกสบายใจที่ได้ถามแพทย์หรือพยาบาลในสิ่งที่สงสัย

☐ 1 ได้รับทราบข้อมูล แต่ผู้สูงอายุไม่เข้าใจ

☐ 2 ได้รับทราบข้อมูลก็ต่อเมื่อถามไปยังแพทย์และพยาบาล แต่จริงๆแล้วอยากทราบ

ข้อมูลมากกว่านี้

☐ 3 ได้รับทราบข้อมูลน้อยมาก และในบางคำถาม แพทย์และพยาบาลหลีกเลี่ยงที่จะตอบคำถาม

☐ 4 ไม่ได้รับทราบข้อมูลเลย

6. ในช่วงสามวันที่ผ่านมา ผู้สูงอายุได้เล่าระบายความรู้สึกของเขาให้กับสมาชิกในครอบครัวหรือเพื่อนหรือไม่

☐ 0 ใช่ ผู้สูงอายุได้เล่าทุกอย่างที่อยากจะพูด

☐ 1 ได้เล่าระบายความรู้สึกเป็นส่วนมาก

☐ 2 ได้เล่าระบายความรู้สึกเป็นบางครั้ง

☐ 3 ไม่ค่อยได้เล่าบ่อย นานๆครั้ง

☐ 4 ไม่เคยเล่ากับใครเลย

7. ในช่วงสามวันที่ผ่านมา ท่านคิดว่าผู้สูงอายุเศร้าใจหรือไม่

☐ 0 ไม่เลย

☐ 1 ไม่ค่อยบ่อย

☐ 2 เป็นบางครั้ง

☐ 3 ค่อนข้างบ่อย

☐ 4 ตลอดเวลา

8. ในช่วงสามวันที่ผ่านมา ท่านคิดว่าผู้สูงอายุรู้สึกดีกับตัวเองหรือไม่

☐ 0 ใช่ รู้สึกดีกับตัวเองตลอดเวลา

☐ 1 ค่อนข้างบ่อย

☐ 2 เป็นบางครั้ง

☐ 3 ไม่ค่อยบ่อย

☐ 4 ไม่รู้สึกดีกับตัวเองเลย

9. ในช่วงสามวันที่ผ่านมา ท่านรู้สึกว่าผู้สูงอายุเสียเวลา ในการนัดหมายเกี่ยวกับการดูแลสุขภาพของผู้สูงอายุหรือไม่ เช่น รอรถมาส่งที่โรงพยาบาล หรือเสียเวลาในการรอคอยการเจาะเลือดซ้ำ หรือเสียเวลาในการรอคอย การเอกซเรย์ซ้ำ

☐ 0 ผู้สูงอายุไม่เสียเวลาเลย

☐ 2 ผู้สูงอายุเสียเวลาเกือบครึ่งวัน

☐ 4 ผู้สูงอายุเสียเวลาเมากกว่าครึ่งวัน

10. ในช่วงสามวันที่ผ่านมา ผู้สูงอายุได้รับการช่วยเหลือในการแก้ไขปัญหาที่เกิดจากความเจ็บป่วยของผู้สูงอายุ ทั้งด้านปัญหาการเงินหรือปัญหาส่วนตัวหรือไม่

☐ 0 ได้รับการช่วยเหลือทันเวลาตามที่ผู้สูงอายุต้องการ

☐ 2 ปัญหากำลังได้รับการช่วยเหลือ

☐ 4 ปัญหายังมีอยู่ และยังไม่ได้รับการช่วยเหลือ

☐ 0 ไม่มีปัญหาอะไรเลย

11. อะไรคือปัญหาหลักหรือปัญหาสำคัญของผู้สูงอายุในช่วงสามวันที่ผ่านมา

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12. โปรดทำเครื่องหมาย √ ให้ตรงกับความสามารถในการปฏิบัติกิจกรรมของผู้สูงอายุมากที่สุด

☐ 0 ผู้สูงอายุสามารถปฏิบัติงานได้ตามปกติ ไม่มีอาการของโรค

☐ 1 ผู้สูงอายุปฏิบัติกิจกรรมได้ตามปกติ มีอาการแสดงของโรคเล็กน้อย

☐ 2 ผู้สูงอายุมีข้อจำกัดในการปฏิบัติกิจกรรม และมีอาการแสดงของโรค

☐ 3 ผู้สูงอายุช่วยเหลือตัวเองได้น้อยลง อยู่บนเตียงมากกว่าครึ่งหนึ่งของเวลา 1 วัน

☐ 4 ผู้สูงอายุช่วยเหลือตัวเองได้น้อยมาก ใช้เวลาทั้งวันอยู่บนเตียง

The Palliative care Outcome Scale (POS) for Family caregiver

Instruction: Please answer the following questions by √ the box next to the answer which you think most accurately describes how the elderly person has been feeling.

1. Over the past 3 days, has the elderly person been affected by pain?

☐ 0 Not at all, no effect

☐ 1 Slightly, but not bothered to be rid of it

☐ 2 Moderately, pain limits some activity

☐ 3 Severely, activities or concentration markedly affected

☐ 4 Overwhelmingly, unable to think of anything else

2. Over the past 3 days, have other symptoms e.g. nausea, coughing or constipation seemed to be affecting how well the elderly person feels?

☐ 0 No, not at all

☐ 1 Slightly

☐ 2 Moderately

☐ 3 Severely

☐ 4 Overwhelmingly

3. Over the past 3 days, has the elderly person been feeling anxious or worried about their illness or treatment?

☐ 0 No, not at all

☐ 1 Occasionally

☐ 2 Sometimes, affects their concentration now and then

☐ 3 Most of the time, often affects their concentration

☐ 4 Patient does not seem to think of anything else, completely preoccupied by worry and anxiety

4. Over the past 3 days, has any of your family been anxious or worried about the elderly person?

☐ 0 No, not at all

☐ 1 Occasionally

☐ 2 Sometimes, it seems to affect their concentration

☐ 3 Most of the time

☐ 4 Yes, they always seem preoccupied with worry

5. Over the past 3 days, how much information has been given to the elderly person and your family or friends?

☐ 0 Full information, the elderly person feels free to ask

☐ 1 Information given but not always understood by the elderly person

☐ 2 Information given to the elderly person on request, the elderly person would have liked more

☐ 3 Very little given and some questions have been avoided

☐ 4 None at all

6. Over the past 3 days, has the elderly person been able to share how they are feeling with family or friends?

☐ 0 Yes, as much as they wanted to

☐ 1 Most of the time

☐ 2 Sometimes

☐ 3 Occasionally

☐ 4 No, not at all with anyone

7. Over the past 3 days, do you think they have felt life was worth living?

☐ 0 Yes, all the time

☐ 1 Most of the time

☐ 2 Sometimes

☐ 3 Occasionally

☐ 4 No, not at all

8. Over the past 3 days, do you think the elderly person has felt good about him/her self?

☐ 0 Yes, all the time

☐ 1 Most of the time

☐ 2 Sometimes

☐ 3 Occasionally

☐ 4 No, not at all

9. Over the past 3 days, how much time do you feel has been wasted on appointments relating to the healthcare of the elderly person, e.g. waiting around for transport or repeating tests?

☐ 0 None at all

☐ 2 Up to half a day wasted

☐ 4 More than half a day wasted

10. Over the past 3 days, have any practical matters resulting from his/her illness, either financial or personal, been addressed?

☐ 0 Practical problems have been addressed and his/her affairs are as up to date as they would wish

☐ 2 Practical problems are in the process of being addressed

☐ 4 Practical problems exist which were not addressed

☐ 0 The elderly person has had no practical problems

11. If any, what has been the elderly person's main problems in the last 3 days?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

12. Please mark √ in the box that is true of performance status of the elderly person?

☐ 0 Fully active

☐ 1 Restricted

☐ 2 Ambulatory

☐ 3 Limited self care

☐ 4 Completely disabled

Appendix C4
The preferences of patients for advance directives at the end of life

แบบสอบถามผู้สูงอายุถึงความต้องการเกี่ยวกับการแสดงเจตนาล่วงหน้าในการรักษาพยาบาลระยะสุดท้ายของชีวิต

คำชี้แจง ขอให้ท่านบอกความต้องการตามข้อความต่อไปนี้ว่าท่านต้องการเพียงใด

โดยทำเครื่องหมาย√ ลงในช่องที่ตรงกับความต้องการของท่าน

ความต้องการ	ระดับความต้องการ					
	มากที่สุด	มาก	ปานกลาง	น้อย	น้อยที่สุด	ไม่ต้องการ
1. ท่านต้องการทราบข้อมูลในเรื่องต่อไปนี้เพื่อใช้สำหรับการแสดงเจตนาล่วงหน้าในการรักษาพยาบาล หากอยู่ในระยะสุดท้ายเพียงใด 1.1 ข้อมูลเกี่ยวกับโรค/ ความเจ็บป่วย						
1.2 ความรุนแรงของโรค						
1.3 ระยะของโรค/โอกาสรอดหรือหายจากโรค						
1.4 การรักษาพยาบาลที่ได้รับหรือแผนการรักษาพยาบาล						
1.5 เป้าหมายของการรักษาพยาบาล						
1.6 ผลดี ผลเสีย/อันตราย จากการรักษา						
1.7 ค่าใช้จ่ายในการรักษาพยาบาล (เช่น ค่ายา ค่าอุปกรณ์ทางการแพทย์)						
2. ท่านต้องการทราบข้อมูลเกี่ยวกับการแสดงเจตนาล่วงหน้าในการักษาพยาบาลของผู้สูงอายุ ในเรื่องต่อไปนี้เพียงใด 2.1 ความหมายของการแสดงเจตนาล่วงหน้า						
2.2 วิธีการแสดงเจตนล่วงหน้า						

ความต้องการ	ระดับความต้องการ					
	มาก ที่สุด	มาก	ปาน กลาง	น้อย	น้อย ที่สุด	ไม่ ต้องการ
2.3 ความหมายของพินัยกรรมชีวิต						
2.4 ช่วงเวลาที่เหมาะสมในการทำพินัยกรรมชีวิต						
2.5 ข้อดี ข้อเสีย ในการทำพินัยกรรมชีวิต						
2.6 ความหมายของผู้ตัดสินใจแทน						
2.7 คุณสมบัติของผู้ตัดสินใจแทน						
2.8 บทบาท หน้าที่ของผู้ตัดสินใจแทน						
2.9 ช่วงเวลาที่ผู้ตัดสินใจแทนเข้ามามีส่วนร่วมในการรักษาพยาบาล						
2.10 ข้อดี ข้อเสียในการมอบหมายผู้ตัดสินใจแทน						
3. ท่านต้องการใช้วิธีการต่อไปนี้ เพื่อการแสดงเจตนล่วงหน้าการรักษาพยาบาลเมื่ออยู่ในระยะสุดท้าย เพียงใด 3.1 การทำพินัยกรรมชีวิตโดยการสั่งหรือบอกผู้ที่เกี่ยวข้องไว้ด้วยวาจา						
3.2 การทำพินัยกรรมชีวิตโดยเขียนเป็นลายลักษณ์อักษร						
3.3 การมอบหมายให้มีผู้ตัดสินใจแทนตามกฎหมาย**เพียงคนเดียว**						
3.4 การมอบหมายให้สมาชิกในครอบครัวร่วมกันเป็นผู้ตัดสินใจแทน**เพียงฝ่ายเดียว**						
3.5 การมอบหมายให้บุคคลที่ท่านไว้ใจ/เคารพนับถือที่อยู่นอกครอบครัวเป็น						

ความต้องการ	**ระดับความต้องการ**					
	มาก ที่สุด	มาก	ปาน กลาง	น้อย	น้อย ที่สุด	ไม่ ต้องการ
ผู้ตัดสินใจแทน**เพียงฝ่ายเดียว**						
3.6 การมอบหมายให้ทีมสุขภาพ (แพทย์ พยาบาล) เป็นผู้ตัดสินใจแทน**เพียงฝ่ายเดียว**						
3.7 การมอบหมายให้สมาชิกในครอบครัว**ร่วมกับ**บุคคลที่ตนเองไว้วางใจ/เคารพนับถือเป็นผู้ตัดสินใจแทน						
3.8 การมอบหมายให้สมาชิกในครอบครัว**ร่วมกับ**ทีมสุขภาพ เป็นผู้ตัดสินใจแทน						
3.9 การมอบหมายให้สมาชิกในครอบครัวบุคคลที่ตนเองไว้ใจ/เคารพนับถือ ทีมสุขภาพ**ร่วมกัน**เป็นผู้ตัดสินใจแทน						
4. ท่านต้องการตัดสินใจในการรักษาพยาบาล เมื่อถึงระยะสุดท้ายของชีวิตโดยวิธีต่อไปนี้เพียงใด (มีภาพประกอบด้านหลังแบบสอบถาม) **4.1 ท่านต้องการยุติรับการรักษาที่ยืดชีวิต**						
4.2 ท่านต้องการรับการรักษาที่ยืดชีวิต						
กรณีเลือกตอบ ข้อ 4.2 รับการรักษาที่ยืดชีวิต ท่านต้องการใช้วิธีการต่อไปนี้เพียงใด						
1. การช่วยฟื้นคืนชีพ						
2. การใส่ท่อช่วยหายใจ						
3. การใช้เครื่องช่วยหายใจ						

ความต้องการ	**ระดับความต้องการ**					
	มาก ที่สุด	มาก	ปาน กลาง	น้อย	น้อย ที่สุด	ไม่ ต้องการ
4. การใช้เครื่องกระตุ้นหัวใจ						
5. วิธีอื่นๆ (ระบุ)………………………						

Appendix C5
The preferences of surrogates for advance directives at the end of life

แบบสอบถามผู้ตัดสินใจแทนผู้สูงอายุถึงความต้องการเกี่ยวกับการแสดงเจตนาล่วงหน้าในการรักษาพยาบาลระยะสุดท้ายของผู้สูงอายุ

คำชี้แจง ขอให้ท่านบอกความต้องการตามข้อความต่อไปนี้ว่าท่านต้องการเพียงใด
โดยทำเครื่องหมาย√ ลงในช่องที่ตรงกับความต้องการของท่าน

ความต้องการ	**ระดับความต้องการ**					
	มากที่สุด	มาก	ปานกลาง	น้อย	น้อยที่สุด	ไม่ต้องการ
1. ท่านต้องการทราบข้อมูลเกี่ยวกับการเจ็บป่วยของผู้สูงอายุเพื่อใช้ประกอบ การแสดงเจตนาล่วงหน้าในการรักษาพยาบาลของผู้สูงอายุเพียงใด 1.1 ข้อมูลเกี่ยวกับโรค/ ความเจ็บป่วย						
1.2 ความรุนแรงของโรค						
1.3 ระยะของโรค/โอกาสรอดหรือหายจากโรค						
1.4 การรักษาพยาบาลที่ได้รับหรือแผนการรักษาพยาบาล						
1.5 เป้าหมายของการรักษาพยาบาล						
1.6 ผลดี ผลเสีย/อันตราย จากการรักษา						
1.7 ค่าใช้จ่ายในการรักษาพยาบาล (เช่น ค่ายา ค่าอุปกรณ์ทางการแพทย์)						
2. ท่านต้องการทราบข้อมูลเกี่ยวกับการแสดงเจตนาล่วงหน้าในการักษาพยาบาลของผู้สูงอายุ ในเรื่องต่อไปนี้เพียงใด 2.1 ความหมายของการแสดงเจตนาล่วงหน้า						

ความต้องการ	**ระดับความต้องการ**					
	มาก ที่สุด	มาก	ปาน กลาง	น้อย	น้อย ที่สุด	ไม่ ต้องการ
2.2 วิธีการแสดงเจตนล่วงหน้า						
2.3 ความหมายของพินัยกรรมชีวิต						
2.4 ช่วงเวลาที่เหมาะสมในการทำพินัยกรรมชีวิต						
2.5 ข้อดี ข้อเสีย ในการทำพินัยกรรมชีวิต						
2.6 ความหมายของผู้ตัดสินใจแทน						
2.7 คุณสมบัติของผู้ตัดสินใจแทน						
2.8 บทบาท หน้าที่ของผู้ตัดสินใจแทน						
2.9 ช่วงเวลาที่ผู้ตัดสินใจแทนเข้ามามีส่วนร่วมในการรักษาพยาบาล						
2.10 ข้อดี ข้อเสียในการมอบหมายผู้ตัดสินใจแทน						
3. ท่านต้องการใช้วิธีการต่อไปนี้ เพื่อการแสดงเจตนล่วงหน้าการรักษาพยาบาลเมื่อผู้สูงอายุอยู่ในระยะสุดท้าย เพียงใด 3.1 การทำพินัยกรรมชีวิตโดยการสั่งหรือบอกผู้ที่เกี่ยวข้องไว้ด้วยวาจา						
3.2 การทำพินัยกรรมชีวิตโดยเขียนเป็นลายลักษณ์อักษร						
3.3 การมอบหมายให้มีผู้ตัดสินใจแทนตามกฎหมาย**เพียงคนเดียว**						
3.4 การมอบหมายให้สมาชิกในครอบครัวร่วมกันเป็นผู้ตัดสินใจแทน**เพียงฝ่ายเดียว**						
3.5 การมอบหมายให้บุคคลที่ท่านไว้ใจ/						

ความต้องการ	**ระดับความต้องการ**					
	มากที่สุด	มาก	ปานกลาง	น้อย	น้อยที่สุด	ไม่ต้องการ
เคารพนับถือที่อยู่นอกครอบครัวเป็นผู้ตัดสินใจแทน**เพียงฝ่ายเดียว**						
3.6 การมอบหมายให้ทีมสุขภาพ (แพทย์ พยาบาล) เป็นผู้ตัดสินใจแทน**เพียงฝ่ายเดียว**						
3.7 การมอบหมายให้สมาชิกในครอบครัว**ร่วมกับ**บุคคลที่ตนเองไว้วางใจ/เคารพนับถือเป็นผู้ตัดสินใจแทน						
3.8 การมอบหมายให้สมาชิกในครอบครัว**ร่วมกับ**ทีมสุขภาพ เป็นผู้ตัดสินใจแทน						
3.9 การมอบหมายให้สมาชิกในครอบครัวบุคคลที่ตนเองไว้ใจ/เคารพนับถือ ทีมสุขภาพ**ร่วมกัน**เป็นผู้ตัดสินใจแทน						
4. ท่านต้องการตัดสินใจในการรักษาพยาบาล เมื่อถึงระยะสุดท้ายของผู้สูงอายุโดยวิธีต่อไปนี้เพียงใด (มีภาพประกอบด้านหลังแบบสอบถาม) **4.1 ท่านต้องการยุติรับการรักษาที่ยืดชีวิต**						
4.2 ท่านต้องการรับการรักษาที่ยืดชีวิต						
กรณีเลือกตอบ ข้อ 4.2 รับการรักษาที่ยืดชีวิต ท่านต้องการใช้วิธีการต่อไปนี้เพียงใด						
1. การช่วยฟื้นคืนชีพ						
2. การใส่ท่อช่วยหายใจ						

ความต้องการ	**ระดับความต้องการ**					
	มากที่สุด	มาก	ปานกลาง	น้อย	น้อยที่สุด	ไม่ต้องการ
3. การใช้เครื่องช่วยหายใจ						
4. การใช้เครื่องกระตุ้นหัวใจ						
5. วิธีอื่นๆ (ระบุ)………………………						

Appendix C6
The caregivers’ capabilities in responding to the spiritual needs

แบบวัดความสามารถของผู้ดูแลในการปฏิบัติการเพื่อตอบสนองความต้องการด้านจิตวิญญาณของผู้สูงอายุ

คำชี้แจง คำถามต่อไปนี้ใช้วัดความสามารถของผู้ดูแลในการปฏิบัติการเพื่อตอบสนองความต้องการด้านจิตวิญญาณของผู้สูงอายุ ในแต่ละคำถามจะมีค่าคะแนนตั้งแต่ 1 ถึง 6 โดย 1 หมายถึง น้อยที่สุด และ 6 หมายถึง มากที่สุด โปรดทำเครื่องหมาย X ลงบนตัวเลขที่ท่านเห็นว่าตรงกับตัวท่านมากที่สุด

น้อยที่สุด มากที่สุด

ความสามารถในการคาดการณ์

1. ท่านรู้วิธีการช่วยผู้สูงอายุให้รับรู้ถึงคุณค่าของชีวิตมากน้อยเพียงใด 1 2 3 4 5 6

2. ท่านรับรู้คุณค่า ความหมายของชีวิตผู้สูงอายุมากน้อยเพียงใด 1 2 3 4 5 6

3. ท่านรับรู้ถึงเป้าหมายในชีวิตของผู้สูงอายุมากน้อยเพียงใด 1 2 3 4 5 6

4. ท่านรู้วิธีการที่จะช่วยให้ผู้สูงอายุได้พูดคุยกับผู้อื่นมากน้อยเพียงใด 1 2 3 4 5 6

5. ท่านรู้วิธีการช่วยให้ผู้สูงอายุได้ปฏิบัติตามความเชื่อ/ศรัทธา 1 2 3 4 5 6
ของผู้สูงอายุมากน้อยเพียงใด

6. ท่านรู้วิธีการช่วยเสริมความหวังในชีวิตของผู้สูงอายุมากน้อยเพียงใด 1 2 3 4 5 6

7. ท่านเห็นว่าการเสริมความหวังในชีวิตของผู้สูงอายุ 1 2 3 4 5 6
มีความสำคัญมากน้อยเพียงใด

8. ท่านเห็นว่าชีวิตของผู้สูงอายุมีคุณค่า ความหมาย มากน้อยเพียงใด 1 2 3 4 5 6

9. ท่านเห็นว่าการช่วยผู้สูงอายุตั้งเป้าหมายในชีวิต 1 2 3 4 5 6
มีความสำคัญมากน้อยเพียงใด

10. ท่านเห็นว่าการให้ผู้สูงอายุได้พูดคุยแลกเปลี่ยนความรู้สึกกับผู้อื่น 1 2 3 4 5 6
มีความสำคัญมากน้อยเพียงใด

11. ท่านเห็นว่าการจัดสภาพแวดล้อมให้เหมาะสมกับความต้องการ 1 2 3 4 5 6
ของผู้สูงอายุมีความสำคัญมากน้อยเพียงใด

12. ท่านเห็นว่าการช่วยให้ผู้สูงอายุปฏิบัติตามความเชื่อ/ศรัทธา 1 2 3 4 5 6
ของผู้สูงอายุมีความสำคัญมากน้อยเพียงใด

ความสามารถในการปรับเปลี่ยนการปฏิบัติ

13. ท่านได้ช่วยผู้สูงอายุปรับวิธีการเสริมคุณค่าให้กับชีวิตมากน้อยเพียงใด 1 2 3 4 5 6

	น้อยที่สุด					**มากที่สุด**
14. ท่านได้ช่วยผู้สูงอายุปรับเปลี่ยนเป้าหมายของชีวิตมากน้อยเพียงใด	1	2	3	4	5	6
15. ท่านได้ช่วยผู้สูงอายุปรับเปลี่ยนวิธีการสร้างสัมพันธ์กับบุคคลอื่นมากน้อยเพียงใด	1	2	3	4	5	6
16. ท่านได้ช่วยผู้สูงอายุปรับเปลี่ยนสิ่งแวดล้อมให้เหมาะสมกับสภาพของผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
17. ท่านได้ช่วยผู้สูงอายุในการเลือกวิธีปฏิบัติตามความเชื่อที่เหมาะสมกับผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
18. ท่านได้ช่วยผู้สูงอายุปรับเปลี่ยนวิธีการสร้างความหวังในชีวิตมากน้อยเพียงใด	1	2	3	4	5	6
ความสามารถในการลงมือปฏิบัติ						
19. ท่านได้ช่วยให้ผู้สูงอายุรับรู้หรือเห็นถึงคุณค่าของชีวิตมากน้อยเพียงใด	1	2	3	4	5	6
20. ท่านได้ช่วยผู้สูงอายุตั้งเป้าหมายในชีวิตให้สอดคล้องกับความเป็นจริงมากน้อยเพียงใด	1	2	3	4	5	6
21. ท่านพึงพอใจในการช่วยเสริมคุณค่าให้กับชีวิตผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
22. ท่านพึงพอใจในการช่วยผู้สูงอายุตั้งเป้าหมายในชีวิตมากน้อยเพียงใด	1	2	3	4	5	6
23. ท่านมีความพึงพอใจในการช่วยให้ผู้สูงอายุได้สร้างสัมพันธ์กับบุคคลอื่นมากน้อยเพียงใด	1	2	3	4	5	6
24. ท่านมีความพึงพอใจในการจัดสภาพแวดล้อมให้เหมาะสมกับความต้องการของผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
25. ท่านมีความพึงพอใจในการช่วยให้ผู้สูงอายุได้ปฏิบัติตามความเชื่อ/ศรัทธาของผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
26. ท่านมีความพึงพอใจในการส่งเสริมความหวังในชีวิตให้กับผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
27. ท่านมีความชำนาญในการช่วยผู้สูงอายุสามารถสร้างสัมพันธ์กับบุคคลอื่นได้มากน้อยเพียงใด	1	2	3	4	5	6
28. ท่านมีความชำนาญในการจัดสภาพแวดล้อมให้เหมาะสมกับความต้องการของผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
29. ท่านมีความชำนาญในการช่วยให้ผู้สูงอายุได้ปฏิบัติตามความเชื่อ/ศรัทธาของผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6

	น้อยที่สุด					**มากที่สุด**
30. ท่านมีความชำนาญในการช่วยเสริมความหวังในชีวิตให้กับผู้สูงอายุมากน้อยเพียงใด	1	2	3	4	5	6
31. โดยรวมท่านมีความสามารถในการปฏิบัติเพื่อตอบสนองความต้องการด้านจิตวิญญาณของผู้สูงอายุได้มากน้อยเพียงใด	1	2	3	4	5	6

Appendix C7
The perceived caregivers’ compassion to the spiritual needs

แบบสอบถามการได้รับการตอบสนองความตองการด้านจิตวิญญาณของผู้สูงอายุจากผู้ดูแล

คำชี้แจง คำถามต่อไปนี้ใช้วัดการได้รับการตอบสนองความต้องการด้านจิตวิญญาณของผู้สูงอายุจากผู้ดูแลโปรดทำเครื่องหมาย X ลงในช่องว่างที่ท่านพิจารณาว่าตรงกับที่ท่านได้รับการตอบสนอง มาก ปานกลาง น้อย ไม่ได้รับ

มาก	หมายถึง	ท่านได้รับการตอบสนองความต้องการด้านจิตวิญญาณจากผู้ดูแล ทุกครั้ง เป็นประจำ สม่ำเสมอ
ปานกลาง	หมายถึง	ท่านได้รับการตอบสนองความต้องการด้านจิตวิญญาณจากผู้ดูแล บางครั้ง ไม่เป็นประจำ
น้อย	หมายถึง	ท่านได้รับการตอบสนองความต้องการด้านจิตวิญญาณจากผู้ดูแล น้อย นานๆครั้ง
ไม่ได้รับ	หมายถึง	ท่านไม่ได้รับการตอบสนองความต้องการด้านจิตวิญญาณจากผู้ดูแลเลย

ข้อความ	มาก	ปานกลาง	น้อย	ไม่ได้รับ
ด้านมีความหมายและเป้าหมายในชีวิต 1. ผู้ดูแลมีเวลาพูดคุยกับท่านเพื่อให้ท่านได้ค้นหาเป้าหมายและความต้องการของตนเอง				
2. ผู้ดูแลเปิดโอกาสให้ท่านได้แสดงความคิดเห็นและวางเป้าหมายในชีวิตร่วมกัน				
3. ผู้ดูแลได้บอกหรือแสดงให้ท่านทราบว่าท่านมีความหมายและเป็นคนสำคัญ				
4. ผู้ดูแลมีส่วนช่วยให้ท่านได้รู้สึกว่าตนเองมีคุณค่า มีความหมาย				
5. ผู้ดูแลเปิดโอกาสให้ท่านได้แสดงออกหรือบอกถึงความต้องการ				
6. ผู้ดูแลเปิดโอกาสให้ท่านรายความรู้สึกความคับข้องใจ				
7. ผู้ดูแลคอยสนใจ เอาใจใส่และแสดงความห่วงใยท่าน เมื่อท่านต้องการความช่วยเหลือ				

ข้อความ	**มาก**	**ปานกลาง**	**น้อย**	**ไม่ได้รับ**
8. ผู้ดูแลบอกท่านว่าชีวิตของท่านมีค่า สามารถทำประโยชน์ให้แก่ครอบครัวและสังคมได้				
9. ผู้ดูได้พาท่านไปบริจาคทาน สร้างบุญกุศล				
10. ผู้ดูแลให้ความจริงใจและสามารถเป็นที่พึ่งพิงสำหรับท่านได้				
ด้านการมีสัมพันธ์กับบุคคลอื่น สิ่งแวดล้อม สิ่งเหนือตนเอง 11. ผู้ดูแลได้จัดให้มีสิ่งที่ท่านเคารพบูชาไว้ใกล้ตัว หรือให้ท่านพกติดตัวเป็นประจำเพื่อเป็นที่พึ่งพิงทางใจและคุ้มครองท่าน				
12. ผู้ดูแลได้แนะนำให้ท่านสวดมนต์เพื่อระลึกถึงผู้นำศาสนา หรือสิ่งที่ท่านนับถือ				
13. ผู้ดูแลได้จัดสถานที่ให้ท่านสำหรับสวดมนต์ภาวนา ทำสมาธิ/ละหมาด/อ่านคัมภีร์				
14. ผู้ดูแลได้แนะนำให้ท่านอภัยในสิ่งต่างๆที่ผ่านมา				
15. ผู้ดูแลได้นำภาพถ่ายของบุคคลที่ท่านนับถือและผูกพันมาไว้ติดตัวท่าน				
16. ผู้ดูแลได้นำบุคคลที่ท่านรัก เคารพนับถือ มาเยี่ยมให้กำลังใจท่าน				
17. ท่านรู้สึกสบายใจที่มีสมาชิกในครอบครัวคอยดูแลเอาใจใส่อย่างใกล้ชิด				
18. ผู้ดูแลได้แสวงหาข้อมูลเกี่ยวกับการดูแลด้านจิตวิญญาณจากผู้มีความรู้มาดูแลท่าน				
19. ผู้ดูแลได้บอกท่านว่า สิ่งสูงสุดที่ท่านนับถือ (พระพุทธเจ้า พระอัลลอฮ์ พระเยซู) และสิ่งศักดิ์สิทธิ์ต่างๆจะช่วยคุ้มครองท่านในระหว่างเจ็บป่วยได้				
20. ผู้ดูแลได้นำท่านไปพูดคุยแลกเปลี่ยนความรู้สึกกับผู้สูงอายุด้วยกัน				

ข้อความ	**มาก**	**ปานกลาง**	**น้อย**	**ไม่ได้รับ**
ด้านการมีความหวัง 21. ผู้ดูแลได้สวดมนต์/อธิษฐานจิตและภาวนาให้ท่านมีอาการดีขึ้น				
22. ผู้ดูแลได้คอยเป็นกำลังใจและแสดงให้ท่านทราบว่าชีวิตนี้ยังมีความหวัง				
23. ผู้ดูแลได้บอกท่านว่าทุกอย่างจะเปลี่ยนแปลงไปในทางที่ดีขึ้น				
24. ผู้ดูแลได้บอกท่านว่าการเจ็บป่วยของท่านจะหายเร็วหรือช้าขึ้นอยู่กับชะตาชีวิต				
25. ผู้ดูแลได้จัดหาอาหารที่ท่านชอบและพอใจมาให้หวังว่าท่านมีความภาคภูมิใจและอาการดีขึ้น				
26. ผู้ดูแลได้พาท่านไปขอพร อ้อนวอนพระผู้เป็นเจ้าหรือสิ่งศักดิ์สิทธิ์ หวังให้ท่านพบสิ่งที่ดีในชีวิต				
27. ผู้ดูแลได้บอกท่านว่าความหวังของผู้ดูแลคือได้เห็นอาการของท่านดีขึ้น				
28. ผู้ดูแลได้บอกท่านว่าในอนาคตแพทย์จะสามารถรักษาอาการเจ็บป่วยของท่านได้				
29. ท่านและผู้ดูแลมีความหวังร่วมกันว่าคงจะไม่มีเหตุการณ์เช่นนี้เกิดขึ้นกับคนในครอบครัวอีก				
30. ท่านและผู้ดูแลมีความหวังร่วมกันว่าท่านจะไม่ทุกข์ทรมานไปมากกว่านี้				
31. โดยรวมท่านได้รับการตอบสนองความต้องการด้านจิตวิญญาณจากผู้ดูแล				

Appendix C8
The Thai version of the Burden Interview

แบบวัดภาระในการดูแลผู้สูงอายุในระยะสุดท้าย

คำชี้แจง โปรดใส่เครื่องหมาย √ ในช่องที่ตรงกับความเป็นจริงและความคิดเห็นของท่าน

	ประจำ	บ่อยครั้ง	บางครั้ง	นานๆครั้ง	ไม่เคยเลย
1. ท่านรู้สึกว่าผู้สูงอายุขอร้องขอความช่วยเหลือมากกว่าความต้องการจริง					
2. ท่านรู้สึกว่าท่านไม่มีเวลาเพียงพอสำหรับตัวเอง เนื่องจากว่าใช้เวลาในการดูแลผู้สูงอายุมาก ไม่มีเวลาเป็นของตนเอง					
3. ท่านรู้สึกว่ามีความเครียดทั้งงานที่ต้องดูแลผู้สูงอายุและงานอื่นที่ต้องรับผิดชอบ					
4. ท่านรู้สึกอึดอัดใจต่อพฤติกรรมของผู้สูงอายุ					
5. ท่านรู้สึกหงุดหงิดใจ หรือโกรธ ขณะที่อยู่ใกล้ผู้สูงอายุ					
6. ท่านรู้สึกว่าผู้สูงอายุทำให้ความสัมพันธ์ของท่านกับสมาชิกในครอบครัวหรือเพื่อนแย่ลง					
7. ท่านรู้สึกเกี่ยวกับสิ่งที่จะเกิดขึ้นในอนาคตกับผู้สูงอายุซึ่งเป็นญาติของท่าน					
8. ท่านรู้สึกว่าผู้สูงอายุต้องพึ่งพาท่าน					
9. ท่านรู้สึกตึงเครียดขณะที่อยู่ใกล้ผู้สูงอายุ					
10. ท่านรู้สึกว่าสุขภาพของท่านไม่ค่อยดี เนื่องมาจากการดูแลผู้สูงอายุ					
11. ท่านรู้สึกว่าท่านไม่มีความเป็นส่วนตัวเท่าที่ต้องการ เนื่องจากการดูแลผู้สูงอายุ					
12. ท่านรู้สึกว่าท่านไม่สามารถมีสังคมได้					

	ประจำ	บ่อยครั้ง	บางครั้ง	นานๆครั้ง	ไม่เคยเลย
ตามปกติ เนื่องจากการดูแลผู้สูงอายุ					
13. ท่านรู้สึกไม่สะดวกในการติดต่อ/คบหาเพื่อน เนื่องมาจากการดูแลผู้สูงอายุ					
14. ท่านรู้สึกว่าผู้สูงอายุคาดหวังในตัวท่านมาก เสมือนมีท่านคนเดียวเท่านั้นที่พึ่งพาได้					
15. ท่านรู้สึกว่าท่านไม่มีเงินเพียงพอที่จะดูแลผู้สูงอายุ					
16. ท่านรู้สึกว่า ท่านจะไม่สามารถอดทนดูแลผู้สูงอายุได้อีกไม่นาน					
17. ท่านรู้สึกว่าท่านไม่สามารถควบคุมจัดการชีวิตตนเองได้ ตั้งแต่ดูแลผู้สูงอายุ					
18. ท่านอยากที่จะเลิกดูแลผู้สูงอายุซึ่งเป็นญาติของท่านและให้คนอื่นมาดูแลแทน					
19. ท่านรู้สึกว่าไม่มีอะไรที่มั่นคงแน่นอนเกี่ยวกับสิ่งที่ทำให้ผู้สูงอายุ					
20. ท่านรู้สึกว่าท่านควรจะได้รับการดูแลจากญาติคนอื่น					
21. ท่านรู้สึกว่าท่านน่าจะดูแลญาติของท่านได้ดีกว่านี้					
22. โดยภาพรวมท่านรู้สึกว่า การดูแลผู้สูงอายุเป็นภาระสำหรับท่าน					

The Burden Interview

Instruction: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. Please draw √ in the blank that is true for you.

	Nearly always	Quite frequently	Sometimes	Rarely	Never
1. Do you feel that your relative asks for more help than he or she needs?					
2. Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself?					
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed about your relative's behavior?					
5. Do you feel angry when you are around your relative?					
6. Do you feel that your relative currently affects your relationship with other family members?					
7. Are you afraid about what the future holds for your relative?					
8. Do you feel that your relative is dependent upon you?					
9. Do you feel strained when you are around your relative?					
10. Do you feel that your health has suffered because of your involvement with your relative?					

	Nearly always	Quite frequently	Sometimes	Rarely	Never
11. Do you feel that you don't have as much privacy as you would like, because of your relative?					
12. Do you feel that your social life has suffered because you are caring for your relative?					
13. Do you feel uncomfortable having your friends over because of your relative?					
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?					
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of your relative much longer?					
17. Do you feel that you have lost control of your life since caring your relative?					
18. Do you wish that you could just leave the care of your relative to someone else?					
19. Do you feel uncertain about what to do about your relative?					
20. Do you feel that you should be doing more for your relative?					
21. Do you feel that you could do a better job in caring for your relative?					

	Nearly always	Quite frequently	Sometimes	Rarely	Never
22. Overall, how burdened do you feel in caring for your relative?					

Appendix C9

Palliative Performance Scale Version 2 (PPS- V2)

แบบประเมินระดับผู้สูงอายุที่ได้รับการดูแลแบบประคับประคอง

ระดับ PPS	**การเคลื่อนไหว**	**การปฏิบัติกิจกรรมและการดำเนินโรค**	**การดูแลตนเอง**	**การรับประทานอาหาร**	**ระดับความรู้สึกตัว**
100%	เคลื่อนไหวปกติ	ทำกิจกรรมและทำงานได้ตามปกติ ไม่มีอาการของโรค	ทำได้เอง	ปกติ	รู้สึกตัวดี
90%	เคลื่อนไหวปกติ	ทำกิจกรรมและทำงานได้ตามปกติ มีอาการของโรคบางอาการ	ทำได้เอง	ปกติ	รู้สึกตัวดี
80%	เคลื่อนไหวปกติ	ต้องออกแรงอย่างมากในการทำกิจกรรมตามปกติ มีอาการของโรคบางอาการ	ทำได้เอง	ปกติ หรือ ลดลง	รู้สึกตัวดี
70%	ความสามารถในการเคลื่อนไหวลดลง	ไม่สามารถทำงานได้ตามปกติ มีอาการของโรคอย่างมาก	ทำได้เอง	ปกติ หรือ ลดลง	รู้สึกตัวดี
60%	ความสามารถในการเคลื่อนไหวลดลง	ไม่สามารถทำงานอดิเรก/งานบ้านได้ มีอาการของโรคอย่างมาก	ต้องการความช่วยเหลือเป็นครั้งคราว	ปกติ หรือ ลดลง	รู้สึกตัวดี หรือ สับสน
50%	นั่ง/นอน เป็นส่วนใหญ่	ไม่สามารถทำงานได้เลย มีการลุกลามของโรคมากขึ้น	ต้องการความช่วยเหลือในการปฏิบัติกิจกรรมบางอย่าง	ปกติ หรือ ลดลง	รู้สึกตัวดี หรือ สับสน
40%	นอนอยู่บนเตียงเป็นส่วนใหญ่	ทำกิจกรรมได้น้อยมาก มีการลุกลามของโรค	ต้องการความช่วยเหลือเป็นส่วนใหญ่	ปกติ หรือ ลดลง	รู้สึกตัวดี หรือ ง่วงซึม +/- สับสน

		มากขึ้น			
30%	นอนอยู่บนเตียงตลอดเวลา	ไม่สามารถทำงานใดๆและมีการลุกลามของโรค	ต้องการความช่วยเหลือทั้งหมด	ปกติ หรือ ลดลง	รู้สึกตัวดี หรือ ง่วงซึม +/- สับสน
20%	อยู่บนเตียงตลอดเวลา	ไม่สามารถทำงานใดๆและมีการลุกลามของโรคมากขึ้น	ต้องการการดูแลทั้งหมด	จิบน้ำได้เล็กน้อย	รู้สึกตัวดี หรือ ง่วงซึม +/- สับสน
10%	อยู่บนเตียงตลอดเวลา	ไม่สามารถทำงานใดๆและมีการลุกลามของโรคมากขึ้น	ต้องการการดูแลทั้งหมด	รับประทานไม่ได้	ง่วงซึม หรือไม่รู้สึกตัว +/- สับสน
0%	เสียชีวิต	-	-	-	-

Palliative Performance Scale Version 2 (PPS- V2)

PPS Level	**Ambulation**	**Activity & Evidence of Disease**	**Self-Care**	**Intake**	**Conscious Level**
100%	Full	Normal activity & Work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & Work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable to do hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activities Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Appendix C 10

The Thai version of interview guidelines

แนวคำถามในการสัมภาษณ์การวิจัย

เรื่อง การพัฒนาชุดกิจกรรมการดูแลผู้สูงอายุระยะประคับประคองที่บ้านในอุดมคติเพื่อส่งเสริมคุณภาพการดูแลและลดภาระการดูแลสำหรับผู้ดูแล

แนวคำถามการสัมภาษณ์และขั้นตอนการเก็บข้อมูลในการวิจัยเชิงปฏิบัติการอย่างมีส่วนร่วมนี้ ใช้แนวคิดของเคมมิสและแม็คแท็กการ์ท (Kemmis & MacTaggart, 1988) ซึ่งแนวคำถามได้พัฒนาขึ้นโดยใช้กรอบแนวคิด LIFESS ของสำนักงานหลักประกันสุขภาพแห่งชาติ (2554) เป็นฐานในการออกแบบ ประกอบด้วย 6 ด้าน ได้แก่ 1) L = living will: ความปรารถนาในบั้นปลายของชีวิต 2) I = individual belief: ความเชื่อเกี่ยวกับการเจ็บป่วย 3) F = function: ระดับความสามารถในการทำกิจวัตรประจำวันหรือการดูแลตนเอง 4) E = emotion and coping: สภาวะทางอารมณ์ 5) S= symptoms: ความไม่สุขสบายทางร่างกายรวมถึงอาการต่างๆ และ 6) S = social and support: ปัญหาทางสังคมและแหล่งสนับสนุน

การพัฒนาชุดกิจกรรมการดูแลผู้สูงอายุที่อยู่ในระยะประคับประคองที่บ้านของผู้ดูแลนี้ จะดำเนินการผ่านขั้นตอนของการวิจัยเชิงปฏิบัติการอย่างมีส่วนร่วม ประกอบด้วย การวางแผน (planning) การปฏิบัติ (acting) การสังเกต (observing) การสะท้อนการปฏิบัติ (reflecting) และการปรับปรุงแผน (re-planning) เพื่อนำไปปรับปรุงและปฏิบัติจนเกิดรูปแบบของกิจกรรมการดูแลผู้สูงอายุระยะประคับประคองที่บ้าน ที่ช่วยส่งเสริมคุณภาพการดูแลผู้สูงอายุ และลดภาระการดูแลสำหรับผู้ดูแลหลักได้

ขั้นตอนและระยะเวลาที่ใช้ในการสัมภาษณ์

การวิจัยครั้งนี้เก็บข้อมูลจากผู้เข้าร่วมวิจัย ได้แก่ ผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว ผู้เข้าร่วมวิจัยจะถูกสัมภาษณ์เชิงลึก ครั้งละ 60-90 นาที เป็นระยะเวลาอย่างน้อย 12 ครั้ง อย่างไรก็ตาม ระยะเวลาและจำนวนครั้งของการสัมภาษณ์อาจเปลี่ยนแปลงได้ขึ้นอยู่กับสถานการณ์ที่เกิดขึ้น และการสัมภาษณ์จะสิ้นสุดเมื่อข้อมูลของกิจกรรมการดูแลผู้สูงอายุระยะประคับประคองที่บ้านมีความอิ่มตัว โดยการบันทึกข้อมูลจากการสัมภาษณ์ประกอบด้วย การบันทึกเทป การจดบันทึก และการถ่ายภาพ

การตรวจสอบข้อมูล

การตรวจสอบข้อมูล โดยการตรวจสอบความตรงของข้อมูล (validity) หรือความถูกต้องของข้อมูลที่ได้รับจากแหล่งต่างๆ (data triangulation) ซึ่งการวิจัยนี้เก็บข้อมูลจากผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว และใช้วิธีเก็บข้อมูลที่หลากหลายวิธี (methodology triangulation) ได้แก่ การสัมภาษณ์ การใช้แบบสอบถามและการสังเกต การดูแลผู้สูงอายุระยะประคับประคองที่บ้าน รวมทั้งการฟังเสียงสะท้อนจากผู้เข้าร่วมวิจัย ผู้วิจัยเสนอผลวิจัยที่ได้สรุปจากข้อมูล ให้ผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัวรับฟังและเสนอความคิดเห็นเพิ่มเติมเกี่ยวกับข้อมูลที่ได้รวบรวม เพื่อตรวจสอบความถูกต้องของข้อมูลก่อนดำเนินการวิเคราะห์ข้อมูลต่อไป

รายละเอียดการเก็บข้อมูลในแต่ละครั้งมีดังต่อไปนี้

กิจกรรมที่ 1 การแนะนำตัวเองและพิทักษ์สิทธิ์ผู้เข้าร่วมวิจัย

กิจกรรมที่ 2 การสร้างสัมพันธภาพและความไว้วางใจ

กิจกรรมที่ 3 การสร้างความเข้าใจในปัญหาร่วมกัน

กิจกรรมที่ 4 การวางแผน

กิจกรรมที่ 5 การปฏิบัติ การสังเกต

กิจกรรมที่ 6 การสะท้อนการปฏิบัติ

กิจกรรมที่ 7 การปรับปรุงแผน

กิจกรรมที่ 8 ทดลองปฏิบัติใหม่และสังเกต

กิจกรรมที่ 9 การสะท้อนการปฏิบัติครั้งที่ 2

กิจกรรมที่ 10 การปรับปรุงแผน

กิจกรรมที่ 11 ทดลองปฏิบัติใหม่ การสังเกต

กิจกรรมที่ 12 การสะท้อนการปฏิบัติครั้งที่ 3

อุปกรณ์

1. เครื่องบันทึกเสียง
2. กล้องถ่ายรูป
3. กระดาษ A4
4. ปากกา
5. สมุดโน๊ต

สถานที่

บ้านของผู้สูงอายุในเขตเทศบาลนครหาดใหญ่ จังหวัดสงขลา รายละเอียดของกิจกรรมในแต่ละครั้งมีดังต่อไปนี้

กิจกรรมที่ 1 การแนะนำตัวเองและพิทักษ์สิทธิ์ผู้เข้าร่วมวิจัย

เป้าหมาย

1. เพื่อชี้แจงและอธิบายวัตถุประสงค์การวิจัยก่อนเก็บข้อมูล
2. เพื่อพิทักษ์สิทธิของผู้เข้าร่วมวิจัยและการยินยอมเข้าร่วมวิจัยด้วยความสมัครใจ
3. เพื่อให้ผู้เข้าร่วมวิจัยเกิดความมั่นใจเรื่องการรักษาความลับและการพิทักษ์สิทธิ์ของผู้เข้าร่วมวิจัย
4. เพื่อรวบรวมข้อมูลเบื้องต้น ประกอบด้วย ข้อมูลส่วนบุคคล ประวัติการเจ็บป่วย ลักษณะสภาพความเจ็บป่วย และข้อมูลอื่นๆที่เกี่ยวข้อง ก่อนการสร้างสัมพันธภาพและสัมภาษณ์เชิงลึก
5. เพื่อเก็บรวบรวมข้อมูลที่เกี่ยวกับคุณภาพการดูแลและภาระการดูแลจากผู้สูงอายุก่อนดำเนินการปฏิบัติการแบบมีส่วนร่วม

ขั้นตอนในการดำเนินการ
1. แนะนำตนเองและผู้ช่วยวิจัย เป็นใคร มาจากไหน และมาทำหน้าที่อะไร เพื่อแสดงถึงการเคารพศักดิ์ศรีและเคารพสิทธิของผู้เข้าร่วมวิจัย
2. ชี้แจงรายละเอียดเกี่ยวกับการวิจัยเชิงปฏิบัติการอย่างมีส่วนร่วม วัตถุประสงค์ ขั้นตอน วิธีการดำเนินการ..

กิจกรรมที่ 2 การสร้างสัมพันธภาพและความไว้วางใจ

เป้าหมาย

เพื่อให้เกิดบรรยากาศที่รู้สึกปลอดภัย ไว้วางใจซึ่งกันและกัน เชื่อมั่นและให้การร่วมมือต่อการวิจัยเชิงปฏิบัติการอย่างมีส่วนร่วมระหว่างผู้วิจัย ผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว

ขั้นตอนในการดำเนินการ
1. จัดสภาพแวดล้อมให้เหมาะสมต่อการสร้างสัมพันธภาพ ....

กิจกรรมที่ 3: สร้างความเข้าใจในปัญหาร่วมกัน (reconnaissance)

เป้าหมาย

การสร้างความเข้าใจในปัญหาร่วมกันเป็นการสำรวจเบื้องต้นเพื่อให้เข้าใจสถานการณ์ร่วมกันระหว่างผู้วิจัยและผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว ผู้วิจัยและผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว จะร่วมกันคิดพิจารณาแนวคิดร่วมกันเกี่ยวกับเรื่องที่สนใจและเป็นความต้องการของผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว ให้เข้าใจตรงกัน

การสร้างความเข้าใจในปัญหาร่วมกันเป็นการศึกษาเพื่อเข้าใจสถานการณ์ปัจจุบันว่าเกิดอะไรขึ้น ผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว รู้สึกอย่างไรต่อเรื่องที่สนใจหรือปัญหา ให้ความหมายอย่างไร และมีแนวคิดที่จะปรับปรุงเปลี่ยนแปลงอย่างไร มีปัญหาหรือข้อขัดแย้งอะไรบ้าง แล้วผู้วิจัยสรุปปัญหาที่จะนำมาสู่การวางแผนเพื่อการปฏิบัติการ

ขั้นตอนในการดำเนินการ
1. ดำเนินการสัมภาษณ์ผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว โดยใช้แนวคำถามที่สร้างไว้..

กิจกรรมที่ 4: การวางแผน (planning)

เป้าหมาย

เพื่อเป็นการจัดลำดับความสำคัญของปัญหาและกิจกรรมที่ต้องการพัฒนา กระตุ้นให้เห็นแนวทางและโอกาสในการพัฒนา พร้อมเสนอทางเลือกและทำข้อตกลงร่วมกันในการปฏิบัติกิจกรรม

ขั้นตอนในการดำเนินการ
1. ร่วมกันพูดคุยเพื่อวางแผนกำหนดกิจกรรมอย่างเป็นระบบตามปัญหาที่ระบุ…………………..

กิจกรรมที่ 5: การปฏิบัติตามแผน (acting)

เป้าหมาย

นำแผนที่วางไว้ไปปฏิบัติร่วมกัน การปฏิบัติขั้นนี้จะเป็นพื้นฐานของการพัฒนาการปฏิบัติในขั้นต่อไป

ขั้นตอนในการดำเนินการ
1. ปฏิบัติกิจกรรมตามแผนที่ได้ตกลงไว้ร่วมกัน
2. ชี้แนะและให้การปรึกษาแก่ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว………......

กิจกรรมที่ 6: การสะท้อนการปฏิบัติ (reflecting)

เป้าหมาย

การสะท้อนการปฏิบัติเป็นขั้นตอนที่ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัวร่วมกันสะท้อนคิดพิจารณาวิเคราะห์บทเรียนที่ได้จากการปฏิบัติกิจกรรม เพื่อหาความเป็นไปได้ของการปฏิบัติกิจกรรม จะช่วยให้ได้ภาพสะท้อนจากการปฏิบัติ ที่จะนำไปสู่การปรับปรุงวิธีการปฏิบัติกิจกรรม การสะท้อนการปฏิบัติเป็นวิธีการประเมินอย่างหนึ่งที่สามารถประเมินผลการปฏิบัติ เป็นไปตามแผนที่วางไว้หรือไม่ การสะท้อนการปฏิบัติสามารถให้ข้อแนะนำในการปฏิบัติต่อไป

การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม อาจจะมีระยะเวลาการดำเนินการที่คาบเกี่ยวกันหรือกระทำไปพร้อมๆกัน บางครั้งอาจหยุดบางกิจกรรมไว้ก่อน ย้อนไปเริ่มต้นกิจกรรมใหม่ หรือพัฒนาต่อเนื่องในขั้นตอนต่อไปพร้อมๆกัน เพราะ การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม ไม่สามารถกำหนดได้ตายตัว สามารถปรับปรุง เปลี่ยนแปลง ให้เหมาะสมตามเงื่อนไขปัจจัยของบริบทที่เกิดขึ้น

ขั้นตอนในการดำเนินการ
1. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว สรุปการปฏิบัติกิจกรรม
2. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว สะท้อนคิดการปฏิบัติกิจกรรมในแต่ละกิจกรรม………………………………………………………………………………..

กิจกรรมที่ 7: การปรับปรุงแผน (re-planning)

เป้าหมาย

การปรับปรุงแผนกำหนดกิจกรรมใหม่เป็นการวางแผนให้สอดคล้องกับสถานการณ์หรือตอบสนองต่อปัญหาหรือความต้องการที่เกิดขึ้นเพื่อปฏิบัติกิจกรรมให้ได้ผลลัพธ์ที่พอใจร่วมกัน อาจเป็นปัญหาเดิมที่ปรับปรุง แก้ไขต่อเนื่อง หรือปัญหาใหม่ที่ผู้วิจัย ผู้สูงอายุ ผู้ดูแล และ/หรือสมาชิกครอบครัว เห็นว่าควรดำเนินการแก้ไข

ขั้นตอนในการดำเนินการ
1. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว สรุปการปฏิบัติกิจกรรมครั้งที่ผ่านมา
2. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว วิเคราะห์และอภิปราย………..

กิจกรรมที่ 8: ทดลองปฏิบัติใหม่ (re-acting)

เป้าหมาย

ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว ร่วมกันปฏิบัติกิจกรรมตามแผนที่ปรับปรุงใหม่อีกครั้งให้เพื่อทำให้ผลของการปฏิบัติกิจกรรมเป็นที่พึงพอใจร่วมกัน

ขั้นตอนในการดำเนินการ
1. ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว ปฏิบัติกิจกรรมร่วมกันใหม่อีกครั้ง
2. ชี้แนะและให้การปรึกษา แก่ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิก………………………

กิจกรรมที่ 9: การสะท้อนการปฏิบัติ (reflecting) ครั้งที่ 2

เป้าหมาย

ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว ร่วมกันสะท้อนคิดพิจารณาวิเคราะห์บทเรียนที่ได้จากการปฏิบัติกิจกรรมอีกครั้ง เพื่อหาความเป็นไปได้และแนวทางปฏิบัติที่เหมาะสมให้ได้ผลลัพธ์ตามเป้าหมายที่วางไว้ร่วมกัน จะช่วยให้ได้ภาพสะท้อนของการปฏิบัติกิจกรรมที่ชัดเจนขึ้น

ขั้นตอนในการดำเนินการ
1. ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว ร่วมกันสรุปการปฏิบัติกิจกรรมอีกครั้ง
2. ร่วมกันสะท้อนคิดการปฏิบัติกิจกรรมในแต่ละกิจกรรม………………………………………

กิจกรรมที่ 10: การปรับปรุงแผน (re-planning)

เป้าหมาย

การปรับปรุงแผน กำหนดกิจกรรมครั้งที่ 2 เป็นการวางแผนเพื่อวิเคราะห์วิธีการที่จะนำไปใช้ปฏิบัติกิจกรรมเพื่อให้เป็นที่พึงพอใจร่วมกัน การปรับปรุงแผนครั้งนี้ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว จะเริ่มเห็นแนวทางในการปฏิบัติที่ชัดเจนยิ่งขึ้น

ขั้นตอนในการดำเนินการ
1. สรุปการปฏิบัติกิจกรรมครั้งที่ผ่านมา
2. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว วิเคราะห์และอภิปราย…………

กิจกรรมที่ 11: ทดลองปฏิบัติใหม่ (re-acting)

เป้าหมาย

ลงมือปฏิบัติกิจกรรมตามแผนที่ปรับปรุงใหม่ครั้งที่ 3 เพื่อให้เหมาะสมกับสภาพแวดล้อมและบริบทของครอบครัว การปฏิบัติครั้งนี้จะช่วยให้ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว และผู้วิจัยสามารถนำแหล่งสนับสนุนต่อการปฏิบัติกิจกรรมมาใช้ประโยชน์ได้

ขั้นตอนในการดำเนินการ
1. ปฏิบัติกิจกรรมร่วมกันใหม่ตามแผนการดูแลอีกครั้ง
2. ชี้แนะและให้การปรึกษา แก่ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว………………..

กิจกรรมที่ 12: การสะท้อนการปฏิบัติ (reflecting) ครั้งที่ 3

เป้าหมาย

ผู้วิจัย ผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว ร่วมกันสะท้อนคิดพิจารณาวิเคราะห์การปฏิบัติกิจกรรมครั้งที่ 3 ในส่วนของ ปัญหาอุปสรรค การดำเนินตามแผน ปัจจัยสนับสนุน บทเรียนที่ได้จากการปฏิบัติ การสะท้อนการปฏิบัติครั้งนี้จะเริ่มมองเห็นถึงองค์ความรู้ที่ได้จากการเก็บข้อมูล เพื่อการพัฒนาชุดกิจกรรมการดูแลผู้สูงอายุที่บ้านที่เป็นรูปแบบที่พอใจร่วมกัน

ขั้นตอนในการดำเนินการ
1. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว สรุปการปฏิบัติกิจกรรมอีกครั้ง
2. ร่วมกันกับผู้สูงอายุ ผู้ดูแลหลัก และ/หรือสมาชิกครอบครัว…………………………………

APPENDIX D

LIST OF EXPERTS

APPENDIX D
LIST OF EXPERTS

Interview guideline was validated the content validity by three experts. They are

1. Associate Professor Dr. Praneed Songwathana
   R.N., Department of Surgical Nursing, Faculty of Nursing, Prince of Songkla University, Thailand
2. Associate Professor Dr. Waraporn Kongsuwan
   R.N., Department of Adult Nursing, Faculty of Nursing, Prince of Songkla University, Thailand
3. Mrs. Kandawasri Tulatummakit
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VITAE

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Student ID 5610430004

Educational Attainment

Degree	Name of Institution	Year of Graduation
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Master of Nursing Science program in Mental Health and Psychiatric Nursing : M.N.S. (Mental Health and Psychiatric Nursing)	Burapha University	2011

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List of Publication

Supaporn, K., Isaramalai, S., & Suttharangsee, W. (2017, November 9-10). *Thai cultural understanding of home-based palliative care for Thai elderly*. Poster presentation at the Sigma Theta Tau International Honor Society of Nursing, Phi Omega Chapter-at Large, Towards Nursing Leadership in Thailand 4.0 Era. Maruay Garden Hotel, Bangkok, Thailand.