# THE CATHOLIC UNIVERSITY OF AMERICA

Comfort as Experienced by Thai Older Patients with Advanced Cancer

## A DISSERTATION

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By

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# Comfort as Experienced by Thai Older Patients with Advanced Cancer

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The study purpose was to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand. Between-method triangulation was utilized and based on the Comfort Theory developed by Kolcaba (2003). For the quantitative phase, purposive sampling was applied to recruit 111 Thai older patients with advanced cancer, determined by the Palliative Performance Scale version 2 (PPSv2) scores equal to or less than 60% and meeting other inclusion criteria, to complete the Hospice Comfort Questionnaire (HCQ) (Patient) and Verbal Rating Scales (VRSs). Every fifth subject of quantitative phase (N = 20) was invited and interviewed in depth following the Semi-Structured Interview Guide.

Descriptive statistics analyzed the quantitative data. The findings showed that Thai older patients with advanced cancer experienced comfort between a moderate and almost high comfort level of the HCQ (Patient) (M = 4.29,  $SD = \pm .50$ ) and between a moderate and fairly high comfort level of the VRSs (M = 6.25,  $SD = \pm 2.09$ ). In addition, the HCQ (Patient) and the VRSs had psychometric properties. Content analysis analyzed the qualitative data. Three domains emerged: *Discomfort, Comfort*, and an *Additional domain*. Discomfort of Thai older patients with advanced cancer encompassed four contexts: physical-physiological (sleep disturbance and pain), psycho-spiritual (worry and/or fear about the illness and symptoms), socio-cultural (no reporting/communication of existing discomfort), environmental (the setting—the patient's room and the restrooms). Four categories of comfort emerged: *Relief, Ease, Transcendence*, and *Inadequate comfort*. Intervening variables, nursing comfort care, nurses (including other healthcare personnel), improvement for comfort care, and comparison between the hospital and the (participant's) house emerged as an additional domain. There were three main comfort providers: nurses, patients' relatives, and the patient him/herself through health-seeking behaviors. In addition, patients comforted each other. The findings showed that nurses focused on providing physical-physiological care such as pain relief. The relatives were the main providers of psychological comfort care. Most patients still needed to comfort themselves and seek transcendence during the end-of–life treatment. These findings provide guidance to develop effective comfort care. Future studies are needed to improve the quality of comfort care.

The dissertation by Yupin Tanatwanit fulfills the dissertation requirement for the doctoral degree in Nursing approved by Janice Griffin Agazio, Ph.D., CRNP, R.N., PNP, as Director, and by Barbara Moran, Ph.D., MS, M.P.H., CNM, RNC, FACCE, and Janalyn Edmonds, Ph.D., R.N., as Readers.

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# **CHAPTER I**

# PROBLEM

As baby boomers born after World War II reach retirement age (Sherman, 2001), the number of older adults is now increasing dramatically. Reasons for this increase include the development of medical and nursing knowledge, improvements in the area of public health, the discovery of antibiotics and other advances of modern medicine and technology, all of which have brought about unprecedented gains in human longevity (Coyle, 2006; Morrison, 2005). As a result, the worldwide population of older adults has increased. For example, in the United States (US), it was reported that in 1900, only about one in twenty adults were over 65 years old, and in 1994, about one in eight of the US population was over 65 (Hobbs, 2001, January 18). However, within 15 years, this number will rise to 20% of the US population (American Psychological Association, n.d.). On the other hand, by the year 2030, this percentage is projected to rise to one in five adults (Hobbs, 2001, January 18; Morrison, 2005). Thailand is one of the countries that is impacted by this change. It is also home to a growing number of older adults, defined as persons who are 60 or more years of age (Bureau of Empowerment for Older Persons, 2004; Institute for Population and Social Research, Mahidol University, 2007). The Institute for Population and Social Research, Mahidol University (2007) has reported that this trend will continue into the future. For instance, the number of older Thai adults (60 years or older) in 2004 was 6.2 million, or approximately 10% of the country's population. In 2007, this number has increased to 6.8 million, or 10.8% of the Thai population (Institute of Geriatric Medicine,

Department of Medical Services, Ministry of Public Health, 2007, July 3), and according Dr. Thaineua, this number will most likely increase to 15% of the Thai population by 2017 (Institute of Geriatric Medicine, Department of Medical Services, Ministry of Public Health, 2007, July 6). It is anticipated that by the year 2024, this percentage will increase to 20% of the Thai population (Bureau of Empowerment for Older Persons, 2004). Trended data demonstrate that the average life expectancy of older adults has consistently increased. For instance, by 2010, in Thailand, the life expectancy will have risen from 68.15 to 68.86 years for males, and from 72.39 to 73.00 years for females. It is significant to note that these older adults have a higher risk of illness (Khao Sod, 2006, January 6), forcing healthcare providers to identify and be concerned about age-associated consequences or problems.

Morrison (2005) stated that during the long lives of elderly or older adults, the vast majority of them will develop one or more chronic illnesses. As a result, Steel et al. (1999; see also Rousseau, 2000) estimated that five percent of American elders aged 65 years and over ever lived in a long-care facility and 33% of them resided in a chronic care facility prior to their deaths. Significantly, most deaths occurred in general hospitals (Mills, Davies, & Macrae, 1994). Reflecting on this trend, the Bureau of Empowerment for Older Persons of Thailand (2004) noted that one fourth of older Thai adults had health problems, and Boonyawongvirot (as cited in Institute of Geriatric Medicine, Department of Medical Services, Ministry of Public Health, 2007, April 23) revealed that almost 6 million (or 87% of them) had suffered from at least one chronic disease.

The group of the younger old persons (60-79 years) constitutes the majority (90.5%) of all the elderly in Thailand (Institute for Population and Social Research, 2007). Those over 75 years of age experience more serious illnesses than people in other age groups (Bureau of Empowerment for Older Persons, 2004). Further, the Bureau of Empowerment for Older Persons (2004) and Institute of Geriatric Medicine (2005) found that chronic diseases were the most significant cause of death among older adults in Thailand, as is true for many other countries in the world. The most common diseases among the older adults in Thailand are cancer, diabetes mellitus, liver disease, renal disease, paralysis, and bronchitis, respectively.

In addition, it is important to consider a particular trend that has occurred in regard to Thailand's older citizens. The rate of cancer, diabetes mellitus, and renal disease has increased from 234.5, 39.9, and 38.3 cases in 1991 to 297.6, 88.4, and 89.6 cases per 100,000 Thai individuals, in 2001, respectively. Supporting the upward incidence of such illnesses are data from the Department of Medical Services, Ministry of Public Health of Thailand (n.d.) on chronic illnesses of Thai older adults: since 2000, cancer has been the most chronic disease and the most significant cause of death and has continuously increased, especially for those older adults who are 60 years and older. Historically, cancer was the 3rd to 6th most common cause of death in the past; however, since 2000, cancer has become the most common cause of death, occurring at a rate of about 63.9 to 68.4 cases per 100,000 population in 2000 and 2001, respectively (Department of Medical Services, Ministry of Public Health of Thailand, n.d.; National

Cancer Institute of Thailand, Department of Medical Services, Ministry of Public Health of Thailand, September 7-9, 2005).

Similarly, research conducted by Wibulpolprasert (2005) also found that the leading cause of death in Thailand is cancer or malignant tumors, since the hospital admission rate of cancer patients increased from 34.7 in 1994 to 89.4 in 2003 per 100,000 individuals. For example, an academic medical-university hospital in the north of Thailand reported that cancer was the first principal diagnosis and the fourth cause of death among 45,756 inpatients in 2006, or about 14.29% of all deaths (Medical Records and Statistics Department, 2006).

Death typically occurs among older adults in connection with an illness (Goldstein & Morrison, 2005); however, before death occurs, these chronic diseases may progress and not respond to any curative treatment for months or years, during which time these elderly individuals must face physical and emotional symptoms of distress and progressive functional dependence and frailty, in addition to requiring high family support (Morrison, 2005). Regarding dying patients with advanced cancer, if cancer has grown beyond its primary region and cannot be removed or cured, patients with cancer may suffer greatly from many distressing symptoms produced by their illnesses during the transition from curative treatment to palliative care (American Cancer Society, 2007, January 16; Vanderlugt, 2007). Dunne, Sullivan, and Kernohan (2005); Imagins (2007, June 24); and Lin et al. (2000) found that patients with advanced metastatic cancer often experience multiple symptoms during the palliative stage of illness. The most common clinical symptoms are dyspnea, anorexia, hypercalcemia,

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malignant effusion, symptomatic metastases, obstructive jaundice, and carcinomatosis of meningeal or pleural surfaces as well as additionally relevant symptoms such as pain, weight loss due to loss of appetite, fatigue, weakness, sleep problems, depression, anxiety, and confusion (National Comprehensive Cancer Network, 2007; Stuart, 1999). As a result, these distressing symptoms often caused individuals to seek admittance to hospitals or hospice care.

The pain symptoms, produced from cancer growth and spread into soft tissues or other organs, have been identified as the most prevalent symptom and have a multidimensional nature (Imagins, 2007, June 24; Lin et al., 2000). They can greatly affect all of the physical, psychological, social, and spiritual aspects of patients with advanced cancer—in terms of physical pain, psychological pain, social pain, and spiritual pain, which some investigators have found are so difficult to manage (Larsson & Wijk, 2007; Lin et al., 2000; Mako, Galek, & Poppito, 2006). In addition to suffering from pain itself, these older adults also encounter other distressing symptoms related to pain.

Aitini and Cetto (2006) stated that terminal or pre-terminal cancer patients inevitably experience pain and loneliness and that such pain needs to be controlled effectively. They also documented that physical pain could stimulate other symptoms; such as anger, anxiety, rejection, depression, feelings of abandonment, and exhaustion; and they found that these emotions emerge not only in patients but also in their families. Similarly, Barsevick, Dudley, and Beck (2006) studied cancer-related fatigue, depressive symptoms, and functional status through experimental design control group (sample size = 151) and treatment group (sample size = 141) via a randomized clinical trial (RCT) as well as a cross-sectional study. The findings showed that functional status, fatigue, and depression were associated with cancer patients' suffering; the poorer the functional status, the higher the fatigue, and the higher the depression.

Noorani and Montagnini (2007) were also interested in reviewing factors associated with depression in patients with advanced diseases, and looked at key elements of its assessment. They showed that depression was one of the major distressing symptoms of patients with life-threatening conditions or advanced cancer, which affected 75% of their study group. The causes of depression in these advanced cancer patients were due to physical, emotional, and psychological factors associated with a cancer diagnosis, side effects of treatment, symptoms and disabilities associated with cancer progression, cerebral dysfunction from carcinomatosis, disrupted relationships, falling into dependence, disfigurement, and approaching death. The depression experienced by these patients was severe and impaired their ability to interact with families and loved ones—all of which contribute to serious suffering.

Eventually, the failure to control pain and suffering caused by distressing symptoms, which produces depression and discomforts, affects the dying patients' quality of life and causes them to consider hastening their own death, or committing suicide (Consumer information: pain and symptom management, n.d; Noorani & Montagnini, 2007; Schroepfer, 2007).

In Thailand, there are only a few research studies of comfort care relating to dying patients, palliative care, or end-of-life care. One study done by Bennett, Sallzar, William, Himmavanh, and Charerntanyarak (1994) about dying at home reported that

patients who had been diagnosed with terminal illnesses were discharged without receiving help for pain control and without receiving medical aid, financial help, or caregiver support (the study was done among patients in four villages in northeast Thailand). Later, Petpichetchian (2001) stated that most Thai patients with cancer still experienced inadequate pain management. In a related statement about end-of-life care in the USA, Quill and Meire (2006) stated that uncontrolled pain and other distressing symptoms were the greatest fear of patients who were facing serious illnesses. These distressing symptoms experienced by older patients with advanced cancer, that is, living with stressful healthcare situations, causes these patients to experience discomfort (Kolcaba, 2003). Discomfort can affect human beings as a whole, and causes more than only negative physical sensation and emotional distress (Wilson & Kolcaba, 2004). Consequently, they need comfort care to give them ease, relief, and transcend all discomforts (Kolcaba, 2003). Thus, providing comfort or comfort care becomes the primary or golden goal of care for dying patients (Curtiss, 2004; Department of Pain Medicine & Palliative Care, 2005.; Egan & Labyak, 2006; Scanlon, 1997, January 7), especially dying patients with cancer who have a special need and right to comfort care both during and after treatment (National Cancer Institute, 2005, September 30).

While comfort care during the last stage of life is greatly needed, Thailand's current health care system, especially with respect to nursing care for terminally ill and cancer patients, is inconsistent. Although care programs for terminally ill patients have begun to develop, they are still in the beginning stages of development and have only recently become part of the national health care system, existing mostly in a few large

hospitals. Furthermore, the first national conference for palliative care intended for dying patients was not held until 2004, at Songkla University; the National Palliative Care Network was founded in early 2005 (Nilmanat & Phungrassami, 2006, July 8-12). Therefore, there is no set of official statistical data on dying patients or older dying patients with advanced cancer, although many health care settings are currently trying to develop specific services for them.

One of these health care settings is the Maharaj Nakorn Chiang Mai Hospital, an academic medical-university hospital. It started a pilot project aimed at developing palliative care services for dying patients in fifty-five units in this hospital only, lasting from May until September of 2006. The document on this project, still unpublished, reported that there were 257 dying patients. Although these patients were more satisfied, the report also emphasized that nursing care needs to be improved for these dying patients and their families. This is because incidents had occurred that showed that some patients and their relatives were not able to cope with these patients' illnesses; nurses did not really understand how to care for the dying effectively, nor did they possess the skills to assess the needs of dying patients and their families. Communication between nurses and patients and their families was not sufficiently effective, and the environment of each unit was not properly arranged to address the needs of these patients. Confirmed by informal interviews with registered nurses and one physician done by this author in July, 2007, the data showed that end-of-life care still needed improvement; particularly, the knowledge and skills of healthcare providers administering holistic care —comfort care including communication and relevant

concepts, inter/multidisciplinary team for palliative care, and policies which facilitate quality end-of-life care.

In addition, based on the researcher's clinical teaching experiences, most dying patients did not receive the significant case-specific end-of-life care they needed. In general, healthcare settings and nursing care services for dying patients did not deviate from traditional nursing care. Only a few hospitals provided some special care practices for dying patients. Therefore, these patients were frequently ignored or abandoned, and were not given the personal nursing care they needed to relieve their distressing symptoms/discomforts prior to their deaths. There were no effective preparations made in order to help dying patients and their families cope with terminal illnesses. These patients suffered and died from distressing symptoms, while their relatives suffered from grief and loss. These problems occurred because nurses did not have enough knowledge, understanding, and skills with regard to the care of dying patients. As a result, nursing care does not focus much on the comfort and quality of life of these patients, and fails to ensure that patients will die with dignity, which is part of the primary goals of the quality of end-of-life care (Curtiss, 2004; Department of Pain Medicine & Palliative Care, 2005.; Egan & Labyak, 2006; Scanlon 1997, January 7).

Based on the evidence referred to above, providing end-of-life care in Thailand's healthcare system, especially in regards to nursing care, is not effective. Nursing institutions urgently need to improve the quality of end-of-life care, which has comfort or comfort care as its primary goal because it enables holistic care and a peaceful and comfortable dying process (Novak, Kolcaba, Steiner, & Dowd, 2001; Poor & Poirrier, 2001).

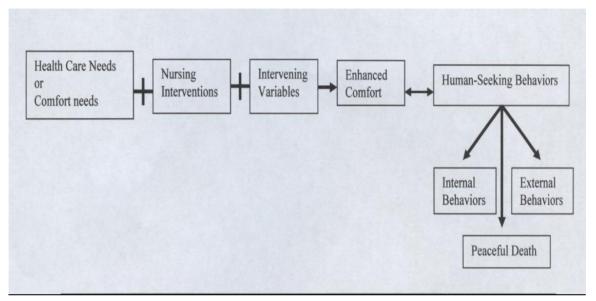
However, to develop or improve the quality of end-of-life care, fundamental information is needed about patients' needs during end of life care in the healthcare settings. Singer and Bowman (2002) reported that the lack of information about the current state of end-of-life care within the population is a fundamental barrier to the improvement of the quality of care provided. In addition, the quality of end-of-life care must adequately respond to both dying patients' and their families' needs. Bowman, Martin, and Singer (2000) stated that the most appropriate way to judge the quality of end-of-life care was to study the care as it was perceived by the patients and their families, because they were the ones directly involved with life-and-death decisions. Supporting this notion, Ryan (2005) documented that health care professionals' perceptions usually differ from the perception of patients or families. Logically, in this study, to obtain the most accurate information regarding the existing quality of end-of-life care, it is important to directly study the experiences of dying patients who are facing this situation. In addition, there is a need to examine the needs and perceptions of older patients regarding end-of-life care in order to fully understand its current status in Thailand. The comfort and primary needs of cancer patients are critical issues at this time. Once healthcare providers, especially nursing organizations, obtain the validated information they can better understand, and will be able to improve the quality of care pertinent to the preferences of dying patients, especially older patients with advanced cancer, in Thailand.

#### **Theoretical Orientation**

Comfort theory is the theoretical orientation utilized in this study. It is a middlerange theory of nursing. Kolcaba (2003) developed this theory based on the philosophy of holism—person-based holism believes that whole persons consist of a mental, emotional, and spiritual life (Kolcaba, 2003). In addition, she combined the theory of personality of Murray, which explains the needs of persons stimulated by a stressful situation, and the concept of health-seeking behaviors (HSBs) of Schlotfeldt (1975), which consists of internal behaviors, external behaviors, and good death (Kolcaba, 2003; "Needs as personality: Henry Murray," 2004, July 27). The comfort theory describes that, when a patient experiences a stressful healthcare situation, she or he demands three types of comfort needs: relief—the state of having a specific comfort need met, ease—the state of calm or contentment, and transcendence—the state in which one can rise above existing problems or pain. This encompasses four contexts: physical, psychospiritual, environmental, and sociocultural contexts (Kolcaba, 2003, 2004).

Kolcaba (2003) defines comfort theory both at a lower level of abstraction or practical level and at the lowest level abstraction or operational level enabled to be measured as a nursing sensitive outcome. The comfort theory includes comfort needs or health care needs, nursing interventions, intervening variables, enhanced comfort, and health-seeking behaviors (see Figure 1). Each conceptual term is defined by Kolcaba (2003, 2004) as follows (Tomey & Alligood, 2002).





*Figure 1.* Middle–Range Theory of Comfort. Reprinted from *Comfort Theory and Practice* (p.112), by K. Kolcaba, 2003. New York: Tri-Graphic Printing Company. Copyright 2003 by Springer Publishing Company. Reprinted with permission.

*Comfort needs or health care needs* are defined by Kolcaba (2003, 2004) as a person's needs that arise from stressful healthcare situations, not met by traditional support systems. These needs include physical, psychospiritual, social, and environmental needs; they are made apparent via monitoring and verbal or nonverbal reports and relate to pathophysiological parameters, education and support, and financial counseling and intervention.

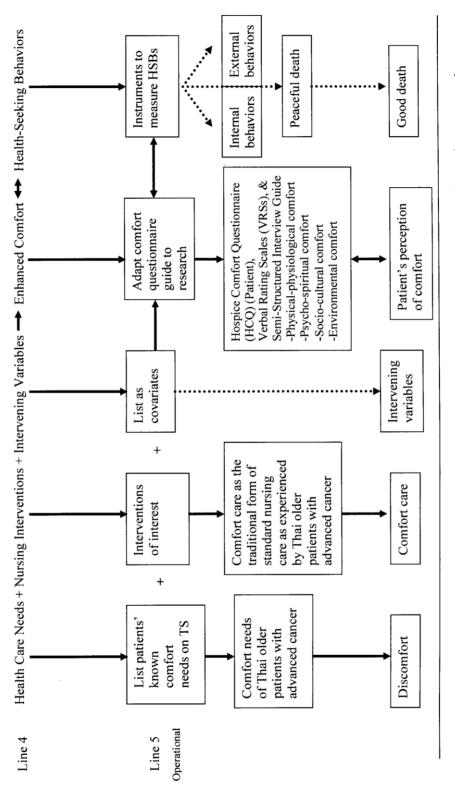
*Comfort measurements (comfort intervention)* in Kolcaba's model (2003) are meant as nursing interventions intentionally designed to address specific comfort needs of recipients, including physiological, social, financial, psychological, spiritual, environmental, and physical aspects.

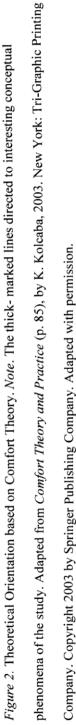
*Intervening variables* in Kolcaba's model (2003, 2004) are interacting forces from external stimuli or sources influencing recipients' perception of total comfort care. Examples of intervening variables are past experiences, age, attitude, emotional state, support system, prognosis, finances, and totality of elements in the recipients' experiences.

*Enhanced comfort* as described by Kolcaba (2003) is the state of a person who experiences comfort intervention or measures that strengthen all holistic aspects by meeting three types of comfort in four contexts.

*Health-seeking behaviors (HSBs)* in the model are "behaviors in which patients engage consciously or subconsciously which move toward well-being" (Kolcaba, 2003, p. 255), consisting of internal behaviors occurring at the cellular and organ level, such as healing and immune functions and external behaviors such as self-care, function, and rehabilitation; finally, these behaviors produce a peaceful death in which conflicts are resolved, symptoms are well managed, and acceptance by patients and family members allow for patients to let go of life quietly and with dignity.

Comfort theory is based on the assumption that in health care situations, patients experience discomforts--a physical, psychospiritual, social, or environmental detractors from comfort--as side effects of illness or treatments; threatening environmental and social experiences; *and emotional sensations* such as fear, anxiety, powerlessness, or loneliness (Kolcaba, 2003) and possess comfort or health care needs. If nurses provide these patients (or their families) with comfort care or nursing intervention addressed by individual patient's specific comfort needs (relief, ease, and transcendence; encompassing physical, psycho-spiritual, environmental, and sociocultural contexts), they will experience enhanced comfort levels. This comfort helps them engage in health-seeking behaviors consisting of internal, external, and, eventually, peaceful deaths. The patient experiences a quiet and dignified death also reported as a good death (see Figure 2) (Kolcaba, 2003, 2004)





Patients perceive comfort care provided as enhancing comfort. Thus,

Kolcaba (1994) defined comfort as a result of comfort intervention, as a "satisfaction (actively, passively, or co-operatively) of the basic human needs for relief, ease, or transcendence arising from health care situations that are stressful"(p. 1178), or as an immediate state of being strengthened by having the needs for three types of comfort (relief, ease, and transcendence) met in four contexts of experience (physical, psychospiritual, environmental, and sociocultural) (Kolcaba, 2003, 2004; Kolcaba & Fisher, 1994). Supporting this approach to patient care, Bottorff (2002) stated that comfort enhances an individual's abilities and engenders hope as well as bringing about ease, especially when loss occurs.

In addition, enhanced comfort is also associated with desirable outcomes, such as, increased satisfaction of patients and family, relieving symptoms of distress or discomfort; enhanced comfort facilitates higher patient functions, quicker discharge from the facility, fewer readmissions, and, finally, more efficient cost-effectiveness of care (Kolcaba, 2004).

In summary, comfort provides desired, holistic, proactive, and sensitive nursing outcomes (Kolcaba, 2003; Novak et al., 2001; Wilson & Kolcaba, 2004). Furthermore, it is determined as a primary goal of end-of-life care (Curtiss, 2004; Department of Pain Medicine & Palliative Care, 2005.; Egan & Labyak, 2006; Scanlon 1997, January 7). Thus, comfort became the significant concept for this study whose findings and knowledge will be useful to improve quality of end-of-life care for advanced cancer patients in Thailand.

#### **Research Question**

What is comfort as experienced by Thai older patients with advanced cancer who are receiving care in an academic medical-university hospital in Thailand?

### **Study Purpose**

The purpose of this proposed study was to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medicaluniversity hospital in Thailand.

## **Definition of Terms**

## **Older Patients with Advanced Cancer**

### **Theoretical definition**

Older adults or patients with advanced cancer were defined as patients aged 60 years or older (Bureau of Empowerment for Older Persons of Thailand, 2004; Meiner & Lueckenotte, 2006) whose genes had developed and mutated, so their bodies could not control cellular division and growth. As a result, these cells divide and grow in ways that produced cancer, and progressed towards advanced cancer (British Columbia Cancer Agency, 2007).

#### **Operational definition**

Hospitalized patients in an academic medical-university hospital in Thailand who were 60 years or older and diagnosed with advanced cancer—a stage where the cancer was growing and spreading to vital organs (National Comprehensive Cancer Network, 2007)--or where advanced-stage cancer had been diagnosed by one or more physicians.

#### **End-of-Life Care**

## **Theoretical definition**

End-of-life care was defined as multi-dimensional care that needed to be implemented through a multi-disciplinary team in order to comprehensively respond to the needs of dying patients; who were in "the final stage of the journey of life" by the presence of chronic disease(s) that was progressively worse, of symptoms, or of persistently temporarily functional impairment; and the needs of patients' families (Dyer, 2006, November 5, p. 1). These conditions required formal or informal care until death.

## **Operational definition**

Traditional standard nursing care with comfort as provided for older patients with advanced cancer by nurses at the end of life was examined in an academic medical-university hospital in Thailand. To determine that the patient was nearing the end of life, a Palliative Performance Scale version 2 (PPSv2) equal to or less than 60, applied by nursing professionals and repeatedly assessed by the researcher, was used to determine that participants were in fact in the end-of-life phase of their illness (survival under six months) (Appendix A).

#### Comfort

### **Theoretical definition**

Comfort, sometimes called comfort care (Allegre, n.d.; LIFE Project, n.d.; Palliative Care, n.d.), was defined as "The immediate state of being strengthened by having the needs (relief, ease, and transcendence) addressed in four contexts (physicalphysiological, psycho-spiritual, environmental, and socio-cultural); much more than the absence of pain" (Kolcaba, 2003, p. 251, 2004, p. 255), or as "the satisfaction (actively, passively, or co-operatively) of the basic human needs for relief, ease, or transcendence arising from health care situations that are stressful" (Kolcaba, 1994, p. 1178), enhancing abilities and engendering hope as well as bringing about ease of mind, especially when loss is experienced (Bottorff, 2002).

## **Operational definition**

Comfort care was measured by Hospice Comfort Questionnaires (HCQ) (Patient), Verbal Rating Scales (VRSs), and the Semi-Structured Interview Guide; assessing three types of comfort: relief, ease, or renewal/transcendence; addressed in four contexts of the human experience (physical-physiological, psycho-spiritual, sociocultural, and environmental contexts). Another focus was the absence of pain or other physical discomforts (Kolcaba, 2003).

#### Significance of the Study

This study was designed to explore and describe comfort as experienced by older patients with advanced cancer in end-of-life care in an academic medicaluniversity hospital in Thailand. Findings from participants' experiences of comfort care can help Thai nurses and other healthcare professionals who are members of an interdisciplinary end-of-life care team to fully understand the illnesses, discomforts and comfort needs of older patients with advanced cancer, as well as the actual care being provided in an initial development stage in this healthcare setting. This new knowledge will be fundamental to the improvement of the quality of end-of-life care with respect to comfort. This information can enable the profession to anticipate and respond to the holistic needs of older patients with advanced cancer and their families.

In addition, nursing colleges and faculties are also affected by the increase of end-of-life care needs in society. They have a responsibility to develop and prepare nursing professionals with particular knowledge and skills for improving the quality of end-of-life care and effectively providing it for their patients. Obviously, the findings of this study will facilitate the appropriate development of both undergraduate and graduate nursing curricula and research, aimed at improving the quality of nursing care. In terms of healthcare administration, administrators will better understand the needs and the importance of improving the quality of end-of-life care by examining these findings. Support for healthcare policy making, healthcare services, and funding for the advancement of nursing knowledge of staff and research could possibly result from a better understanding of the needs of older patients with advanced cancer at the end of life. The knowledge and findings of this study relating to a sample of older Thai patients with advanced cancer will encourage comfort-oriented end-of-life nursing care to improve as quickly and effectively as possible.

#### Assumptions

- 1. Comfort is valued and important at the end of life.
- 2. Nurses can provide comfort.
- 3. Patients enrolled in the palliative care program in Thailand receive similar levels of care from healthcare providers. Health care providers want to provide patients with comfort at the end of life.

- 4. Patients enrolled in the palliative care program in Thailand will share their thoughts and feelings with honesty and openness.
- 5. Patients enrolled in the palliative care program in Thailand will receive similar support and concern from their family and friends.

#### **CHAPTER II**

#### **REVIEW OF LITERATURE**

The purpose of this study was to explore and describe comfort as experienced by older patients with advanced cancer who are hospitalized in an academic medicaluniversity hospital in Thailand. Prior research studies have mainly focused on end-oflife care with respect to comfort care; such research has especially focused on older patients with advanced cancer (Dunne et al., 2005; Heyland et al., 2006; Rodriguez, Barnato & Arnold, 2007; Ryan, 2005). The term comfort has been used in the nursing profession since the Florence Nightingale era, and was noted in Nightingale's model of nursing (Wills, 2007). Later, based on the position statement of the American Nursing Association (ANA) launched to relieve pain of dying patients in 1991, comfort was considered and promoted as a primary goal of palliative care, hospice palliative care, or end-of-life care (American Nursing Association, 2008; Curtiss, 2004; Department of Pain Medicine & Palliative Care, 2005; Egan & Labyak, 2006; Scanlon 1997, January 7). By the year 1988, Kolcaba (1991) began to develop and analyze the concept of comfort. Kolcaba (1994, 2003, 2005) published the comfort theory in the Journal of Advanced Nursing in 1994. In addition, Novak et al. (2001) developed comfort measures, particularly as they applied these measures to end-of-life patients and caregivers in 2001. Beyond, there have been many nursing research studies related to comfort, end-of-life care, and quality of end-of-life care (Cameron, 1993; Fleming et al., 1987; Hamilton, 1989; Morse et al., 1994). However, there has still been the limitation for these issues in Thailand until now.

The review of literature for this study is organized into three sections: (a) an overview of older patients with advanced cancer, (b) an overview of end-of-life care, and (c) an overview of comfort. This review emphasizes end-of-life care with respect to comfort care and quality of care at the end of life.

#### **Older Patients with Advanced Cancer**

#### **Definition of Older Adults (In general and in Thailand)**

Older adults (or older patients in this study) are defined as younger old persons (American Psychological Association, n.d.). The definition of older or elderly persons is not the same in all countries of the world. For example, most developed countries, such as the United States, have recommended the age of 65 and over as older adults. However, the United Nations has agreed to establish age 60 and over to refer to the older population (World Health Organization, 2007). In Thailand, the Bureau of Empowerment for Older Persons (2004) established that Thai elderly or older adults were persons at age 60 years and over. In addition, it is projected that the number of Thai older adults (or approximately 10% of all of its citizens), and this number will grow to 11.3 million by 2020, or up to 14 million (or 20% of all of its citizens) (Bureau of Empowerment for older Persons, 2004; Khao Sod, 2006, January 6). Consequently, the average life expectancy in Thailand will have risen from 68.15 to 68.86 for males, and from 72.39 to 73.00 for females by 2010.

The consequence of the developing aging process is that the health status of older adults declines while their health problems increase, which further develops as a

chronic disease (Meiner & Lueckenotte, 2006). Like older persons in other countries, most Thai older patients (about 87% of them) have experienced and suffered from chronic diseases, at least one disease until death (Boonyawongvirot as cited in Institute of Geriatric Medicine, Department of Medical Services, Ministry of Public Healt, 2007, April 23; Bureau of Empowerment for Older Persons, 2004). The chronic disease of Thai older persons is mostly concerned with cancer because the number of Thai cancer older patients increases every year and it becomes the most common or leading cause of death for them (Department of Medical Services, Ministry of Public Health of Thailand, n.d..; Kuhaparma, n.d.; Medical Records and Statistics Department, 2006; National Cancer Institute of Thailand, Department of Medical Services, Ministry of Public Health of Thailand, September 7-9, 2005; Sriplung, Wiangnon, Sontipong, Sumitsawan, & Matin, 2006; Wibulpolprasert, 2005). Therefore, cancer as a progressive disease ("Cancer", 2010, September 3), especially advanced cancer, has become a critical healthcare problem in Thailand.

### **Advanced Cancer**

Advanced cancer is defined as "cancer that has grown beyond the organ where it first started" (American Cancer Society, 2007, January 16, p.1), especially getting carried to one or more vital organs. It cannot be removed, and is commonly identified as "stage IV with distant metastasis" (Stuart, 1999, p. 3). This means that advanced cancer cannot be cured (American Cancer Society, 2007).

Cancer, currently associated with over 200 diseases, is the disease in which cells of an organ or a tissue in the body become abnormal, grow rapidly, and multiply uncontrollably. When growing and having the potential to invade and destroy the normal cells, as well as spreading to distant parts of the body, the cancer is called a malignant tumor. Usually, it detaches from an original site or organ—a primary tumor—to another site or organ and becomes a secondary tumor. This process is called a metastasis (British Columbia Cancer Agency, 2007). Although it spreads to another organ, the diagnostic label is based on its primary cancer site.

The metastasis of cancer to another organ occurs due to four main processes: spreading through the lymphatic system called embolization, the circulatory system, especially by veins rather than arteries, local invasion by intruding on the healthy cells around the cancer tumor, and implantation or inoculation, usually occurring rarely as a result of a faulty biopsy (British Columbia Cancer Agency, 2007). As a result, treatments for cancer require simultaneously considering what type of cancer it is as well as how far it has spread anatomically, which is called the cancer staging system. Dunn (2002, July 26) described the staging system of cancer by saving that it commonly refers to the overall stage grouping system and the Tumor Node Metastasis system (TNM system), providing more details of the presenting cancer. The TNM system is described by T (tumor), N (lymph nodes), and, especially, M (metastasis) defined as 0-no metastasis and 1-metastasis. The overall stage grouping establishes four stages: (a) stage I--localized cancer, (b) stage II and stage III--advanced cancer and/or with involving local lymph nodes, and (d) stage IV—distantly recurrent cancer meaning it recurs after being eliminated. The stage of each cancer depends on the different types of cancer. In sum, the final stage of both staging systems—stage IV and distant metastasis or recurrent cancer, is determined as advanced cancer that is incurable (Cancercare, n.d.; "Cancer staging", 2009, August 20; Stuart, 1999).

The advanced cancer stage is not the same in individual patients because it not only depends on what its primary region is, but also on the additional congruency of clinical symptoms of advanced diseases. For instance, dyspnea, anorexia, hypocalcaemia, malignant effusion, symptomatic metastases, obstructive jaundice, and carcinomatosis of meningeal or pleural surfaces may occur with advanced cancer (Stuart, 1999). Furthermore, these illnesses produce additional distressing symptoms, which cause more suffering (National Comprehensive Cancer Network, 2007). In conclusion, older patients with advanced cancer confront suffering from both clinical symptoms and subsequent distressing symptoms of their illness status.

# **Overview of Distressing Symptoms of Older Patients with Advanced Cancer**

The older adult population has an increased risk for cancer and advanced cancer due to the process of aging and the development of mutated genes that can progress toward advanced cancer (Steele & Steele, 2006). The Department of Medical Services, Ministry of Public Health of Thailand (n.d.) reports that the prevalence rate of every type of cancer is higher in the age group of 60 years or more than it is for the group of individuals under 60 years old. When this cancer progresses toward advanced cancer, it is acknowledged that no treatment can cure the condition, and that any alternative efforts to combat the progress of cancer are exhausted (Tang & McCorkle, 2002). This development places the older adult with advanced cancer into the terminal illness stage with the expected survival rate within six-months (Stuart, 1999). During this terminal period, older adults or patients with advanced metastatic cancer experience multiple symptoms (Dunne et al., 2005; Imagins, 2007, June 24; Lin et al., 2000). Beyond the most common clinical symptoms such as dyspnea, anorexia, hypocalcaemia, or malignant effusion, cancer patients confront additionally relevant symptoms which are pain, weight loss due to loss of appetite, fatigue, weakness, problems sleeping, depression and anxiety, and confusion (National Comprehensive Cancer Network, 2007; Stuart, 1999). Hence, these distressing terminal symptoms cause older patients with advanced cancer to experience extreme physical, psychological, social, and spiritual suffering (Dunne et al., 2005; Larsson & Wijk, 2007; Lin et al., 2000; Mako et al., 2006).

The pain symptoms, produced by the generation of cancer and its spreading into soft tissues or other organs, become the most prevalent symptoms and are multidimensional in nature (Imagins, 2007, June 24; Lin et al., 2000). It can affect all physical, psychological, social, and spiritual aspects of older patients with advanced cancer, which are difficult to manage (Lin et al., 2000). In addition to suffering from pain itself, older patients with advanced cancer also encounter distressing symptoms related to pain. Vallerand, Saunders, and Anthony (2007) studied the perceptions of control over pain by patients with cancer and their caregivers (10 patient-caregiver dyads) via semi-structured interviews and field notes. They found that their patients expressed pain that took from them their ability to perform the most basic tasks, such as dressing, taking a bath, walking down the driveway, getting out of bed, eating a meal, etc. These relate specifically to their functional well-being. Hence, this pain caused them to no longer be able to sleep, and to ultimately experience desperate emotions that are difficult to control. Approximately 50% of cancer patients experience difficulty in coping with sufferings from pain on a daily basis (Imaginis, 2007, June 24). In addition, Larsson and Wijk (2007) interviewed three patients with different types of cancer about pain experiences at the end of life. These participants expressed cancer pain as dreadful, and reminding them of the cancer and the uncertainty of their future.

Another study done by Stromgren, Groenvold, Sorensen, and Andersen (2001) focused on symptom recognition in advanced cancer: A comparison of nursing records and patients' self-rating was made by 56 advanced cancer patients receiving noncurative or life-prolonging treatment. The patients listed their impairments as follows: physical function (88%), role function (91%), fatigue (96%), nausea/vomiting (44%), dyspnea (91%), sleep disturbances (42%), diarrhea (23%), and financial difficulties (25%). In addition, when they used the self-reporting instrument, the Edmonton Symptom Assessment System (ESAS), they reported other significantly distressing symptoms: pain (80%), inactivity (91%), nausea/vomiting (47%), depression (47%), anxiety (47%), drowsiness (76%), reduced appetite (78%), impaired well-being (85%), and dyspnea (55%). In addition, pain and poor physical functioning symptoms were identified by both patients and nurses as major issues. Importantly, other symptoms were recorded more often by patients than by nurses.

Aitini and Cetto (2006) stated that the terminal or pre-terminal cancer patients inevitably experience pain and loneliness, and that these needed to be controlled effectively. They also documented that the physical pain could stimulate other

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symptoms: such as anger, anxiety, rejection, depression, abandonment, and exhaustion; these emotions affected not only patients but also their families. Barsevick et al. (2006) tested the mediating effect of functional status on the direct and indirect relationship between cancer-related fatigue and depressive symptoms. This study was a secondary analysis of the data from the cross-sectional study to compare the efficacy of the energy conservation and activity management (ECAM) and of nutrition-control (or healthy diet) intervention on fatigue reduction and maintenance of functional performance of cancer patients receiving treatments, which was previously conducted as an experimental design by Barsevick et al (2004). In the secondary analysis, the number of subjects was 151 in the control group and 144 in the treatment group who learned skills designed to minimize the impact of fatigue on functioning following the ECAM. The findings from the secondary analysis showed that functional status, fatigue, and depression were associated with cancer patients' suffering. The poorer the functional status, the higher the fatigue and the higher the depression. Hence, functional status was an important factor to manage fatigue.

In a study by Teunissen, de Graeff, Voest, and de Haes (2007) of 79 hospitalized patients with advanced cancer, the authors studied the correlation between anxiety, depressed mood, as well as its presence and intensity of physical-symptom burden of their patients. Although the finding showed that the correlation of these variables was low, the interesting finding revealed that these patients had high levels of anxiety (34%), depressed mood (56%), or both (29%).

Similarly, Noorani and Montagnini (2007), who reviewed the key elements of the assessment of depression in palliative care patients, defined the meaning of depression as a frequently encountered psychiatric disorder in terminally ill patients. It was one of the major distressing symptoms of patients with a life threatening condition or advanced cancer, which impacted patients' quality of life and decreased the sense of hope, sense of peace, and meaning. Up to 75% of patients with life-threatening conditions or advanced cancer experienced depression. Based on this evidence, depression in relation to cancer illness was incorporated into palliative care treatment. They concluded that the causes of depression in advanced cancer patients was due to physical, emotional, and psychological factors: cancer diagnosis, side effect of treatment, symptoms and disability associated with cancer progression, cerebral dysfunction from carcinomatosis and suffering from disrupted relationships. Other factors were: falling into dependence, disfigurement, and approaching death. This depression impacted patients severely, as well as their ability to interact with families and the loved ones—which constitutes additional serious suffering.

Supporting this position, Goldstein and Morrison (2005) documented that emotional and psychosocial distress commonly occurred among individuals facing the terminal phase of an illness and impending death. McClain, Rosenfeld, and Breitbart (2003, May) stated that "Feelings of depression and hopelessness and anxiety were common reactions of individuals as they approach the terminal phase of an illness" (p. 1603). In support of this finding, Royak-Schaler et al. (2006) stated that chronically ill and dying patients also faced difficulties when dealing with the healthcare system, which compromised their physical, emotional, and spiritual integrity towards the end of their lives.

More importantly, using triangulation, Mako et al. (2006) examined spiritual pain experienced by 57 patients with advanced cancer in palliative care. They argued that all distressing symptoms occurring in older adults with advanced cancer were related to spiritual pain. They also found that about 96% of advanced cancer patients experienced this spiritual pain and produced sufferings: despair, loss, regret, or anxiety (as the intrapsychic spiritual pain [48% of patients]); feeling abandoned by God, being without faith, and/or a religious/ spiritual community (as the spiritual pain in relation to the divine 38%); and feeling unwanted by families and disconnected from others (as the interpersonal spiritual pain 13%).

All of these distressing symptoms have a great impact on the quality of life of dying patients, encompassing physical, psychological, social, spiritual aspects. Tang, Aaronson, and Forbes (2004) studied the relationship between spirituality, pain, physical status, social support, and quality of life in 60 patients who suffered from terminal illnesses and who were receiving hospice care (response rate 71%). The findings revealed that the most significant distressing symptom was pain, with an occurrence of 55.7%; fatigue ranked at 47.5%, and shortness of breath at 26.2%. Additionally, this study reported that spirituality, pain, physical performance status, and social support were significantly related to these individuals' quality of life.

The result of the suffering from these distressing symptoms—as discomforts--or dying in a distressing environment, older patients with advanced cancer feel hopeless

and consider hastening toward early death (Schroepfer, 2007). Stuart (1999) stated that the declining of the person's ability to do anything and reduction in functional status, relates to and becomes the most common predictor for prognosis. The more advanced the cancer, the more it becomes detrimental to the patient's functional ability; the worse the prognosis, the lesser the chance of survival as well.

Theoretically, dying patients with advanced cancer, as well as their families, require special care that addresses the physical, emotional, social, and spiritual aspects of the total person. In actual clinical practice, however, patients may receive inadequate treatment, suffering from distressing symptoms, and may still be facing feelings of distress until their death. To further support this notion and based on the literature reviews focusing on terminal care during the last weeks of life, Plonk and Arnold (2005) affirmed that approximately 75% of all Americans died in institutions where they received traditional care that focused on curative rather than palliative care. Furthermore, the researchers indicated that providing effective end-of-life care is still a critical problem, and that it does not meet the comprehensive needs of these patients.

Teno et al. (2004) surveyed the perspectives of 1,059 families (67.1% of 1,578 them) of patients who died in a last place of care: home with home care nursing services, home with hospice care, nursing home, and hospitals in 2000. In this study, 32% indicated that patients' pain control was not adequate, 56% felt that patients did not receive emotional support, 50% thought there was a communication problem, 80% thought that patients received treatment that lacked respect, and 51% wanted more contact with physicians. Beyond pain control, which is frequently ineffective, the

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management for fatigue, breathlessness, and other symptoms is also inadequate. Eventually, failure to control pain and other distressing symptoms produces depression and discomforts, affects the dying patients' quality of life, and causes them to consider hastening their death, or commit suicide (Consumer information: pain and symptom management, n.d; Noorani & Montagnini, 2007; Schroepfer, 2007).

Schroepfer (2007) studied clinical events in the dying process: the potential for physical and psychosocial suffering was surveyed by interviewing 96 terminally ill elders in palliative care hospital units. This study revealed that when these elderly persons perceived insensitive and uncaring communication of a terminal diagnosis, they experienced unbearable physical pain and unacknowledged feelings regarding the impact of chemotherapy or radiation treatment. These patients were dying in a distressing environment and were motivated to consider hastening their own deaths.

In Thailand, providing specific end-of-life care has just recently been developed and established in few healthcare settings. Based on searching from websites: Academic Search Premier, CINAHL Plus with full text, Journal@Ovid (Nursing), MEDLINE (EBSCO and Ovid), and PubMed, there are no publications focusing on distressing symptoms in Thai patients with advanced cancer, especially at the end of life. However, Petpichetchian (2001) conducted descriptive, cross-sectional studies to investigate the experience of cancer pain in 300 Thai patients in different institutions, located in three regions. He reported evidence that two thirds of the subjects were diagnosed with advanced cancer or stage IV of cancer. All subjects still experienced inadequate pain management. Consequently, they suffered from moderate to severe cancer-related pain. The suffering from uncontrolled pain and other distressing symptoms produces the greatest fears of patients facing their serious illnesses (Quill & Meire, 2006)

Based on the results of all these studies, older patients with advanced cancer experience and suffer from these physical, psychological, social, and spiritual distressing symptoms, as well as still face distressing environments hastening death. In addition, the evidence shows that end-of-life care for older patients with advanced cancer is important and requires improvement, especially in regards to the Thai healthcare system.

## **Overview of End-of-Life Care**

The end of life is the period of time prior to death and it is difficult to identify exactly when patients enter it (Ferrell & Coyle, 2002). However, Dyer (2006, November 5) defined end of life as "The period of time marked by disability or disease that is progressively worse until death" or "The final stage of the journey of life" (p. 1). In summary, the end-of-life status consists of two components: the presence of chronic disease(s) or symptoms, or persistently temporary functional impairment; these conditions require formal or informal care until death (Dyer, 2006, November 5). Based on the reports of the World Health Organization (WHO) in 2006 and 2008 (2009, 2010), cancer is a leading cause of worldwide death and its number is increasing globally and annually; for example, 7.4 million people died of cancer (or about 13% of all deaths) in 2004 and up to 7. 6 million people in 2005. According to the WHO, cancer deaths will continue to rise to approximately 12 million in 2030. In Thailand, the Department of Medical Service, Ministry of Public Health of Thailand (n.d.) and Wibulpolprasert (2005) documented that cancer has become the most common cause of death since 2000. The Thai older adults who are 60 years and over are at highest risk of cancer. In other words, cancer—advanced cancer—is the leading diagnosis among Thai older patients at the end of life. Typically, at the end of patients' lives, most of them suffer from physical, psychological, social, or/and spiritual symptoms, which further affect the person's entire being (Ferrell & Coyle, 2002). Cancer affects not only patients themselves, but also their families. It was reported that there were five people or relatives of each cancer patient who were affected profoundly by the patient death (Bowman et al., 2000). As a result, both dying patients and their families need effective end-of-life care or hospice palliative care (Egan & Labyak, 2006).

Palliative care, developed from hospice care, provides end-of-life care because it is focused on the relief of suffering and support for the best possible comfort, dignity, and quality of life for patients facing serious life-threatening illness, and their families, regardless of whether the final outcome is death or cure of the illness (Egan & Labyak, 2006; Ferrell, 2005, Supplement 1). In addition, the British Geriatric Society (2006) defined palliative care as "the active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, of social, psychological, and spiritual problems is paramount. It may be delivered by any health care professional." (p. 1). Palliative care may be provided at any time during illness, from the time of diagnosis until the time of death (National Consensus Project for Quality Palliative Care, 2004; Ferrell, 2005). It also includes care after death. Regarding the definition of end-of-life care, Kanabus (2007, August 1) stated that it "is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline" (p. 3). More specifically, Ross and Fisher (as cited in Seymour et al., 2005) stated that end-of-life care encompasses more than the immediate period before death as described in the following:

End of life care for seniors requires an active, compassionate approach that treats comforts and supports older individual who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement (p. 1).

Based on these definitions, end-of-life care sometimes is called hospice palliative care (Egan & Labyak, 2006; Ferrell & Coyle, 2002; Kanabus, 2007 August 1).

From the current situation of end-of-life care in the healthcare system, it is found that end-of-life care becomes a crucial problem at the local, national and global levels because of the number of dying persons. The number of life-threateningly ill patients has increased continuously. Frequently, these patients do not receive effective end-oflife care or adequate treatment. Another issue is the lack of adequate training of providers (Barbera, Paszat, & Chartier, 2006; Bowman et al., 2000; Ferrell & Coyle, 2002; Singer & Bowman, 2002). This is because determining or assessing patients for transfer from traditional or acute illness to end-of-life care is a late decision which makes this transition one of the most difficult times (Schonwetter, 1996, May-June). As a result, the quality of end-of-life care is recognized as limited, causing concern worldwide. This is a grave concern and many are trying to improve the end-of-life care, and attempt to shape it to become an important part of the continuum of cancer care (Schonwetter, 1996, May-June)

The primary goals of quality end-of-life care or hospice palliative care focus primarily on comfort, dignity, quality of life, relationship closure, and patients' and families' choice of care (Curtiss, 2004; Department of Pain Medicine & Palliative Care, 2005.; Egan & Labyak, 2006; Scanlon, 1997, January 7), similar to palliative care. Heyland et al. (2006) further explained that the quality of life for terminally ill patients, the quality of death and dying, and quality care at the end of life were associated and were used to evaluate to improve end-of-life care. However, the quality of care at the end of life focused more on the optimization of care and satisfaction of care, which clearly links to the measurement and improvement of quality. End-of-life care encompasses many dimensions and needs to be implemented through a multidisciplinary team in order to comprehensively respond to dying patients' and their families' needs. For example, the National Consensus Project for Quality Palliative Care (2004) proposed eight domains of guidelines developed for life-threatening or debilitating illness. These guidelines included (a) "Structure and Process of Care;" (b) "Physical Aspects of Care;" (c) "Psychological and Psychiatric Aspects of Care;" (d) "Social Aspects of Care;" (e) "Spiritual, Religious, and Existential Aspects of Care;" (f) "Cultural Aspects of Care;" (g) "Care of the Imminently Dying Patient;" and (h) "Ethical and Legal Aspects of Care" (National Consensus Project for Quality Palliative Care, 2004, p. 616). Furthermore, based on the study of Brazil et al. (2006), they conducted a cross-sectional survey to study the practice of end-of-life care in long-term care (LTC) by facilities in the Province Ontario, Canada, reported by 426 directors of care (senior nurses) with a 76% response rate. The findings revealed three main problems of care: the communication between care providers and families, inadequate staffing levels providing EOL care, and needs of EOL training of staff. In addition, the results indicated eight ideal predictors to improve the quality of end-of-life care. These indicators included (a) quality of care, (b) consensus in the facility about contributions for quality end-of-life care, (c) sufficient pain management, (d) accurate assessment for the conditions that were existent as the patient deceases, (e) confidence to discuss dying and death, (f) having knowledge and skills to address the multicultural preference, (g) number of beds (less than 100 beds), and (h) good communication among staff for care. All of these factors influence improvement in the quality of end-of-life care.

Regarding the importance and the quality of end-of-life care for older patients with advanced cancer, there are several publications examining this issue, for example, the studies of Dunne et al. (2005); Heyland et al. (2006); Rodriguez, Barnato, and Arnold (2007); Ryan (2005); and Steinhauser et al.(2000).

Dunne et al. (2005) conducted a phenomenological study to describe the experiences of 25 district nurses who provided advanced cancer patients with palliative care. The participants reported that the quality of end-of-life care needed to consist of

(a) effective symptom control or management by interdisciplinary teamwork, such as pain control, which could cause physical, psychological, social, and spiritual distressing symptoms; (b) helping families to deal with seriously ill problems to relieve their anxiety and stress; (c) high-quality communication among healthcare professionals relevant to care; and (d) effective communication to relieve nurses' conflicts and negative emotion in providing care. Thus, the higher quality of care benefited all patients, families, and healthcare providers who were nurses.

Heyland et al. (2006) studied what matters most in end-of-life care, as perceived by 434 seriously ill patients and their 160 family members. The findings revealed that the three extremely important key elements of quality end-of-life care rated by patients were "To have trust and confidence in doctors looking after you," "Not to be kept alive on life support when there is little hope for an honest manner," and "That information about your disease be communicated to you by your doctor in an honest manner" (p. Online 4). Elements important to the family of the patient were "To have trust and confidence in doctors looking after you," "Not to be kept alive on life support when there is little hope for a meaningful recovery (by the patient)," and "That information about your family member's disease be communicated to you by the doctor in an honest manner" (p. Online 5). When comparing the three most important concerns of the patients with cancer and non-cancer, it was found that they were the same, but of a different order.

Rodriguez et al. (2007) studied the perception and utilization of palliative care services in acute care hospitals as expressed by 129 healthcare providers, including the oncology social workers. They found that, beyond nurses, not many participants identified palliative care's role earlier in the disease process and were too late to respond to patients' needs. Patients would be referred to palliative service when they neared death. Some believed that palliative care was futile in regards to expected outcomes of care. The researchers suggested that it was the time to increase end-of-life consultation by communicating with resistant doctors and changing the hospital culture from high-intensity care to comfort measure and palliative care, especially perceiving palliative care as not just providing services related to the individual's demise.

Steinhauser et al. (2000), using a survey approach, studied the factors that patients, family, physicians, and other care providers considered to be important at the end of one's life, using a sample of 2,000 individuals with a 77% response rate and final size of 1,885 respondents. They found that Peace with God and pain control were most important for patients and families. Four groups of their sample provided information about the quality of end-of-life care by rating six important items (from 26 survey items developed from 12 focused groups and interviews with patients, family, physicians, and other care providers previously). These items were: (a) symptoms and personal care, (b) preparation for the end of life, (c) achieving a sense of completion about one's life, (d) decision about treatment, (e) being treated as a whole, and (f) patients' relationships with health care professionals.

Ryan (2005) interviewed five patients diagnosed with advanced cancer and approaching death. This study revealed that end-of-life care should consist of genuine caring, compassionate honesty, effective communication, relationship support, caring

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gestures, acknowledging patients by name and remembering, and listening to the losses. These were meaningful to the individual participants and affected their comfort and quality of lives in addition to providing faith and hope.

Brokel and Hoffman (2005) focused on hospice methods to measure and analyze nursing-sensitive patient outcomes from 103 nurses. These nurses indicated four important patient-outcome indicators for dying patients: (a) expressing symptom control, (b) appearing calm and tranquil, (c) expressing readiness for death, and (d) expressing pain relief.

In addition, Tamburini et al. (2003) reported their findings from a study of various-type cancer patients' needs during hospitalization, using both quantitative and qualitative methods (N = 182). Based on the quantitative method, the findings showed the first five items identified as needs as follows: information about patients' future condition (61%), better service from the hospital: bathroom, meals, and cleaning (59%), better dialogue with clinicians (45%), information about diagnosis and more information about economic-insurance (40%). Furthermore, the findings of the qualitative method (N = 8) illustrated themes that emerged as patients' needs: (a) information on diagnosis, examination, and treatments as well as future condition; (b) involvement in therapeutic choices; (c) communication with sincerity, by way of dialogues with doctors and being reassured by doctors; (d) establishing relationships by sharing the experience with a group of others undergoing the same experience, being reassured by patients' families, and commiseration from others; and (e) intimacy by receiving respect for patients' intimacy, more attention from nursing staff, and better

services from the hospital. A new issue that emerged from this study was that the environment of the healthcare setting was also important for dying patients, as it helped them accept their situations and peacefully face death at the end of their lives.

Volker and Limerick's study (2007), about a dignified death from the oncology advanced practice nurses, also confirmed that the environment of care influences the quality of end-of-life care and would help the patient to make the transition from life to death in peace—in short, experiencing a good death. The quality of end-of-life care should consist of, first, going in peace, referred to as connecting with loved ones; conveying final messages, dying in quiet, non-chaotic environment, not suffering from physical and existential distress, and meeting spiritual needs. Second, maintaining bodily integrity referred to the assistance in regards to maintaining body functions, body appearance, and individual privacy during the dying process and after death, including care respecting the individual. Lastly, on their own terms, participants referred to as respect for the patient's personal preferences regarding dying circumstances, such as, setting for death, that is, at a home/hospital, being with the loved ones, non-commotion or calm dying. This also includes the families who are losing the loved one.

In summary, end-of-life care can serve quality care by responding to the needs of older patients with advanced cancer encompassing physical, psychological, spiritual, social, cultural, and environmental aspects. When these needs are met, the golden goal of palliative care, that is, comfort care, is also fulfilled (Curtiss, 2004; Department of Pain Medicine & Palliative Care, 2005; Egan & Labyak, 2006; Scanlon, 1997, January 7).

### **Overview of Comfort**

Illnesses of dying patients progress to greater levels of seriousness and are rarely alleviated by curative treatments, but instead cared for through palliative approaches. During this end-of-life period, progressive illness produces symptoms which create much suffering and lead to distress characterized by physical, psychological, social, environmental, and spiritual aspects (Fleming, Scanlon, & Scannell D' Agostino, 1987; Hamilton, 1989; Novak et al., 2001; Morse, Bottorff, & Hutchinson, 1994). Symptoms resulting from the final days, weeks, and months cause further discomfort. Inpatients do not receive end-of-life symptom management or receive it too late and tend to lack comfort-oriented care (Walling, Brown-Saltzman, Barry, Quan, & Wenger, 2008). As a result, many patients die with discomfort.

A critical question emerges for the nursing profession: How can nurses alleviate discomfort for dying patients and provide for a comfortable peaceful, death with dignity?

Fortunately, many healthcare organizations acknowledge the end-of life care challenge and are alert to the necessary quality of care, making efforts to offer it to dying patients, especially to patients with advanced cancer and their families. Curtiss, (2004) referred to one important organization, the American Nurses Association (ANA), whose goal statements attempt to measure the quality of care at the end of one's life by promoting comfort and relieving pain. In 1991, the ANA (as cited in Curtiss, 2004) stated that: ".... When the patient is in the terminal stage of life when cure or prolongation of life in individuals with serious health problems is no longer possible, the focus of nursing is on the individual's response to dying. Diagnosis and treatment then focuses on the promotion of comfort which becomes the primary goal of nursing care. ...." (p. 134)

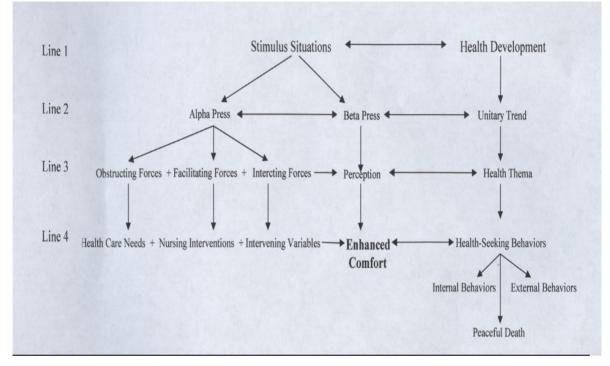
The ANA (as cited in Curtiss, 2004) also stated that comfort care is produced by "...maximizing comfort through adequate management of pain and discomfort as this is consistent with the expressed desires of the patient. ...." (p. 134). Later, Scanlon (1997, January 7) extends the ANA consensus statement and states that "Nurses have embraced the obligation to provide relief of suffering, comfort, companionship, and when possible, a death that is congruence with the dying person's wish" (p. 3). This goal exemplifies the ANA's belief that end-of-life care is essential to help patients, their families and friends find comfort in the experience of dying, an experience which is often more important than adhering to medical routines or correcting symptoms of physiological abnormalities. If the dying individuals are not as comfortable as possible, it means that quality end-of-life care has failed (Mills et al., 1994). Obviously, comfort is one of the most significant goals for improving the quality of end-of-life care. The National Cancer Institute (2005, September 30) also supports this goal to help cancer patients live every day to the fullest by providing them comfort and that hospice as a health care setting provides the necessary quality end-of-life care. Cancer patients also have a right to comfort care both during and after treatments. Advanced cancer patients who are dying need to receive comfort via *palliative care* (National Cancer Institute,

2005, September 30.), which is sometimes referred to as *comfort care* (Allegre, n.d.; LIFE Project, n.d.; Palliative Care, n.d.).

The term *Comfort* was mentioned in Nightingale's model of nursing and has been central to the nursing profession since the Nightingale era (Wills, 2007). Many nursing experts, such as Fleming et al. (1987), Hamilton (1989), and Kolcaba (1991), recognize the provision of comfort care as a principal nursing practice. In 1988, Kolcaba began to analyze the concept of comfort and publicly presented it in 1991 (Kolcaba, 1991, 2003). In 1994, she developed a Middle-Range (MR) nursing theory named "Comfort theory or Comfort care" (see Figures 3) (Kolcaba, 1994, 2003). Chapter one presented the various components of Kolcaba's Comfort theory. Kolcaba (2003) developed the Comfort theory by including *Personality*, focused on human needs developed by Murray ("Needs as Personality: Henry Murray", 2004, July 27), and (man's) health-seeking behaviors (HSBs) (or coping behaviors) (Schlotfeldt, 1975).

To better understand the Comfort Theory, the concepts applied from Murray's personality and motivation theory are explained. The theory of personality and motivation explains three types of human needs: "'Viscerogenic,' 'Psychogenic needs,' and 'Process needs'" ("Henry Murray-Personology," n.d., pp. 1-2). The viscerogenic needs are also called as "'Primary needs'" and the psychogenic needs is called as "'Secondary needs'" ("Needs as Personality: Henry Murray," 2004, July 27, p. 1). First, viscerogenic needs involve biological basics, elements internal to human beings, whereas psychogenic needs are stimulated by external stimuli or sources which are called the "'Press'" by Murray ("Henry Murray-Personology," n.d., p. 3). Lastly,

process needs are related to play, role, understanding, thinking, and creating ("Needs as Personality: Henry Murray," 2004, July 27). Focusing on the psychogenic needs of humans, the press or objects as stimuli in an environment is classified into "Alpha press"-characteristics of each stimulus-and "Beta press"-perception and evaluation of a human being to an individual stimulus or stimuli impacting him or her ("Henry Murray-Personology," n.d., p. 3). When patients are in a stressful health care situation as the total environment which has multiple stimuli, they, as human individuals, develop and accumulate impressions to determine whether the stimuli are positive or negative and whether their health behaviors produce failure or success. Hence, this development is repeated throughout an individual life and becomes a single pattern, which is called "'Unity themas'" ("Henry Murray-Personology," n.d., p. 3) and later "health thema" (Kolcaba, 2003, p. 80), which nurses and healthcare providers seek to promote for their patients. These themas enable patients to engage in healthseeking behaviors (HSBs). These concepts are illustrated in Lines 1, 2, and 3 (see Figure 3).



*Figure 3*. Comfort Theory Subtracted from the Theory of Human Press. Reprinted from *Comfort Theory and Practice* (p.15) by K. Kolcaba, 2003, New York: Tri-Graphic Printing Company. Copyright 2003 by Springer Publishing Company. Reprinted with permission.

Kolcaba (2003) bases her theory on the works of Murray and Schlotfeldt to further develop Comfort theory. Kolcaba (2003) defines the *alpha press* and classifies this as "obstructing forces"—health care needs or discomfort or comfort needs, "facilitating forces"—nursing intervention or comfort care, and interacting forces— "intervening variables" affecting the patient's perception of comfort in Line 4 (p. 65). The *beta press*, a person's perceptions and evaluation of any objects or stimuli from an individual environment, such as comfort care, is defined by Kolcaba as the patient's perception of enhanced comfort leading to reinforcement of habits and goals that are successful in reducing negative tensions and discomfort. These orient the health thema of "'need-integrated patterns'" in order to provide direction for future necessary actions promoted by nursing or other health care providers ("Henry Murray-Personology," n.d., p. 3). The HSBs were conceptualized by making clear internal behaviors, external behaviors, and a dignified peaceful death, as parts of the Comfort theory in Line 4 (see Figure 3).

Comfort theory refers comfort needs to three types of comfort: *relief*—the state of having a specific comfort need met; *ease*—the state of contentment, which may included disappearance of discomfort or ability to do another activity due to relieving discomfort; and *transcendence*—the state in which one can rise above problems or pain. Comfort needs encompass four contexts: the physical, psycho-spiritual, environmental, and socio-cultural contexts (Kolcaba, 2003, 2004; Kolcaba & DiMarco, 2005).

To attain comfort, Kolcaba (2003) proposes the taxonomic structure (TS) of comfort as a guide to assess discomfort of patients and design comfort interventions, that describe end-of-life patients responding to individual needs (see Figure 4).

|                 | Relief | Ease | Transcendence |
|-----------------|--------|------|---------------|
| Physical        |        |      |               |
| Psychospiritual |        |      |               |
| Environmental   |        |      |               |
| Sociocultural   |        |      |               |

*Figure 4.* Taxonomic structure of Comfort. Reprinted from *Comfort Theory andPractice* (p.15) by K. Kolcaba, 2003, New York: Tri-Graphic Printing Company.Copyright 2003 by Springer Publishing Company. Reprinted with permission.

Context in which comfort occurs is described as follows (Kolcaba, 2003, p. 13)

Physical—pertaining to bodily sensations, homeostatic mechanisms,

immune function, etc.

Psychospiritual—pertaining to internal awareness of self, including esteem, identity, sexuality, meaning in one's life, and one's understood relationship to a higher order or being.

- Environmental—pertaining to external background of the human experience (temperature, light, sound, odor, color, furniture, landscape, etc.)
- Socio-cultural--pertaining to interpersonal, family, and societal relationships (finances, teaching, health care personnel, etc.). Also to family traditions, rituals, and religious practices

Kolcaba and colleagues successfully applied the Comfort theory to various nursing areas and patient populations such as a perianesthesia (Krenzischek, Wilson, Newhouse, Manaril, & Kane, 2004; Wilson & Kolcaba, 2004), and pediatric nursing (Kolcaba & DiMarco, 2005). Interestingly, Comfort theory has been used in nursing care for end-of-life patients and can be found as the theoretical framework for several recent palliative care studies (Dowd, Kolcaba, & Steiner, 2006; Novak et al., 2001; Vendlinski & Kolcaba, 1997, November/December).

Vendlinski and Kolcaba (1997, November/December) used the comfort framework for a case study involving hospice nursing. This study applied the comfort care map, based on the taxonomic structure of comfort. The results revealed that the patients successfully achieved comfort and reflected the effectiveness of comfort care on nursing practice.

Novak et al. (2001) tested the psychometric properties of three tools. The first two tools were the Hospice Comfort Questionnaire (HCQ) (Patient) and the Hospice Comfort Questionnaire (HCQ) (Caregiver), developed from the original General Comfort Questionnaire (GCQ) of Kolcaba (1992, September). The first two were designed as four-item and six-item Likert scales. The third one was the Visual Analog Scales (VASs) which had four lines to measure the overview of comfort care. All instruments were tested for concurrent validity. In this study, the VASs also had two designs (the vertical and horizontal lines). The different formats of these tools were compared to determine which one was better to measure comfort during end-of-life. Thus, this study was divided into two phases (I and II). The six-item Likert scale and vertical-line VASs were used in the phase I, while the four-item Likert scale and horizontal-line VASs were used in the phase II. Although preliminary statistical results from 36 dyads of patients and their families demonstrated the power of .8, the moderate correlation (r) = .45 at the significant level of .05, to allow compensating incomplete or excluded subjects, 52 dyads for phase 1 and 51 dyads for phase 2 were recruited. Consequently, the final sample size of this study was 38 dyads for the analysis. The findings demonstrated that the three instruments had good psychometric properties for evaluating comfort care as experienced by end-of-life patients and their caregivers. However, the six-item Likert scale questionnaire and the vertical-line VASs had better psychometric properties than the other ones (the four-item Likert scale of the HCQ (Patient) and the horizontal-line VASs).

The Healing Touch Comfort Questionnaire (HTCQ) was developed from the GCQ by Dowd et al. (2006) and based on the GCQ of Kolcaba (1992, September). This instrument consists of 35 items and six levels of agreement (disagreement = 1 to strongly agreement = 6). Content validity was tested by seven Healing Touch (HT) experts and the researchers. The purpose of this study aimed to examine internal consistency reliability of the HTCQ and the correlation between the number of HT sessions and comfort levels. Fifty six convenient subjects received the HT therapy for problems such as pain relief, stress reduction, low energy and depression, and cancer. Although the preliminary analysis showed that statistical power for 36 subjects was .8, the moderate correlation ( $r \ge .45$ ), with a two- tailed *t*-test at a significance level of .05, 100 clients who received and were familiar to the HT were approached by the

practitioners. However, as there were some incomplete-questionnaire packets, the total sample size was 56. Healing touch data were classified into 1 to 4 sessions and 5 or more sessions. The result of this study showed that the HTCQ had strong internal consistency reliability (r = .94, p = .05) although two items had a low correlation with the total scale. Furthermore, the number of HT sessions and increasing levels of comfort were positively correlated. The group with 1 to 4 sessions of the HT had lesser levels of comfort than did the group receiving 5 or more sessions (p = .037, statistically accepted).

Some experts in nursing, such as Cameron (1993), Fleming et al. (1987), Hamilton (1989), and Morse et al. (1994), tried to use scientific methods to better understand and describe the meaning of comfort as determined periodically. All of them have recognized the importance of comfort or comfort care in nursing as a fundamental aspect of nursing practice.

Fleming et al. (1987) recognized comfort as the primary nursing concern in providing care for patients with advanced cancer, shifting the nursing focus from cure to palliation. At that time, comfort needs of patients with advanced cancer were not identified and clarified. To independently and accurately reflect comfort needs as perceived by nursing staff, the researchers studied this issue via a self-report survey---Patient Care Needs Survey Questionnaire which was developed by Calvary Hospital's Inpatient Services nursing staff. This questionnaire focused on asking nurses what they did to provide comfort for advanced cancer patients and how frequently they performed that task. This approach emphasized care as a means to reduce physical and emotional suffering as well as interaction with patients as a necessity to achieve this goal. The purposively selected subjects were 93 nursing professionals and 192 paraprofessionals (Cancer Care technicians) working for the Calvary hospital. The response rate was 50% (N = 145, 30 from professional nurses and 115 from paraprofessional staff). Findings revealed seven categories of comfort needs of patients with advanced cancer: (a) physiological aspect-normal activities of daily living, (b) spiritual aspect-activities involving religious or faith beliefs of patients, (c) psychosocial aspect-emotional care for patients, (d) patients' rights and dignity-activities enhancing the patient's sense of an individual human being, (e) reducing severity of illness—activities minimizing symptoms and suffering, (f) families/friends—activities providing emotional support for patients' families or friends, and (g) multidisciplinary team-team of care which consisted of specialists from other disciplines. These findings demonstrated that professional nurses provided comfort care to a greater extent and with more frequency than that provided by the paraprofessional staff. In summary, all identified comfort needs were deemed necessary and valuable for nursing care of patients with advanced cancer.

Hamilton (1989) conducted a descriptive qualitative study to explore definitions of comfort and factors that contributed to comfort, detracted from comfort, and made the hospitalized older adult with chronic illness more comfortable. Thirty participants whose ages were over 65 were recruited from a 284-bed chronic geriatric hospital in Hamilton, Ontario, Canada, for this study. They were interviewed via Hamilton Comfort Interview Guide consisting of four questions. Five main themes emerged from the data: disease process, self-esteem, position, approach and attitudes of staff, and hospital life. First, comfort need was identified in the disease process producing pain and bowel malfunction as well as disability. Quality of pain management, with medication, and maintaining adequate bowel function helped patients remain comfortable. Second, comfort meant that patients were independent, could make independent decisions, felt relaxed, and reported faith in God. These perceptions promoted patient's self-esteem. Third, therapeutic body positioning or positions as requested by patients led to more comfort. Fourth, friendly, caring, nice staff and good patient-staff relations comforted patients. Conversely, waiting for nurses to respond to a patient's calls and requests detracted from his or her sense of comfort. Researchers also found that hospital environments that were home-like provided more comfort for patients. To help patients achieve comfort, nurses educated patients about the meaning of comfort and provided it to individual patients when requested.

Cameron (1993) studied the nature of comfort in 10 hospitalized medical patients on medical and surgical units in a large teaching hospital in a metropolitan area of Canada. Grounded theory was conducted to answer the research questions. Researchers wanted to better understand what the nature of comfort was, how patients described comfort, and what were the outcomes of comfort as experienced by patients. Findings demonstrated that comfort was an active and dynamic process called "integrative balancing process," consisting of "monitoring," "networking," and "enduring" (p. 426). The process started with *monitoring* internal and external environments and providing information useful for processing or acting the process. The *networking* formed the social structure to help patients meet their own need. Last, the *enduring* was a complicated performance developed by patient's thoughts, feelings, and actions, such as patient's suffering, waiting, grieving, or hoping. Within the hospital environment, patients felt discomfort engendered by the life threatening situation they were facing. The integrative balancing process helped these patients reduce the disequilibrium associated with discomfort. At the same time, this process enabled them to increase their personal comfort levels and progress along the comfort continuum (Cameron, 1993).

Morse et al. (1994) used phenomenological methodology to explore the everyday experience of comfort in patients, with their enriched narratives, who experienced symptoms, such as pain and discomfort, and traumatic injuries or lifethreatening illnesses. Nine themes emerged and focused on the body which reflected states of discomfort, including how to achieve comfort. Morse et al. (1994) named these themes as the "dis-eased body," "disobedient body," "vulnerable body," "violate body," "enduring body," "resigned body," "deceiving body," "betraying body," and "betraying mind" (pp. 190-193).

Beginning with the theme of *dis-eased body*, patients looked for their symptoms to know the pattern of dis-ease. They would achieve comfort if they received information about diagnosis, treatment, and caring. Second, the *disobedient body* involved changing the relationship of patients' bodies as well as its degree. Comfort occurred when accepting the assessed degree, such as a degree of disability, and by taking charge and learning to control the situation to return to independence. Third,

when the sickness became exaggerated, the feeling of the *vulnerable body* happened. These patients needed protection, encouragement, buffering, and advocacy from nurses or other care providers to increase secure, safe, and trustful feeling. As a result, they felt more comfortable. Fourth, the violate body included the feelings experienced by patients (i.e., embarrassment, anger, and so on) when their bodies were invaded by treatments or opened to public examination. Nurses helped patients rid themselves of the negative experiences and provided patients with security and safety. Fifth, the enduring body or being with intolerable discomfort made patients need more energy and strength to endure, fostering hope for the future. Often, sickness led to a patient body that was in a limited state described by researchers as the *resigned body*. Helping patients accept, learn, and adapt to life with new limitations was found to comfort them. The patients who were distrustful in their bodies when their diseases continuously progressed and undetected coined the term for their condition the *deceiving body*. Reassurance helped patients' comfort needs. *The betraying body* was defined as body symptoms resulting from unresolved stress of patients and was expressed through coping. To comfort these patients, nurses needed to learn and observe the subtle signs of stress, understand their meanings, and provide the appropriate care. The betraying mind was the final categorized theme. It referred to a poorly controlled mind, which performed in unaccustomed ways. The illness impacted individual patient's minds and interfered with the harmonious, social world and/or the ability to function physically (i.e., feeling frail, hypersensitivity of something, lacking coordination, and feeling

unrealistic hopelessness). To comfort patients, nurses, religious supporters, and patient's loved ones collaborated to support the patient's being more comfortable.

Furthermore, Morse et al. (1994) summarized the disruption caused by the nature of illness invading each patient's body and becoming sick. The persons who were sick without comfort searched for ways to relieve their discomfort. If they did not enhance comfort or cannot tolerate discomfort, they became more distressed as a result of their suffering. In summary, finding innovative ways to assess discomfort and provide comfort care tailored to individual patient's needs was a challenging task for nurses.

Recently, Evans and Hallett (2007) studied the meaning of comfort care as described by nurses. Fifteen nurses working in hospice in North West of England were purposively sampled for this study. The study participants responded to questions addressing how these nurses pursued comfort care in the hospice setting and what it meant to provide hospice patients with comfort care. A phenomenological approach and the semi-structured interview guide were used for this study. Findings revealed three main themes: comfort and relief, peace and ease, and spiritual and meaning. First, focusing on comfort and relief, the researchers explained that patients often suffered from symptoms of bodily malfunctioning which brought a myriad of discomforts. Among dying patients, pain became a big health problem. Providing comfort care was insufficient for the dying patients. A sense of rest, ease, and peace would occur if pain or patho-physiological symptoms were relieved. In addition, the findings revealed that spiritual comfort was important and associated with relief of emotional and spiritual suffering which dying patients expressed in various ways (i.e., fear of beginning to die). The researchers called these distresses soul pain.

A comfort care study that reflects the importance of end-of-life comfort in general hospital care was done by Bascom (1997, March/April). The author described the clinical activities of the comfort care team in the Oregon Health Sciences University (OHSU), Center of Ethics in Health Care. This comfort care team consisted of a physician, nurse, pharmacist, social worker, and chaplain. It was established in 1994 to make hospice-like care available for patients not served by the current hospice model. It started providing consultation for any patients with serious illness (both terminal and non-terminal ill patients). This researcher found many American patients were admitted to hospitals or academic medical centers, where they were aggressively treated. Most physicians still lacked skills of hospice care and had fewer chances to transition from curative treatments to palliative and hospice care. The findings showed that this team was requested for 67 consultations for comfort care. Comfort care needs addressed during these consultations involved pain, psychosocial concerns, decision making at the end of life, and other symptoms (dyspnea, nausea, and so on). Based on the findings, the author reported that the OHSU Comfort Care Team could benefit the hospice-like care, focusing on comfort care, for seriously ill patients in the hospital. Likewise, Quill and Meier (2006) documented that comfort was one of four important needs of patients receiving palliative consultation (achieving relief and comfort, improving quality and meaning, altering the course of illness, and preparing for dying).

Beyond the study of the meaning of comfort care, especially for end-of-life patients, there are some research results that demonstrate comfort is one of nursing indicators of improving the quality of end-of-life care. For example, Steinhauser et al. (2000) surveyed 1,885 purposively sampled participants (with a 77% response rate) to assess factors at the end of life. Beyond the six categories cited previously in the overview of end-of-life care, these researchers additionally considered and established the top ten factors most important at the end of life. These factors were being kept clean (99%), naming a decision maker (98%), having a nurse with whom one feels comfortable (97%), knowing what to expect about one's physical condition (96%), having someone who will listen (95%), maintaining one's dignity (95%), trusting one's physician (94%), having one's financial affairs in order (94%), being free of pain (93%), and maintaining a sense of humor (93%). Obviously, comfort is the third most important factors of dying patients' needs.

Lastly, Ryan (2005) supported the thesis that comfort, quality of life, and faith and hope of older patients suffering from advanced cancer would be promoted by genuine caring, compassionate honesty, caring gestures, effective communication, acknowledging patients by name and remembering, listening to the losses, and finally providing relationship support.

## **Summary**

This literature review indicates that comfort, comfort care, and the comfort framework are not only important for nursing practice but have been also verified by several qualitative and/or quantitative studies. Comfort care is an effective holistic care approach for patients at the end-of-life. Populations benefiting from this framework and clinical knowledge include hospice patients, older patients, and patients with advanced cancer. Furthermore, comfort is a strong nursing sensitive outcome to evaluate or improve the quality of care, especially end-of-life care. Unfortunately, most studies are conducted outside Thailand, such as the United States, the United Kingdom, and Australia. Thailand has just begun to recognize and improve the quality of care for patients at the end of life. This framework for comfort care and end-of-life care instituted through the Thai health care system needs to be studied for its utility and efficacy in improving quality of care at the end-of-life.

Although end-of-life care with respect to comfort has been established for many years throughout developed countries, Thailand only recently introduced this concept to the health care system. Hence, end-of-life care in Thailand is in its initial stage of formation. The knowledge of end-of-life care with respect to comfort in Thailand is limited and insufficient to provide guidance to improve the quality of end-of-life care. The proposed study focuses on Thai older patients with advanced cancer and will be a significant contribution for health care professionals as well as nursing professionals. To effectively improve the quality of the end-of-life care, such research needs to be conducted to provide the preliminary knowledge of end-of-life care with respect to comfort pertinent to the needs of Thai older patients with advanced cancer.

The current study will attempt to fill gaps in the knowledge base encompassing existing end-of-life care with respect to comfort and the patients' preferences about it. This knowledge will be a basis upon which an attempt to improve the quality of care can be structured. The findings derived from this study are useful not only for clinical practice with Thai older patients who have advanced cancer, but also for the development of future education, research, and healthcare policies of Thailand.

## **CHAPTER III**

#### METHODOLOGY

In this chapter, the methodology employed for the study is described. The chapter consists of five major divisions: (a) study design, (b) setting and participants, (c) procedure for data collection, (d) method of data analysis, and (e) summary.

#### Purpose

The purpose of this proposed study was to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medicaluniversity hospital in Thailand. The study was designed to use both quantitative and qualitative designs.

#### **Research Question**

What is comfort as experienced by Thai older patients with advanced cancer who are receiving care in an academic medical-university hospital in Thailand?

## **Study Design**

The purpose of this proposed study was to explore and describe comfort as experienced by 100 older patients with advanced cancer in an academic medicaluniversity hospital in Thailand (as the preliminary sample size allowing 20 participants for the qualitative study). This sample size was determined by the power of .88 and medium effect size ( $f^2 = .099$  and  $r^2 = .09$ ) at the alpha level of .05 (Cohen, 1988). The current research focused on older advanced cancer patients who were hospitalized in an academic medical-university hospital in Thailand that recently adopted palliative and end-of-life care. The healthcare system of Thailand, including this hospital, has been experiencing a significant increase in the number of older adults who are at higher risk for illness, especially cancer, and suffer from distressing symptoms produced by the cancer itself, the treatment, and the illness. Because end-of-life care for older patients with advanced cancer is in its initial development stage, there are only limited relevant studies. To obtain a sufficient information or knowledge base to improve the quality of this care, it was important to accurately study these subjects in depth and breadth. Therefore, one type of triangulation research at the level of design, called "betweenmethod triangulation" (Speziale & Carpenter, 2007, p. 384), was utilized to better ensure the confirmation and completeness of the data (Patton, 2002; Speziale & Carpenter, 2007). This triangulation employed a quantitative method—the survey descriptive method done via the Hospice Comfort Questionnaire (HCQ) (Patient) and Verbal Rating Scales (VRSs)--as the core component. With a simultaneous qualitative supplementary component, a descriptive-qualitative method was served via Semi-Structured Interview Guide (Munhall, 2007). A purposive sampling method was used for this research (N = 100). In this simultaneous triangulation, the qualitative sample was a subset of the larger quantitative sample (Speziale & Carpenter, 2007). That is, every fifth participant was invited to participate in the qualitative phase (N = 20).

Theoretically and scientifically, the between-method triangulation approach was selected to improve the validity, confidence, and creditability of the findings from the study (Halcomb & Sharon, 2005; Speziale & Carpenter, 2007). Use of this method created a more accurate description of the phenomenon of comfort during initial end-of-life care (Speziale & Carpenter, 2007).

In summary, the information and knowledge gained from this preliminary research significantly added to what we know about the concept of comfort as defined by Thai older patients with advanced cancer or at the end-of-life. These findings should form a basis for further improving the quality of end-of-life care and the palliative care system in Thailand, especially for those older adults with advanced cancer.

#### **Setting and Subjects**

## Setting

The study was conducted in a healthcare setting in Thailand, in an academic medical-university hospital owned by the Thai government. This hospital has 80 units and consists of 1,800 beds for inpatient services, especially patients from the north of Thailand, who were referred from another setting and who need more complex treatments. Presently, to maintain the quality of care, the administration tries to control the number of patients. Thus, based on the statistically updated data during January and September 2007, the actual average of inpatients was 1,086 cases per day, and of new inpatients, 127 cases per day, or 162 cases per weekday and 53 cases per weekend. In 2006, neoplasms comprised the first of ten diagnoses of inpatients and became the third ranking cause of deaths, causing approximately 14.29% of all deaths (Medical Records and Statistics Department, 2006). In addition, it reported that this hospital had patients who were admitted with cancer about 3,677 cases in 2007 and 3,645 cases in 2008. Therefore, this setting has developed a palliative care service for cancer and dying patients.

Specifically, the nursing department in this hospital has established palliative and end-of-life care as holistic care by setting up a palliative care committee whose members volunteer on every ward to support the project and provide palliative care as a model or mentor for their individual wards. This committee supports and provides expertise on palliative and end-of-life care and encourages the exchange of palliative care experiences between nurses inside and outside of the hospital. At this hospital, nursing care focuses on comfort or comfort care as the traditional form of standard nursing care. This philosophy of nursing care is currently prevalent, which is realized and provided for all admitted patients, including older patients with advanced cancer towards the end of their lives. This care, encompassing physical and personal care provided by assigned nurses, is based on basic principles of palliative care in order to realize and express concern. Its goal is to provide comfort and psychological, social, and spiritual care by a member of the palliative care team for each ward. It includes coordination with monks to arrange for religious activities, such as spiritual consultation, and offers the chance for patients to engage in religious ceremonies in the hospital. Fortunately, the administrative physicians recently created a formal palliative care team, which establishes the palliative care system and collaborates with the nurses to provide palliative care service by way of multidisciplinary clinical teams. This is a significant component in the quest for quality palliative or end-of-life care (Imhof, Kaskie, & Wyatt, 2007, June; Rice & Betcher, 2007).

In this study, there were approximately 21 wards, (eight medical wards, six surgical wards, two orthopedic wards, two ear-nose-throat wards, one gynecological

ward, and two specific wards (only for patients receiving radiotherapy as well as monk patients). These two wards are arranged to provide palliative care for older patients with advanced cancer. The number and names of these wards may be changed because this hospital is developing some wards to provide palliative or end-of-life care particular to dying patients.

## **Subjects**

Purposive sampling was conducted to obtain 100 participants for this study. To be included in the present research, the participants had to be diagnosed with advanced cancer by a primary doctor and their diseases were not responsive to any curative treatment. Prospective participants were preliminarily assessed by the ward nurses (RNs) via a Palliative Performance Scale version 2 (PPSv2) modified to replace the old one--Palliative Performance Scale (PPS) which was developed by Anderson, Downing, Hill, Casorso, and Lerch, 1996. This tool was currently used routinely in the setting of this study to assess their palliative care need and to estimate their anticipated length of survival. The PPSv2 had to be validated repeatedly by the researcher. Conceptually, the patients were determined to not be able to survive longer than six months if the PPSv2 score was equal or less than 60% (Lau, Downing, Lesperance, Show, & Kuziemsky, 2006). This was the criterion score for this study. Moreover, additional inclusion criteria consisted of the following:

- 1. Age 60 or older, with a diagnosis of advanced cancer,
- 2. Admitted to the hospital for at least one week and within four weeks of enrollment—the best period for clinically significant effect of healthcare

intervention at the end of life (Tang & McCorkle, 2002),

- 3. Willingness to participate in the study,
- 4. Lucidity and ability to communicate using the Thai language, and
- 5. Adequate physical capacity to participate in the study, determined by the patients themselves.

The estimated number of sample size for quantitative phase was 100, which provides the value of statistical power equal to .88, based on the medium effect size  $(f^2 = .099 \text{ and } r^2 = .09)$  at the alpha level of .05 (Cohen, 1988). The number for the sample size of the qualitative phase was a subset of the number of the sample size of quantitative study. That is, every fifth subject in the quantitative study (N = 20) was invited to be part of the qualitative component of the study to be interviewed.

#### Instruments

As this study assigned the six-month survival of a participant as one of its inclusion criteria and applied comfort theory as the orientation framework, four instruments as well as open-ended questions based on comfort care and end-of-life care were used in this study. These were: (a) Palliative Performance Scale version 2 (PPSv2) (Appendix A), (b) Demographic Data Form (DDF) (Appendix B), (c) Hospice Comfort Questionnaire (patient) (Appendix C), (d) Verbal Rating Scale (VRSs) (Appendix D), and (e) Semi-Structured Interview Guide consisting of five open-ended questions with probes (Appendix E).

#### **Palliative Performance Scale Version 2 (PPSv2)**

The PPSv2 tool (Appendix A) was used to assess the prognosis of individual participants in the study, showing that he or she would die within the following six months. The PPSv2 tool is a popular prognostic tool for estimating survival times of patients with life-limiting illness or at the end of life in a palliative care unit (Lau et al., 2006). It focuses on assessing the changing functional status of palliative care patients. This scale was developed by Anderson et al. (1996) and was adapted from the Karnofsky Performance Scale's functional dimensions of ambulation, activity level and evidence of disease (Karnofski, Abelmann, Craver, & Burchenal, 1948), adding self-care, oral intake, and level of consciousness. The information used for this assessment was collected from the medical record.

PPSv2 scores are determined by reading horizontally and downwards at each level (10% deductions from 100%), by starting in the left column first. Congruently, the investigator looks at the description of the ambulation level, which is most appropriate for the individual patient status to find a best fit level. It cannot be measured for a half-fit value (such as 45%). The scores range from 0% = death to 100% = full ambulation or normal status. This tool was tested by Lau et al. (2006). The findings revealed that it was a strong predictor of survival in patients who needed palliative care, both significantly and statistically; and, additionally, it was found that 94-99% of patients whose PPSv2 scores are 60% or less were predicted to have a median survival of approximately six months. Thus, a score of 60% or less on the PPSv2 was used as the criterion for eligibility.

Later, Ho, Lau, Downing, and Lesperance (2008, August 4) tested the reliability and validity of the PPSv2 tool. For the reliability testing, fifty-three administrators and senior clinicians of palliative care institutes in Canada and USA were invited and participated in a web-based scenarios study in which 22 histories of palliative care patients were presented into two equal groups randomly (11 cases per group). The cases in each group were presented in a random order, but not the same among the participants. These administrators and senior clinicians (n = 28 for the group 1 and n = 25 for the group 2) reviewed 11 case histories and used the PPSv2 to score for these cases when they logged onto this web as the time-1 and did the same cases again two weeks later as the time-2). The PPSv2 scores of the group 1, 2, and the scores assessed by three physicians and three nurses (called as the Case Development Experts) who discussed face to face and finalized the case-PPSv2 scores were analyzed by the single rating intra-class correlation coefficient (ICC) to test the total variation of measurement (of the same objects by different raters). The finding showed that there were differences in the cases but not varied in the participants who used this tool and the tool was consistent (r = .96 approximately, p = .05). In addition, the Cohen's Kappa means was used to analyze the PPSv2 scores (between the time 1 and 2) for the rater reliability. The results showed 0.67 for the group 1 and 0.71 for the group 2, as satisfactory results. Hence, based on the finding, 67.6% of all PPSv2 scores measured from the participants and the Case Development Experts were the same.

For the validity testing, 15 physicians and nurses who had used the PPSv2 for two years were interviewed by the phones on five themes: PPSv2 as clinical assessment tool, impacts of PPSv2 scores on decision making, PPSv2 usefulness, problems in using PPSv2, and the adequacy of PPSv2 instruction. The finding demonstrated that the PPSv2 was standard and a valuable clinical assessment tool in palliative care, not needing to be modified.

Thus, the PPSv2 tool has had sufficient reliability and validity. It is effective for recruiting purposive participants for this study.

## **Demographic Data Form (DDF)**

The Demographic Data Form, including medical-record data, is a multidimensional socio-demographic survey developed by the researcher. It is an 18-item questionnaire consisting of the subject's age, gender, marital status, ethnicity/race, religion, educational level, employment, income per month, area of residence/address, relation between each participant and his or her caregivers, and current social support. It took about five or ten minutes to fill out this form (Appendix B).

## Hospice Comfort Questionnaire (HCQ) (Patient)

The HCQ (Patient) (Appendix C) was developed by Novak et al. (2001), being built on the theoretical definition of comfort of Kolcaba (2003). As each item is relevant to the content domain of comfort and end-of-life experiences, this instrument is used to specifically measure comfort care at the end of life, in regards to three comfort needs (relief, ease, and transcendence) in four contexts (physical, psychospiritual, environmental, and sociocultural aspects). It is based on the patient's reported comfort experience provided in the given healthcare setting. It consists of 49 items, and uses a six-item Likert scale questionnaire. Because there were no other measures available for comfort care to compare for external validity--the validity of the HCQ (Patient) was not able to be confidently generalized to a situation outside the researcher setting, the association between the HCQ (Patient) and the Visual Analog Scales (VASs) or the Total comfort lines (TC) was tested by the Spearman rho nonparametric measure because the data of the TC from the previous study were not a normal distribution. The finding showed the concurrent validity (one type of the criterion-related validity), by significant correlation (r = .45 for first administration and .48 for second administration, p = <.001) (DeVon et al., 2007; Novak et al., 2001; Siegle, n.d.). In addition, Novak et al. (2001) used the test-retest approach for testing the HCQ (Patient) reliability which has been performed (r = .98, p < .001). Thus, this measure has sufficient validity and reliability for the purpose of this study. In the current study, this questionnaire was filled out by all subjects. However, the researcher or research assistant was asked to assist to fill out the questionnaire for some individual patients if they requested help filling out the form. The answers or rating depended on the patient's determination. Approximately, each subject took about 20-85 minutes to complete this tool.

## Verbal Rating Scale (VRSs)

The VRSs (Appendix D) is a numerical scale which Dowd, Kolcaba, Steiner, and Fashinpaur (2007) developed to measure the Total Comfort Right Now. The Total Comfort Right Now was the outcome of a previous experimental study using: Healing Touch, Coaching, or Combined methods as interventions to reduce stress of the younger college students. This study was a creditable study because of the sufficient number of the sample size (N = 52), determined as power .8, moderate effect size, at the level significance of .10. As part of this study the researchers also examined general comfort by the Healing Touch Comfort Questionnaire (HTCQ) and stress by the Stress Test and the Stress Numeric Rating Scales. Simultaneously, the researchers of this study aimed to test the psychometric properties of the VRSs and the HTCQ—concurrent validity.

The VRSs has only one item with rating values addressed from 0 to 10. Each scale describes the level of comfort in brief. The 0, 5, and 10 values are defined as no comfort at all, moderate comfort, and highest comfort possible, respectively. In this study, the Total Comfort Right Now was measured by the VRSs before and after each intervention.

The HTCQ was generated by Dowd et al. (2006) from the General Comfort Questionnaire (GCQ) of Kolcaba (1992). Kolcaba (1992, 2003) verified that the GCQ possessed construct validity and was tested for its internal consistency of reliability, showing a Cronbach's alpha coefficient of .90, equal to .70 or more statistically accepted (DeVon et al., 2007). The HTCQ was tested for its content validity by seven HT experts and three nursing experts and showed a Cronbach's alpha coefficient of .95 (Dowd, 2006). The general comfort was measured by the HTCQ at three time points: before the first intervention as a baseline, immediately before the third intervention, and one week after completion of the treatment protocol.

In addition, the Stress Test, including the Stress Numeric Rating Scales, was used to measure the stress of the students. The Stress Test contained a checklist responding to how serious and how often symptoms were experienced; the Stress Numeric Rating Scales followed the same format of the VRSs. From this study's findings, both these tools correlated when averaged over three time points (r = .48, p = .001).

Regarding the results of comfort measured by the HTCQ, comfort was not significantly different at each time point among treatment groups, but it significantly improved at the 2<sup>nd</sup> and 3<sup>rd</sup> time point in each treatment group. Interestingly, the comfort of these students was significantly different between the treatment and the control group at the 2<sup>nd</sup> time point (F = 4.27, p = .01) and at the 3<sup>rd</sup> time point (F = 4.55, p = .00). These results showed that the stress levels of both time points were decreased. For the confirmation, the stress measured by the Stress Test was not different in the control group at all three time points. This showed the convergent validity of the HTCQ with the Stress Test (r = -.71, -.72, and -.56, p = .0001 at three time points, respectively).

Regarding the result of the VRSs examined by the pretest-posttest method, the Total Comfort Right Now of each three treatment groups also showed a significant increase between the pre-intervention and post-intervention (p = .0001). In addition, this tool demonstrated the concurrent validity when compared with the HTCQ, showing a high correlation (r = .74, p = .001) (Munro, 2005).

In summary, the VRSs has sufficient psychometric properties to measure comfort for the current study, showing concurrent validity and high sensitivity. In the current study, each participant took about five minutes to respond to the VRSs. It was projected that about 30 minutes would be spent by individual subjects to complete the HCQ (Patient) and VRSs in the quantitative phase. However, it actually took about 25-90 minutes for subjects to complete this phase of the study.

#### **Semi-Structured Interview Guide**

The qualitative portion of this study was addressed via a Semi-Structured Interview Guide that consists of five open-ended questions and examples of probes developed by the researcher based on the Comfort theory as theoretical orientation (Appendix E). This guide focused on four contexts (physical-physiological, psychospiritual, socio-cultural, and environmental aspects), and the concept of quality endof-life care. These questions encouraged participants to share and describe their experiences of comfort during end-of-life care. Two tape recorders were used for this process. Completion of the interviews took from 24 minutes to 48 minutes. The recorders were placed so that the participants controlled their function and discontinued their use if they wished. During the interview process, the researcher documented what was heard, seen, thought, or experienced as field notes (Speziale & Carpenter, 2007). These notes provided validation for important points during data analysis.

The HCQ (Patient), VRSs, and Semi-Structured Interview Guide were translated from English into the Thai language. To verify the translation, the translated tools were back translated and validated by two bilingual experts on cancer care and on end-of-life care. They were then reviewed by the comfort theorist, that was Kolcaba. Furthermore, they were tested for their reliability and validity by means of a pilot study based on at least 10% of full the sample suggested by Lombard, Snyder-Duch, & Bracken (2005). However, for this study, approximately 20 cases for comfort care questionnaires in order to allow five cases for the Semi-Structured Interview Guide were considered. Likewise, all the qualitative data later were transcribed and translated verbatim into English by the researcher. They were then back translated and validated by four nursing experts before data analysis and interpretation were conducted.

## **Protection of Human Subjects**

Prior to commencement of the study, approval was sought from (a) the Vice Provost and the Dean of Graduate Studies (VP/DGS), (b) the Committee for the Protection of Human Research Subjects, Catholic University of America, and (c) the Research Ethics Committee of the Faculty of Medicine, Chiang Mai University. In addition, all participants invited to serve in this study received a detailed explanation of the study and were asked to sign the Consent Form (Thai version) (Appendix K), allowing the researcher and research assistants (only for quantitative portion) to access and collect their medical records which are a part of demographic data. In addition, in Thailand the term of advanced cancer is sensitive to cultural difference in how diagnoses are communicated to patients. In this study, this term was replaced by the term of advanced diseases in the Consent Forms of both the quantitative and qualitative phases of this study.

The Consent Form is meant to assure that the risk for these participants is minimal. The anticipated time associated with participants was about 30 minutes for the processes of answering both questionnaires and 45 minutes for the interview which was recorded by two tape recorders. The collection of data actually took 20-85 minutes for the quantitative phase and 24-48 minutes for the qualitative phase. Throughout the process, these two recorders were placed where the participants could turn them off at any time. As the dying phenomenon is a sensitive issue, putting both participants and the researcher in this vulnerable situation, the researcher and research assistants had to pay attention to everything that produced fatigue or discomfort, especially for the participants. Each participant was informed that they could permanently or temporarily withdraw from this study at any time if she or he felt discomfort, without impacting their treatment and services. Thus, the appointments for approaching and conducting the study might require more than one meeting in some cases, which depended on the participants' existing conditions and preference.

Throughout this study, a code number was assigned to individual participants. The researcher kept patterned identifiers separate from the instruments used to collect data, in a locked file. The medical record data also were kept confidential. Finally, all recorded documents and audiotapes used will be shredded within or after five years.

#### **Procedure for Data Collection**

It was anticipated that the study would be conducted from April through July, 2009 (for four months). However, in fact, it took five months. The data were collected by the researcher and by research assistants. In the quantitative portion of the study, two registered nurses, who are members of the *Palliative Nursing Care Team* of this hospital and who were interested in this study, were invited and trained as research assistants, following the Program of Training Research Assistants (Appendix G) on how to administer standard questionnaires. The researcher and the research assistants also had to obtain the Certificate of Completion from the National Institutes of Health (NIH) Web-based training course *Protection Human research Participants*, as a formal human subject's research training before approaching the research subjects. These two research assistants helped collect data only for the quantitative portion of the research study.

After this study was approved by the Vice Provost and the Dean of Graduate Studies (VP/DGS), the Committee for the Protection of Human Research Subjects at the Catholic University of America, and Research Ethics Committee of the Faculty of Medicine, Chiang Mai University, the researcher approached the director of the Nursing Division, relevant nursing supervisors and the head nurses of each ward that serves older adults with advanced cancer to inform them of the purpose and design of the study, and to request collaboration. By the preliminary information, 21 wards were planned for the data collection. As cancer patients in four wards did not meet all inclusion criteria, there were 17 wards which were actually involved the study (six medical wards, four surgical wards, two orthopedic wards, two ear-nose-throat wards, one gynecological ward, and two specific wards [only for patients receiving radiotherapy as well as monk patients]).

One of the nursing administrators worked as a coordinator for access to the clinical areas but was not involved in the process of data collection. Registered nurses (RNs) in those wards, especially members of the Palliative Nursing Care Team selected the patients who were admitted in those wards and who met the inclusion criteria, including meeting the criterion scores of the PPSv2 (60% and less, assessed from the clinical and the medical-record information). They also provided these patients with the

letter--*Letter Invitation for Participating to the Research Study*--(Appendix J) to ask their permission for the researcher to approach them. To the interested patients in the study, the researcher and/or the research assistant introduced herself or himself to the potential participant, as well as his/her family, and invited him/her into the study. Every fifth participant was invited to participate in the qualitative phase of the study. Then, the researcher informed the prospective participant about the purpose and the process of this study, answered any question about the study, and explained how the protection for human subjects would be conducted. All participants completed the Consent Forms before the data collection began. A copy of the signed Consent Form was given to the participant. The researcher then applied the PPSv2 to assess the participant again.

The appropriate time and place for pursuing the study depended on the individual participants' decision. This step was conducted at the bedside or in the individual unit, if possible. The steps of collecting data started first by asking the participant for information required for the Demographic Data Form (DDF). The clinical characteristics were derived by accessing the medical record. Secondly, the self-report questionnaires (HCQ [Patient] and VRSs were conducted. The researcher and research assistant provided help if the participant requested help in this process. However, every answer was based on the individual participant's determination. Each participant took approximately 20-85 minutes to complete these two instruments. For every fifth case, if the patient agreed to continue, after they signed the Consent Form (Appendix L), the interview for the qualitative portion of the study was done, during which the researcher interviewed the patient based on the Semi-Structured

Interview Guide, consisting of five open-ended questions with probes. The interview was tape-recorded and the interview took between 24-85 minutes to complete.

To consider and follow all ethical concerns, only the researcher and two research assistants had knowledge of the participants' identities. A coding approach and pseudonyms were used for the data collection and reporting of the findings, respectively, in order to protect their confidentiality. The process of the patientresearcher relationship during data collection was sincere and respectful. As the dying process is a sensitive issue, both participants and researchers found themselves in a vulnerable situation. The researcher had to pay attention to everything that produced discomfort, especially for the participants. Each participant could permanently or temporarily withdraw from this study without any repercussions at any time if she or he felt uncomfortable. Thus, the appointments for approaching and conducting the study might take more than one meeting; that depended on the individual participants' existing condition and preference.

#### Method of Data Analysis

#### **Data analysis**

As this study was a between-method triangulation, consisting of both quantitative and qualitative methods, a statistical approach was used for quantitative data analysis, including demographic data, and content analysis was used for the qualitative data.

#### **Quantitative Data Analysis.**

- 1. Internal consistency of the study instruments the PPSv2 and HCQ (Patient) were tested by using Cronbach's alpha coefficient.
- 2. Descriptive statistics (frequencies, percentages, and means) were used to analyze the demographic data and the scores of the HCQ (patient) and VRSs.
- 3. A correlational techniques (Pearson Correlation, including Kendall's tau\_b and Spearman's rho) were used to compute the data on the experience of comfort during end-of-life care derived from the HCQ (patient) and from VRSs data. This approach examined the relationships between comfort scores from these two measures to determine whether or not they demonstrated the concurrent validity, able to reflect end-of-life comfort phenomenon exactly.

To respond to these objectives, all quantitative data were analyzed by the statistical package for the social sciences (SPSS) version 17.

## **Qualitative Data Analysis.**

Data from the Semi-Structured Interview Guide, which consisted of five openended questions with probes, were analyzed via content analysis. Content analysis is a research method that analyzes a text by counting words or extracting objective content to examine themes and their patterns, called "core meanings" (Patton, 2002, p. 453); these core meanings appear or are latent in the manifest content through the systematic classification of coding (Zhang, 2006). The process of content analysis consists of two main methods: conceptual analysis and rational analysis (Busch et al., 2005). It can be segmented into seven steps (Busch et al., 2005; Zhang, 2006).

#### Steps of Content Analysis.

Step 1: Interview transcription

To implement the process of content analysis, conceptual analysis was used. In this step, the researcher listened to the information revealed by the tapes or model participants' information relating to their comfort care experience; the researcher then transcribed the information provided and read these verbatim texts several times to obtain an initial understanding of the text. Prior to the next step, all these verbatim texts were translated from Thai into English by the researcher. They were back translated and validated by four bilingual nursing experts.

Step 2: Coding units

During the reading of the texts, the keywords for each paragraph were written down in the right margin to set levels of coding or to generate preliminary codes—a single word or set of words. Commonly, the messages were unitized into six coding units (word, concept, sentence, paragraph, whole text, and theme, or a combination of these). In this study, the thematic units were focused.

Step 3: Developing categories and coding schemes

As this study aimed to describe the process of end-of-life nursing care based on comfort care, the categories and coding schemes were derived from the data themselves, previous related studies, and comfort theory as the theoretical orientation for this study (Krippendorff, 2004). In this step, the constant comparison technique was important and was used to stimulate thoughts and make differences between apparent categories for the consistency (Zhang, 2006). The number of times a code appeared or also referred to as word frequency count yielded categories reflecting those concepts and themes that emerged.

Step 4: Developing rules or criteria

The step of developing rules or criteria for coding the texts derived to maintain consistency and coherence is also of importance. These criteria are created as a tool, or "instruction dictionary" or codebook, to calculate the indices later (Zhang, 2006, p. 3). The codebook consists of categories, names, definitions, and rules of codes as well as examples and additional field notes (Zhang, 2006). These field notes helped to validate the data by providing additionally important points of information. In addition, this step considers how the researcher will deal with irrelevant information: he or she may ignore, reexamine, or alter the coding. Then, the criteria derived also needed to be tested —referred to as criterion testing—with a small number of data units randomly chosen as representatives of the sample. Although Johnson and LaMontagne (1993) suggest using 10-15% of the data units to be tested for inter-rater reliability, this study chose five units randomly for testing process (25% of all data units). Then, the Cohen's Kappa statistics (Stemler, 2001) was employed to calculate inter-coder or inter-rater reliability. In this study, there were two inter-raters because Lombard et al. (2005) suggested having at least two inter-raters for testing the reliability raters). If the consistency is low, it means that the coding rules need to be revised to strengthen intercoder agreement to close to 100 %, or perfect agreement. Exactly, the same rating for each object, or an identical conclusion is the goal, although the Cohen's Kappa alpha

coefficient of .80 or greater is considered acceptable for a well-developed psychosocial measurement instrument (Burns & Grove, 2005; Lombard et al., 2005; Stemler, 2001).

Step 5: Coding all texts

In this step, the coding rules were applied to code all the texts.

Step 6: Coding and categorizing each interview

After category preparation, the coding of the texts was done by hand.

Step 7: Analyzing patterns

In the final step, all data were systematically analyzed to identify the patterns of concepts or themes that emerged. Rational analysis was used to consider the relationships and meanings of those concepts and themes by exploring category properties and dimensions, identifying relationships between categories, uncovering patterns, and testing categories against the full range of data (Bradley, 1993). If there existed some information that should not be coded, the investigator stepped back to coding again, moving forward and backward, iteratively. Lastly, a conclusion regarding the findings was drawn. To obtain reliable results, content analysis required two coders to independently check and recheck codes, categories, concepts, and themes, again until they achieved homogeneity.

To respond to trustworthiness, all processes of content analysis were done rigorously with respect to *credibility, transferability, and dependability* (Bradley, 1993; Graneheim & Lundman, 2004; Zhang, 2006). *Credibility* refers to "the adequate representation of the constructions of the social world under study." (Bradley, 1993, p. 436), by working in a prolonged stay in the field, persistent observation, and/or triangulation (Bradley, 1993). The current study was designed on the triangulation method providing sufficient information of a real phenomenon-comfort as experienced by Thai older patients with advanced cancer in the hospital where palliative care was provided for them--with sufficient sample size determined on the power of .88 (p = .05). Importantly, the themes of the study were coded and categorized from the verbatim interview transcriptions, without bias in coding process by testing the inter-rater reliability. This rigor of the judgment and presenting findings with quotations provides the transferability. The last one is dependability—"the coherence of the internal process and the way the researcher accounts for changing conditions in the phenomena" (Bradley, 1993, p. 437). It also includes confirmability—"the extent to which the characteristics of the data, as posited by the researcher, can be confirmed by other who read or review the research results" (Bradley, 1993, p. 437). Both rigors were maintained by coding clearly and consistently as well as coding based on only the raw interview data and the researcher's field notes derived from a real phenomenon.

#### **Summary**

Thailand is a country experiencing a significant increase in the number in older adults who are at a higher risk of illness. Cancer is one of the most common diseases. Especially, advanced cancer threatens these older adults with an early death, and causes them to consider hastening their death. In addition, distressing symptoms caused by the advanced cancer itself and its illness produce sufferings encompassing physicalphysiological, psycho-spiritual, socio-cultural, and environmental aspects. The health problems of older adults with advanced cancer force Thai healthcare organizations, including the Thai government, to realize and be concerned about the need to improve the quality of care to enhance the comfort of older adults with advanced cancer, to relieve sufferings as much as possible at the end of life, and to strengthen them for a good death eventually. Thus, the purpose of this study was to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand. Its findings provide fundamental knowledge of existing end-of-life care and the optimal quality of care based on the preferences of Thai older patients with advanced cancer in breadth and depth. This knowledge will be useful as a guide to develop or improve the quality of the end-of-life care with respect to comfort in the light of the preferences and values of Thai older patients with advanced cancer, including other dying patients.

Based on the purpose of this study and limitation of knowledge of comfort care for older patients with advanced cancer due to being in the initial development of palliative care in Thailand, between-method triangulation was utilized to provide validated and confirmed findings. The PPSv2 helped to assess and determine the dying stage of older patients with advanced cancer. The HCQ (Patient) and VRSs were used to measure comfort experiences of these patients (quantitative phase). The Semi-Structured Interview Guide was employed to provide their comfort experiences in depth and breadth. Descriptive statistics of the SPSS version 17 analyzed the quantitative data whereas content analysis analyzed the qualitative data. Thus, this chapter describes the methodology of this study. It consists of five major divisions: (a) study design, (b) setting and participants, (c) procedure for data collection, (d) method of data analysis, and (e) summary.

## **CHAPTER IV**

#### **PRESENTATION OF FINDINGS**

This chapter presents the results of the study, the objective of which was to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand. Between-method triangulation (consisting of the quantitative and qualitative parts) was utilized to respond to the research question, *What is comfort as experienced by Thai older patients with advanced cancer who are receiving care in an academic medical-university hospital in Thailand?* This study was oriented by the Comfort theory developed by Kolcaba (2003). Consequently, there are two main presentations: descriptions of the quantitative and the qualitative findings.

For the quantitative phase, there were two research assistants who were key palliative-care nurses, one worked in the surgical nursing department and the other in the medical nursing department. The researcher approached and scheduled to train them for the certification of the *Completion of Protecting Human Research Participants*, as shown in Appendix G. However, because both these nurses had scheduling conflicts, it was too difficult to arrange for a two-day training program. Thus, it was arranged to provide the training on one day, lasting from 8:00 a.m. to 7:00 p.m. The two research assistants and four other nurses who were interested in palliative care and comfort care participated in the training session. The number was limited to seven persons because the training day took place on a weekend that was not convenient for other nurses.

arranged periodically. The research assistants started collecting only the quantitative data after they obtained the official certification for participant protection, and the research proposal was approved by the Research Ethics Committee of Faculty of Medicine, Chiang Mai University. In addition, the hospital director and the director of the Nursing Division approved access to the hospital setting.

The data and results of the quantitative study are presented according to the following outline: (a) pilot study (to test internal consistency of the Hospice Comfort Questionnaire [HCQ] [patient] and to test-retest the reliability of the Palliative Performance Scale version 2 [PPSv2]); (b) description of the demographic data: personal data and clinical characteristics; (c) description of the characteristics of the instruments (as they relate to PPSv2, HCQ [patient], and Verbal Rating Scale [VRSs] as well as the analyses to test the concurrent validity between the HCQ [patient] and VRSs); (d) description of comfort analysis and results; and (e) description of additional findings.

The qualitative presentation is divided into two parts: description of the demographic data (personal data and clinical characteristics) as well as description of qualitative data and results that focuses on the two main domains: descriptions of discomfort and comfort, as outlined by the Comfort Theory, as well as one additional domain. Based on the data related to discomfort, four categories emerged: *physical-physiological, psycho-spiritual, socio-cultural, and environmental discomfort.* Three types of comfort: *relief, ease, transcendence*, and a new category—*inadequate comfort-* - were established. The additional findings that emerged from this study are: *intervening* 

*variables* relating to discomfort and comfort, *nursing comfort care*, *nurses (including other healthcare personnel)*, *improvement for comfort care*, and *comparison between the hospital and the house* categories. Finally, a summary of the findings from both the quantitative and qualitative data is presented.

#### **Presentation of Quantitative Data and Results**

## **Pilot study**

Twenty participants were recruited for the pilot study to test the reliability (internal consistency) of the tool--the HCQ (Patient). However, twenty-three Thai older patients with advanced cancer who met the inclusion criteria were approached because one subject was too weak to complete the questionnaire and two were discharged from the hospital before they could participate. The data collection procedure was restricted to protect the human subjects. The average time to complete the questionnaire was 42.25 min ( $SD = \pm 14.91$ ). Cronbach's alpha coefficient of the HCQ (patient) of .885 was deemed acceptable based on Burns and Grove (2005). They reported that an instrument whose value of the coefficient alpha ranges from .8 to .9, thus slightly lower than 1, could reflect the fine discriminations on the construct levels. Supported by George and Mallery (2009); Nunnally (1978); and Schmitt (1996), a coefficient alpha reliability of .7 or higher is adequate to measure construct validity. This is especially true for the value of .8, which is considered a good value.

The PPSv2 was a one-item questionnaire that could not be computed for the internal consistency–coefficient alpha. However, there was PPSv2 data for each participant, recorded by both the researcher and the ward nurses (recorded in the patient

chart). Therefore, based on the concept of stability-test-retest reliability, the correlation coefficient was used to analyze and to test the correlation between both the PPSv2 scores. The findings disclosed that they were not correlated, which became an issue of concern. However, the correlation coefficient of the PPSv2 tool needed to be tested again for the full study.

In addition, the scores of the VRSs were tested with the scores of the HCQ (Patient) for the correlation coefficient. For the creditable finding, two sets of the scores were explored. The results revealed that the skewness of the HCQ (Patient) (= -.582)and of the VRSs (= -.024) were not seriously irregular. This can be explained by referring to Nunnally's (1978) statement that whenever the correlation of two continuous variables continues to show the same shape--here both data sets had negative skewness, their means being less than the median--do not seriously violate the assumptions, such as the J shape. This position is based on the concept of the productmoment (PM) correlation, and there would not be great damage to its PM coefficient (r). This means that the nonlinearity correlation could be employed without affecting the interpretation of the results. Similarly, Glass and Stanley (1970), regarding the interpretation of the correlation coefficients  $(r_{xy})$ , stated that there were not any important assumptions, except in the case where the frequency distributions of two variables demonstrated their skewness with different directions. Thus, the scores of the HCQ (patient) and VRSs were further analyzed. The findings showed that both correlated significantly with three methods (see Table 1), showing a moderate relationship that is satisfactory for a human behavior study (Munro, 2005).

In summary, the results of the pilot study confirmed that all items of the HCQ (Patient) were internally consistent and showed acceptable coefficient alpha reliability. Both the HCQ (Patient) and the VRSs, being the main tools of the study, were concurrent and could conceptually and sufficiently measure comfort in Thai older patients with advanced cancer.

Table 1

|                         | HCQ (patient) (1-6) and VRSs (0-10)  |                 |  |
|-------------------------|--------------------------------------|-----------------|--|
| Statistical correlation | Correlation coefficient ( $N = 20$ ) | Sig. (2-tailed) |  |
| Pearson Correlation     | .641**                               | .002            |  |
| Kendall's tau_b         | .449                                 | .009            |  |
| Spearman's rho          | .598                                 | .005            |  |

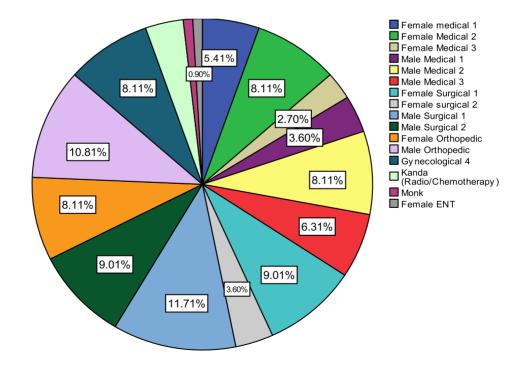
The Correlation Coefficients of the HCQ (Patient) and the VRSs

Note. \*\* Correlation is significant at the 0.01 level (2-tailed).

## **Description of Demographic Data (Quantitative Study)**

## **Personal Data**

Using purposive sampling technique and in order to obtain 20 participants for the qualitative study, the final sample involved 119 participants selected from 16 wards (see Figure 5). The number of wards was less than the amount originally planned because of the new arrangement of the hospital to admit cancer patients. Two wards of the medical department and two wards of the surgical department could not provide potential subjects that met the inclusion criteria of the study. In addition, in two earnose-throat wards, communication became difficult with the patients who underwent the tracheostomy procedure because they retained the tracheostomy tube, or had clinical deformity of their faces. As a result, only one patient was recruited from one of these ear-nose-throat wards. Throughout the progress of the study, eight subjects were excluded because of: being too weak to complete the questionnaires (two cases); being discharged before the appointments (two cases); refusing participation in the study after signing the informed consent form (two cases); and inability to rate the questionnaire (especially the items responded by the negative answers) (two cases). Thus, the final total for this study was 111 participants.



Names of wards

Figure 5. Frequency of the Older Thai Patients with Advanced Cancer from Each Ward

Derived from the demographic data of 111 participants (see Table 2), the participants included 52.3% males and 47.7% females. Their average age was 68 ( $SD = \pm 6.15$ ). Most of them (64.9%) were married and 24.3% were widowed. Almost all of them (98.2%) were Thais and Buddhists. Focusing on education, the participants were mostly primary school-educated (76.6%), with most of them only reading (Por 4-- equal to USA grade 4) (62.2%). The employment data showed that 42.3% of the participants were retired and 37.8% of them needed to stop working because of their illness. One of them was a monk.

Furthermore, the study revealed that the main financial resource of most participants was a subsidy of 500 Baht (about \$16, calculated on the currency rate 30 Baht per dollar) provided by the Thai governmental policy, the Universal Healthcare Coverage (UC) provided by National Health Security. Of these subjects, 29.7% of them received only the subsidy and 63.1% received the subsidy as well as from another resource, such as the patient's relatives (e.g., the wife, son, nephews, etc.), a former employer's pension, or an income from the patient's occupation, such as the trade of selling groceries, production or craft jobs, and working in the rice farm and garden. For the monk (0.9%), he was financially supported from the Hospital Foundation for Monks. When looking at the amount of money received per month, not including the subsidies (see Figure 6), the study found that the participants received monthly about 2,001-5,000 Baht (about \$66-166) (18%) and 1,001-2,000 Baht (about \$33-166) (15.3%). Importantly, the findings also showed that 28.8% of the participants did not receive any money, and 14.4% could not exactly indicate the amount of their monthly money. The financial support for the hospital costs of these participants was mostly provided by the subsidy called the "Universal Health Card or Gold Card" where patients do not pay anything except 30 Baht at the beginning of each admission ("The Universal Coverage Policy of Thailand: An Introduction," n.d., p. 7). This subsidy was funded by the Universal Healthcare Coverage (UC) of the Thai Government (82.9%) or paid by the Thai governmental health subsidy through fringe benefits provided to the patient's son or daughter if he or she is working as a governmental employee (see Table 2). Three subjects required the support of the Social-Work Division of the hospital because two of them were non-citizens, and one was in the process of applying for the Gold Card.

In addition, the findings demonstrated that most participants (63.1%) had their hometown in other provinces, away from the hospital location. Their caregivers mostly were their son(s) or daughter(s) (55.0%), or included a spouse (12.6%). As the study focused on regular wards, which had insufficient space and did not make it possible for relatives to be with the participants at all times, most family caregivers (87.4%) provided care only during visiting the participants during the hospital's visitation times.

In summary, the age of most participants for this study was between 60 and 64 years (M = 68 years,  $SD = \pm 6.15$ ). They mostly had little education and required financial or social support.

# Table 2

# Frequency and Mean of Demographic Characteristics of the Thai Older Patients with

| Variables                            | n                         | %    |
|--------------------------------------|---------------------------|------|
| Gender                               | 58                        | 52.3 |
| Male                                 | 53                        | 47.7 |
| Female                               | 55                        | +7.7 |
| Age (years)                          | $(M = 68, SD = \pm 6.15)$ |      |
| 60-64 years                          | 42                        | 37.8 |
| 65-69 years                          | 28                        | 25.2 |
| 70-74 years                          | 25                        | 22.5 |
| 75-79 years                          | 10                        | 9.0  |
| 80-84 years                          | 6                         | 5.4  |
| Marital status                       |                           |      |
| Single                               | 6                         | 5.4  |
| Married                              | 72                        | 64.9 |
| Widowed                              | 27                        | 24.3 |
| Separated                            | 1                         | .9   |
| Divorced                             | 5                         | 4.5  |
| Race                                 |                           |      |
|                                      | 109                       | 98.2 |
| Thai                                 | 1                         | .9   |
| Chinese<br>Others (non Thei sitizen) | 1                         | .9   |
| Others (non-Thai citizen)            |                           |      |
| Religion                             |                           |      |
| Buddhism                             | 109                       | 98.2 |
| Protestant                           | 1                         | .9   |
| Muslim                               | 1                         | .9   |

## Advanced Cancer

# Table 2 (continued)

# Frequency and Mean of Demographic Characteristics of the Thai Older Patients with

## Advanced Cancer

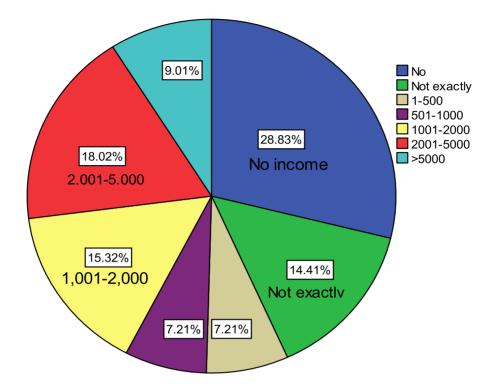
| Variables   | п    | %      |
|---|------|--------|
| Education level                                     |      |        |
|   | 16   | 14.4   |
| Not able to read and/or write                       | 1    | .9     |
| Able to read (without attaining educational system) | (17) | (15.3) |
| (Not educated)                                      | 85   | 76.6   |
| Elementary school<br>(Por 4 [=USA grade 4])         | (69) | (62.2) |
| Secondary school                                    | 7    | 6.3    |
| Undergraduate                                       | 2    | 1.8    |
|   |      |        |
| Employment  |      |        |
| Employed  | 1    | .9     |
| Unemployed  | 11   | 9.9    |
| Disabled (stopping working due to this illness)     | 42   | 37.8   |
| Retired   | 47   | 42.3   |
| Resign (stopping working due to other diseases)     | 9    | 8.1    |
| Monk  | 1    | .9     |
| ncome/Financial status                              |      |        |
| Income  | 3    | 2.7    |
| Subsidy of 500 Baht                                 | 33   | 29.7   |
| (Universal Healthcare Coverage [UC])                |      |        |
| Governmental pension                                | 1    | .9     |
| (The Civil Servants' Medical Benefit Plan)          | 1    | 0      |
| Sons and/or daughters                               | 1    | .9     |
| Governmental subsidy with other resources           | 70   | 63.1   |
| More than one resource                              | 2    | 1.8    |
| Hospital Foundation for Ill Monks                   | 1    | .9     |
| Hospital-cost support                               |      |        |
| Subsidy of 30 Baht/Gold Card                        | 92   | 82.9   |
| (Universal Healthcare Coverage [UC])                |      |        |
| Retirement pension                                  | 1    | .9     |
| (Civil Servant Medical Benefit Plan [CSMBS])        |      |        |

# Table 2 (continued)

Frequency and Mean of Demographic Characteristics of the Thai Older Patients with

| Advanced Cancer |  |
|-----------------|--|
|                 |  |

| Variables   | п   | %    |
|---|-----|------|
| Governmental health subsidy (The fringe benefit of the patient's son and daughter as a governmental employee) | 15  | 13.5 |
| Social-Work Division of the Hospital  | 3   | 2.7  |
| Area of residence   |     |      |
| CM province (the same province as the setting)  | 41  | 36.9 |
| Other provinces   | 70  | 63.1 |
| Caregiver   |     |      |
| Spouse  | 15  | 13.5 |
| Son(s) or/and daughter(s)   | 61  | 55.0 |
| Nephew(s)/niece(s)  | 9   | 8.1  |
| Spouse with son(s) and daughter(s)  | 14  | 12.6 |
| Relative(s) such as sister(s) or brother(s)   | 2   | 1.8  |
| Other(s), such as someone employed for providing care   | 9   | 8.1  |
| No caregiver  | 1   | .9   |
| Types of the caregiver's care   |     |      |
| Bedside or being with the patient   | 8   | 7.2  |
| During hospital visiting time   | 97  | 87.4 |
| No care or being at home  | 6   | 5.4  |
| Total   | 111 | 100  |



*Figure 6. Frequency of the Monthly Incomes of the Thai Older Patients with Advanced Cancer* 

#### **Clinical Characteristics**

After reviewing the medical record, the findings revealed that the majority of the diagnoses was lung cancer (19.8%). Apart from that, cervical cancer, cancer of the liver, or rectal cancer was listed (9.9%) (see Table 3). Interestingly, when considering the data of TNM-stage system and advance of these cancers (see Table 4), the numbers of the participants between each stage and characteristics of advanced cancer were the same: stage IV and metastasis were at about 81.1%, stage III and advanced cancer at about 16.2%, or stage II and locally advanced cancer about 2.7%, which is mostly found in the cervical or vaginal cancer group. The primary regions of these cancers mostly could not

be classified at that time as unknown primary regions and mostly occurred in the lungs. Both these numbers were equal (13.5%). In addition, the cancer mostly spread into more than one region in 51.4% of cases, and to a lesser degree into important organs, such as bones (12.6%), lungs (11.7%), and liver (7.2%). When focusing on the time period at which the patients were diagnosed with these cancer diseases, the data showed that most of them were in the second week or the second month of the investigation (at the day of data collection), 18.9% (n = 21) or 18% (n = 20), respectively (see Table 5).

Frequency of the Types of Cancer Diagnosis of the Thai Older Patients with Advanced

Cancer

.

| Types of Cancer Diagnosis | п  | %    |
|---------------------------|----|------|
| Lung cancer               | 22 | 19.8 |
| Cervical cancer           | 11 | 9.9  |
| Liver cancer (HCC, ICCA)  | 11 | 9.9  |
| Rectal cancer             | 11 | 9.9  |
| Bone cancer               | 10 | 9    |
| Lymphoma                  | 9  | 8.1  |
| Cancer of the stomach     | 8  | 7.2  |
| Breast cancer             | 4  | 3.6  |
| Cancer of the bladder     | 4  | 3.6  |
| Leukemia                  | 3  | 2.7  |
| Unknown primary           | 2  | 1.8  |
| Sarcoma                   | 2  | 1.8  |
| Cancer of the esophagus   | 2  | 1.8  |
| Cancer of the pancreas    | 2  | 1.8  |
| Other cancers             | 10 | 9    |

*Note*. Other cancers: cancer of the supraglottis, cancer with radiation cystitis, cancer of thyroid, malignant melanoma, cancer of prostate gland, and vaginal cancer

Frequency of Clinical Cancer Characteristics of the Thai Older Patients with Advanced

Cancer

| Variables                                    | п  | %    |
|--|----|------|
| Stages by Tumor Node Metastasis (TNM) System |    |      |
| Stage II                                     | 3  | 2.7  |
| Stage III                                    | 18 | 16.2 |
| Stage IV                                     | 90 | 81.1 |
| Characteristics of advanced cancer           |    |      |
| Locally advanced cancer                      | 3  | 2.7  |
| Advanced cancer                              | 18 | 16.2 |
| Metastasis (spread to other organs)          | 90 | 81.1 |
| Primary region of cancer                     |    |      |
| Unknown primary                              | 15 | 13.5 |
| Lung   | 15 | 13.5 |
| Liver  | 12 | 10.8 |
| Cervix                                       | 11 | 9.9  |
| Rectum                                       | 11 | 9.9  |
| Lymph-node glands                            | 10 | 9    |
| Stomach                                      | 8  | 7.2  |
| Bladder                                      | 5  | 4.5  |

## Table 4 (continued)

Cancer

| Variables                            | п   | %    |
|--------------------------------------|-----|------|
| Breast                               | 4   | 3.6  |
| Bone marrow                          | 4   | 3.6  |
| Other regions                        | 16  | 14.6 |
| Secondary regions                    |     |      |
| Spread areas >1                      | 57  | 51.4 |
| Bones                                | 14  | 12.6 |
| Lung                                 | 13  | 11.7 |
| Liver                                | 8   | 7.2  |
| Surrounding primary organ: vessel(s) | 5   | 4.5  |
| Lymph node(s)                        | 4   | 3.6  |
| Vagina                               | 3   | 2.7  |
| Not indicated                        | 3   | 2.7  |
| Bladder                              | 2   | 1.8  |
| Adrenal gland                        | 1   | 0.9  |
| Intestine                            | 1   | 0.9  |
| Total                                | 111 | 100  |
|                                      |     |      |

Frequency of Clinical Cancer Characteristics of the Thai Older Patients with Advanced

*Note.* Other regions: prostate gland, pancreas, thigh, larynx (supraglottis), and feet

## Frequency and Mean of the Period of the Diagnosed Time of the Thai Older Patients

| Period of the diagnosed time | n   | %    | Range | М    | SD   |
|------------------------------|-----|------|-------|------|------|
|                              |     |      | 1-9   | 4.81 | 2.50 |
| 1-7 days                     | 9   | 8.1  |       |      |      |
| 8-14 days                    | 21  | 18.9 |       |      |      |
| 15-21 days                   | 8   | 7.2  |       |      |      |
| 22-30 days or 1 month        | 10  | 9.0  |       |      |      |
| 2 months                     | 20  | 18.0 |       |      |      |
| 3 months                     | 13  | 11.7 |       |      |      |
| 6 months                     | 12  | 10.8 |       |      |      |
| 1 year                       | 5   | 4.5  |       |      |      |
| >1year                       | 13  | 11.7 |       |      |      |
| Total                        | 111 | 100  |       |      |      |

with Advanced Cancer

In regard to underlying diseases (see Table 6), most participants (43.2%) had only one disease and 31.5% of them had no other diseases, except for the diagnosed cancer. In the group with underlying diseases, 24.3% of them had more than one underlying disease. Furthermore, the number with hypertension was the highest (13% of all participants).

# Frequency of the Underlying Diseases of the Thai Older Patients with Advanced

Cancer

| Underlying diseases                          | n   | %    |
|--|-----|------|
| Number of underlying diseases                |     |      |
| None   | 35  | 31.5 |
| 1.00   | 48  | 43.2 |
| 2.00   | 17  | 15.3 |
| 3.00   | 10  | 9.0  |
| 4.00   | 1   | .9   |
| Types of underlying disease                  |     |      |
| No underlying disease                        | 35  | 31.5 |
| More than one disease                        | 27  | 24.3 |
| Hypertension                                 | 13  | 11.7 |
| Stomachache                                  | 8   | 7.3  |
| Diabetic mellitus                            | 5   | 4.5  |
| Chronic obstructive pulmonary disease (COPD) | 5   | 4.5  |
| Heart diseases                               | 3   | 2.7  |
| Other underlying diseases                    | 15  | 10.8 |
| Total  | 111 | 100  |

Note. Other underlying diseases: kidney disease—uremia, osteoarthritis (OA), etc.

In addition, the study found that a large majority of the participants was admitted to this setting for the first time (n = 72, f = 64.9%) (see Table 7), causing most of them to not have received treatment at this hospital in the past (61.3%). The average of the period of their stay was 10.98 days ( $SD = \pm 5.00$ , Range = 7-30 days). For this admission, most of them, 97.3% (n = 108), received more than one treatment. These treatments included one of the following or a combination of them: between medications (depending on their current conditions); general analgesics/sedative drugs; treatment at the pain clinic; chemotherapy; radiotherapy; surgeries; rehabilitation with or without a Jewett brace; total parenteral nutrition (TPN); and additional investigations such as biopsy, bronchoscopy, esophagogastroduodenoscopy (EGD), x-ray, Computed Tomography (CT), Magnetic Resonance Imaging (MRI), and Trans-arterial Oily Chemoembolization (TOCE).

Frequency and Means of Number of Admissions, Length of Stays, History of Treatment,

| Variables                   | п  | %    | Range | М     | SD   |
|-----------------------------|----|------|-------|-------|------|
| Number of admissions (time) |    |      | 1-13  | 1.90  | 1.98 |
| 1                           | 72 | 64.9 |       |       |      |
| 2                           | 19 | 17.1 |       |       |      |
| 3                           | 10 | 9.0  |       |       |      |
| 4                           | 3  | 2.7  |       |       |      |
| 5                           | 2  | 1.8  |       |       |      |
| 8                           | 1  | .9   |       |       |      |
| 9                           | 2  | 1.8  |       |       |      |
| 10                          | 1  | .9   |       |       |      |
| 13                          | 1  | .9   |       |       |      |
| Length of stays (days)      |    |      | 7-30  | 10.98 | 5.00 |
| 7                           | 26 | 23.4 |       |       |      |
| 8                           | 24 | 21.6 |       |       |      |
| 9                           | 10 | 9.0  |       |       |      |
| 10                          | 11 | 9.9  |       |       |      |
| 11                          | 7  | 6.3  |       |       |      |
| 12                          | 3  | 2.7  |       |       |      |
|                             |    |      |       |       |      |

and Main Current Treatment

# Table 7 (continued)

# Frequency and Means of Number of Admissions, Length of Stays, History of

| Variables                 | п   | %    | Range | М | SD |
|---------------------------|-----|------|-------|---|----|
| 13                        | 9   | 8.1  |       |   |    |
| 14                        | 3   | 2.7  |       |   |    |
| >15≤30 days               | 18  | 16.2 |       |   |    |
| History of treatment      |     |      |       |   |    |
| None (or first admission) | 68  | 61.3 |       |   |    |
| More than one             | 33  | 29.7 |       |   |    |
| Additional investigations | 5   | 4.5  |       |   |    |
| Chemotherapy              | 3   | 2.7  |       |   |    |
| Surgery                   | 1   | .9   |       |   |    |
| TOCE                      | 1   | .9   |       |   |    |
| Main current treatment    |     |      |       |   |    |
| More than one             | 108 | 97.3 |       |   |    |
| Pain clinic               | 1   | .9   |       |   |    |
| Chemotherapy              | 1   | .9   |       |   |    |
| TPN                       | 1   | .9   |       |   |    |
| Total                     | 111 | 100  |       |   |    |

## Treatment, and Main Current Treatment

The last information related to palliative nursing care was collected by asking participants and examining their medical documents, such as their charts or nursing kardexes or asking nurses. The findings showed that almost all of them (n = 107, f = 96.4%) did not apparently receive palliative nursing care (see Table 8). Similarly, most of these participants (n = 108, f = 97.3%) could not indicate if palliative nursing care was available or not, or describe the difference between palliative and routine nursing care, such as the physical care which was provided to them. However, for this setting where the palliative care has just initially developed, three participants (2.7%) agreed that they received counseling from nurses, which provided them with comfort.

In summary, most of the participants of this study were almost equal in numbers of males or females. Their average age was 68 years ( $SD = \pm 6.15$ ) and the level of their education was mostly primary school (Por 4). Typically, they were in the second week or month following their cancer diagnosis.

Frequency of the Thai Older Patients with Advanced Cancer who Received Palliative Nursing Care

| Palliative nursing care                          | n   | %    |
|--|-----|------|
| Receiving palliative nursing care (comfort care) |     |      |
| Yes  | 4   | 3.6  |
| No   | 107 | 96.4 |
| Kinds of palliative nursing care                 |     |      |
| Inability to identify                            | 108 | 97.3 |
| Counseling                                       | 3   | 2.7  |
| Total  | 111 | 100  |

#### **Description of Characteristics of the Instruments**

For the same reason that was explained in the pilot study, the scores from all the instruments (HCQ [Patient], PPSv2, and VRSs) of all participants (N = 111) were explored and examined. The data of the PPSv2 recorded by the ward nurses had two missing scores; therefore, the total number of the PPSv2 scores used for analyses was 109, whereas the total number of the HCQ (Patient) and VRSs scores was the same, at 111. The results of the exploration were as shown in Table 9. It was found that each dataset did not show serious skewness, each value not more than 1: the skewness of the PPSv2 scores were recorded by the researcher (skewness = -.165), by the ward nurses (skewness = -.095), and included the skewness of the HCQ (Patient) scores (skewness =

-.608) and the VRSs scores (skewness = -.654). Importantly, the skewness values of the PPSv2 measured by the researcher and by the ward nurses as well as the skewness of the HCQ (Patient) and of the VRSs showed the same direction, being entirely negative values and not contradicting any statistical assumption (Glass & Stanley, 1970; Nunnally, 1978). As a result, all datasets were further computed.

|                                  | PPSv2 scores by the researcher | res by the r               | esearcher | PPSv2 scores by ward nurses | es by ward                 | l nurses | HCQ (Patient) scores | atient) s | scores | VF    | VRSs scores |      |
|----------------------------------|--------------------------------|----------------------------|-----------|-----------------------------|----------------------------|----------|----------------------|-----------|--------|-------|-------------|------|
| Statistical                      | (N = 109                       | (N = 109, Missing 2 cases) | cases)    | (N = 109,                   | (N = 109, Missing 2 cases) | cases)   | R                    | (N = 111) | -      | U     | (N = 111)   |      |
| Description                      | Value                          | SD                         | SE        | Value                       | SD                         | SE       | Value                | SD        | SE     | Value | SD          | SE   |
| Mean                             | 67.61                          | 13.187                     | 1.263     | 48.99                       | 8.383                      | .803     | 4.292                | .495      | .047   | 6.252 | 2.086       | .198 |
| 95% Confidence Interval for Mean | nterval for N                  | Mean                       |           |                             |                            |          |                      |           |        |       |             |      |
| Lower bound                      | 65.11                          |                            |           | 47.40                       |                            |          | 4.199                |           |        | 5.860 |             |      |
| Upper bound                      | 70.12                          |                            |           | 50.58                       |                            |          | 4.385                |           |        | 6.645 |             |      |
| 5% Trimmed Mean                  | m 67.80                        |                            |           | 49.18                       |                            |          | 4.312                |           | i,     | 6.356 |             |      |
| Median                           | 70.00                          |                            |           | 50.00                       |                            |          | 4.347                |           |        | 7.000 |             |      |
| Variance                         | 173.887                        |                            |           | 70.268                      |                            |          | .245                 |           |        | 4.354 |             |      |
| Minimum                          | 30                             |                            |           | 30                          |                            |          | 2.61                 |           |        | 00    |             |      |
| Maximum                          | 100                            |                            |           | 60                          |                            |          | 5.29                 |           |        | 10.00 |             |      |
| Range                            | 70                             |                            |           | 30                          |                            |          | 2.67                 |           |        | 10.00 |             |      |
| Interquartile                    | 20                             |                            |           | 20                          |                            |          | .67                  |           |        | 3.00  |             |      |
| Skewness                         | 165                            |                            | .231      | 095                         |                            | .231     | 608                  | .229      |        | 654   |             | .229 |
| Kurtoeie                         |                                |                            | 150       |                             |                            |          |                      |           |        |       |             |      |

#### **Reliability of the PPSv2**

Focusing first on the PPSv2 score, the mean of the PPSv2 recorded by the researcher was 48.99 ( $SD = \pm 8.38$ ), whereas the one recorded by the ward nurses was 67.61 ( $SD = \pm 13.19$ ). Furthermore, although the PPSv2 data were accepted on the assumption of the normal distribution to confirm the results, the correlation between the dataset of the PPSv2 recorded by the researcher and the ward nurses were tested by three methods (Pearson Correlation, Kendall's tau b, and Spearman's rho). The findings as shown in Table 10 demonstrated that they were correlated significantly with the correlation coefficient: .321 (p = .001), .241 (p = .003), and .284 (p = .005), respectively. However, Munro (2005) states that these correlation coefficient values tend to be low. When looking for intervening variables, which might involve the applying of the PPSv2 between the researcher and the ward nurses, the PPSv2 of both resources were recorded by different recorders and at a different time. (However, both scores from the two datasets were recorded in the same week.) In addition, the setting was chosen to be that of the initiation of developing palliative care, and the nurses had just begun to apply the PPSv2 to assess their dying patients. Their skill of applying the PPSv2 might have been insufficient; therefore, the researcher reviewed the means of the PPSv2 scores and focused on the differing mean = 18.62 (between the mean of the PPSv2 scores recorded by the ward nurses =  $67.61 [SD = \pm 13.19]$  and the mean of the PPSv2 scores recorded by the researcher =  $48.99 [SD = \pm 8.38]$ ). To decrease these differences, the matchpaired scores whose different values were more than 18 were excluded. Apparently, the total number of the participants that remained was only 41 (n = 41). These datasets were explored and computed to test the correlation for a second time. The results showed that both datasets still exhibited abnormal distribution but not seriously, showing the same direction (skewness coefficient of both = -.581 and -.721) (see Figure 7 and 8). This finding confirmed that they still correlated significantly but its correlation was higher and better for the three methods (see Table 10) (Munro, 2005).

Table 10

Correlation Coefficient of the PPSv2 Scores Measured by the Researcher and Ward Nurses

| Statistical correlation – | PPSv2 scores | s measured by the | researcher and | ward nurses     |  |
|---------------------------|--------------|-------------------|----------------|-----------------|--|
|                           | N = 109      |                   | N = 41         |                 |  |
|                           | Correlation  | Sig. (2-tailed)   | Correlation    | Sig. (2-tailed) |  |
|                           | Coefficient  |                   | Coefficient    |                 |  |
| Pearson Correlation       | .321**       | .001              | .768**         | .000            |  |
| Kendall's tau_b           | .241**       | .003              | .697**         | .000            |  |
| Spearman's rho            | .284**       | .003              | .754**         | .000            |  |

*Note.* \*\* Correlation is significant at the 0.01 level (2-tailed).

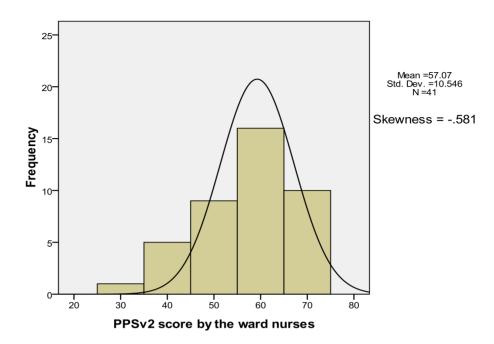


Figure 7. Frequency and Mean of the PPSv2 Scores Recorded by the Ward Nurses

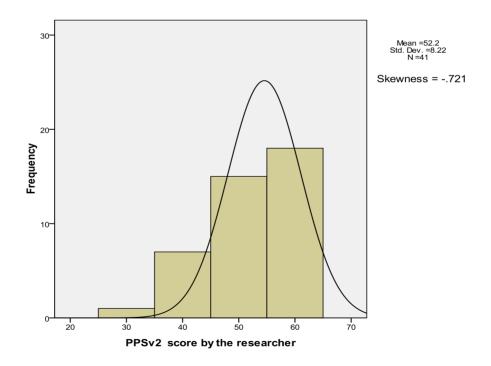


Figure 8. Frequency and Mean of the PPSv2 Scores Recorded by the Researcher

#### Reliability and Validity of the HCQ (Patient) and VRSs

Next, the dataset (N = 111) of the HCQ (Patient) was computed to test the internal consistency of all 49 items. Satisfactorily, the coefficient alpha obtained was .898, which is acceptable for a well-developed psychosocial instrument (Burns & Grove, 2005) and excellent evidence to the construct validity of comfort (George & Mallery, 2009).

Finally, the computation was focused on the correlation between the HCQ (Patient) and VRSs. The findings illustrated that two of these tools correlated significantly with Pearson's correlation coefficient .557 (p = .000), moderately (see Table 11) (Munro, 2005). Although this value was not high, Munro (2005) stated that this value (r > .50) was fine for a human study in which many factors are involved. Table 11

| Statistical correlation | HCQ (Patient) (1-6) and VRSs (0-10)<br>(N=111) |                 |  |  |
|-------------------------|--|-----------------|--|--|
|                         | Correlation Coefficient                        | Sig. (2-tailed) |  |  |
| Pearson Correlation     | .557**   | .000            |  |  |
| Kendall's tau_b         | .358**   | .000            |  |  |
| Spearman's rho          | 475**  | .000            |  |  |

Correlation between the HCQ (Patient) and VRSs

*Note.* \*\*Correlation is significant at the 0.001 level (2-tailed).

In summary, the PPSv2 instrument had sufficient stability reliability,

especially when the extraneous variables were eliminated from the analysis (n = 41). In regards to the HCQ (Patient), the findings revealed that it also qualified as a welldeveloped tool to examine the concepts of the Comfort theory, and showed a good construct or concurrent validity by correlating significantly to the total comfort tool, the VRSs.

#### **Description of Comfort Analysis and Results**

Regarding the HCQ (Patient) and VRSs, based on the data (N = 111), the results show the mean of the HCQ (Patient) scores to be 4.29 ( $SD = \pm .50$ ), demonstrating that older patients with advanced cancer tended to experience comfort between a moderate to almost high level, and the mean of the VRSs scores was 6.25 ( $SD = \pm .2.09$ ), reflecting the comfort experience between moderate and fairly high levels. Focusing on the frequency of their scores, to make revision easier and to facilitate understanding, the final two decimal HCQ (Patient)-rating scores for each participant was transformed into the integer form; for example, the interval of scores from 1.01 to 1.99 transformed as 1, from 2.01 to 2.99 transformed as 2, and so on. The study found that participants experienced comfort at level 5--the high level (n = 71, f = 64%); at level 4 (n = 30, f = 64%); f = 27%); and at level 6 (n = 8, f = 7.2%) (see Table 12). Likewise, the VRSs scores showed that the comfort levels of these participants mostly tended to be high. The scores ranged between fairly high comfort (n = 25, f = 22.5%), between fairly high and high comfort (n = 24, f = 21.6%), and moderate comfort (n = 23, f = 20.7%), and very high comfort (n = 12, f = 10.8%) (see Table 13). In addition, the VRSs demonstrated

that there were only two participants who experienced extreme comfort (at comfort level 10), and another individual experienced complete discomfort (at comfort level 0).

In summary, most Thai older patients with advanced cancer experienced comfort between moderate and almost/fairly high levels. The results of the HCQ (Patient) and the VRSs were congruent.

Table 12

Frequency and Mean of the Comfort level (HCQ [Patient]) of the Thai Older Patients with Advanced Cancer

| Comfort level                 | n   | %    | М    | SD  |
|-------------------------------|-----|------|------|-----|
| Comfort level (HCQ [Patient]) |     |      | 4.29 | .50 |
| 3.00                          | 2   | 1.8  |      |     |
| 4.00                          | 30  | 27.0 |      |     |
| 5.00                          | 71  | 64.0 |      |     |
| 6.00                          | 8   | 7.2  |      |     |
| Total                         | 111 | 100  |      |     |

# Frequency and Mean of the Comfort Level (VRSs) of the Thai Older Patients with

| Comfort level                                | n   | %    | М    | SD   |
|--|-----|------|------|------|
| Comfort level (VRSs)                         |     |      | 6.25 | 2.09 |
| 0 (No comfort at all)                        | 1   | .9   |      |      |
| 1 (A little bit of comfort)                  | 1   | .9   |      |      |
| 2 (Between a little bit and some comfort)    | 5   | 4.5  |      |      |
| 3 (Some comfort)                             | 5   | 4.5  |      |      |
| 4 (Between some and moderate comfort)        | 8   | 7.2  |      |      |
| 5 (Moderate comfort)                         | 23  | 20.7 |      |      |
| 6 (Between moderate and fairly high comfort) | 6   | 5.4  |      |      |
| 7 (Fairly high comfort)                      | 25  | 22.5 |      |      |
| 8 (Between fairly high and high comfort)     | 24  | 21.6 |      |      |
| 9 (Very high comfort)                        | 12  | 10.8 |      |      |
| 10 (Highest comfort possible)                | 1   | .9   |      |      |
| Total  | 111 | 100  |      |      |

#### **Description of Additional Findings**

To optimize the HCQ (Patient) data, they were analyzed to show which five items represented the lowest and the highest comfort scores. The findings demonstrated that the five lowest scores were item 24, 27, 39, 14, and 34 (see Table 14). These were related to physical-physiological, psycho-spiritual, socio-cultural, and environmental discomfort. On the other hand, the five highest scores were item 46, 7, 35, 9, and 10, which reflected spiritual comfort (see Table 14).

| HCQ (Patient) items                      | Comfort scores ( $N = 111$ ) |         |      |      |     |
|--|------------------------------|---------|------|------|-----|
|  | Minimum                      | Maximum | М    | SD   | Sum |
| Five lowest scores of comfort            |                              |         |      |      |     |
| 24 R I have experienced changes          | 1.00                         | 6.00    | 2.33 | 1.19 | 259 |
| which make me feel uneasy                |                              |         |      |      |     |
| 27 R My mouth and skin feel very dry     | 1.00                         | 6.00    | 3.10 | 1.41 | 344 |
| 39 <i>R</i> I need to be better informed | 1.00                         | 6.00    | 3.10 | 1.45 | 344 |
| about my condition                       |                              |         |      |      |     |
| 14 R My pain is difficult                | 1.00                         | 6.00    | 3.13 | 1.47 | 347 |
| 34 R I think about my discomforts        | 1.00                         | 6.00    | 3.17 | 1.39 | 352 |
| constantly                               |                              |         |      |      |     |
| Five highest scores of comfort           |                              |         |      |      |     |
| 46 I have found meaning in my life       | 2.00                         | 6.00    | 5.14 | .74  | 570 |
| 7 My beliefs give me peace of mind       | 3.00                         | 6.00    | 5.16 | .82  | 573 |
| 35 I feel confident spiritually          | 3.00                         | 6.00    | 5.29 | .76  | 587 |
| 9 My life is worthwhile right now        | 2.00                         | 6.00    | 5.34 | .75  | 593 |
| 10 I know that I am loved                | 1.00                         | 6.00    | 5.40 | .86  | 599 |

The Five Lowest and Highest Comfort Scores

Note. R items defined as the negative items whose scores were converted

#### **Presentation of the Qualitative Data and Results**

In the qualitative phase, the researcher obtained in-depth information about the comfort as experienced and perceived by Thai older patients with advanced cancer in order to ensure sufficient validity of, credibility for, and confidence in the quantitative results from this study. The design required 20 interviewees, obtaining information from every fifth subject of the quantitative study. As expected, 11 subjects that were part of the quantitative study were not available for the interview process (five subjects were too tired to talk for long periods of time, three subjects did not agree to being interviewed without giving any reason, two subjects worried about being recorded and refused to be interviewed, and the last one was too old to talk for a long period of time). Thus, the interviewing of these members was postponed and replaced by the next participant.

All of the participants were interviewed by the researcher. It was possible to interview almost all of the participants on the same day of the questionnaire process, except one who wanted to be interviewed later (one day after the questionnaire process).

In summary, the total number of the participants recruited for this qualitative study was 20.

#### **Description of Demographic Data (Qualitative Study)**

#### **Personal Data**

The demographic data are shown in Table 15. The number of males and females was equal (n = 10, f = 50%). Most participants (n = 10, f = 50%) were in the age group of 60–64 years. The mean age was 66.45 years ( $SD = \pm 5.88$ ). Seventy percent of them

(n = 14) were married. 95% of the participants (n = 19) were Thai citizens and Buddhists. Most of them (70%, n = 14) had received little education. Fifty percent (n = 10) were retired and 45% (n = 9) needed to stop working due to the illness. So, the income of 70% of these participants (n = 14) needed to be supported by the governmental subsidy as well as by other financial resources, such as the patient's children, wife, other relatives, etc. In addition, the findings revealed that the caregivers of thirty percent of them were the patient's spouses (n = 6) or children (n = 6) (see Table 15), who provided care for the patients during visiting time as set by the hospital schedule (about 12:00-1:00 p.m. and/or 3:00-8:00 p.m.) about 80% (n = 16) (see Table 15). Regarding the hospital costs, most of the participants (n = 14, f = 70%) were supported by the government via the Gold Card Project. However, about 20% of them (n = 4) were supported by the government via their children's privilege of receiving government employee fringe benefits; 5% of them (n = 1) were assisted by the individual retirement pension or from the Social-Work Division of the hospital.

In summary, the demographic characteristics of the participants in the qualitative study were similar to those of the subjects of the quantitative study.

# Frequency and Mean of the Demographic Characteristics of the Thai Older Patients

| with Advanced Cancer for the Qualitative Study |
|--|
|--|

| Variables                     | n            | %               |
|-------------------------------|--------------|-----------------|
| Gender                        | 10           | 50              |
| Male                          | 10           | 50              |
| Female                        | 10           | 50              |
| Age                           | M = 66.45, J | $SD = \pm 5.88$ |
| 60-64 years                   | 10           | 50              |
| 65-69 years                   | 5            | 25              |
| 70-74 years                   | 3            | 15              |
| 75-79 years                   | 1            | 5               |
| 80-84 years                   | 1            | 5               |
| Marital status                |              |                 |
| Single                        | 2            | 10              |
| Married                       | 14           | 70              |
| Widowed                       | 4            | 20              |
| Race                          |              |                 |
| Thai                          | 19           | 95              |
| Others (Alien)                | 1            | 5               |
| Religion                      |              |                 |
| Buddhism                      | 19           | 95              |
| Protestant                    | 1            | 5               |
| Education level               |              |                 |
| Not able to read and/or write | 3            | 15              |
| Elementary school             | 14           | 70              |
| (Por 4 [=USA grade 4])        | (11)         | (55)            |
| Secondary School              | 2            | 10              |
| Undergraduate                 | 1            | 5               |

## Table 15 (continued)

# Frequency and Mean of the Demographic Characteristics of the Thai Older Patients

| Variables  | n  | %   |
|--|----|-----|
| Employment   |    |     |
| Unemployed   | 1  | 5   |
| Disabled (stopping working due to this illness)        | 9  | 45  |
| Retired  | 10 | 50  |
| Income/Financial support                               |    |     |
| Income   | 2  | 10  |
| Subsidy of 500 Baht (Universal Healthcare Coverage)    | 3  | 15  |
| Governmental pension                                   | 1  | 5   |
| (The Civil Servants' Medical Benefit Plan)             |    |     |
| Governmental subsidy with other resources              | 14 | 70  |
| Caregivers   |    |     |
| Spouse   | 6  | 30  |
| Son(s) or/and daughter(s)                              | 6  | 30  |
| Nephew(s)/niece(s)                                     | 2  | 10  |
| Spouse with son(s) and daughter(s)                     | 3  | 15  |
| Relative(s) (sisters or brother(s)                     |    |     |
| Other(s) (such as someone employed for providing care) | 2  | 10  |
| No caregiver   | 1  | 5   |
| Where the caregivers provide care                      |    |     |
| Bedside or being with the patient                      | 2  | 10  |
| During hospital visiting time                          | 16 | 80  |
| No care or being at home                               | 2  | 10  |
| Hospital-cost support                                  |    |     |
| Subsidy of 30 Baht/the Gold card                       | 14 | 70  |
| (Universal Healthcare Coverage [UC])                   |    |     |
| Retirement pension (CSMBS)                             | 1  | 5   |
| Governmental health subsidy                            | 4  | 20  |
| Social-Work Division of the Hospital                   | 1  | 5   |
| Total  | 20 | 100 |

# with Advanced Cancer for the Qualitative Study

#### **Clinical Characteristics**

Based on the data of the clinical characteristics, the findings showed that most participants were diagnosed with lung cancer (n = 4, f = 20%), breast cancer, or lymphoma (n = 3, f = 15%), and cancer of the cervix, stomach, or bladder (n = 2, f = 10%) (see Table 16). The majority of the cancer cases (n = 75, f = 75%) were in stage IV and in metastasis (see Table 17). Regarding the primary region of each cancer, it mostly spread into the lungs, lymph-node glands, or breasts, individually about 15%. The primary organ and the type of diagnosis for this group did not affect the same area because each participant was diagnosed based on the area that his/her dominant and current symptoms involved or caused them to be admitted at this time, not defining the original area of the cancer occurrence.

Frequency of the Types of Cancer Diagnosis of Thai Older Patients with Advanced Cancer for the Qualitative Study

| Types of cancer diagnosis | n  | %   |
|---------------------------|----|-----|
| Lung cancer               | 4  | 20  |
| Breast cancer             | 3  | 15  |
| Lymphoma                  | 3  | 15  |
| Cervical cancer           | 2  | 10  |
| Cancer of the stomach     | 2  | 10  |
| Cancer of the bladder     | 2  | 10  |
| Other cancers             | 4  | 20  |
| Total                     | 20 | 100 |

Note. Other cancers: liver cancer (hepatocellular carcinoma [HCC], intra-

cholangiocarcinima [ICCA]), cancer of the esophagus, rectal cancer, and cancer of the vulva

Frequency and Means of Cancer Characteristics of Thai Older Patients with Advanced Cancer for the Qualitative Study

| Cancer characteristics                       | n  | %  |
|--|----|----|
| Stages by Tumor Node Metastasis (TNM) System |    |    |
| Stage II                                     |    |    |
| Stage III                                    | 5  | 25 |
| Stage IV                                     | 15 | 75 |
| Characteristics of the advanced cancer       |    |    |
| Locally advanced cancer                      |    |    |
| Advanced cancer                              | 5  | 25 |
| Metastasis                                   | 15 | 75 |
| Primary region of cancer                     |    |    |
| Lung   | 3  | 15 |
| Lymph-node glands                            | 3  | 15 |
| Breast                                       | 3  | 15 |
| Cervix                                       | 2  | 10 |
| Stomach                                      | 2  | 10 |
| Bladder                                      | 2  | 10 |
| Unknown primary                              | 1  | 5  |
| Liver  | 1  | 5  |
|  |    |    |

Frequency and Means of Cancer Characteristics of Thai Older Patients with Advanced Cancer for the Qualitative Study

| Cancer characteristics            | п  | %   |
|-----------------------------------|----|-----|
| Esophagus                         | 1  | 5   |
| Rectum                            | 1  | 5   |
| Vulva                             | 1  | 5   |
| Secondary regions                 |    |     |
| More than one area                | 12 | 60  |
| Liver                             | 2  | 10  |
| Surrounding primary organ: vessel | 1  | 5   |
| Lymph node(s)                     | 1  | 5   |
| Lung                              | 1  | 5   |
| Bones                             | 1  | 5   |
| Vagina                            | 1  | 5   |
| Not indicated                     | 1  | 5   |
| Total                             | 20 | 100 |

Regarding the participants' underlying diseases, the finding showed that the percentages of no underlying disease, only hypertension, and obtaining more than one underlying diseases were equal (n = 4, f = 20%). Most of them (n = 12, f = 60%) had only one underlying disease (see Table 18).

| Qualitative Study              |    |     |
|--------------------------------|----|-----|
| Variables                      | п  | %   |
| Underlying diseases            |    |     |
| No underlying disease          | 4  | 20  |
| Hypertension                   | 4  | 20  |
| More than one disease          | 4  | 20  |
| Heart disease                  | 2  | 10  |
| Kidney – uremia                | 2  | 10  |
| Other underlying diseases      | 4  | 20  |
| Numbers of underlying diseases |    |     |
| 0                              | 4  | 20  |
| 1                              | 12 | 60  |
| 2                              | 1  | 5   |
| 3                              | 2  | 10  |
| 4                              | 1  | 5   |
| Total                          | 20 | 100 |

Frequency of Underlying Diseases of Thai Older Patients with Advanced Cancer for the

Note. Other underlying diseases: osteoarthritis, stomachache, allergy, and psoriasis

Next, focusing on admission data (see Table 19), the admissions of most participants (n = 14, f = 70%) were first admissions and, as a result, their histories of illnesses and treatments at this hospital were not available, except for the referring histories. From the day of the individual admission to the day of the interview (the length of stay [LOS]) for 25% of them (n = 5) showed a LOS of about 7 or 8 days. Furthermore, the study revealed that 90% (n = 18) of them received more than one type of treatment.

Frequency and Means of Number of Admissions, Length of Stays, History of Treatment, and Main Current Treatment for the Qualitative Study

| Variables              | n  | %   | М     | SD   |
|------------------------|----|-----|-------|------|
| Number of admissions   |    |     | 2.25  | .59  |
| 1                      | 14 | 70  |       |      |
| 2                      | 1  | 5   |       |      |
| 3                      | 2  | 10  |       |      |
| 4                      | 1  | 5   |       |      |
| 9                      | 1  | 5   |       |      |
| 10                     | 1  | 5   |       |      |
| Total                  | 20 | 100 |       |      |
| Length of stays (days) |    |     | 12.10 | 7.28 |
| 7                      | 5  | 25  |       |      |
| 8                      | 5  | 25  |       |      |
| 9                      | 2  | 10  |       |      |
| 10                     | 2  | 10  |       |      |
| 13                     | 1  | 5   |       |      |
| 14                     | 1  | 5   |       |      |
| >14≤30 days            | 4  | 20  |       |      |

#### Table 19 (continued)

Frequency and Means of Number of Admissions, Length of Stays, History of Treatment, and Main Current Treatment for the Qualitative Study

| Variables                 | п  | %   | М | SD |
|---------------------------|----|-----|---|----|
| History of treatment      |    |     |   |    |
| None (or first admission) | 14 | 70  |   |    |
| Chemotherapy              | 1  | 5   |   |    |
| More than one             | 5  | 25  |   |    |
| Current main treatment    |    |     |   |    |
| Pain clinic               | 1  | 5   |   |    |
| Chemotherapy              | 1  | 5   |   |    |
| More than one             | 18 | 90  |   |    |
| Total                     | 20 | 100 |   |    |

Finally, based on the data involving palliative care, the findings showed that the ward nurses' assessment of the mean of the PPSv2 score was 70 ( $SD = \pm 3.08$ ), and the researcher's assessment was 50 ( $SD = \pm 8.58$ ). What should be considered is the finding that 95% of them did not receive palliative nursing care or could not distinguish palliative care from regular care provided by nurses (inability of telling the difference between the current nursing care during the serious illness and the previous nursing care) (see Table 21). However, apparently, the mean of their comfort was greater than

moderate (M = 4.19,  $SD = \pm .45$  by the HCQ (Patient) and (M = 5.95,  $SD = \pm 1.88$  by the VRSs) (see Figure 9 and 10).

Table 20

Frequency of the PPSv2 Measured by the Ward Nurses or the Researcher for the

Qualitative Study

| PPSv2 | B  | y the wa | ard nurse | s    | E  | By the re | esearcher |      |
|-------|----|----------|-----------|------|----|-----------|-----------|------|
| 11572 | n  | %        | М         | SD   | n  | %         | М         | SD   |
| PPSv2 |    |          | 70.00     | 3.08 |    |           | 50.00     | 8.58 |
| 30    | -  | -        |           |      | 1  | 5         |           |      |
| 40    | 2  | 10       |           |      | 4  | 20        |           |      |
| 50    | -  | -        |           |      | 9  | 45        |           |      |
| 60    | 4  | 20       |           |      | 6  | 30        |           |      |
| 70    | 6  | 30       |           |      | -  | -         |           |      |
| 80    | 6  | 30       |           |      | -  | -         |           |      |
| 90    | 2  | 10       |           |      | -  | -         |           |      |
| 100   | -  | -        |           |      | -  | -         |           |      |
| Total | 20 | 100      |           |      | 20 | 100       |           |      |

Frequency of Receiving Palliative Care, and Type of Palliative Care for the Qualitative

Study

| Variables                 | п  | %   |
|---------------------------|----|-----|
| Receiving palliative care |    |     |
| Yes                       | 1  | 5   |
| No                        | 19 | 95  |
| Type of palliative care   |    |     |
| Inability to identify     | 19 | 95  |
| Counseling                | 1  | 5   |
| Total                     | 20 | 100 |

# Table 22

Means and Standard Deviations of the Comfort Level of Thai Older Patients with

Advanced Cancer Who Were Interviewed for the Qualitative Study

| Comfort level              | Ν  | М    | SD   |
|----------------------------|----|------|------|
| HCQ (Patient) (Rating 1-6) | 20 | 4.19 | .45  |
| VRSs (Rating 1-10)         | 20 | 5.95 | 1.88 |

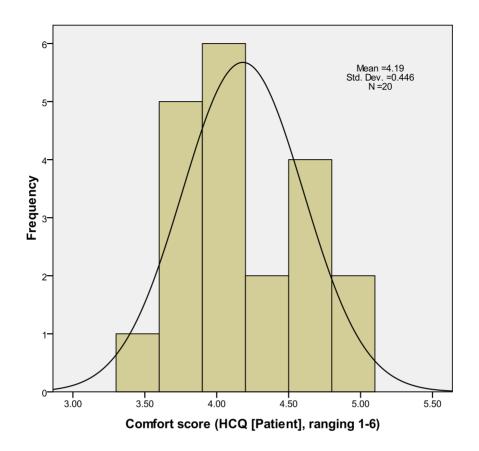


Figure 9 Mean and Standard Deviation of the Comfort Level Assessed via the HCQ (Patient) of Thai Older Patients with Advanced Cancer Who Were Interviewed for the Qualitative Study

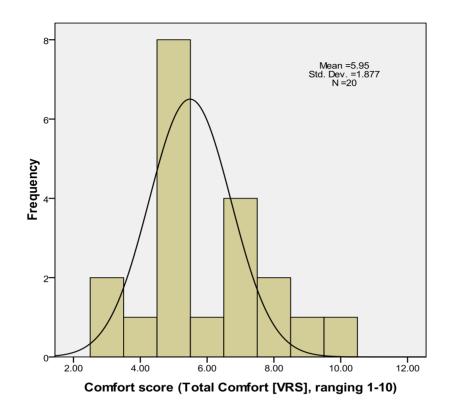


Figure 10. Mean and Standard Deviation of the Comfort Level Assessed via the VRSs of Thai Older Patients with Advanced Cancer Who Were Interviewed for the Qualitative Study

In conclusion, the interviewed participants were equally male and female, and the average of their ages was 66.45 years ( $SD = \pm 5.88$ ). Lung cancer advancing into other areas or organs was the most prevalent disease process among these participants for whom palliative nursing care was not provided or provided insufficiently.

#### **Description of Qualitative Data and Results**

Content analysis described by Busch et al. (2005) and Zhang (2006) was used to analyze interview data from 20 participants. Each interview was conducted using the Thai language and was guided by the Semi-Structured Interview Guide, which consisted of five major open-ended questions: (a) "In your opinion, please tell me about the nursing care you are receiving for this admission.," (b) "In your opinion, what are your expectations about the care you should be receiving?," (c) "How would you describe nursing care which comforts you?," (d) "In your opinion, what are the barriers to provide the comfort care for you?," and (e) "In your opinion, how could the nursing care provided be improved for better comfort care?" (see Appendix E). During the process of the first five interviews, the researcher became familiar with and noted the important factors or techniques supporting or interrupting the interview process, such as the suitable time for interviewing or the ideal technique for how to approach the individual participant with the content of each question. After obtaining five interviews, the researcher found that the interview time should approximately be between 9:00 a.m. to 12:00 p.m., 1:00 p.m. to 3:00 p.m., or 6:00 p.m. to 8:00 p.m. because there were no clinical rounds done by doctors and families are not visiting. This review of five datasets confirmed that the content of all questions and probes in the Semi-Structured Interview Guide did not need revision and was continuously used as the guide for the next 15 interviews.

To proceed step-by-step through content analysis, all the tapes recorded in Thai were transcribed verbatim and were reviewed by the researcher who listened to the taped recordings to confirm the transcribed data.

To develop the codebook, the researcher randomized five transcriptions to be initially categorized. The transcriptions were translated into English by the researcher and validated via a back translation by four bilingual nursing instructors. As this study was modeled after the Comfort Theory put forth by Kolcaba (2003), the *preliminary domains, categories* and *themes* were developed and defined based on two main domains: *discomfort* (or comfort needs) and *comfort*. The discomfort domain encompassed four contexts or categories: *physical-physiological, psycho-spiritual, socio-cultural,* and *environmental*; the *comfort domain* consisted *of relief, ease,* and *transcendence* categories; as the preliminary coding.

To unitize the statements of these five transcriptions, the researcher repeatedly listened to the audio tape recorder to fully understand each participant's situation and subsequently, each transcription was read over again several times. At the same time, the individual field notes, including some information taken from the medical record, were used appropriately and periodically for environmental information and to capture nonverbal communication. As a result, four categories as well as 55 themes of discomfort emerged along with four categories as well as 48 themes of comfort, including inadequate comfort as a new category. In addition, five themes (comfort variables, discomfort variables, knowledge of nurses, characteristics of good nurses, and nursing-care improvement) were not grouped easily. They needed to be categorized repeatedly by the researcher before the codebook was refined and ready to be used for analysis.

For integrity of the data analysis, two reliability raters, who were nursing faculty of a Thai university, reviewed and validated the categories and themes with the definitions listed in the codebook. They accepted that all statements (100%) fit with the individual theme after the researcher related additional information about the individual participant. When considering the appropriateness between the themes and their categories, 95.2% of themes were accepted by the external reviewers as a good fit with the individual categories. To obtain 100% agreement, five themes were moved to the appropriate categories: two themes moved from the physical-physiological category to a new category, was moved to a new category relating to nurses; one theme from the environmental category was moved to the socio-cultural theme, and the last one was moved from the environmental category to a new theme – communication problem of nurses.

In addition, the definitions of the predetermined categories and themes in the codebook were reviewed again and finally accepted by the major advisor of the dissertation, and the comfort theorist. This set of domains, categories, and themes became part of the coding rules for categorizing each of the follow-up transcriptions. Based on the results of the categorization of all 20 transcriptions, two main domains (discomfort and comfort as outlined by the Comfort Theory) as well as the additional domain with its own categories and themes emerged. All of them were reviewed and

validated again by the major advisor and one member of the dissertation committee who partially adjusted a few themes before final approval.

The domains and the categories of this study were used to analysis as shown in Table 23.

Table 23

Domains and Categories of Comfort as Experienced by Thai Older Patients with Advanced Cancer

| Domain            | Category                                      |
|-------------------|---|
| Discomfort        | Physical-physiological discomfort             |
|                   | Psycho-spiritual discomfort                   |
|                   | Socio-cultural discomfort                     |
|                   | Environmental discomfort                      |
| Comfort           | Relief  |
|                   | Ease  |
|                   | Transcendence                                 |
|                   | Inadequate comfort                            |
| Additional domain | Intervening variables                         |
|                   | Nursing comfort care                          |
|                   | Nurses (including other healthcare personnel) |
|                   | Comparison between the hospital and the house |

#### **Description of Discomfort Domain.**

Based on the comfort theory, *Discomfort* was defined as the needs of an individual person that arise from stressful healthcare situations – during illness or hospitalization – that are not met by traditional support systems. From the data relating to discomfort of this study, there were four categories that emerged. These categories were the *Physical-physiological discomfort* (n = 20, f = 253), *Psycho-spiritual discomfort* (n = 20, f = 234), *Socio-cultural discomfort* (n = 20, f = 116), and *Environmental discomfort* (n = 20, f = 58) (see Table 24, 28, 30 and 32).

## Category One: Physical-Physiological Discomfort.

*Physical-physiological discomfort* was a statement reflecting discomfort relating to physical, physiological, or bodily functions. Four themes emerged within the Physical-physiological context (see Table 24).

Theme: *Physically distressing symptoms* defined as clinical symptoms experienced by 20 Thai older patients who were diagnosed with advanced cancer. These symptoms made them suffer, feel distress or discomfort during this admission.

Theme: *Deficits of activities of daily of living (ADLs) or disability strategies* defined as inability or less ability for doing ADLs because of this illness.

Theme: *Needs for hygiene care* defined as no hygiene care, needing help to clean some body areas: back, anus after defecation, or taking a bath as opposed to a partial bed bath or using a wet wipe.

Theme: *Overall physical discomfort* defined as discomfort (without any comfort) occurred while being admitted to the hospital and was not identified clearly.

# Frequency of the Themes of Physical-Physiological Discomfort

| Category/Themes  | п  | f       |
|--|----|---------|
| Physical-physiological discomfort                        |    |         |
| 1. Physically distressing symptoms (3 – 8 symptoms/case) | 20 | 231     |
| Top 10 of the distressing symptoms                       |    |         |
| 1. Sleep disturbance                                     | 18 | 54      |
| 2. Pain  | 17 | 49      |
| 3. Gastro-intestinal tract disorders                     | 14 | 21      |
| 4. Immobility  | 10 | 24      |
| 5. Elimination problems                                  | 9  | 19      |
| 6. Tiredness/fatigue/no energy                           | 8  | 15      |
| 7. Respiratory problems (dyspnea or difficult breathing) | 7  | 10      |
| 8. Abdominal distension                                  | 5  | 9       |
| 9. Numbness  | 4  | 9       |
| 10. Itching  | 3  | 4 (214) |
| Other symptoms   | 10 | 17      |
| 2. Deficits of ADLs or disability strategies             | 8  | 10      |
| 3. Needs for hygiene care                                | 7  | 10      |
| 4. Overall physical discomfort                           | 2  | 2 (253) |
| Total  | 20 | 253     |

*Note.* Other symptoms: headache, loss of voice, bleeding from the vagina, etc.

### Descriptive Data Supporting the Themes.

#### Theme: Physically Distressing Symptoms.

Every participant expressed that they experienced physically distressing symptoms. The top 10 of these symptoms, listed here as sub-themes, were sleep disturbance, pain, gastrointestinal tract disorders, immobility (inability to walk or changing positions by oneself), elimination problems (constipation and/or diarrhea), tiredness/fatigue/no energy, respiratory problems (dyspnea or difficult breathing), abdominal distension, numbness, and itching.

## Sub-theme: Sleep Disturbance.

Most of the patients experienced sleep disturbance (n = 18, f = 54), which was mostly due to worrying about the illness or about the family or related to the intravenous fluid which might run out before the nurses' noticing, (n = 7, f = 17). In this study, pain also became one cause of sleeplessness (n = 5, f = 13) (see Table 25).

| Frequency of | of the | Causes | of Sleep | Disturbance |
|--------------|--------|--------|----------|-------------|
|              |        |        |          |             |

| Causes of sleep disturbance                              | п  | f  |
|--|----|----|
| Worries  | 7  | 17 |
| Pain   | 5  | 13 |
| Noise from other patients' talking or people walking     | 4  | 5  |
| Around   |    |    |
| Sleeplessness without any reason                         | 3  | 5  |
| Fear of not being able to get well or fear of conditions | 2  | 5  |
| Fear of the treatment                                    | 1  | 2  |
| Being disturbed by the treatments or nursing procedures  | 1  | 3  |
| Missing the husband and house                            | 1  | 1  |
| Other causes: cold weather, diarrhea, etc                | 3  | 3  |
| Total  | 18 | 54 |

Patient statements related to sleep disturbance:

ID 1 ".... As I am ill, .... Sometimes, I can not sleep, which occurs by itself." # "(What noise disturbs your sleeping?) The talking of other patients. Sometimes, I wake up by this noise. So, I lie and listen to them, not sleeping. Often (--the patient was disturbed). (Everyday?) No, sometimes in the daytime or sometimes at night."

ID 4 "Sometimes, I am sleepless. Sometimes, I am restless. It is hard to close my both eyes. I can not fall asleep again."

ID 11 "..., I fear that my condition will become worse. This fear makes sleep difficult. I felt uncomfortable when I am sleepless. I am worried and continuously brood." # "I am afraid that I may not recover. .... I, as a patient

experiencing these symptoms, also think if I can or can not recover. I do not know what my disease is. This is my thinking. Some nights, I can not sleep because I think about my illness, what it is."

ID 20 "I did not sleep. I want to sleep. I feel sleepiness but it is difficult to get sleep. It is too hard to have a deep sleep. I do not know why it is difficult to sleep. Sometimes, I want to rest and sleep but I can only have a nap. I feel that I have just started to sleep. My sleep usually seems to be broken, and I do not know why it is.... I can sleep for a short time, and then I wake up. I have never felt that I get sufficient sleep."

Sub-theme: Pain Symptom.

Pain was another symptom that was frequently reported about by the participants (n = 17, f = 49). Most pain was caused by the disease itself (chest pain/pain at their chest, pain from cystitis, neck pain, back pain, wound pain, etc.); treatments (administering intravenous fluid, procedure of intercostals drainage (ICD), or vaginal dough); sitting for a long time; smelling from harmful food; or drinking water, which could produce abdominal pain. The types of pain mentioned frequently were abdominal pain (n = 5, f = 9), heavy chest pain (n = 4, f = 7), and wound pain (n = 4, f = 7) (see Table 26).

| Types of Pain          | п  | f  |
|------------------------|----|----|
| Abdominal pain         | 5  | 9  |
| Heavy chest pain       | 4  | 7  |
| Wound pain             | 4  | 7  |
| Pain from treatments   | 3  | 4  |
| Back or neck pain      | 2  | 4  |
| Pain of the whole body | 1  | 4  |
| Urination pain         | 1  | 4  |
| Pain from coughing     | 1  | 4  |
| Other pain symptoms    | 4  | 6  |
| Total                  | 17 | 49 |

## Frequency of the Types of Pain

Note. Other pain symptoms: pain from cancer masses, anal pain, harmful food

Patient statements related to the pain symptoms:

ID 3 "I still have had pain. I felt a sharp pain last time. I feel a lot of pain during the dressing of the wound. I groan. Beyond the dressing of the wound, there is no pain." # "I need to tolerate the pain very often and wait for the sunrise.... It is not my pretence. I really get that pain." # "If I sit down for a long time, I will have a body ache and pain."

ID 14 "The actual thing which causes me the most discomfort is a tumor in my liver. This tumor adheres to the gall bladder. As it adheres to the gall bladder, the bile is obstructed and can not flow. This makes me feel distension in my abdomen. It makes me inflate up to the vertebra. The pain is a colicky pain, which occurs in the whole abdomen. ..., this is the greatest discomfort I have. This is the only pain I have. The pain causes quick breathing and crying...."

ID 16 "For this illness, if I smelled something, like harmful food I feel dizzy. Or, this might happen from smelling roasted squids. I usually smell some pickled food such as pickled bamboos. Unh-unh, first I got a funny smell. Although I do not need to eat those harmful things, just smelling, I will feel uncomfortable, only from smelling it. I will get an ache just because of the smell. Because of these harmful foods' smells, I will have a body pain, such as bone pain and ear pain."

ID 20 "..., I will feel a lot of chest pain." # "Ow, when I am urinating, I have so much pain. That seems to really hurt my heart. I get the pain krab. My pain makes me scream, ow! .... Uh-huh, it feels like difficult and burning urination (--cystitis). I think it may be burning urination.... Krab, I still have pain every time I urinate. Especially at the beginning of urination, and also when I am almost done urinating."

## Sub-theme: Gastro-Intestinal Tract Disorders.

Gastro-intestinal disorders found in these participants were defined as lack of appetite, inability to swallow, flatulence, nausea and/or vomiting, eating less than the usual, belches, being hungry and thirsty, needing different menus for each meal, the hospital food is either too spicy or the patient eats less food and the food is too spicy, inability of eating or following the doctor's order of not taking in food orally (as the nothing per oral [NPO] order). The total number of participants reporting this disorder was 14 (f = 21). No appetite (n = 5, f = 8) and nausea/vomiting (n = 2, f = 3) were the most important causes for their disorders of the gastro-intestinal tract (see Table 27).

\_

| Gastro-intestinal Tract Disorders                  | n  | f  |
|--|----|----|
| No appetite  | 5  | 8  |
| Nausea/vomiting                                    | 2  | 3  |
| Inability to taste food                            | 2  | 2  |
| Inability to swallow food                          | 1  | 2  |
| Other symptoms                                     | 5  | 5  |
| Need of being serving and eating in bed (-in lying | 1  | 1  |
| position)  |    |    |
| Total  | 14 | 21 |

## Frequency of Gastro-Intestinal Tract Disorders

Patient statements related to the gastro-intestinal tract disorders were the

following:

ID 1 ".... I need to drink it gradually (little by little). I can not drink it all at one time. If I do drink it all, I can not swallow and vomit."

ID 6 "In addition, I have nausea and no appetite. However, I do not vomit. Sometimes, on the day that I have not appetite, I also vomit. When a meal is served, although I do not eat it, I have the symptom of vomiting." # "It is not bad for me that I can eat for 4-5 tablespoons. I can eat only 4-5 tablespoons. It is impossible to eat more. If I try to eat, I will vomit."

ID 10 "My mouth and throat sense a bitter taste. I have no appetite, as if I am pregnant."

Sub-theme: Immobility.

Immobility is defined as the inability to walk or go anywhere and a limitation on

range of positions: inability of walking without assistance, less mobility than usual, and

partial movement. There were 10 participants who experienced discomfort due to their

immobility (f = 24). The participant with known cerebro-vascular disease described the

limitations of his movement. He was reminded by nurses to stay in bed or to walk

carefully. The participants of this group stated:

ID 1 ".... No, I have never gone anywhere. I can not go. In addition, nurses do not want me to go anywhere. They told me to be at or in my bed." # ".... No, I can not walk (without the intravenous-fluid pole)." # "I can not get up or sit down by myself. So, I always have to ask them (--the nurses) to help me to do so."

ID 8 "The second (of my discomforts) is that I can not sit down completely.... It is not as usual (--The patient could not sit down absolutely because of anal pain from the rectal cancer)."

ID 9 ".... Yes, I can not move my body.... I can not walk anywhere or make a move. As for movement, I can move my body only partially." # "I can raise my legs only to this level (The participant raised her legs for showing). No, no. I can not stretch my legs straight forward. I can not endure to make them fully straight. They (the patient's both legs) have just gotten the edema. The doctor said the edema of my legs had also occurred because of receiving the intravenous fluid." # "..., I want to take a walk but I can not do this."

Sub-theme: Elimination Problems.

Elimination problems were reported by nine Thai older patients with advanced

cancer (f = 19) were characterized as constipation/difficulty of bowel movements and/or

diarrhea. To be specific, the numbers for constipation or diarrhea were 4 (f = 8), or

3 (f= 8), respectively. Furthermore, two patients faced both symptoms--constipation and

diarrhea (n = 2, f = 3). The participant statements reflected these problems as follows:

ID 2 "... constipation everyday.... I seldom have a bowel movement."

ID 5 "I have difficulty defecating. In the past, I usually have bowel movement every day. When my hands were numb, over a few days I had bowel movements only one time. In this hospital, I needed to apply the enema two times for bowel movements."

ID 13 "I sometimes have constipation. If I eat harmful foods, I might get constipation or diarrhea. Now, in the hospital, I can defecate every day. However, the stool is still liquid."

ID 20 "Krab (--yes), I have not gone to the bathroom for bowel movement. Krab, I have not defecated since the admission." # "Unh-unh, I do not defecate. I have not defecated since being admitted. I have not defecated until right now. (The patient had just had bowel movement.) I only fart and only gas comes out."

Sub-theme: Tiredness/Fatigue/Insufficient Energy.

The symptoms of tiredness, fatigue, or insufficient energy were suffered by eight

Thai older patients with advanced cancer (f=15). Mostly, these symptoms resulted from

the cancer disease itself, with the result that these participants were not able to eat or

breathe deeply due to the abdominal distension or the pleural effusion. They stated:

ID 9 "It (--the abdominal distension) makes me restless and so tired. How about this illness? It is annoying for me. It makes me so tired...."

ID 20 "When I do something, I feel tired. It is my exhaustion. I feel tired due to two symptoms (The patient referred to the difficulty urinating due to cystitis and difficulty breathing due to lung cancer.)."

Sub-theme: Respiratory Problems.

Respiratory problems were defined as dyspnea or difficulty breathing. The

number of participants who were distressed from the dyspnea or had difficulties

breathing was 7 (f = 10). Statements that demonstrate these symptoms include:

ID 2 "(Pain and dyspnea?) ... getting much dyspnea."

ID 11 "...I feel uncomfortable and breathe uncomfortably, and have a back pain."

ID 19 "It is uncomfortable for me to breathe.... The difficult breathing results from the lower mass. (The patient pointed to the mass (about 2x2 cm) below her left breast.)."

Sub-theme: Abdominal Distension.

In this study, Thai older patients with advanced cancer defined the experience of

abdominal distension as feeling bloated in the abdomen, abdominal inflation,

uncomfortable abdomen, or abdominal discomfort. This abdominal distension occurred

in five participants (n = 5, f = 9), who stated for example:

ID 9 "I have constipation or not have bowel movement. I feel bloated. They can not do anything to relieve my abdominal inflation.... They helped me but their help could not relieve my abdominal distension." # "My greatest discomfort is the distension...abdominal distension." # "I have only one discomfort, my abdominal distension."

ID 14 "The actual thing which causes me the most discomfort is a tumor in my liver. This tumor adheres to the gall bladder. As it adheres to the gall bladder, the bile is obstructed and can not flow. This makes me feel distension in my abdomen. It makes me feel inflation up to the vertebra...."

Sub-theme: Numbness.

Four Thai older patients with advanced cancer reported that the numbness was

one symptom of their discomfort (f = 9). In the study, the participants also described

their numbness in this manner: when the numbness started to appear, it involves parts of

the body, causing numbness there, and co-symptoms such as spasticity of the muscles.

The examples of their statements reflecting numbness are as follows:

ID 5 "My numbress still appears. I want to recover from this symptom." # "More than 20 days of having a numb feeling in my hands, I am not sure." # "The numbress started on my left hand first. A few days later, my right hand started to feel the numbress." # "(...what makes you most uncomfortable and worries you the most?) The patient raised both hands, which were numb, without answering."

ID 15 "Well, while receiving chemotherapy. There usually is a side effect which I have (--referring to the numbness.)."

Sub-theme: Itching.

Itching was the last of the top 10 physical symptoms distressing three Thai older

patients with advanced cancer. Some of them have had itching symptoms before

admission. They described their itching as follows:

ID 4 "I itched on my back. There is uticaria on my back."

ID 17 "I itched, itching on the whole of my body. Last night, I could not sleep...." # "At Chiang Rai, I had the itch a little bit. However, I have just felt so itchy here."

Theme: Deficits of ADLs or Disability Strategies.

Regarding the theme of the deficits of ADLs or disability strategies, ten

participants (f = 10) defined this as the inability or reduced ability for doing ADLs

because of this illness, which brought about individual weakness or insufficient energy

and, for example, an inability to work or do anything in a normal manner.

ID 1 "(You can not take care for yourself, can you?) No, I can not." # "I think..., presently, ... but I can not walk and work as before."

ID 3 "(At the present, you are staying in the hospital. What can you do for yourself?) Nothing. I have no energy and can not do anything." # "(The patient answered instead of his daughter who was asked by the researcher with the question, 'Usually, how often did your father go to the temple?') Not often. I did not go anywhere, not even a party. Stopped altogether. All activities were stopped...."

Some participants responded clearly to the questions by talking about their

ADL ability, stating that they could not maintain the usual activities of their daily lives,

as the questions and answers listed below show:

ID 1 "(For each day, what are the daily activities which you are able to do by yourself?) My pain makes albeit impossible to do anything."

ID 2 "(What are the daily activities which you can do by yourself?) I do not Do anything."

ID 4 "(Please consider your daily activities which you can still do by yourself in this hospital in comparison to the ones you did when you were at home.) Only lying in bed all day (--restricted to the bed). I can not do anything."

Theme: Needs for Hygiene Care.

Based on the findings, seven of twenty participants (f = 10) indicated that they

still needed hygienic or personal care, such as taking a bath or partial bed bath, using a

wet wipe, shampooing, or changing clothes. In addition, the study showed that there

were some participants whose personal care had been abandoned while they were too

tired to do it for themselves. They stated:

ID 11 ".... Nurses let me wipe by myself but I do not want to do that. I want to take a bath every day. It is not comfortable for me if I only use a wet wipe. I feel sticky."

ID 19 "(Do they help you take a bath?) No, there is not any help for me." # "I needed to go to the restroom by myself, only me. I need to tolerate to do for myself. (Do you need to tolerate?) Jow (--yes), I have to tolerate."

ID 20 "Today, I used a wet wipe. I did it by myself. They (--the nurses) told me that I had to do it by myself. Thus, I did it but I could not clean my back by myself." #

However, in this study, there was one participant who indicated that he preferred

to get help for personal care from his wife rather than from nurses. He stated that:

ID 8 "They, the nurses, do not need to provide hygiene care for me. Krab (-yes), I can do the personal care for myself. I do not need to be dependent on nurses for personal care." # "I can do several activities by myself, such as taking a bath, walking, eating, and moving. However, I can not do them as usual, and I need some help. The person who helps me is my wife. (Do nurses provide this help for you?) No, nurses do not need to help me. This is because I do not request help from them. My wife stays with me to help. I can do these activities without nurses' help."

Theme: Overall Physical Discomfort.

There was one participant who complained directly that he had had discomfort throughout this treatment. Although this participant first did not particularly identify this need, when he was asked to elaborate, he said that his greatest discomfort related to the uncomfortable weather and the helplessness of nurses, as the following statement shows

ID 3 "Ah! I have some discomforts. (What made you feel unhappy or uncomfortable?) While sleeping at night, it was too cool. It is difficult to explain how cold it can be. It is too cold at night. I called a doctor (nurse), but she/he did not want to come. She/he did not come when I called. Excuse me, they did not like to come to help me although I had a bowel movement. When I had a bowel movement, they did not like to come to help me. When I finished, they came to me. Sometimes, I had bowel movements. It was late to get help. They sometimes asked me 'Why don't you walk?' I said, 'I can not walk.' Nobody helps me."

#### Category Two: Psycho-Spiritual Discomfort.

Psycho-spiritual discomfort is a statement that reflects the impact of the illness

on the psychological or spiritual condition. Every participant experienced this

discomfort (f = 234). Following the interview data, 19 themes relating to psycho-

spiritual discomfort emerged (see Table 28). However, Thai older patients with

advanced cancer shared the top 10 themes of the psycho-spiritual discomfort: worry

and/or fear, worry (solely), impact on the meaning of life, need for spiritual support,

discomfort relating to hope, fear (solely), missing family members/relatives, sympathy/pity with nurses or relatives, suffering/distress from the illness, and loneliness. What was observed about the concepts of worry and fear is that both of them might occur on the same issue in one participant, or the worry or fear might occur on the same issue but in different participants. The definitions of the top 10 themes showed following are found in Table 28.

Frequency of the Top 10 Psycho-Spiritual Discomfort

| Category/Themes   | п  | f       |
|---|----|---------|
| Psycho-spiritual discomfort                               |    |         |
| Top 10 Psycho-spiritual discomforts                       |    |         |
| 1. Worry and/or fear (about the same issue)               | 19 | 60      |
| 2. Worry (family, financial, working/ability, and income) | 14 | 35      |
| 3. Impact on the meaning of life                          | 13 | 27      |
| 4. Need of spiritual support                              | 13 | 19      |
| 5. Discomfort relating to hope                            | 8  | 16      |
| 6. Fear (solely)  | 6  | 11      |
| 7. Missing family members/relatives                       | 5  | 14      |
| 8. Sympathy/Pity with nurses or relatives                 | 5  | 11      |
| 9. Suffering/distress from the illness                    | 5  | 8       |
| 10. Loneliness  | 5  | 7 (208) |
| Other discomforts   | 12 | 26      |
| Total   | 20 | 234     |

*Note*. Other discomforts: Needing emotional support (--crying), Meaning of cancer, Finality of death, Annoyance, Endurance/anguish/sorrow, Boredom, Body-image impact, Depression from seeing other patients, and Sadness and/or uncertainty Worry and/or fear is a condition that reflects the participant's feeling of worry or fear responding to his/her stressful situation from the illness (n = 19, f = 60) (see Table 28). In addition, the findings showed that there were some participants who responded to the same issue with both worry and fear. Under this theme--worry and/or fear--eight sub-themes emerged: illness and symptoms, falling, fear of the self, feeling as a troublemaker (that one causes trouble) for the nurses or relatives, the one' s repercussion, treatment or outcomes of treatment, being diagnosed with cancer, and suffering from distressing symptoms (see Table 29). Their definitions showed the following:

| ear |
|-----|
|     |

| Sub-theme                           | п  | f  |
|-------------------------------------|----|----|
| Worry and/or fear                   |    |    |
| Illness and symptoms                | 10 | 21 |
| Falling                             | 5  | 7  |
| (Fear of) The self                  | 4  | 7  |
| Being seen as a troublemaker        | 4  | 6  |
| Repercussion                        | 4  | 6  |
| Treatment or outcomes of treatment  | 3  | 6  |
| Being diagnosed with cancer         | 3  | 5  |
| Suffering from distressing symptoms | 2  | 2  |
| Total                               | 19 | 60 |
|                                     |    |    |

Descriptions of the Sub-themes.

Sub-theme: Worry and/or Fear related to Illness and Symptoms.

Worry/fear of illness and symptoms were found in 10 participants (f = 21) and defined as worry and/or fear relating to the progress of the illness or a worsening of the conditions, non-healing or recurrence, and distressing symptoms: pain, bleeding from the vagina, inability to defecate, facial edema, future conditions, inability to recover, the length of recovery, non-healing of the abdominal wound (because one participant

experienced the eviscerations two times), numbness, and sleeplessness. The

statements that reflected the worry and/or fear of the participants are the following:

ID 4 "(As you experience pain and learned that it causes much suffering for you, have you ever been afraid of getting that pain again?) I have thoughts like that. At that time, the surgery was not done. So, I was afraid of pain."

ID 8 "My greatest discomfort is that I am afraid of one thing. That is the fear of the inability to defecate. If I can not defecate, everything is over, right? There will be consequences. The consequences are complications. When I feel afraid, I think of only one thing. That is, will I die or will I recover?"

ID 13 "And I worry about my pain too. Fear is what I feel. I am afraid of my pain. The fear of the pain is my greatest fear, very much so, but I am not afraid of death."

ID 18 "Uh-huh. There is some psychological discomfort. I have discomfort in my face, which is edematous." # "I feel extremely uncomfortable because of my edematous face. Jow (--yes), this symptom makes me think a lot.

Sub-theme: Worry and/or Fear of Falling.

This study showed that a worry and/or fear of falling were experienced by five

participants (n = 5, f = 7). The important cause of their worries and/or fears about

falling was related to previous experiences of falling. Fear of falling was illustrated as

follows:

ID 10 "I used to fall several times. I fell at my home and, then, I needed to go to a hospital. The fall happened a long time ago. This time does not involve the fall. Because of the previous fall, I needed to go to the hospital. Yes, I have a fear of falling. Because of my last fall, I needed to hold on to something to support myself. It (the falling) made me uncomfortable, as dizziness. Yes, I am still afraid while walking because there is still fainting and vertigo."

ID 11 "This is because I do not want to walk by myself. I am afraid of falling when walking alone. I want them to help every time."

ID 20 "I am afraid of falling down. ... that was the reason for why I was not allowed to get out of the bed. ..., a fall may occur because of the weakness of my legs. My legs have no energy."

However, there was one participant who said that he was not afraid of falling. Based on the observation of the researcher, this participant tried to explain that he just needed to be careful to prevent himself from falling again. However, he confirmed that he used to have this fear. During the interview, he expressed that he had a lot of concerns about walking and falling. He reflected:

ID 1 "Ah, previously in that hospital, I was afraid of my walking disability. (Did this fear occur when you were admitted due to your fall?) Krab (--yes). (And now?) I can walk (The patient still needed a supporter—the intravenous fluid pole--for walking). .... I am not afraid. I always remind myself that I have to be careful, not allow myself to fall again. If I fall, it makes the recovery difficult." # "I thought that if I went to a place and fell, I would be in trouble." # "The sequence of the second fall will make my treatment difficult."

Sub-theme: Worry and/or Fear of the Self.

Four of the participants expressed the worry and/or fear that there would be

negative outcomes for their own well-being. They defined the negative outcomes as the

non-recovery, inability of self care or walk, and trouble for themselves (f = 6). They

reflected:

ID 4 "I fear not being able to recover from my illness."

ID 5 "If I receive the surgery, will I recover? I want to recover from my illness. If I can not recover, what can I do?" # "I think about how I want to completely recover, or I think about my trouble in the future...." # "It will be good for me if my hands can recover and can work. If not, I will be in trouble."

ID 17 "I fear of not being able to get well, that is. As for my disease, I am afraid that I will not recover. I fear a lot, not recovering. ...."

Sub-theme: Worry and/or Fear of being seen as a Troublemaker.

There were four participants who expressed worry and fear that they would

cause trouble for the nurses or their families (f = 6). In addition, one of four told his

family that they did not need to worry about him. (as the ID 1 did not want his

families to worry and did not want to cause trouble). These participants said:

ID 1 "Krab (--yes). When they (the families of the patient) called me, I told them not to worry about me. Krab. I said there was nothing that worries me. I told them that they should not worry about me."

ID 2 "I said, 'I do not want to bother Jew (the wife's name of the patient).' My admission troubles Jew."

ID 6 "Usually, I have always have feces and dirt on my clothes. That was an example. I thought that this causes a problem. Was it correct? That causes the problem for others. The others are nurses. Because I think that it will cause a problem for nurses, I will not drink the Ovantine." # ".... Afraid? I was afraid that they might not sleep comfortably (The patient referred to his wife and daughter who waited for the visiting time by spending the nights at some places because they were not officially allowed to enter the hospital and wards.)"

Sub-theme: Worry and/or Fear of Repercussions.

Worry and/or fear of repercussion were reported by four participants (f = 6).

They defined this sub-theme as the worry or fear relating to the responses from nurses

or families to something that they did. These repercussions were described as: blame

from nurses or families or annoying nurses, and resulting for example in receiving more

painful treatment.

ID 1 "If I go and fall down, the nurses will blame me, 'I told you that you need to be careful; you may fall. If you fall repeatedly, it will be hard to be treated you again. So, please, do not fall down.""

ID 3 "If I sleep for a long time, my daughters like to complain to me. When I slept for a long time, the urine bag is always full; so, my daughter liked to complain. When I woke up, I was wet or soaked (with urine)." # "(Do you want nurses to talk or encourage you more frequently?) No, it will force us close together. Too close together. I may be blamed."

ID 13 "I think they were good for apologizing. They were the persons who give me medications; so I should not frown at them. If I expressed anger to them, they might cause me to feel a lot more pain."

Sub-theme: Worry and/or Fear of Treatment and Outcomes of Treatment.

Three participants reported that they worried and/or were afraid about the current or planned treatment and medications, including their outcomes (f = 6). Their worry or fear mostly referred to what types of treatment were available, who the surgeon was, what the outcome of the treatment would be, and what the procedures of some treatments were. They stated:

ID 8 ".... Thirdly, I worry about the surgery for me...." # ".... Now, I worry about two things. One is the surgery. I worry about the doctor who will do surgery for me. Will he be the medicine teacher? The second is that I am afraid of receiving chemotherapy." # "Uh-huh, now, the big worry of mine is the treatment plan for me."

ID 15 "There is some hopelessness (the patient laughed) because I do not know what the result (of the investigation) is. Now, I know about the treatment, which is chemotherapy. But I do not know its outcome. .... Uh-huh. I worry somewhat...." # "First, I worried about my disease. I was not sure about what would happen to my life, and what would happen in the future. I did not know the ways of the treatment. As I had never been admitted to a hospital, these questions made me worry and I wanted to know what things would be like...."

Sub-theme: Worry and/or Fear of Being Diagnosed with Cancer.

Worry and/or fear to be diagnosed with cancer emerged by three participants

(f = 5). They expressed that they often thought about the nature of their diseases.

However, they wondered whether their diseases might be diagnosed as cancers, which

they feared. They stated:

ID 11 "Uh-huh, I have anxiety. I do not know what my diagnosis is. I think about what my disease is. I do not know anything about it. While staying here, I think about what my disease is. I asked myself if it is this disease or that disease I often think at night.... I think what or how I will be, especially when I have bleeding. I do not know what my illness is." #..., I wait for the diagnosis of my illness. Yes, I fear that cancer is the diagnosis. My bleeding makes me think that my diagnosis may be a cancer. The elderly (in the patient's village) who was diagnosed with cancer used to have the same symptom. I am afraid. I am afraid to be diagnosed with this bad disease. .... I only think about two issues: am I diagnosed with cancer or not?"

ID 14 "Sometimes, I think and fear that I may be diagnosed with cancer for a while and, then, this thought disappears."

Sub-theme: Worry and/or Fear of Suffering from Distress Symptoms.

Beyond worries or fears regarding the occurring symptoms, some of the patients

revealed that they also worried and/or feared the sequences of the symptoms, especially

their distress or suffering, such as pain, sleeplessness, or vaginal bleeding (n = 2, f = 2).

The statements related these feeling:

ID 7 "I worry about if I will die. I am afraid. My greatest fear is distress. (Are you afraid of distress?) Ka (--yes). If there is no distress and I can die easily, it is okay for me."

ID 16 "I am afraid of suffering. The suffering is defined as sorrow or pain distressing symptoms which can not be alleviated. That means a serious pain with distress. .... I am afraid a lot."

ID 19 "Jow (--yes), I am afraid of the distress and its suffering. It is the pain of which I am afraid. But I am not afraid to die."

Theme: Worry.

In this study, the theme of worry was also related mostly to family and family members of the participants as well as the participants themselves. The number of participants who reported worries was 14 (f = 35). These worries were defined as worry about the family: the house, the probability of an accident of the children, about the patient's rice farm, and so forth (n = 8, f = 14). As for financial problems, the patients referred to insufficient financial security of the family, family debts, the costs associated with the family traveling to visit the participant, and so forth (n = 6, f = 11). Another form of worry or fear was related to working/the ability of working, earning income,

and how to earn money for oneself or the family (n = 5, f = 8). Examples of worry

follow:

ID 7 ".... I am not happy if their family (--the sons' families) has problems. I worry about the business of my youngest son. There have not been any orders. He has not been able to export goods for three months. I worry about him and his family."

ID 10 "I have this farm of about eight Rais (as units for measuring areas in Thailand). My husband can not work in the farm. .... I employed someone to plow for me. Right now, I do not know if there is enough water in my farm."

ID 13 "To my psychological discomfort, I think and think about my house, my job, and the money which I will pay in the future. I think about financial problems. The financial problem is the most serious problem for me. The financial problem is the greatest burden for me." # "There is insufficient psychological comfort because I still think that, ah, what I will do in the future. What will I have for my children? When I have received the surgery, can I be employed and work? .... I worry about myself and my family. Those are my two worries."

There was one participant who suffered from breast cancer and metastasis of

vertebra who had two younger sisters. The relationship between them was not good.

The participant lived with one sister who was a drinker. This participant expressed her

worry about the caregiver after she was discharged. She said:

ID 5 "... or I think about my trouble in the future. I also think about my younger sister and her family. I don't know what they think (taking care of the patient later). Their family is not good. The younger sister with whom I have stayed has been divorced for a long time. The other one (The participant paused.), she does not stay with me. (In a different village?) Jow (--yes). .... But her family is not good." # "I worry about her too. I always have a headache with her problems. Every time I talk about her problems, I get a headache. I can not receive her help. I need to take care of myself. If I become a disabled person, I am sure that I will be troubled."

Meaning of life was an emerging theme that had an impact on the patient. The changing meaning of life was reflected upon by 13 participants (f = 27). It was classified into two periods: during treatment and after discharge. The meaning of life during treatment was defined as life during stressful situations, a machine, two possibilities [recovery or death], uncertainty, a life that might not be good, a life that was too hard, and a troubled life (n = 11, f = 20). The other option was that the meaning of life after discharge or in the future was defined as *feeling down, no long-term survival, focus on the financial status*, and *a death* which was the end for everything (n = 3, f = 7). The following statements reflected the meaning of life:

The meaning of life during the treatment:

ID 6 "I am like a machine, such as our car, which does not work and gets more damaged every day. Yes, I think of myself like a machine that can not work and needs to be changed. The machine can not speak but I, as a human being, can speak."

ID 13 "Since this is the first admission, I feel that my life is so depressed. Ah, I feel annoyed with myself. The finality of my life is really final. This is my finality which is admitted in this hospital. If I am discharged, how long I will be able to survive. I think I may not have long life because I think my age is old." # "If I die, my relatives do not need to take time to look after me. It will be ended completely. Differently, the illness requires them to take care of me without knowing when it will be ended. Death can end this in short time. I look at my future that if I will be ill again, I will come to be cured. But if I am seriously ill and reach at the time of death, let myself die. This is my future. Ah, if the illness is the most serious and I can not make my mind to accept it, I can not make my mind to accept, I will not able to live."

The meaning of life after discharge (or in the future):

ID 13 "I look in the future if or not I will be poor or rich eternally."

ID 19 "I think a lot. I am thoughtful that I may not get the recovery. That is so thoughtful, extremely. If I can not get well, I have to die. It means that if I can not get well, I will die. I think that my life may not be good. Jow (--yes), it may not be good. Not good life is defined as my illness will not be recovered."

Theme: Need of Spiritual Support.

Need of spiritual support of Thai older patients with advanced cancer were

reflected in statements that focused on the needs or deficits of spiritual care, relating

to information about spiritual activities, lack of spiritual care, conditions too

uncomfortable or distressed to engage in spiritual practice, and illness as a barrier to

spiritual activity. Thirteen participants talked about these themes (f = 19). Their

statements are as follows:

ID 9 "I have not gone to the temple since my previous discharge. It has been for one month or more." # ".... I do not do any religious activity for this admission. I do not do any religious activity, including medication. Yes, I want the hospital to support these religious activities for patients."

ID 17 "Nobody knows that I pray. (Do nurses suggest you doing?) No, nurses do not tell me to pray because they do not know about my praying. Nurses do not provide religious support at all. They come to me and hurry to go for working in another space (--within the same ward)."

Based on the finding, two participants directly stated that distressing symptoms

are barriers of religious practices, and one participant shared his view that the nurses did

not provide religious support; however, she did not wish for it either. These statements

were:

ID 7 "(Are there nurses support you to pray or provide you with Dharma books?) No, no ka (--a polite word). When they came in and saw me being praying, they did not do anything, just seeing and getting out. (Is there not help or support for you?) No, they do not help to do. Ah.... (To encourage you?) That is not important for me because I can do these activities by myself."

ID 11 "No, I do not do meditation during I worry about something so much. But I sit and think about only that thing. I only sit and do think If I get the pain symptom or when I feel uncomfortable, I do not do it (--the meditation). I can not do if having pains."

Theme: Discomfort Relating to Hope.

Discomfort as related to the notion of hope was defined as having no hope for

the future, hopeless, having some hope, fearful when thinking about the future, not

looking forward to the future, and needing hope support. The total number of

participants whose hope was impacted by the illness was 8 (f = 16). From this number,

most of them shared the view that they had no hope for the future (n = 3, f = 7) and felt

hopeless (n = 2, f = 6). Statements reflecting this discomfort follow:

ID 9 "I wanted them to help but when I asked the nurses, they said that that symptom occurred by the side effect of the medication. .... When they told me that the distension had occurred due to the side effect of the medication, I do not do anything." # ".... Uh-huh, I feel that I seem not to receive help. If it is possible, I want them to relieve (pause) my abdominal distension. Now, I am hopeless. I do not want to think about the hope." # "I do not know why I am hopeless. There are many problems...many problems (--abdominal distension, difficult eating, and sleep)." # "That will be just enough for nurses doing for me. (--The participant's responsive sound expressed less hope from nursing care.)"

ID 14 "I hope that my life (The participant paused and then continued.) How can I hope? (Then, the patient laughed.).

ID 16 "No, I do not think about a future. I think only this (The participant meant not getting a serious pain.). Now, I do not think more than this thing. I am afraid of thinking about the longer future of my life."

Theme: Fear.

The theme of fear was defined as fear of dying (n = 3, f = 5), recurrence of

disease (n = 2, f = 4), drug addiction to analgesics (n = 1, f = 1), and, importantly,

non-professional care (n = 1, f = 1). The total of participants who experienced fear

was 6 (f = 11). They said:

ID 3 "Sure, being afraid (--of death). I am afraid not being able to live."

ID 18 "Nurses told me that I could request for an analgesic. But I was afraid to take any analgesic. Usually, I do not brave to take an analgesic because I am afraid. I am afraid of analgesic addiction. Jow (--yes), I fear the drug addiction. It is not me to take an analgesic for every time I feel a little bit of a pain."

Theme: Missing the Family Members and Relatives.

Five participants stated that they missed their families (f = 14). The notion of missing emerged as missing the house (n = 1, f = 2) and missing the family: the husband and nieces/nephews (n = 5, f = 12). Interestingly, the missing mostly focused on nieces or nephews more than others (n = 3, f = 4). The following statements reflect these feelings:

ID 10 ".... When will I be discharged from the hospital? I miss my husband. I am unhappy and worry that my husband may accidentally fall in the swamp."

ID 15 "Sometimes, I miss my family. It is a common. That is, missing the house deteriorates psychological health. ..., I miss my niece."

ID 18 "However, I miss my nephews. In my heart, I always think of my nephews."

ID 18 "I miss my house. I had just had the '*Keun Baan Mai*' (--a new house ceremony of Buddhism) on the date eighth. The '*Keun Baan Mai*' ceremony was done. .... That is my compassion on myself so much."

Theme: Sympathy/Pity with Nurses or Relatives.

There were five participants who expressed sympathy or pity with the nurses

who worked very much without having sufficient break time (n = 2, f = 7) and with their

relatives, such as their wife, daughter(s), or nieces(s), who needed to carry the burden of

caring for them (n = 4, f = 4). The following statements reflect these feelings.

ID 2 "I pity my wife. She needs to come to take care for me and make me comfortable (--traveling and visiting the participant everyday)."

ID 3 "My daughter carries the whole burden for me. (The patient starts to cry again.) I feel sad about my daughter."

ID 4 "I sympathize with her (The patient had only one niece who took care for her, visited her, and provided money whereas the other did not help with anything.)."

ID 7 "They need to work all the time each day. They have not time. I am sympathy with the nurses here. They can take a break only in their lunchtime. They have not enough time. Most patients here are so serious." # ".... These nurses need to be tired. I pity with them." # "Want something? I want to have nurses more than now. I feel sympathy with them. ...."

Theme: Suffering/Distress from the Illness.

Suffering and distress from the Illness were defined as feeling distressed because

of symptoms, especially pain or being tired, and the inability of caring for oneself (n =

5, f = 8). The patients described their suffering and distress in the following statements:

ID 2 "About my current symptoms, I never had them before." # "Yes, it distresses me very so much."

ID 13 ".... My current distress is only the distress from my illness and pain. Beyond, there is not any distress. Yes, I am distressed because of my pain."

ID 19 "..., currently, I suffer." # ".... The pain is the most cause of my suffering." # "..., this is because I suffer from pain so much."

#### Theme: Loneliness.

In this study, loneliness was the last of the 10 aspects of psycho-spiritual

discomfort of Thai older patients suffering from advanced cancer. There were five participants who felt lonely and perceived that they needed to be alone during admission. They defined this feeling as being alone and nobody to whom they could

talk, who could help them, and whom they knew or who was familiar with what had

occurred at the beginning of the admission. The number of patients who felt this

way was seven. Loneliness was expressed as follows:

ID 1 "I am here alone." # "When I think a lot, I always tell to myself, 'I am

thinking alone; so why do I think?""

ID 5 "I do not know how to speak and whom I can speak with. I stay by myself."

ID 13 "I do not like to be alone. I do not like being without others or not having anybody to talk to or sitting down alone. .... I feel lonely when there are no people or their walking sounds."

Based on Table 27, regarding other themes of psycho-spiritual discomfort

experienced by Thai older patients with advanced cancer from this study, two final

themes emerged: finality of death (n = 2, f = 3) and needing emotional support (n = 3, f = 3)

f = 8) were critical and need to be of concern for nurses even though only a few

participants reflected this discomfort. These patients cried, suffered a great deal and

were without hope, which forced them to think about a hastened death, as the following

statements show:

ID 9 "I want the illness to end quickly. My children are uncomfortable. (What is your definition of the ending?) It is death." # ".... Sometimes, a nurse used to say, 'What needs to be done if you go into shock?' (--It meant a cardiac arrest) I said that you did not have to pump me (--Cardiopulmonar resuscitation— CPR). Do not pump me. ...."

ID 13 "If I die, my relatives do not need to take time to look after me. It will be ended completely. Differently, the illness requires them to take care of me without knowing when it will be ended. Death can end this in short time."

# Category Three: Socio-Cultural Discomfort.

Socio-cultural discomfort relates to patient or family needs, involving unmet

interpersonal, family, and societal relationships. In this study, it is defined as: no

reporting/communication of existing discomfort, need for medical information, need for financial support, discomfort relating to the family system, and no talking with anyone (n = 20, f = 116). All of these are presented from the highest to the lowest number of occurrences one (see Table 30).

## Table 30

Frequency of Socio-Cultural Discomfort

| Socio-cultural discomfort                            | n  | f   |
|--|----|-----|
| No reporting/communication of existing discomfort    | 18 | 47  |
| Need for medical information                         | 14 | 34  |
| Need for financial support                           | 6  | 12  |
| Uneasiness expressing an opinion about existing care | 4  | 12  |
| Discomfort relating to the family system             | 5  | 10  |
| No talking with anyone                               | 1  | 1   |
| Total  | 20 | 116 |

Theme: No Reporting/Communication of Existing Discomfort.

In this study, the item--*No reporting/communication of existing discomfort* became the biggest socio-cultural discomfort of Thai older patients with advanced cancer. This statement showed that participants who were experiencing distressing symptoms did not report their symptoms to nurses or other healthcare providers due to several reasons (n = 18, f = 47) (see Table 31), ordered from the highest to the lowest

number of occurrences. Most of them reasoned that they did not want to disturb or

bother nurses who were already very busy and tired and worked very hard (n = 6,

f = 10); the patients were too afraid to ask (n = 5, f = 7), or the nurses, expected by these

participants to ask certain questions, did not do so (n = 4, f = 5). The statements

reflected the reasons of these participants, whose distressing symptoms were not

reported as follows:

ID 2 "I thought that this was my problem (personal/individual problem). I did not want to bother them (--nurses). No, I did not tell her (--about pain)" # "No, this was because I did not give her any information. I do not get them (--analgesics) today. I am not brave enough to request the medications."

ID 6 "I do not talk about this symptom with the doctors (including nurses). I think the problems of loss of appetites and nausea/vomiting are too minor to tell the nurses. The nurses have seen that I can not eat. They asked me how I was and whether or not I could eat. They only asked me; that was it. Actually, in my mind, I want them to ask me what I want to eat. This is an example. That is not possible."

ID 13 "No, I do not tell nurses about my sleeplessness. This is because it is only difficult to sleep, not related to the pain." # "Unh-unh. I do not talk with the nurses (--referring to worry about finance). They did not ask me. It is not the time for me to tell them."

ID 14 "I did not tell nurses about my inability to eat. Oh! No, I never told the nurses that I have not appetite. They did not do anything...."

ID 17 "Actually, I do not tell nurses (about the problems) because I fear that they will scold me. If I ask too much, they may castigate me." # "Ah, sometimes, I want to ask them but I could not catch them to ask. For example, on the day that a nurse gave me the medication for my itch. I was going to tell her but she walked away before. She went away before I could call her."

ID 20 "I did not tell them (--nurses) about my coughs. I have thought that my illness might not be so serious. Thus, I did not tell them (about the coughs) Krab (--a polite word), I think my symptom is not very serious. In addition, I am both considerate and not seriously ill."

# Table 31

| ThemeNo reporting/communication of existing discomfort   | п  | f  |
|--|----|----|
| Undesired to disturb/bother or being considerate to tell nurses (who were so busy and tired and worked hard) | 6  | 10 |
| Fear/no courage to ask   | 5  | 7  |
| No questioning from nurses   | 4  | 5  |
| Not knowing how to ask   | 2  | 4  |
| Uneasiness asking  | 2  | 3  |
| Nothing after reporting  | 2  | 2  |
| A quiet-life behavior (Keeping quiet)  | 2  | 2  |
| Other reasons  | 9  | 14 |
| Total  | 18 | 47 |

Frequency of the Theme--No Reporting/Communication about Existing Discomfort

*Note*. Other reasons: a minor problem, not a serious problem, fear to be castigated for talking too much, not having a chance to talk, nurses' sleep while on duty, going away before asking, as a temporary hospital resident, having been told not to worry about risks, nurses themselves should know the patient's needs because of their profession, nursing care should be provided without having to request it, and insufficiently developed relationship for talking—normal level

# Theme: Need for Medical Information.

Need for medical information was defined as the need for information of Thai older patients with advanced cancer relating to their illness: symptoms and conditions,

recovery or non-recovery, time to get well or recover, and treatment and its

function, such as uretherostomy. Fourteen participants indicated that they still did not

know about diseases or understood their symptoms, although they really wanted to

know and receive explanation (f = 34). They expressed their need for medical

information in the following ways:

ID 7 "I wish nurses would sit down and talk with me. (For what?) To consult about what I do not understand (about medical information and disease). (Information?) Ka (--yes)."

ID 9 "I do not know what happens at my neck, where I feel a pain." # "Ah, the kidney was already checked. But they still do not tell me anything."

ID 17 "..., they do not tell me anything. I think that this investigation might involve my difficulty breathing. They did not tell me anything." # ".... I do not know about my illness. Please tell me what my illness is" # "Uh-huh, about my head, I do not know what it is. Including the abdominal symptom, what is it? I still do not know what it is." # "..., I want them to talk with me more than they do. In addition, they should tell me if there is some information which I do not know." # "The thing that I want to know or ask about is symptoms and illness. I want to know how my illness has been developing since I was admitted"

ID 18 "Here, one doctor called my daughter and left the room. I asked her why the doctor called her; what the doctor talked with her about; and how serious my illness was. Please let me know what the doctor said. .... I thought in my mind all the time if I have a serious illness. I said with my daughter, 'Please let me know if my illness is serious or if it progresses to the third stage.'"

Theme: Need for Financial Support.

The statements that correspond with this theme: Need for financial support was

deemed insufficient or the patient received no financial support from the family or no

governmental subsidy. The findings revealed that there were six participants who had

financial problems (f = 12). They stated:

ID 6 "The money! My wife does not have it." # "The money given by my daughter only helps to maintain my living. It helps me maintain my life day by day."

ID 17 "There are some financial problems. Previously, they tried to gather money to bring me to come here. I do not know its details. To me, I have had no money. .... The insufficiency of money is our existing problem. ...."

One member of this group had no Thai identification number. This meant that

she could not receive the Gold Card from the Thai government. She and her husband

were very poor and earned their income by growing vegetables, and they had some

livestock for food. In addition, the sons of her husband (as the patient's step-in-law

sons) lost contact with their father and did not provide any support. She concerned

about the hospital costs and described her financial status by saying the following:

ID 19 "No, I do not have the Gold Card (for the medical cost from the Thai government). ..., I do not have it." # "Beyond growing vegetables and looking after a few chickens, I domesticate pigs. Uh-huh, there are two or three pigs." # "I look after the chickens (—hens) for food." # "His sons (--the patient's stepsons) has not helped with anything for several years. I know that they live in the Mae Kha area but I do not know where their houses are located."

#### Theme: Uneasiness Expressing an Opinion about Existing Care.

Uneasiness expressing an opinion about existing care was defined as discomfort if the participants verbally or nonverbally expressed that they did not feel able, were uncomfortable, or avoided sharing information/answering questions about the current nursing care that they received. They seemed to be too considerate or felt insecure to discuss the issue. Four participants expressed and produced this theme (f = 12). They stated:

ID 3 "(Do you have other discomforts?) I do not know how to explain it to you. (The patient knew what his discomfort was) (Do you have other discomforts?) I do not know how to explain it to you."

ID 5 "(..., what nursing care do you want? And, what is the nursing care which should be improved?) (Silence and no any answer from the patient). (..., what nursing care do you want but do not tell them about?) I do not know how to explain it to you. (.... Is this the second one that there should be someone who understands you and talks with you?) No, I do not want anyone. (No? What do you mean?) I do not know how to explain it. (Do you feel uncomfortable to talk about this issue?) I don't know how to tell you or to speak with you." (The researcher perceived that the patient was not comfortable to talk further and stopped the interview about this issue.)

ID 8 "(It seems that there is something which should be improved for the patient, doesn't it?) Well, for me it is difficult to say."

## Theme: Discomfort Relating to the Family System.

Based on the interview data, some discomfort relating to family systems

emerged. Five participants (f = 10) described their discomfort in a way that reflected the

idea that in the family unit, the illness of a family member impacted others, brought

about a change of family relationships, and facilitated a protective role of the patient for

other family members; it also expressed a preference for family visits. These statements

are given below:

ID 1 "If I am fine, they (--the patient's wife and son) will feel comfortable too. Conversely, if I am ill or will not be cured, there will be trouble for them."

ID 11 "I want them to visit me more frequently."

In addition, one participant accepted the fact that the relationship between the

wife and him, including their roles, has changed:

ID 13 "My family relationship has changed and it is different between staying at home and the hospital environment. When I am lying down, I think that, well, I lie in the hospital while my wife has to work."

Theme: No Talking with Anyone.

No talking with anyone was expressed by one participant (f = 1). She expressed and defined her most discomfort as "keeping quiet" because there was no one with whom she could talk or discuss her problem, as the below statement shows.

ID 16 "(What is your greatest discomfort?) This is, here, I did not talk with anyone and I worry about my house a little bit. Especially, I worry about my husband; thus, I told my sons to take care of their father."

# Category Four: Environmental Discomfort.

*Environmental Discomfort* is a statement reflecting unmet needs of the participants or families, which were related to: hospital setting, lack of knowledge about hospital culture (expected hospital behaviors or manners), loss of internal locus of control, and insecurity of personal belongings (n = 20, f = 58). These themes were shown from the highest to the lowest number of occurrences (see Table 32).

Table 32

| Environmental discomfort                 | п  | f  |
|--|----|----|
| Hospital setting                         | 11 | 31 |
| Lack of knowledge about hospital culture | 8  | 17 |
| Loss of internal locus of control        | 7  | 9  |
| Insecurity of personal belongings        | 1  | 1  |
| Total                                    | 20 | 58 |

# Frequency of Environmental Discomfort

## Theme: Hospital Setting.

Hospital setting reflected environmental discomfort related to the room (n = 8, f = 23), restrooms (unsatisfying, unacceptable, uncomfortable, and insufficient numbers) (n = 3, f = 7), and invisible nursing stations (n = 1, f = 1). The total number of participants who experienced environmental discomfort from the hospital setting and the frequency of this theme was 31 (n = 11). Each sub-theme is presented as follows:

# Sub-theme: Discomfort caused by the Room.

Discomfort caused by the room defined as *noise* (other patients' talking or shouting, many patients or visitors/relatives of other patients, coming from the outside of the room, the construction, or nursing carts) (n = 8, f = 9), many patients (n = 3, f = 3), many patients with or without their making environmental dirty (n = 1, f = 1), uncomfortable weather (n = 3, f = 5), uncomfortably bright light in the room (n = 3, f = 4), and pitying-look and moaning atmosphere (n = 1, f = 1). The quotations below illustrate these discomforts.

#### Noise.

ID 7 "There is some noise from the push-cart which is used all day; that is it." # "There is nothing besides the noise from the nursing cart which is used all day and night."

ID 11 "The noise just comes from the outside of this room. Sometimes, some patients talk to each other."

## Uncomfortable weather.

ID 3 "...at night, it was too cool. It is difficult to explain how cold it was. I am cold, too cold at night."

ID 5 ".... There should be...electric fans. They make the weather less hot and help patients be comfortable."

ID 4 "It is bright. Sometimes, I can not sleep."

ID 11 "I feel uncomfortable when there is no light. If the lights are turned off, it is not easy to see something. .... I still do not sleep at that time (when the lights are turned off). ...."

# Many patients (with or without their making environmental dirty).

ID 4 "I want to be in the quiet room. There are too many visitors. It is so loud."

ID 9 ".... In that room, there were several kinds of patients. They ate something with their hands and, then, swing the hands, which makes everything very dirty. The nurses complained about this untidiness. Hm! (pausing to think) I can not tell if it was dirty. Although there was a place to wash or clean their hands, including the hanging towel, they did not use it. They did not clean or scrub their hands after eating. They made oily spots and caused a bad smell. .... It was so greasy. It was dirty and full of urine. I felt uncomfortable because of this."

# Pitying-look and moaning atmosphere.

ID 2 "During staying in the hospital, I see only patients and health care personnel. I do not want to see these. I feel upset about their moaning. It is not the same (The patient compared between the hospital and the house.). I see persons who are lying on the beds. There are only patients."

One of them described several discomforts about the room.

ID 17 "It is so loud. .... Jow (--yes), its smell should be improved. It should be improved for good smell and cleanliness. It should be clean. It has many odors. .... Yes, the brightness makes it difficult to sleep for me."

# Sub-theme: Discomfort caused by the Restrooms.

Discomfort caused by the restrooms was defined as unsatisfying or

unacceptable, uncomfortable restrooms, and insufficient numbers of the restrooms

(n = 3, f = 7).

ID 8 "There is not a restroom in this room. Thus, I need to wait for the restroom. Sometimes, I really need to defecate but I need to wait in line. Yes. Yes. It is time to defecate, at which I can not sit down. Still, I need to only stand and try to control myself in order to be able to wait." # ".... Some restrooms are too narrow to cleanse my body." # "One unsatisfying thing is the restrooms." # "The unacceptable thing is the restroom."

ID 11 "There was some residue of the patient's vomit in the restroom. Some patients vomited in the restroom and they did not clean it. Often nurses complained about this problem. We did not know who did it. Sometimes, there were sanitary pads that were remained in the restroom. ...."

Sub-theme: Discomfort from the Invisible Nursing Station.

Discomfort from the invisible nursing station defined as a need of easiness to

call and contact with nurses at an invisible nursing station. There was one participant

expressed this interesting need (n = 1, f = 1).

ID 1 ".... When it gets dark, nurses are in their area while I am here. They are in their area, aren't they? Yes, they are. Sometimes when I feel sick, I need to call them. They answer me, 'Krab krab (--answering to acknowledge a call) and ask me, 'How are you?' "

Theme: Lack of Knowledge about Hospital Culture.

Lack of knowledge about hospital culture was defined by eight Thai older

patients with advanced cancer as insufficient or lack of knowledge and information

about the Rights of Patients and the hospital culture for effective care. The services that

the patient missed were nursing care, religious service, consulting service, quality of

care, and so on. They stated:

ID 6 "(What is the nursing care you want or can make you or the other patients satisfied? Or, what is the nursing care that is important to patients?) I do not know how to explain what care patients need."

ID 12 "(What nursing care do you expect to receive during this admission?) I do not know or can not imagine what expected nursing care is.

ID 14 "I do not know what religious activities should be arranged for support, laughing. Krab (--yes), I can not create support for religious activity right now. Unh-unh, I do not want anything." # "I can not know how to consult with her

(--a nurse). Krab, I can not know how to consult her. I have no issue to talk with her about. Krab, there is no issue to talk about." # "I do not want anything else."

ID 16 "Just a little bit. There is a little bit for dissatisfaction; and I can not tell certainly what it is (laughing)."

ID 20 "(Is there nursing care which you expected for this admission but are not getting it?) Nothing. (The patient did not know what he could request.)

Theme: Loss of Internal Locus of Control.

Loss of internal locus of control was defined as discomfort for Thai older

patients with advanced cancer by including into this definition lowering or losing

internal locus of control for the hospital environment contrary to the patient's

expectations. On the other hand, the hospital environment was observed to be controlled

by others, such as nurses or healthcare providers, as an external locus of control. In this

study, seven participants described a loss of internal locus of control for the hospital

environment with the following statements:

ID 5 "(What can you control or do in the hospital?) What I can do here! I do not do anything. Jow (--yes), only nurses turn off those lights. (Did they ask for your opinion before turning off the lights?) No. The lights are turned off at the time at which they think it is suitable to do so. (What is the usual time to turn off the lights?) At 8:00 p.m. Sometimes, it is about 8:00 p.m. ...."

ID 6 "As for the ability of the control in the hospital, although I say that I want TV, I have no TV. Where can I get it, a TV? Thus, I have to let the room be quiet."

ID 17 "Some nurses come here and turn off the lights. If they finish providing nursing care or cleaning up something, they sometimes turn off the electrical fans. Sometimes the temperature is hot if the nurses do not turn them on. …" # "…. At my house, I could watch TV. If I want to sleep, I would turn off the lights. Jow, if I want to watch TV or to sleep, I can do so. Uh-huh, I can not do what I want here. …."

Insecurity of personal belongings was defined as insecurity regarding the patient's personal belongings in the patient's room. It may become lost during cleaning of the room and changing of bed sheets. There was only one participant who described such an experience.

ID 8 "I do not want to keep a Buddhist image with myself for this admission. This is because I used to bring one Buddhist image along with me for the previous admission, in another hospital. Usually, I kept it under my pillow, in the pillow case. Then, the pillow case was sent for the laundry. I lost my Buddhist image. Now, to my wife, before she wants to sleep, she keeps her Buddhist images on the bed at her head level. For the previous admission, we were not careful enough and lost them."

In summary, most Thai older patients with advanced cancer of this study

experienced discomfort encompassing four contexts: physical-physiological discomfort (distressing symptoms such as sleeplessness and pain); psycho-spiritual discomfort (such as worry and/or fear, impact on the meaning of life, need of spiritual support, etc.); socio-cultural discomfort (such as no reporting/communication of existing discomfort, need for medical information, need for financial support, etc.); and environmental discomfort (such as discomfort relating to the hospital setting)

#### **Description of Comfort Domain.**

Comfort, defined as three categories based on Comfort theory of Kolcaba (2003), emerged from the interview data as the following: Relief, Ease, and Transcendence, in addition to a new category—Inadequate comfort. In addition, enhanced comfort of Thai older patients with advanced cancer who participated in this study was provided by three main groups of individuals: professional nurses, relatives, and the participants themselves, as defined by Health Seeking Behaviors (HSBs), including patient self care. Based on these findings (see Table 33), nurses mostly provided comfort in the form of *Relief* (n = 19, f = 177), *Ease* (n = 17, f = 58) and *Inadequate comfort* (n = 12, f = 32), respectively. However, nurses did inadequately support participants regarding *Transcendence* (n = 4, f = 6). Focusing on comfort care from relatives, similarly, the relatives mainly supported the patient regarding *Relief* (n = 18, f = 98). Individual participants needed to seek ways of how to provide comfort care for themselves (HSBs): providing *Relief* (n = 20, f = 197) and *Transcending* the self (n = 17, f = 53). Further, the findings showed that other patients in the same room could provide comfort care for each other (n = 7, f = 7). This presentation of data consists of four categories: Relief, Ease, Transcendence, and Inadequate comfort as displayed in Table 33.

Table 33

Comfort of Thai Older Patients with Advanced Cancer

|                            |                         | )             | Comfort care (CC)              |          |         |     |
|----------------------------|-------------------------|---------------|--------------------------------|----------|---------|-----|
| Comfort                    | By nurses (and setting) | (and setting) | By relatives                   | tives    | By HSBs | SBs |
|                            | и                       | f             | и                              | £        | и       | f   |
| Relief                     | 19                      | 177           | 18                             | 86       | 20      | 197 |
| Ease                       | 17                      | 58            | 7                              | 12       | 6       | 12  |
| Transcendence              | 4                       | 9             | 7                              | 8        | 17      | 53  |
| Inadequate comfort         | 12                      | 32            | б                              | 5        | 9       | 11  |
|                            |                         | n Comfe       | Comfort care by other patients | patients |         |     |
| Relief from other patients |                         | 7             |                                |          | L       |     |
| Ease from other patients   |                         | Э             |                                | 7        | 4       |     |
|                            |                         |               |                                |          |         |     |

# Category One: Relief.

*Relief* in this study was analyzed within four contexts and also defined by identifying four themes: *Physical-physiological relief*, *Psycho-spiritual relief*, *Socio-cultural relief*, and *Environmental relief* (see Table 34). Participants needed to take care of themselves regarding physical-physiological relief (n = 20, f = 133) and psychospiritual relief (n = 19, f = 58). Similarly, nursing care also mainly provided physical-physiological relief (n = 19, f = 58). Similarly, nursing care also mainly provided physical-physiological relief (n = 19, f = 58). Similarly, nursing care also mainly provided physical-physiological relief (n = 19, f = 159), whereas relatives focused on psycho-spiritual care and socio-cultural care (n = 14, f = 36 and n = 14, f = 40, respectively). However, the environmental relief was not provided by either the nurses or relatives. There were only three participants who tried to adapt themselves to obtain environmental relief (n = 3, f = 3), which was insufficient to help participants meet their needs of the total comfort. As the care in each theme was delivered by nurses, relatives, and/or the participants (HSBs), presentation of data is presented following this order of care providers and is displayed in Table 34-36 and 38-39.

Table 34

Relief of Thai Older Patients with Advanced Cancer

|   |      |                | Comfort | Comfort care (CC) |                 |      |
|---|------|----------------|---------|-------------------|-----------------|------|
| ComfortKeliel                             | By n | By nurses      | By rel  | By relatives      | By HSBs         | ISBs |
| 1   | и    | f              | и       | f                 | и               | f    |
| Physical-physiological relief             | 19   | 159            | 10      | 22                | 20              | 133  |
| Psycho-spiritual relief                   | 6    | 15             | 14      | 36                | 19              | 58   |
| Socio-cultural relief                     | 3    | 3              | 14      | 40                | ς               | С    |
| Environmental relief                      |      |                |         |                   | С               | 3    |
| Total                                     | 19   | 177            | 18      | 98                | 20              | 197  |
| Social relief from others                 |      | Other patients |         | H                 | Thai government | nt   |
| Ι   | и    |                | f       | и                 |                 | f    |
| Referring to other patients as helpers    | 7    |                | 7       | -                 |                 | -    |
| Financial support by the 1 hai government |      |                |         | 4                 |                 | 4    |
|   |      |                |         |                   |                 |      |

Table 35

Relief within Four Contexts of Thai Older Patients with Advanced Cancer

|                                |           |      | Comfort care (CC) | are (CC)     |      |         |
|--------------------------------|-----------|------|-------------------|--------------|------|---------|
| ComfortRelief                  | By nurses | rses | By rel            | By relatives | By F | By HSBs |
|                                | и         | f    | и                 | f            | и    | f       |
| Physical-physiological relief  | 61        | 159  | 10                | 22           | 20   | 133     |
| Professional care              | 12        | 23   | 1                 | 1            |      |         |
| Technical CC                   | 6         | 17   |                   |              |      |         |
| ADLs                           |           |      | 1                 | 1            | 4    | 4       |
| Hygiene care                   | 14        | 41   | 5                 | 7            | 11   | 13      |
| Food support                   | 6         | 18   | 9                 | 9            | 10   | 21      |
| Care for elimination           | 4         | 6    | ı                 | ı            | 10   | 15      |
| Care for movement/mobilization | 7         | 6    | 7                 | б            | 12   | 21      |

Relief within Four Contexts of Thai Older Patients with Advanced Cancer

|                                   |      |           | Comfort care (CC) | are (CC) |      |         |
|-----------------------------------|------|-----------|-------------------|----------|------|---------|
| ComfortRelief                     | By n | By nurses | By relatives      | atives   | By F | By HSBs |
|                                   | u    | f         | u                 | f        | u    | f       |
| Relief from Distressing symptoms: | 14   | 47        | 4                 | 4        | 19   | 59      |
| Pain                              | 11   | 32        | ю                 | б        | 13   | 22      |
| Sleep disturbance                 | c    | 4         | 1                 | 1        | 16   | 28      |
| Fatigue                           | 1    | 1         | ,                 | ı        | 2    | 7       |
| Tiredness                         | ·    | ı         | ı                 | ı        | 1    | 1       |
| Itching                           | 3    | S         | ı                 | ı        | 1    | 1       |
| Diarrhea                          | 1    | 1         | ı                 | ·        | ı    | ı       |
| Fever                             | 1    | 1         | ·                 | ı        | 1    | 1       |
| Cough                             | ı    | ı         | ı                 | ı        | 1    | 1       |
| Abdominal distension              | 1    | 7         |                   |          | 2    | 2       |

Relief within Four Contexts of Thai Older Patients with Advanced Cancer

|   |      |           | Comfort care (CC) | rre (CC)     |      |         |
|---|------|-----------|-------------------|--------------|------|---------|
| Comfort-Relief  | By n | By nurses | By re             | By relatives | By F | By HSBs |
|   | и    | f         | и                 | f            | и    | f       |
| Dyspnea/difficult breathing                           | 2    | 3         |                   |              |      |         |
| All conditions normal now (by HSBs)                   |      |           |                   | ĸ            | 1    | 1       |
| Psychological relief                                  | 6    | 15        | 14                | 36           | 61   | 58      |
| Psychological care by nurses                          | 9    | 10        |                   |              |      |         |
| Psychological care by relatives/friends               |      |           | 14                | 35           |      |         |
| Psychological care by HSBs                            |      |           |                   |              |      |         |
| Hope support (by positive thinking)                   | 5    | 5         | 1                 | 1            | 19   | 37      |
| Psychological care                                    |      |           |                   |              | 8    | 20      |
| Acceptance and understanding<br>the current situation |      |           |                   |              | 4    | 9       |
|   |      |           |                   |              |      | 1       |

Relief within Four Contexts of Thai Older Patients with Advanced Cancer

| Comfort care (CC) | By relatives By HSBs     | r n f n f | 3 4                 | 2 4                  | 1 2            | 1 1                     | 1 1           | 1 1                            | 1 1  | 1 1                               |
|-------------------|--------------------------|-----------|---------------------|----------------------|----------------|-------------------------|---------------|--------------------------------|--|-----------------------------------|
|                   | Comfort-Relief By nurses | n f       | Seeking information | Encouraging the self | Thinking alone | Preparation for a death | Keeping quiet | Changing the topic of thinking | Reminding the self about the advantages/consequences | Loss of internal locus of control |

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Relief within Four Contexts of Thai Older Patients with Advanced Cancer

|   |      |           | Comfort care (CC) | ure (CC)     |      |         |
|---|------|-----------|-------------------|--------------|------|---------|
| Comfort-Relief                                | By n | By nurses | By re             | By relatives | By F | By HSBs |
|   | и    | f         | и                 | f            | и    | f       |
| Socio-cultural Comfort care                   | ŝ    | Э         | 14                | 40           | £    | ŝ       |
| Providing medical information                 | 2    | 2         |                   |              |      |         |
| Family relationship support                   | 1    | 1         | 10                | 24           | 1    | 1       |
| Financial support from the family             |      |           | 9                 | 12           | 1    | 1       |
| Family support for things                     |      |           | 0                 | 4            |      |         |
| Keeping friendly relationship with nurses     |      |           |                   |              | 1    | 1       |
| Environmental context                         |      |           |                   |              | ŝ    | ŝ       |
| Avoiding to look dirty                        |      |           |                   |              | 1    | 1       |
| Accepting being together and noise from other |      |           |                   |              | 2    | 2       |
| Total   | 19   | 177       | 18                | 98           | 20   | 197     |

Physical-physiological relief was mostly provided by nurses and the individual participants (HSBs). First, the theme--physical-physiological relief—was provided by nurses and defined as *professional care* (defined as taking care, paying attention, and helping); *technical comfort care* (defined as nursing or medical procedures provided professionally, such as administering IV fluids, providing medications, preparation for the examination, or wound care); *ADL support*; *hygiene care*; *food support*; *care for elimination*; *care for movement/mobilization*; and *relief from distressing symptoms*.

The findings demonstrate that nurses provided comfort to relieve distressing symptoms and hygienic care more than any other care (n = 14, f = 47) and (n = 14, f = 41), respectively. Pain was the one distressing symptom that nurses were most interested in alleviating, more than other such symptoms (n = 11, f = 32). The nursing care for relief is presented as follows:

#### Sub-theme: Relief from the Distressing Symptom—Pain—by Nurses.

Relief of the distressing symptom—pain (mostly pain from the disease itself or wound-related pain)--by nurses was defined as: providing medications, treatment by the Pain Clinic (consulting service and providing strong analgesics by anesthesiologists), asking and encouraging the patient, providing medications and suggesting rest, consoling, calling, reporting, and consulting doctors, applying ointment, and suggesting that the patient report to the doctor directly. These are transcripts related to the subtheme of pain relief provided by nurses:

ID 7 "Regarding my pain, they provide care too. They nurse me. They will call a doctor to help me if they can not do anything for me. They take care of me. If

they can not do anything to help me, they call and consult a doctor." # "They will help me. If I have pain somewhere, they will give me medication. Or, apply an ointment with a massage. (By a nurse?) Ka (--yes). Applying the ointment and then massaging. If my relatives are here, my relatives will do it; if not, they (nurses) will do it."

ID 9 ".... Here, nurses who provided an injection console me that grand mum please was careful. .... The encouragement would help me not feel that pain. Over time, the perception of the pain did not matter to me."

ID 14 "To relieve my pain, nurses will apply this (Fentanyl) patch. They are the nurses on the ninth floor. The nurses are the persons who help me. Those nurses help me so much by giving me medications (--analgesics)."

ID 16 "They asked where I felt my pain. They asked if I had a pain, how my pain was, and how its severity was. They (--the nurses) help me relieve the pain."

Sub-theme: Hygiene Care Relief by Nurses.

Hygiene care provided by nurses is defined as a partial bed bath; a wet wipe; a

wet wipe for some areas of the body (such as the back); cleaning the body and rubbing;

shampooing; dressing or changing clothes; providing clothes; providing bed dressing;

preparing water for self-care. The participants described nursing care for hygiene as

follows:

ID 1 "In the late afternoon or evening, they (--nurses) help me change my clothes and provide a wet wipe for me.... They help me with dressing, a partial bed bath, ...."

ID 20 "I am on the bed. They usually prepare water for a wet wipe. A nurse (--a practical nurse) who is a man helped me to clean my back. That is the person who helped me. (The patient pointed to a practical nurse.). He still helps to provide a sponge bath on my back."

For some participants, nurses provided hygienic care for them only when their

relatives were absent.

ID 12 "Oh, supposedly, when my wife does not come to stay with me, Nurses will do it for me instead. They do care for me with pleasure. Such a sponge bath, they do it for me."

ID 18 "Ah, a group of nurses (--nursing personnel) provide a partial bed bath for me. Jow (--yes), I receive the partial bed bath from them. If I let the grand father (The patient called her husband.) do it, he can not do well because he is a man. They will come and provide a partial bed bath. ...."

Based on the interview data, the findings revealed that the participants had to seek and help themselves (HSBs) to meet their physical-physiological needs, or, if possible, alleviate or eliminate their discomfort, especially sleep disturbance and pain. In addition, the concept of self care in regards to movement/mobilization and food support also emerged in this study.

Sub-theme: Relief from Distressing Symptoms—Pain and Sleep Disturbance by HSBs.

Almost all of participants engaged in health-seeking behaviors to relieve distressing symptoms. The symptom that was mentioned the most was sleep disturbance (--sleeplessness and insufficient sleep) (n = 16, f = 28). The next less frequent symptom of distress was pain (n = 13, f = 22). First, relief from disturbed sleep was defined as reminding oneself or thinking about the advantage of sufficient sleep, asking for medications (sedatives), sleeping less over the day time, sleeping in the daytime, trying to stop thinking, trying to stop thinking and trying to get sufficient sleep, letting the time pass, telling a nurse, getting up and sitting down with or without talking to other patients, and quietly lying on the bed and turning the body left and right. They said:

ID 2 "I try to take a rest as much as I can. However, I do not want to sleep deeply because I worry that I may not be able to sleep well at night."

ID 20 "I told (the nurses) about sleeplessness at nights. Sometimes, I can sleep but, sometimes, I am sleepless...." # "If I have difficulty sleeping, I will get up and sit down. Sometimes, after sitting down, if I feel sleepy, I will sleep again."

The causes of pain mostly were diseases, wounds, or changing of positions. The

participants defined relief from their pain as calling or reporting symptoms to nurses or

doctors, holding/supporting the painful area, asking nurses for medications, calling a

nurse for medication by using an electrical bell, avoiding the cause of the pain,

adjusting to a certain position in order to urinate more easily, taking analgesics and

sleeping a lot, simply letting the pain occur, trying to understand the fact that he/she

cannot relieve the pain, taking the medications that were given to the patient, and being

careful about the function of the uretherosomy tube (the cause of the pain). They stated:

ID 11 "To relieve these pains, I take medications and analgesics. There are medications, analgesics, which relieve pain. To relieve the body ache, I take the medication and sleep. Sleeping is the only thing I do. It is better; so I need to sleep a lot."

ID 12 "I understand that they can not relieve the discomfort (the pain) because they need to investigate me by using sound (The patient referred to the ultrasound.) to find out what happens in my stomach." # "To solve the distressing symptoms, I let what will happen occur. Like when I was receiving the chemotherapy, I felt pain in this or that area. I let this pain occur."

ID 20 "To help myself to urinate more easily, I need to get up and support my buttock with a blanket to ease urination. This helps the stream of the urine to be expelled in a stream. .... Likewise, we pour water from the high level to the lower level."

The physical-physiological relief provided by relatives did not include much of

this type of care for participants. However, most of their care focused on hygiene care

(n = 5, f = 7), which referred to helping to go to a restroom or providing a sponge bath,

and offering food-related support (n = 6, f = 6) which referred to buying and bringing

food, cooking and preparing food, feeding, peeling fruit, and serving food. The

reports that illustrated this type of relief were as follows:

ID 2 "My wife did it (--a partial bed bath) for me. (Does she do everyday, in the morning and evening?) Krab (--yes)."

ID 3. "She (--the patient's daughter) comes and helps me to take a bath in the evening."

ID 18 "To comfort me, my daughter came to provide me with a sponge bath and gives me something, and prepares some fruits (--peeling) for me."

Theme: Psycho-Spiritual Relief.

Most psycho-spiritual relief was provided by the participants themselves (HSBs) (n = 19, f = 58). Relatives provided the psycho-spiritual relief (n = 14, f = 36) more than nurses did (n = 9, f = 15). The psycho-spiritual relief achieved by the participants themselves included two sub-themes that were defined as hope support (n = 19, f = 37) and psychological care (n = 8, f = 20).

## Sub-theme: Hope Support by HSBs.

Hope support, used by most participants as their HSBs, was the expectation or *hope to get well or recover* (n = 17, f = 21) and *hope to go home* (n = 6, f = 16). In addition, they also hoped to be able to care for themselves, which they could accept although the recovery could not return them to their full former ability in regards to working, living, and living a long life without serious illnesses. A belief in folk medicine as well as bargaining to do merit or to take care of the children or wife if they are fine was mentioned as well. Regarding their hope, the patients said the following:

ID 3 "Ah, I will go (stop speaking) to find a folk medicine. I will apply the medicine of Poo Change (called one elderly in the village who had knowledge and had practiced the methods for treating diseases and illness through family

generation) in my village. When the medications given to me by the doctor have run out, I will find and use this folk medicine. It will help me recover from my illness. It is the folk medicines in my village. I will let my daughter find it."

ID 7 "I hope ka (--as a polite word). I hope that if I can bargain, I will ask to survive for two more years (pausing) to do merit activities and to look after my children. It will be better if I survive longer. There is nobody (to support the patient's hope). I think for myself."

ID 8 ".... Towards the end, I do not hope for anything. There is only one thing that I hope for. That is, I only hope to recover. My hope is for recovery. The hope is for my recovery because of my pain. I came here because I had hoped that I will recover from my illness. ...."

## Sub-theme: Psychological Care by HSBs.

In this study, psychological care by HSBs is defined as accepting and

understanding the current situation, seeking information, encouraging oneself, thinking

alone, preparation for death, keeping quiet, changing the topic of one's thoughts, and

reminding oneself about the advantages or consequences. Most of the HSBs used for the

psychological care was accepting and understanding the current situation, such as

admission and staying in the hospital alone (n = 4, f = 6). They stated:

ID 8 "I feel that I am old. The time had come for me to be admitted. I used to talk with my guys, 'Previously, we resided in the world. But now diseases reside within our bodies.' (The patient used two Thai words—"Roke" as a disease and "Loke" as the earth--which have the similar sounds in his statement.)" # "However, doctors and nurses have the opportunity to help each patient a lot. How much can they help? They can provide much help. However, it also depends on the state of my body. They want to help me a lot but my body does not fully respond to this help. So, how can they help me? .... But if I do not get well, this is inevitable for me. They try very hard to help me. I can accept the results (--of the treatment: the chemotherapy and elective surgery).

ID 11 "My bleeding makes me think that my diagnosis may be a cancer. The elderly (in the patient's village) who was diagnosed with cancer used to have the same symptom. I also asked some villagers who visited me at this hospital...."

#### Theme: Socio-Cultural Relief.

Socio-cultural relief had seven sub-themes: providing medical information, financial support from the family, family relationships, family support for things (such as food or something for ADLs), keeping friendly relationships with nurses, referring to other patients, and financial support from the Thai government (see Table 35). The findings appeared to show that the relatives of participants became important care providers because most socio-cultural relief was provided through them (n = 14, f = 40), whereas nurses and the participants themselves were equally involved this theme, although this is true for only three of them (n = 3, f = 3). The main relief provided by relatives is defined as family relationships and financial support. The relief provided by nurses (including the doctors) was providing medical information and family relationship support. According to the HSBs, three participants maintained family relationship, received financial support from the family, and kept friendly relationships with nurses, reflecting their socio-cultural comfort.

First, the sub-themes related to the care offered by relatives: family relationships and financial support are presented.

## Sub-theme: Family Relationship Support by Relatives.

This theme--family relationship support provided by the relatives—was defined as how the participants' relatives maintain family relationships between the participant and themselves during the participants treatment at the hospital while not being able to be with the participant at all times. Sometimes, their neighbors collaborated to assist them to maintain the relationship. This care was defined as visiting (by spouses or children), calling and providing encouragement (by spouses, children, or the sister), and getting family information from relatives (for example, through the niece). The participants gave the following statements:

ID 6 "On that day, she visited and mont two or three

ID 6 "On that day, she visited and spent two or three nights here. My wife came to visit me too." # "They encourage me well. Only one daughter visited me. The older daughter stays and works in Had Yai (an amphur of the province in the south of Thailand). (However) She called and talked with me."

ID 11 "They alternate and visit me two times per day." # "All children come and visit me. My son who works in Pitsanulok province will visit me on the sixth or seventh. He calls and talks with me periodically." # "During this illness, I talk with everyone. They call and talk with me. They always talk and ask how much I can eat and what the doctor said to me about my illness."

Sub-theme: Financial Support by Relatives.

Financial support by relatives was defined as paying for the additional costs of

health care, paying for other expenditure related to the illness, encouraging and

proposing payment of the parent's debts, and providing some or sufficient money for

living expenses. Six participants mentioned financial support as relief they received

from their relatives (f = 12). The statements related to this theme were the following:

ID 11 "I receive enough money to sustain myself and some for saving. It is enough to pay and save to do merits and alms, sufficiently for me. Uh-huh, I have no financial problems. The financial situation of all of my children is fine. Someone's salary is not much. I said she or he does not need to give me money; I have money. However, later, she or he still wants to give me to pay for myself."

ID 17 "There are some financial problems. Previously, they tried to gather money to bring me here. I did not know the details. To me, I have not had any money. Thus, they bought something and brought food for me. Usually, my daughter who stays with me does pay for me. She keeps money collected by my other children for me. It is not much. One son (who is an attorney), he helps and shares the money too. ...." In this study, the additional findings showed that the participants mentioned

financial support offered by the Thai government (n = 4, f = 4).

Sub-theme: Financial Support through the Thai Government.

Financial support from the Thai government mentioned by the elderly Thai

group in this study was defined as the 500-Baht subsidy under the Social Welfare

Program (n = 1, f = 1); the 30-Baht subsidy or the Gold Card (n = 2, f = 2); and a fringe

benefit from the participant's son or daughter who works as a governmental employee

(n = 1, f = 1) (see Table 34). The elderly patients said:

ID 8 "I can get the healthcare subsidy from Thai government (as a fringe benefit from his daughter)."

ID 11 "I receive 500 baht because of the subsidy."

ID 15 "My financial status is not affected by my illness. This is because I did not work and have no responsibility for the financial status of my family. My wife and my children, they usually work. The costs of the illness do not affect the expenditure. There is no additional cost because I use the Gold Card, which pays for all my expenses."

Next, the presentation focuses on relief provided by nurses and doctors.

Sub-theme: Providing Medical Information.

Nurses (and doctors) providing medical information was defined as providing

explanations and visiting with the patient as well as sharing knowledge of disease and

treatment (n = 2, f = 2). The participants said:

ID 15 "The visits by doctors and nurses help me know more about the progress of the remedy."

ID 17 "They treat me by using radiotherapy. They explained to me that there still was a small-size mass. It is a small mass. They said they could control this mass. They could control it."

Sub-theme: Family Relationship Support by Nurses.

Nurses helped to maintain the family relationship (n = 1, f = 1). The participant defined family relationship care provided by nurses as greeting, talking with and educating relatives about how to take care of the participant. The following are statements made by the participant:

ID 1 ".... Previously, the nurse said that if my relatives visited me, they would teach them how to prepare a blenderized diet for me.... My wife said that it was good for me if she came to visit. The doctors and nurses feel proud. They worry about my food, which would be prepared by my wife for me at home. The nurse met with my wife and taught her step by step...."

Regarding relief from the participants, there were three sub-themes.

Sub-theme: Family Relationship Support by HSBs.

There was one participant who shared her experience of how to maintain a good

relationship of her family (n = 1, f = 1). She defined it as avoiding conflict between the

families. The following quote demonstrates this:

ID 4 "We do not talk about anything that could cause conflicts.... We do not

have any conflicts."

Sub-theme: Financial Support by HSBs.

Similarly, only one participant comforted himself by understanding the situation

and limitation of support although he received insufficient financial support from his

daughter (n = 1, f = 1). He expressed the following:

ID 6 "The money I get from my daughter only helps me to maintain for my living. It helps me maintain my life day by day.... Will she give me money the way I gave her money? No, it is possible.... It is common that the daughters cannot help me as I did.... I am not upset about her limited help."

Sub-theme: Keeping Friendly Relationships with Nurses.

Keeping friendly relationships with nurses was mentioned by one participant (n = 1, f = 1). He kept up a good relationship with healthcare providers—the nurses—by speaking nicely with them, as the following statement shows:

ID 1 "I try to be nice with them. I speak to them nicely."

Theme: Environmental Relief.

In this study, environmental relief was not offered by the nurses or relatives.

Three participants needed to adapt themselves to the hospital environment. Therefore,

the environmental relief was mentioned in terms of the HSBs definitions and was

defined as avoiding to look dirty (n = 1, f = 1) and being accepting of the proximity of

others and their noise (n = 2, f = 2). They stated:

ID 6 "The sound of the room is accepted. It is common to stay among many patients."

ID 9 ".... There was dirty and full of urine on the floor. How could I do? I could not do anything to that dirt, only avoiding looking at that. (The patient referred to the former patient's room. Later, the patient was moved to the current room in which she felt more comfortable.)

ID 13 "Sometimes, there is some noise from other patients. If I have pain, I would make some noise too. I think that it is taking turns among patients (--making noise). ...."

Theme: Reference to Other Patients.

Interestingly, reference to other patients was mentioned as well (see Table 33).

Seven participants demonstrated that other patients in the same room collaboratively

provided comfort for each other as helpers, counselors, or conversation partners and

friends.

ID 1 ".... In addition, the patients help to take care of each other.

ID 7 "(Here, when you are stressed, whom do you talk with?) I talk with the patients who lie next to my bed."

ID 14 "Apparently, the patient beside my bed suggested me to use it (--the electric bell). I needed to learn how to use it from that patient. He suggested me to press, ... to press the electrical bell to call a nurse to come to me. "

Besides participants receiving help or comfort from other patients, one of them

(ID 14) saw himself as a helper of other patients. He stated:

ID 14 "I can ... and help another patient. The patient beside my bed cannot walk. I brought him to the restroom. .... If I have no abdominal pain, I can help him." # ".... Then, I help some patients."

#### Category Two: Ease.

*Ease* is a state of contentment that reflects a feeling of comfort or a perception that in this study is defined as being satisfied, feeling comfort/more comfort/psychological comfort, happiness or warmth, being glad/pleased, being fine/okay/all right, feeling good, and feeling more than one type of ease (see Table 36). In addition, *ease* also included the conditions of participants whose symptoms disappeared or the participants became stronger and able to do more activities because of nursing care or comfort care. The same as for relief, the comfort of *ease* was provided by three main groups of care providers; those were nurses (n = 17, f = 58), relatives (n = 7, f = 12), and the HSBs (n = 9, f = 12), as well as other patients (n = 4, f = 4). Interestingly, *ease* provided to the participants by these three main groups mostly emerged as feeling comfort or more comfortable. Nurses were the most important providers of care related to the concept of ease. Furthermore, the hospital setting also made the participants feel ease. To better understand this, the concept of *ease* used in this study will be presented based on the group of providers, not by the comfort contexts in Table 36.

Table 36

Ease of Thai Older Patients with Advanced Cancer

|   |           |       | Comfort care (CC) | tre (CC)     |       |         |
|---|-----------|-------|-------------------|--------------|-------|---------|
| Comfort—Ease  | By nurses | Irses | By re             | By relatives | By F  | By HSBs |
|   | n (17)    | f(58) | n (7)             | f(14)        | n (9) | f(14)   |
| <i>Being satisfied</i> (from paying the attention for care, calling and telling what the patient's needs were, etc.)      | 2         | 4     |                   |              |       |         |
| Comfort/more comfort/ psychological comfort:  | 8         | 13    |                   |              |       |         |
| Talking/speaking nicely   | З         | 9     |                   | ~            |       |         |
| Overview from admission   | ю         | ŝ     |                   |              |       |         |
| Providing medication, food, or hygiene care   | 1         | 3     |                   |              |       |         |
| Familiarity and paying the attention of nurses  | 1         | 1     |                   |              |       |         |
| <i>Happiness or warmth</i> (providing sponge bath; taking care; talking, reporting, and consulting with the doctor, etc.) | 9         | 10    |                   |              |       |         |
| $Being\ glad/pleased$ (talking and suggesting to tolerate or being admitted and providing vaginal care)                   | 7         | ŝ     |                   |              |       |         |
| <i>Being fine/okay/all right</i> (providing medications or suggestion to eat to relieve vertigo)                          | ŝ         | ŝ     |                   |              |       |         |

Table 36 (continued)

Ease of Thai Older Patients with Advanced Cancer

|  |           |       | Comfort care (CC) | tre (CC)     |       |               |
|--|-----------|-------|-------------------|--------------|-------|---------------|
| Comfort—Ease   | By nurses | Irses | By re             | By relatives | By F  | By HSBs       |
|  | n (17)    | f(58) | n (7)             | f(14)        | n (9) | <i>f</i> (14) |
| <i>Feeling good</i> (saying apology of nurses, providing treatment, or fresh weather for walking in the morning) | 2         | 4     |                   |              |       |               |
| Disappearance of distressing symptoms (pain or dizziness by providing medications)                               | 4         | S     |                   | ×            |       |               |
| Enhancing other activities (such as sleeping from pain relief or being proud of receiving comfort care and food) | 7         | 7     |                   |              |       |               |
| Being comfortable or psychological comfort (from visits, calls by phones, talking, consulting, etc.)             |           |       | S                 | S            |       |               |
| <i>Happiness</i> (from hope support and talking with relatives or the children, visiting, etc.)                  |           |       | 7                 | 7            |       |               |
| Warmth (from the good family relationship)   |           |       | Ι                 | Ι            |       |               |
| $Being\ glad/pleased$ (from encouragement of the wife or talking with the niece)                                 |           |       | 7                 | 7            |       |               |
| <i>Being good or okay</i> (from relative visiting or taking with the son about the niece)                        |           |       | 7                 | 2            |       |               |
| <i>Feeling fresh</i> : (from nourishing the self by eating food, getting sleep, and walking)                     |           |       |                   |              | Ι     | 7             |

.

Table 36 (Continued)

Ease of Thai Older Patients with Advanced Cancer

|   |                | 1     | Comfort care (CC) | ure (CC)     |                |              |
|---|----------------|-------|-------------------|--------------|----------------|--------------|
| Comfort—Ease  | By nurses      | urses | By re             | By relatives | By H           | By HSBs      |
|   | n (17)         | f(58) | n (7)             | f(14)        | n (9)          | f(14)        |
| $Being\ comfortable\ (from relieving\ distressing\ symptoms:$ dyspnea, anal pain, etc.)       |                |       |                   |              | S              | 6            |
| $Being\ comfortable\ (from the acceptance of being together in the same room)$                |                |       |                   | i,           | Ι              | Ι            |
| $Being\ happy$ (from encouraging the self: hope on the lottery winner or from the surgery)    |                |       |                   |              | 7              | 7            |
| <i>Being fine/okay/all right</i> (from telling nurses and eating rice to relieve the vertigo) |                |       |                   |              | Ι              | 7            |
| Multiple types of ease  | 6              | 14    | 2                 | 7            | Ι              | Ι            |
| Comfort-Ease  |                |       |                   | Other I      | Other patients |              |
|   |                |       | и                 | n (3)        | f(             | <i>f</i> (4) |
| Being happiness/warmth (as a friends of talking)  |                |       |                   | 1            |                | -            |
| Being comedy and happy (as satisfying friends of talking)                                     |                |       |                   | 1            |                | 1            |
| Being glad/pleased or good and comfort (from the help of other patients)                      | ther patients) |       |                   | 1            |                | 7            |

Theme: Ease by Nurses.

Based on the content analysis, there were eight sub-themes of ease that emerged from nursing care (see Table 36). However, the findings revealed that there were only three dominant kinds of ease emerging from nursing care. These were comfort/more comfort/psychological comfort (n = 8, f = 13); happiness or warmth (n = 6, f = 10); and disappearance of distressing symptoms (n = 4, f = 5).

Sub-theme: Comfort/More Comfort/Psychological Comfort by Nurses.

Comfort/more comfort/psychological comfort provided by nurses is defined as

talking (with nurses or with the researcher), asking/talking/suggesting by speaking

nicely, talking and joking, encouraging and providing support hope, and providing

medications (IV fluid) or food. The participants stated:

ID 13 "Nursing care which *produces comfort* to me is the providing of caring and curing. When I have a symptom, they give me medications, bring something for me to eat, and ask me how I am."

ID 11 "The results of care made me feel *physical comfort* in regards to my illness and experience *comfortable sleepiness*. In addition, they talked with me to convince me to eat a lot, to bless to get the recovery, and support me not to think about anything to make *my mind comfortable*. I told a nurse about my sleeplessness. She said that the IV fluid could help me. So, it was given to me continuously (--bag by bag). She told me to take care of my *psychological comfort*, and that I would recover. ...."

Sub-theme: Happiness or Warmth by Nurses.

Happiness or warmth provided by nurses was defined as providing a sponge

bath, talking and reporting or consulting with the doctors about the patent's symptoms,

and persuading talk in the form of psychological comfort by way of speaking in a

friendly manner. The statements reflecting this type of ease is presented in the

following excerpts from the transcripts:

ID 7 "If I have diarrhea, they consult a doctor to talk about a medication that I might need. If I have heavy chest pain, they provide care for me the same way. If I have this burning pain symptom (from the cystitis), I will tell them. They will report this to the doctor. ...."

ID 11 ".... I feel happy when talking with them (--the nurses)."

ID 13 "About nursing care, I am happy with this nursing care. They take good care of me krab (--a polite word). They come to take care of me or cure me. They give me medications and help me take these medications." # "The providing me with a sponge bath makes me happy."

Sub-theme: Disappearance of Distressing Symptoms by Nurses.

Disappearance of distressing symptoms was one of the outcomes of the nursing

care that was also classified as ease comfort (Kolcaba & DiMarco, 2005). This type of

care was mentioned by four participants of the current study (f = 5). Nursing care,

including other treatments from other healthcare personnel during the treatment period,

alleviated the distressing symptoms to disappear such as pain or dizziness. The

participants stated:

ID 17 "If I get dizzy, I take the oral medication which they give me. As a result, my dizziness disappears. They gave me injections too." # "Sometimes, the symptom (difficult breathing) *disappears* by itself. Or, it *disappears* after taking some medications."

ID 18 "Currently, I *have no pain* (in the chest and shoulder). There was pain only on the day of the lumbar puncture."

Sub-theme: Ease Related to the Hospital Setting.

The participants noted the fact that some characteristics of the hospital setting

could help them gain a state of greater ease (see Table 37). Most of these characteristics

involved the patients' rooms (n = 13, f = 21). They defined ease by relating to the setting as feeling good, comfortable, or being satisfied with the comfortable room, standard room, good bed, good bed sheets, no smell, cleanliness, standard level (of the hospital services), environmental convenience to use, having enough space and ventilation, having a quiet room, and having fresh air in the room. The *ease* provided by the hospital setting emerged as follows:

ID 1 "Ah, I *am satisfied with the bed, mattress, and bed sheets*. They are the best for me. .... They make it comfortable for me."

ID 8 "I feel that this building is sufficiently accessible. It is easy to go in and out. It is comfortable. It is convenient to go anywhere. In the room, it is comfortable for me. ...."

ID 9 "The environment, that is good. The place is good. The thing that I like is the cleanliness. I like it because it is clean and neat. .... The hospital is quiet. As for noise, this room is good. .... *No noise at night*. There is no dissatisfying thing in the hospital. Here (--this room) is good."

Table 37

Environmental Comfort of Thai Older Patients with Advanced Cancer

|  |              |            | Comfort care (CC)  | re (CC)      |            |       |
|--|--------------|------------|--------------------|--------------|------------|-------|
| Comfort— Environment   | Relief       | ief        | Inadequate comfort | e comfort    | Ease       | se    |
|  | и            | f          | и                  | f            | и          | f     |
| Hospital setting   |              |            |                    |              |            |       |
| Everything in the hospital: good   |              |            | 1                  | 1            | -          | 1     |
| Hospital service: moderate, acceptable, or good  |              |            |                    | L.           | 3          | 4     |
| Hospital environment: good or fresh  |              |            |                    |              | 8          | 6     |
| Hospital location/place  |              |            |                    |              | 3          | б     |
| Rooms: comfortable room, no smell, cleanliness, standard level of hospital services, environmental convenience, etc. |              |            | 1 (a)              | 1            | 13         | 21    |
| Restrooms: relief (1); inadequate: not too far for walking or better (2), or good [1]                                | 1            | 1          | 2                  | 2            | 1          | 1     |
| HSBs for the environmental comfort (b)   | 3            | 3          |                    |              | 5          | ٢     |
| Note. (a) a few-bed room was better than the multi-bed room; and (b) HSBs for the environmental comfortcase (6[10]   | room; and (ł | ) HSBs for | r the environr     | nental comfo | ortease (6 | 5[10] |

repeated cases): accepting to be together (2[2]), avoiding looking the dirty (1[1]), and ability of external locus of control

(5[7])

#### Theme: Ease by Relatives.

There were five sub-themes of ease that emerged: being comfortable/ psychological comfort, happiness, warmth, being glad/pleased, being good/okay, and feeling more than one type of ease or emotion. The feeling of comfort/psychological comfort was primarily mentioned (n = 5, f = 5). It arose from the relatives' care, such as visits, calls by phone, talking, consulting, seeing the children, or giving of money. The participants stated:

ID 7 "(Shortly before, you said about your children. Do they comfort you in this hospital?) Yes. (What comforts you?) They *visit me, coming both in the morning and evening*. If they can not come, then they will call me. They encourage me and remind me not to eat spicy food or other certain kinds of food. They let me tell them what I want or like to eat. Mostly, I refuse (any needs) because I have no appetite right now."

ID 8 "Mostly, we, my wife and me, consult each other.... I always discuss my worries with my wife. I *feel comfortable after talking with my wife*. She says that everything depends on my decision. She follows my determination."

#### Theme: Ease by HSBs.

Beyond the concept relief, the participants still needed to find ways of how to provide ease for themselves. The sub-theme of *being comfortable* was stated more frequently than any other feeling (fresh, happy, fine/okay/all right, and proud) (see Table 36). The care provided to the participants made them feel content and comfortable, which relieved distressing symptoms: dyspnea was relieved by taking a rest, and pain was relieved by lying down and supporting positions; disappearing of the symptoms (anal pain); releasing mucus from the body; or ability to care for oneself (eating, walking, and sleeping). Participant responses that address this care and comfort–ease– are given below. ID 6 "When sleeping, I need to support my back with a blanket. Ah, this Current position may be too high for sleeping. If I lie in a good position, I will *Feel comfortable*. If the lying position makes me uncomfortable, I need to support my back."

ID 8 "I have not had any diarrhea. But my stool contains some contents and mucus. After receiving radiotherapy, it is about 11:00 p.m. or midnight, at which time the mucus usually comes up from my anus. Then, *I will feel comfortable*."

Theme: Ease by Other Patients.

The finding also revealed that other patients in the same room helped and

provided comfort for each other. The comfort participants received from other patients

and described was related to having a friend they could help and talk with, as the

following responses show.

ID 3 "Sometimes, there was another elderly patient. I asked for his help. *I was pleased with his help*." # "(Uncle, how about this room?) *Good*. There is someone who helps me."

ID 13 "If I am unhappy, I like to speak with the satisfying patients. We stay and talk together, which entertains us and gives us *happiness*.

In addition, some participants revealed that they felt ease in more than one way

or type of ease. Three sub-themes that emerged were classified by providers, including

nurses (or other healthcare personnel) (n = 6, f = 14), relatives (n = 2, f = 2), and the

individual him-/herself (HSBs) (n = 1, f = 1) (see Table 36).

Sub-theme: Multiple Types of Ease by Nurses.

The sub-theme--Multiple Types of ease by nurses--was a statement which

reflected that nursing care helped participants experience two or more types feelings of ease. These feelings were: feeling good, comfortable, familiar and comfortable with the healthcare personnel, satisfied, fine, relaxed and entertained, proud, and full of happiness (from providing IV fluid or analgesics and servicing a bed pan). In

addition, some feelings of ease originated in the convenient hospital setting or location.

The responses reflect a number of different nursing care-related feelings:

ID 9 ".... Before admission, I was afraid to be brought to another hospital. I do not know anything and can not tell you about my feelings (—fear) exactly. .... Ah, I can not tell you exactly what I was afraid of. *Here is comfortable for me. I feel familiar and, ah, feel comfortable.* My fear was that I would be sent to a place with which I was not familiar. How can I tell you correctly? The reason is the same as I told you before. I experienced to see the other patient with whom the nurse spoke with vulgarity."

ID 11 "The administering of the intravenous fluid makes me feel good or comfortable."

Sub-theme: Multiple Types of Ease by Relatives.

Two participants experienced ease more than one feeling, which resulted from

their relatives' caring (f = 2). Their ease emerged as: comfort, happiness, symptom

disappearance, and/or feeling better. These are some of the responses reflecting ease:

ID 17 ".... Sometimes, I have some dizziness. I let my daughter pat my head. *My daughter's massages make me better and feel more comfortable*. Such as the spasm in my legs, the massages also *make it disappear*."

ID 20 "I talked with my children (about my worry). After talking, *I felt comfortable*. If I did not talk with them, I would not be comfortable. If I talked, *I would happy*."

Sub-theme: Multiple Types of Ease by HSBs.

Multiple types of ease by HSBs were defined as being proud of oneself and

feeling good because of the meditation practice. This quote came from the eleventh

participant (n = 1, f = 1).

ID 11 "In the hospital, I do meditation before sleeping. I take a long time to meditate. The meditation helps me be *proud of myself, be comfortable, and sleep comfortably.*"

### **Category Three: Transcendence.**

Transcendence is a statement that reflects the ability of each participant to rise above existing discomforts when they cannot be avoided. In this study, the findings showed that religious beliefs and practice were the most important action, and were mostly used for the transcending stressful circumstances. Most of the transcendence was initiated by the individual participant (HSBs) (n = 17, f = 53) (see Table 38). However, the nurses and relatives collaborated in their support for the participant's transcendence, (n = 4, f = 6) and (n = 7, f = 8), respectively. Based on these providers, the concept of transcendence that emerged was classified into three themes.

### Theme: Transcendence by Nurses.

The participants defined the nurses' activities that supported transcendence during illness or discomfort as suggesting a Buddhist way of thinking, such as futility of thinking about the obvious occurrence, encouraging the patient to come to a conclusion, blessing or praying for the patient's recovery, providing religious activities in the wards, and providing information about religious sites in the hospital. The following responses showed the nurses' support of transcendence-related comfort.

ID 1 "They supported me and told me that what's done is done. It was not useful to think about it. I answered them, krab (--a polite word). To protect me from thinking too much, they said 'Do not worry or think a lot about your illness. It is not useful for yourself or your health.' They also said they had the responsibility to provide care for me. So, thinking a lot about an illness which has already occurred would not be useful for me."

ID 7 "Nurses persuaded me to talk. They said that I had a fresh outlook and enough bravery to face the situation. They gave me an example of how stress could happen to everyone. They suggested to me that I should not be stressed and try to come to a conclusion....The doctor told me that my disease was not cured. As a human being, we die only one time. I do not mind when it will occur. My age is old; that is how I think. I do not worry about my descendants. They all are happy." # "The nurses, they said: Aunt, please fight and fight for yourself."

Theme: Transcendence Provided by Relatives.

The relatives supported the participants' transcendent attitude. These

participants referred to the transcendence support provided by their relatives as

collaborating to practice Yorae, bringing food and offering it to the monks on behalf of

the patient (This was done by the participant's daughter.), vowing for the participants,

engaging in meritorious actions (by the relatives or son), and praying for the patient

(done by the patient's wife). They stated:

ID 4 ".... My niece visited me with some desserts and fruits such as mangosteens. Then, I lifted them up to touch my forehead for blessing." # "She helps me by bringing food and fruits to the monks for me. Although I can not do it by using my own hands, I can raise these things to touch my forehead (to reflect the patient's respect) before it is given to the monks."

ID 14 "When the grand mother (--the patient referred to his wife) comes here, we practice it (—Yorae), not often. Krab (--yes), she encourages me to do it." The patient's wife said, 'You should make your mind happy.""

ID 15 "Well, this is, this (--The participant referred to a religious support) seems to occur when my wife comes here. She makes a vow in the morning and evening. Krab (--a polite word). She can vow here because the vow does not need a concrete ceremony."

ID 17 ".... In addition, my daughter buys something, I use it to make a vow and then she will offer it to the monks (putting food in the alms bowls of individual monk). In addition to offering food to monks, my daughter does meritorious deeds and gratefully recognizes my parents, done in this way."

Table 38

Transcendence of Thai Older Patients with Advanced Cancer

|   |           |       | Comfort care (CC) | are (CC)     |         |      |
|---|-----------|-------|-------------------|--------------|---------|------|
| Comfort— Transcendence  | By nurses | Irses | By re             | By relatives | By HSBs | ISBs |
|   | u         | f     | и                 | f            | и       | f    |
| Transcendence by nurses (suggesting a Buddhist way of thinking, encouraging the patient to come to a conclusion, etc.)  | 4         | 6     |                   |              |         |      |
| Transcendence by relatives (collaborating to practice<br>Yorae, bringing food and offering it to the monks on behalf of<br>the patient, vowing for the participants etc.) |           |       | L                 | 8            |         |      |
| Transcendence by HSBs (perception and acceptance of the current illness and the factual future conditions of illness, thinking and practicing based on Buddhist precepts) |           |       |                   |              | 17      | 53   |

Transcendence by HSBs is most important to face existing distressing

symptoms. Seventeen participants defined this concept as *perception and acceptance of the current illness and the factual future conditions of illness; thinking based on* 

Buddhist precepts: the two choices of the life for possible outcomes (--death or

recovery), death as an inevitable experience, being at the presence, thinking and letting

that which will be occur; and religious belief, faith, and practice: Wai Pra or paying

respect to sacred things, worshipping, blessing, praying, meditation, vowing, and doing

merits for good results in future. In addition, this concept was defined by participants as

Karma, detachment and letting things occur, having hope, letting the daughter do

meritorious activities, and the practice of Yorae. The statements provided by the

participants described transcendence as the following:

ID 1 "(Please let me ask you, 'Have you ever thought about the death? And, have you ever feared death?') No, I have not. *Having life and being dead is an experience which everyone has to face. Everyone is born and, then, has to die.*" # "I told him (a male nurse) that I respect the Buddha image and worship. Then, sometimes, *I pay respect to thank my parents to demonstrate my gratefulness.*"

ID 2 "Sometimes, *I make Samadhi* (a term for meditation) and pray. Sometimes, I also bless myself. I bless myself to get better from the pain and from my illness day by day. (Do you decide to bless yourself?) Krab (--yes). *I also pray for my good health* and to be able to do my job as usual."

ID 7 "Uh-huh, in the hospital, *I do Wai Pra everyday*. *I pray everyday*.... *I only pray and pay respect in my mind*."

ID 14 "Uh-huh, sometimes I did 'Yorae'. Unh-unh, I did it because only taking the analgesics cannot eliminate my pain at all."

ID 18 "When I get up and look at my face, it is so edematous. I pray, "May my face descend, may my face collapse." Jow (--yes), I do pray when I think about

my face. Jow, *I do meditation to bless* my smaller face. *I say NaMo* (Buddhist term used before doing religious activities). ...."

#### **Category Four: Inadequate comfort.**

*Inadequate comfort* is a statement reflecting care from professional nurses or other healthcare personnel (including partial comfort responding to the hospital setting and environments), relatives, or the participant him/herself could not eliminate all discomfort of the participants or could provide only insufficient comfort for them. In this study, *inadequate comfort* was defined as feeling better, not feeling as good as the participant wished, moderate comfort, a small amount of comfort, and being a little bit dissatisfied (see Table 39). Regarding the concept of feeling better, it emerged mostly as care provided by nurses (n = 12, f = 32). The care provided by relatives and HSBs did not greatly produce inadequate comfort, which was described by three of the participants as care by relatives (n = 3, f = 5) and six of them for the HSBs (n = 6, f = 11). Thus, the themes were presented by the providers (see Table 39).

Theme: Feeling Better from Nursing Care.

*Feeling better from nursing care* was facilitated by alleviating distressing symptoms, technical comfort care, and the hospital setting (room (s) or weather). The following quotes reflect this feeling.

ID 11 "The doctors have continuously given me the IV fluid. Right now, I am not giddy and dazzled. My mind is good. *I feel better*. *I feel much better*."

ID 17 "My previous pains were so discomforting. Right now, I feel less pain, no serious pains. I feel pain in my legs.... Nurses gave me an analgesic. After taking this analgesic, *I felt better*." # "*The symptom in my legs is better*.... I have had weakness on my right arm entirely. Nurses gave me injections. ..., but *it made me feel better*."

Table 39

Inadequate Comfort of Thai Older Patients with Advanced Cancer

| tte comfort<br>48)<br>mptoms              |                             |                                    |        | COIIIIOLI CALE (CC) |                  |       |
|---|-----------------------------|------------------------------------|--------|---------------------|------------------|-------|
| 48)<br>mptoms                             | By nurses/<br>pital environ | By nurses/<br>hospital environment | By rel | By relatives        | By HSBs          | SBs   |
|   | n (12)                      | f(32)                              | n (3)  | f(5)                | u (6)            | f(II) |
| l<br>distressing symptoms                 | 10 (5 [a])                  | 26 (6)6                            | n      | 5                   | 5 (b [1]) 10 (1) | 10(1) |
|   | -                           | 32                                 |        | ~                   |                  |       |
|   | 6                           | 21                                 |        |                     |                  |       |
| Technical comfort care                    | 1                           | °                                  |        |                     |                  |       |
| Hospital setting (the rooms or weather) 2 | 5                           | 3                                  |        |                     |                  |       |
| Consoling/supporting                      |                             |                                    | 3      | 4                   |                  |       |
| Massaging                                 |                             |                                    | 1      | 1                   |                  |       |
| Ability for ADLs                          |                             |                                    |        |                     | 1                | 1     |
| Talking with relatives                    |                             |                                    |        |                     | 1                | 7     |
| Trying to sleeping                        |                             |                                    |        |                     | e                | 4     |

Table 39(continued)

Inadequate Comfort of Thai Older Patients with Advanced Cancer

|   |                                    | C                   | Comfort care (CC) | re (CC)      |       |         |
|---|------------------------------------|---------------------|-------------------|--------------|-------|---------|
| Comfort— Inadequate comfort                           | By nurses/<br>hospital environment | Irses/<br>wironment | By rel            | By relatives | By F  | By HSBs |
|   | n (12)                             | f(32)               | n (3)             | f(5)         | (9) u | f(11)   |
| Massaging for the self                                |                                    |                     |                   |              | 1     | 2       |
| Financial status                                      |                                    |                     |                   | ,            | 1     | 1       |
| Comfort a little bit                                  | 2                                  | 2                   |                   |              |       |         |
| Alleviating distressing symptoms                      | 1                                  | 1                   |                   |              |       |         |
| Hygiene care  | 1                                  | 1                   |                   |              |       |         |
| Not good as the self's wish (the bed)                 | 1                                  | 1                   |                   |              |       |         |
| Moderate comfort                                      | 1                                  | 1                   |                   |              |       |         |
| Be satisfied a little bit (waiting for the restrooms) | 1                                  | 1                   |                   |              |       |         |
|   |                                    |                     |                   |              |       |         |

Note. (a) Referred to inadequate comfort from hospital environments (b) Referred to inadequate comfort from the

patient's good social status (ID 2)

Besides feeling better, other expressions reflecting inadequate comfort were

exemplified by the following statements.

ID 3 "Ah! I have some discomfort. When sleeping at night, it is too cool. It is difficult to explain how cold it is. I am cold, too cold at night." # "I feel a little uncomfortable."

ID 4 ".... Only receiving a partial bed bath. I felt more comfortable (from a partial bed bath), but *just a little bit*. It was not like taking a bath.

ID 15 "This bed is okay. It is difficult for the bed to be as good as we wish."

Theme: Feeling Better from Relatives' Care.

Some caring of the relatives of three participants helped to relieve their

discomforts. As a result, they perceived that their conditions were better. This care was

defined as consoling, encouraging, massaging, or talking, as shown in the following

examples.

ID 9 "When my daughter visits me, *she helps me feel better* by massaging my legs."

ID 18 "I mostly talk with my daughter. If I am not happy, I will talk with my daughter. ..., *I feel better* after talking with her."

Theme: Feeling Better by HSBs.

The self care of six participants provided inadequate comfort, such as taking

medications and sleeping, massaging, ability to get up and walking around, and so forth.

The patients described inadequate comfort from the HSBs as follows:

ID 11 "To relieve the body ache, I took the medication and slept. Sleeping is the only one thing I do. *It is better*; so I need to sleep a lot."

ID 18 "I do not want to take any analgesic medication if I only have a little pain. So, I decided not to take a medication but to squeeze my shoulder instead. Later, as a result of the squeezing, the pain got better. Finally, I could sleep until the sun came up. Since that day, my pain has not appeared again. Jow (--yes), *my symptoms are better*."

## **Description of Additional Domain**

Based on the interview data, the participants shared topics beyond discomfort and comfort. They responded to two main questions: (a) "In your opinion, what are the barriers to provide the comfort care for you?" and (b) "In your opinion, how could the nursing care provided be improved for better comfort care?" The findings revealed that their opinions reflected pros and cons. Thus, the reflections were grouped into an *Additional Domain*. Then, five categories relating to comfort emerged: *Intervening variables, Nursing comfort Care, Nurses (including other healthcare personnel), Improvement for comfort care, and Comparison between the hospital and the House* (see Table 40).

# Table 40

| Category              | Theme                               | n  | f  |
|-----------------------|-------------------------------------|----|----|
| Intervening variables | Comfort variables                   | 8  | 17 |
|                       | Discomfort variables                | 12 | 23 |
| Nursing comfort care  | Quality of existing care            | 12 | 22 |
|                       | Ineffective existing comfort care   | 6  | 10 |
|                       | No comfort care responding to       | 10 | 25 |
|                       | specific discomfort                 |    |    |
|                       | Requesting comfort care             | 14 | 57 |
|                       | Communication problem of nurses     | 14 | 34 |
| Nurses (including     | Quality of nurses                   | 10 | 23 |
| other healthcare      | Relationship                        | 6  | 9  |
| personnel)            | Speaking                            | 10 | 21 |
|                       | Knowledge base of Nurses            | 19 | 25 |
|                       | Need of additional course training  | 3  | 4  |
| Improvement for       | No need of improvement              | 5  | 8  |
| comfort care          | Need of improvement                 | 13 | 28 |
| Comparison between    | Differences                         | 15 | 24 |
| the hospital and      | Both (differences and similarities) | 3  | 6  |
| the house             |                                     |    |    |

# Frequency of the Additional Domain

#### Category One: Intervening Variables.

*Intervening variables* were defined as two themes: comfort variables and discomfort variables.

#### Theme: Comfort Variables.

Eight participants reflected on the theme of comfort variables (f = 17). The variables influencing comfort (such as hope, happiness, bravery etc.) were related to: characteristics of nurses or other healthcare personnel and their care (speaking nicely and with kindness, encouragement, paying attention, and good relationships between healthcare personnel and patients), non-cancer diagnosis, accurate examination, safe treatment, characteristics of the patients (personality, age, and attitudes), inability of self care, the family of the individual patient (ability of earning of the patients' families, or good financial status of the family business), and the culture of a region. The following excerpts illustrate these comfort variables.

ID 7 ".... Helping patients when they are ill. Patients can consult nurses, who then approach and to provide them with care." # "I will be pleased if I can go to the restroom by myself in order to take care of myself, such as taking a bath and shampooing."

ID 9 "The encouragement is of the greatest most importance. .... The healthcare personnel's characteristic that is the most important for the patient's mind is their tenderness. Speaking nicely with their patients is important too. Encouraging their patients. This encouragement is most important."

ID 15 "Fortunately, this is the northern region where there is no arrogance. It helps to easily make friends among patients. Merely greeting can make relationships or can provide help for each other. ...."

Discomfort variables reflected by participant statements made them feel discomfort or other uncomfortable feelings, such as having no hope, not living a long life, losing temper easily, and so on. These discomfort variables were described by 12 participants (f = 23) as status of illness, distressing symptoms (such as pain), medical treatment, inability of self-care, individual personality and attitude, aging, and uncomfortable weather.

ID 3 ".... I did not go to anywhere, including parties. I stopped altogether because I have not been able to walk as others do. I have been so tired. (The patient started crying again.) Uh-huh. I ask myself why I don't die. I know I am a short-temper man." # "(The patient's daughter said, 'Sometimes, he needs to defecate but he does not want to call a nurse because it smelled so strong. He feels self-conscious because he himself can not walk.')" # "Sometimes, I told the nurse, 'Doctor, please tolerate me."" # "(The patient's daughter said, 'He said that the care related to urination and defecation is dirty work.')"

ID 4 "I can not see how it (--her future) will be.... At my age, three years away from being 70 years old, I am not sure if I will be alive...."

ID 18 "To walk, if I am not connected to this tube (--the left ICD), I can walk." # "I feel most uncomfortable because of this tube. Uh-huh. From this chest tube."

ID 19 "I feel pain when the weather is so cold."

## Category Two: Nursing Comfort Care.

Nursing comfort care was defined as nursing intervention or activities arranged

by nurses or other healthcare personnel in order to provide comfort for the patients.

Four themes relating to comfort nursing care emerged: quality of existing nursing care

(n = 12, f = 22), ineffective existing comfort care (n = 6, f = 10), no comfort care

responding to specific discomforts (n = 10, f = 25), requesting comfort care (n = 14,

f = 57), and communication problems of nurses (n = 14, f = 34) (see Table 41). As became apparent, the two last themes were most commonly mentioned and complained about (see Table 41).

Table 41

Frequency of Nursing Comfort Care

| Category             | Theme                                  | n  | f  |
|----------------------|--|----|----|
| Nursing Comfort Care | Quality of existing nursing care       | 12 | 22 |
|                      | Fair                                   | 2  | 2  |
|                      | Good/international standard            | 9  | 17 |
|                      | Best                                   | 2  | 2  |
|                      | Satisfying                             | 1  | 1  |
|                      | Ineffective existing comfort care      | 6  | 10 |
|                      | No comfort care responding to specific | 10 | 25 |
|                      | discomforts                            |    |    |
|                      | Requesting comfort care                | 14 | 57 |
|                      | Physical-physiological comfort care    | 7  | 28 |
|                      | Psycho-spiritual comfort care          | 8  | 17 |
|                      | Socio-cultural comfort care            | 6  | 11 |
|                      | Environmental comfort care             | 1  | 1  |
|                      | Communication problems of nurses       | 14 | 35 |
|                      | Only having short talks                | 7  | 17 |

| Category | Theme                               | п  | f   |
|----------|-------------------------------------|----|-----|
|          | No talking                          | 3  | 5   |
|          | Daily/routine/general conversations | 3  | 4   |
|          | Going away before being asking      | 2  | 3   |
|          | No time/chance of talking           | 2  | 2   |
|          | Castigation/scolding manners        | 1  | 2   |
|          | Feeling uneasy about talking        | 1  | 1   |
|          | Insufficient nurses with effective  | 1  | 1   |
|          | communication                       |    |     |
|          | Total                               | 19 | 149 |
|          |                                     |    |     |

Frequency of Nursing Comfort Care

## Theme: Quality of Existing Care.

Twelve participants discussed the quality of nursing intervention currently provided to them. They described it in terms of degree of quality, those being fair, good or international-standard, and best. Most nursing care qualified as good or international standard (n = 9, f = 17). The number of participants and frequency of the items fair and best were equal (n = 2, f = 2). There was only one person who said that it was satisfying. Most participants were likely to criticize physical care (such as changing clothes and diapers) or psychological care (such as consolation, encouragement, coming and looking after the patients) more than other contexts. The following responses

are examples of their opinions:

ID 11 # "Helping me to change my clothes is the most important nursing care from nurses for me while I am treated here. The pampers (diapers) were changed for me all the time. .... For me, I prefer to go to the restroom. I could go there. To them, they do not want me to get out of my bed. They are afraid that I might fall from the bed and fall down. Nurses do not want me to go. They or the nurses provide me with good care."

ID 15 "I feel that the nursing care provided to me is good. The nursing care means curing and caring. Such as administration of IV fluid, including chemotherapy, and monitoring my symptoms." # "Since being admitted, there have not been any problems relating to care. The care provided here is fair."

Theme: Ineffective Existing Comfort Care.

The interview data of this study revealed that there were some inappropriate

nursing interventions that were provided or suggested by six participants. Some nursing

care was done based on a schedule rather than a suitable time or the actual needs of an

individual. As a result, they felt uncomfortable or experienced complications, as the

following interview responses show.

The following participant had a problem with eating – no appetite and not being

able to taste anything. He said that most nurses (including other personnel) asked him

only routine questions, not really involving his needs.

ID 2 "They do not often ask me about my eating. (Do you want nurses to ask you about these issues?) Yes.... They only ask me about how often I have bowel movements and urination everyday."

The next participant suffered from the experience of having two abdominal eviscerations and needed to wait for wound care, which is usually provided by a medical student, with no exactly scheduled time frame. ID 3 "Today, it (--the wound) is not completely treated yet. I need to wait for the doctor to do it." # ".... They also said "Try to walk often because this is almost one month (after the surgery). .... They told me only five days, I then cannot walk after those five days. Mae! (--his exclamation) After only five days to let me walk. I can not walk. Ah! I have some discomforts."

The last participant was provided with care following a routine schedule.

ID 5 ".... Sometimes, it is about 8:00 p.m. However, sometimes, it seems to be about at 10:00 or 11:00 p.m. This is to call other patients to wake up to urinate before sleeping. Another time is about 2 or 3:00 a.m. At 6:00 a.m. again. Sometimes, I need to wait a while to urinate. That means that I can not urinate at the time of providing a bed pan."

## Theme: No Comfort Care Responding to Specific Discomforts.

Ten participants reported that sometimes there was no care particular to their needs or distressing symptoms (f = 25). Most distress was focused on both physical-physiological and psychological symptoms; for instance, the physical-physiological aspect, such as pain or abdominal pain, diarrhea, no appetite, abdominal distension and sleeplessness, and the psychological aspect, such as feeling depressed. In addition, they complained directly in term of not receiving care or help, for example, no partial bed bath, no help for going to the bathroom, and no help for the movement. The participants

who experienced this discomfort stated:

ID 10 "Presently, I still experience itching. Beyond it, I also feel a burning pain. They have not provided any help for this burning pain." # "(When you are serious or unhappy, is there a nurse who comes to talk with you or provide a consultation?) No, there is no nurse to talk with me or provide a good consultation when I am unhappy."

ID 17 "Nurses did not help me with the sleeplessness. They were just afraid that I might not able to sleep. I did not tell nurses about my sleeplessness because they were also sleeping, while I need to be with myself, like this, here. They, the nurses, sleep too. They slept already (before the patient could sleep)."

ID 20 "To me, I usually have difficulties of defecation. They (nurses) usually do not work on me a lot. Uh-huh, nurses never know how difficult defecation is for me. Krab (--a polite word), they do not know about my defecation. This is because they are not the persons who have this problem. The person who knows about this problem is me. I used to tell them that I usually have difficulties with defecation." # "When I had so serious pain, they did not come to meet with me. They did not come to meet me (while the patient had serious pain). Ah, especially, when I have serious pain."

## Theme: Requesting Comfort Care.

Although the setting includes policies relating to the support and providing of palliative care for dying patients, based on the interview data of this study, some nursing care was not provided or was absent. Thus, some of the participants still indicated unmet needs and requested nursing care to respond to their comfort needs and to provide them with comfort (n = 14, f = 57) (see Table 41). Furthermore, comfort care mentioned by participants encompassed four contexts of comfort, especially physical-physiological comfort care (n = 7, f = 28), psycho-spiritual comfort care (n = 8, f = 17), socio-cultural comfort care (n = 6, f = 11), almost in equal amounts. However, care relating to environmental comfort was mentioned by only one participant (n = 1, f = 1).

## Sub-theme: Requesting Physical-Physiological Comfort Care.

Requesting physical-physiological comfort care was defined as requesting care or help to relieve or eliminate distressing symptoms, such as pain, to receive a removal surgery, and to recover. They stated:

ID 19 "I also want to receive a surgery. What can I do to receive a surgery?" # "I want nurses to help me. Please let them take care of me." # ".... I want them to reduce my pain. (The patient laughed after speaking.) I want nurses to help me about ... and relieve my pains. Jow (--yes), to help to reduce my pain." # "I want my illness to be treated. I want only want them to help me recover. I want them to help me achieve recovery. Yes, I want help to recover, and ...."

Sub-theme: Requesting Psycho-Spiritual Comfort Care.

Requesting psycho-spiritual comfort care was defined as talking, asking more questions to reflect encouragement, paying attention, counseling, providing more explanations without or before being asked, and providing spiritual support. The responses reflected these needs as follows:

ID 8 "Nurses can help me by consolation, I think. I want nurses to talk with me or tell what my conditions are and to provide suggestions to relieve my worries." # "Yes, that is the responsibility of the doctors. As for nurses, they should pay attention to providing care and alleviation. In addition, they should encourage the patient. They should encourage and spend time on the patient." # "While waiting, I want nurses to help and console me. Nurses should console, pay attention, pray for me to recover, and encourage me not to worry about anything."

ID 13 "If it is possible, I want the nurses to talk with me. Uh-huh, I want to talk with them. I want them to talk with me about my illness, such as where I feel pain, how I am, and so on." # "Yes, it will be all right if they ask me.... That is correct, the talking will help me be happy."

Sub-theme: Requesting Sociological Comfort Care.

Requesting sociological comfort care was focused on the nurses introducing

patients to each other, which would relieve the feeling of loneliness, especially between

old and newly admitted patients staying in the same room, remembering the patients,

and helping the participant avoid hospital costs. They stated:

ID 15 "Well, it would be good if nurses promote introduction between the current patients and a new patient. We, as patients, would like to know each other."

ID 19 "(The patient laughs.). I want the doctors and nurses to help me so much. Please request help from them for me. Yes, please help me. (What help do you want?) I want them to help me about the hospital expenses. I want them to help me about the medical costs." # "I want nurses to help me about the medical costs and...."

#### Sub-theme: Requesting Environmental Comfort Care.

Environmental comfort care manifested itself through one of the participants' requests. It was defined by one participant as comfortable weather (cold weather or air-conditioned climate), private/semi-private room, and hotel-like service. He gave the following statement:

ID 15 "As for environmental comfort, the weather should be cold and the environment should be quiet.... Krab (--ves), including the privacy. Well, because of receiving the IV fluid, it should be in a separate room. This is because there should be nurses who monitor if bottles of the IV fluid are empty. That room may have several patients. ....; it (--the nurses' administering the IV fluid) is not done continuously. In another room, patients do not need to wait or worry when the IV fluid will be empty. In addition, we can call the nurses to change it. These nurses will be able to change as soon as it is over." # "Well, if it is possible, I agree to have a multi-bed room but it should be air-conditioned. Ah, only by adding an air conditioner, the climate will be fresh. If the temperature is cool, we will feel comfort. The environments should be like my home environment, which makes me comfortable. Actually, the room should provide privacy. For instance, a private room. That means that there is only me in the room. However, in fact, the current system offers multi-bed rooms. The single-room system is not managed. A private room, that is needed." # "I think the hospital should provide a service similar to when I stay in a hotel, where there is a service that can be contacted all the time. I mean the contact between nurses and their patients. They should check (--assessment) what the patient needs at all times "

#### Theme: Communication Problems of Nurses.

The issue of communication became an important problem of nursing care in

this study. This theme focused on the content of the communication. The nurses'

communication problems were defined as only having short talks, no talking at all,

daily/routine/general conversations or greetings, going away before being asked, no

time/chance of talking, castigation/scolding manners, feeling uneasy about talking, and

few nurses with effective communication (see Table 41). Interestingly, the item

"only having short talks" was mentioned most dominantly and most frequently (n = 7,

f = 17). The quotations related to nurses' communication problems were as follows:

ID 6 "They come and ask me how I am. Am I fine? That is the common conversation between us." "..., if it is possible, I want nurses to ask me, 'How are you?' and 'Are you comfortable?' or 'Uncle, how are you?' Are you fine?' In addition, they should ask, 'Can you sleep?', these kinds of questions. There are some nurses who do not pay their attention to ask about these questions."

ID 11 "Yes, I want them to talk with me more than they do now.... Yes, I want nurses to provide more care. I want them to come and ask how I am, or if I am comfortable. Uh-huh. There is not long talking. The conversation is short each time. Conversations with nurses are not long. Yes, I want to talk for a long time and be consoled. Yes, I want them to console me and talk with me longer to let me be happy, so that I don't worry, and tell me that the doctors can help me."

ID 19 "Yes, I want them to help me to..., and want the nurses to talk with me longer and more often."

### Category Three: Nurses (Including Other Healthcare Personnel).

Nurses (Including Other Healthcare Personnel) are described by their

characteristics, which were described by all participants (n = 20, f = 82). Four sub-

themes emerged: quality of nurses, relationships with nurses, conversations and how

they are related to the nurses' personality and knowledge of nurses (see Table 42).

Themes: Quality of Nurses.

Ten of the participants talked about the quality of nurses as the main providers of care during their end-of-life stage (f = 23). These participants classified the quality of the nurses into: fair, good—only moderate level, good, best, and both good and best levels. The *good* level was mentioned the most (n = 8, f = 16). Examples of applicable responses are:

ID 12 "When I ask for or request something, they help a lot. I think they do Not need to improve. They are good and speak nicely. They are not the same as nurses in the past."

ID 19 "They (--the doctors and nurses) are good. Jow (--yes), the hospital, including the doctors and nurses, is good. They are good, moderately." # "In addition, the doctors and nurses are the best."

# Table 42

| Category          | Themes                                    | n  | f  |
|-------------------|---|----|----|
| Nurses (including | Quality of nurses                         | 10 | 23 |
| other healthcare  | Fair                                      | 1  | 1  |
| personnel)        | Good—only moderate level                  | 1  | 1  |
|                   | Good                                      | 8  | 16 |
|                   | Best                                      | 2  | 3  |
|                   | Good and Best                             | 1  | 2  |
|                   | Relationships with nurses                 | 6  | 9  |
|                   | Good relationship                         | 2  | 2  |
|                   | Satisfying relationship                   | 1  | 1  |
|                   | Smiling and friendly expression           | 1  | 2  |
|                   | Familiarity with nurses                   | 1  | 1  |
|                   | Familiarity with nurses more than doctors | 1  | 1  |
|                   | Same familiarity with nurses and doctors  | 1  | 1  |
|                   | Fear during the first period of the       | 1  | 1  |
|                   | Treatment                                 |    |    |
|                   | Speaking Behaviors of Nurses              | 10 | 21 |
|                   | No problem                                | 1  | 1  |
|                   | Good welcome                              | 1  | 1  |

# Characteristics of Nurses, Including Other Healthcare Personnel

## Table 42 (continued)

| Category | Themes                                    | п  | f  |
|----------|---|----|----|
|          | Speaking nicely                           | 8  | 16 |
|          | No castigation                            | 1  | 2  |
|          | Few nurses with effective communication   | 1  | 1  |
|          | Knowledge base of nurses                  | 19 | 25 |
|          | Tendency for improvement                  | 1  | 2  |
|          | Enough (no improvement)                   | 5  | 6  |
|          | Enough (improvement for better quality of | 1  | 1  |
|          | care)                                     |    |    |
|          | Enough (needs to be improved)             | 10 | 13 |
|          | Enough (but improved as the nursing       | 1  | 1  |
|          | professional)                             |    |    |
|          | Enough for some nurses                    | 1  | 2  |
|          | Need of training or additional courses    | 3  | 4  |
|          | Total                                     | 20 | 82 |

Characteristics of Nurses, Including Other Healthcare Personnel

## Themes: Relationships with Nurses.

Relationships with nurses were referred to as the relationship between the participant and the nurses or other healthcare personnel. It was described and defined by six participants (f = 9) as having a good relationship, satisfying relationship, encountering smiling and friendly expressions, familiarity with the patient, familiarity

with nurses more than doctors, and equal familiarity with nurses and doctors.

Obviously, the relationship between the nurses and the participants of this study tended

to be good or positive. Although there was one case in which the patient felt afraid of

the nurses, this fear occurred only at the beginning of his admission. These participants

stated:

ID 8 "As for interpersonal relationships, doctors or nurses provide me with a lot of comfort. It is satisfying. There are no unsatisfying things about our relationship." # "Every hospital where I went, nurses make me feel familiar. There is no problem."

ID 12 "The fear to ask about something might occur first when starting treatment. But now I feel that every nurse is good." # "The nurses are more familiar with me than the doctors are."

Themes: Speaking Behaviors of Nurses.

Ten participants commented on the individual nurses' speaking behavior (f = 21)

(see Table 42). Most comments showed that the nurses who provided care to them

spoke nicely with their patients (n = 8, f = 16). The reports reflected communication by

the nurses as follows:

ID 10 "Every nurse speaks nicely. Every doctor who talks with me is good and speaks nicely. No, I have not ever been scolded by nurses. They talk with me in a nice way."

ID 12 "I think they do not need to improve. They are good and speak nicely. They are not the same as nurses in the past." # "Nursing care is better than the care in the past. Oh, in the past, nursing care was not the same as it is right now. Presently, they speak nicely and politely."

Themes: Knowledge base of Nurses.

Knowledge base of nurses was one of the emerging themes relating to the

nurses. The participants mostly thought that the nurses in this hospital had enough

knowledge to provide care to them (n = 19, f = 25). However, based on sufficient knowledge, they offered additional ideas: sufficient knowledge without any necessity for improvement (n = 5, f = 6) or with improvements such as improvement for better quality of care (n = 1, f = 1), nursing as a professional characteristic (n = 1, f = 1), or without any reasons (n = 10, f = 13). Furthermore, there were three participants who suggested that the nurses should be trained more or should take some additional courses to improve their knowledge and skills (f = 4). They said the following:

ID 8 "Nurses here have enough knowledge to provide care." # "Nurses do not need to be trained because they were trained a lot, were they not? They work the way they were trained. Later, in the case that there may be different issues from what they were trained for, they should be updated or trained additionally. The nurses need to study a lot, don't they? Beyond the current knowledge of nurses, there is additional knowledge that has progressed."

ID 10 "Nurses here have a lot of knowledge. The nurses' knowledge is sufficient. I do not know what should be improved."

ID 17 "I think nurses have knowledge. However, they should be trained or improve on medical knowledge, drugs, and having longer talks with their patients."

Nevertheless, there were only two participants who thought that the nurses did

not need to be trained; however, one of them additionally said they might be trained as

professionals. Both participants said:

ID 12 "Nurses here have several levels of nursing knowledge. To be trained, it is typical for nurses to do this. Nursing is a professional occupation; so, nurses have to receive additional training."

## Category Four: Improvement for Comfort Care.

Based on the results of this study, there were two themes of Improvement for

comfort care that emerged: No need for improvement and Need for improvement.

No need for improvement meant that nursing care did not need to improve (n = 5, f = 8). However, thirteen participants agreed that the existing nursing care still needed to improve for effective comfort care (f = 28) (see Table 43). Clearly, the findings revealed that there were more participants who suggested or wanted the existing nursing care to be improved than those who did not want improvement of nursing care. These themes were described as follows in Table 43:

Table 43

| Category      | Themes                              | n  | f  |
|---------------|-------------------------------------|----|----|
| Improving for | No any need for improvement         | 5  | 8  |
| Comfort care  | Need for improvement                | 13 | 28 |
|               | Physical-physiological comfort care | 6  | 12 |
|               | Psycho-spiritual comfort care       | 4  | 4  |
|               | Socio-cultural comfort care         | 6  | 6  |
|               | Environmental comfort care          | 4  | 5  |
|               | Total                               | 16 | 36 |
|               |                                     |    |    |

Frequency of Improvement for Comfort Care

The participants defined this as nurses or nursing care being good and not

needing improvement. These participants stated:

ID 11 "Everything is good. (You are saying that it (--the hospital) is good. Do you not think that it should be improved?) No, it does not need to be improved." # "The nursing care is not dissatisfying."

ID 12 "They do not need to improve.... (Are there some things that need to be improved?) No, there is nothing that needs to improve." # "I think they do not need to do anything for improvement. They, these nurses, do well or are best. I see them working well. Their or others' services do not need to be better than they currently are."

ID 15 "To be improved? I think they are fine or good. Krab (--yes), the talking between nurses and their patients and providing time for patients is fine."

Theme: Need for Improvement.

Need for improvement was an item that reflected that the participants received nursing care but that it was not as good or as satisfying as they wanted. In this study, thirteen participants wished that nursing care or nurses would improve, encompassing four contexts of holistic comfort care: physical-physiological, psycho-spiritual, socio-cultural, and environmental care (f = 28) (see Table 43). Six participants equally wished that physical-physiological and socio-cultural care would improve, more so than they wished for improvement of the other two items (f = 12 and 6, respectively).

To be specific, most suggested improvement of nursing care and nurses within these contexts: *physical-physiological context*, defined as paying more attention and providing more care, and responding to the patient's need more quickly; *psychospiritual context*, defined as asking about discomforts and talking with the patient to provide psychological support; *socio-cultural context*, defined as speaking and talking nicely and politely, as well as educating the patients; *environmental context*, defined as needing more electric fans, cleanliness, and good smell. In addition, they suggested having a sufficient number of nurses appropriate for the number of the patients, and improving nursing care to ensure better or high quality. The responses below demonstrate the need for these improvements relating to the nurses and nursing care.

ID 6 "It will be good if the hospital will be improved for quality of care for patients." # "To become better, they need to improve to respond to each patient's needs quickly. They should respond more quickly to the patient's requests, especially when the patient requests help. For example, they walk slowly. They walk slowly. Their walking is too slow. What I want is that when I request something, I want them to respond to me immediately. I want nurses to respond to me as soon as I request something."

ID 9 "The hospital should improve to hire additional nurses. There should be more nurses.... Now, there are few nurses. This (a pause), this hospital has few nurses. When there are many patients, they can not finish providing nursing care in time. It should have more nurses. ...."

One of participant suggested improving nursing care for better quality of care

although its existing service was good; however, she did not identify what should be

improved. She said:

ID 19 "The hospital is better than any other hospitals. This hospital is good. (Does it need improve for better quality?) That is correct. It should improve for better quality.

## Category Five: Comparison between the Hospital and the House.

Seventeen participants evaluated comfort by comparing their lives in the

hospital with those at their house (f = 30) (see Table 44). Two main themes that

emerged were: Differences and Both differences and similarities. Most of them thought

that there were differences between both places (n = 15, f = 24). There were only three

who indicated that they were both different and similar, in some points (n = 3, f = 6).

# Table 44

| Theme                               | n  | f  |
|-------------------------------------|----|----|
| Differences                         | 15 | 24 |
| Hospital better                     | 10 | 17 |
| House better                        | 6  | 7  |
| Both (Differences and Similarities) | 3  | 6  |
| Total                               | 17 | 30 |
|                                     |    |    |

Comparison between the Hospital and the House

Theme: Differences between the Hospital and the House.

Two sub-themes of the *Differences* category emerged as participants compared between the hospital and the house. The definitions used in this study were: the hospital is better than the house (n = 10, f = 17) or vice versa (n = 6, f = 7) (see Table 44). In the case that the hospital was better, this was defined as: providing greater psychological comfort, was more comfortable, provided trust and did not cause fear, provided what the patient wanted, feeling uneasy about doing something, and better environments: quieter, cleaner, and more tidy. However, the most commonly mentioned expression was *more comfort*.

Otherwise, some participants said that their houses were better than hospital. They defined the things they liked better about their house as having more freedom, less people, not waiting for the restroom, cleaner, and not annoying.

The following responses describe their comparisons.

The reports that reflected that the hospital was better were:

ID 3 "(What are the differences?) If I want to urinate, at my house (pausing), I can urinate on the terrace (by using a spittoon) or in the toilet. I can not find a place for my bowel movement (--referring to the hospital). (You can not find it, can you?) No, I can't. If I feel sleepy and am almost sleeping, I will keep a spittoon close to me. This one! (The patient looked at the bed pan which was under the bed).... At my house, there was nothing like this. If it is hot, I would feel better soon after I poured water over my body. When it is hot, I poured water over my back. And, if it is very hot, I would take a bath. Especially at night."

Another participant who was a poor man and stayed in a small house - a one-

bed-room house said:

ID 6 ".... Instead, I used to feel discomfort when staying at home. But I now am here. I feel more comfortable when I am in the hospital. To compare with my house, the hospital is better. When I think about doctors, they will come. There is no doctor at my house." # "To evaluate, my house provides comfort about 40%. As for the hospital, it is more comfortable, around 150%. It is about 150% more comfortable.

ID 20 "Uh-huh, it was distressing for me to stay at my house. Here, I am not afraid of anything. I do not need to be afraid because I am near doctors (-- referring to doctors and nurses)."

The following reports show that some participants felt more comfortable at their

houses.

ID 11 "To compare, the house is better. The cleanliness. Nobody disturbs me. At home, there are only my children. At home, I slept comfortably.... Yes, at home, there was nothing to annoy me. Here, I am disturbed a little bit. It's loud (in the hospital). The noise is annoying for me. One of the differences is that the people here walk all the time – back and forth. My house is more comfortable. In addition, here, there are many people who need to wait to use the restroom. We need to wait for the restroom...."

ID 15 "At my house, there is privacy for an individual. Based on the privacy, the life is free. The freedom is that I can do everything. Krab (--yes), I can control what I want (at the patient's house). Such as the freedom of ADLs or the ability to do ADLs. For example, taking a walk, talking with my friends, going to a market, and others, having a normal ADLs like regular people. Krab, I cannot do

these activities when I stay in the hospital. I am less capable of doing these things, and I have less privacy."

ID 19 "(The patient laughs.) The difference is that there are many patients. A lot of patients. At home, I stayed with father (The patient meant her husband.). Two persons, grandfather and grandma (The patient meant her husband and herself.), staying together quietly."

In addition, another participant criticized that the hospital and the house

had different benefits or were good in different ways.

ID 13 "It is different between my house and the hospital. Differently, I feel physical comfort while staying in the hospital where I can lie, take a rest, and wander around. When I stayed at home, I did not rest but I needed to work. Uhhuh, in the hospital, I feel physical comfort but not psychological comfort. As for my psychological discomfort, I always think about my house, my job, and the money which I will need in the future." # "I stay here with 100% of comfort. That is, 100%. I feel comfortable. It is 100% of physical comfort. The physical comfort is 100%, but the psychological comfort is less. I feel comfortable psychologically at about 70% or 80%."

# Theme: Both Differences and Similarities.

Comparing between the hospital and the house, three participants felt that the

hospital and the house were both different and similar. They defined this as: the aspect

of comfort, chance of recovery, care, convenience, and degree of the self-care. The

following interview responses illustrate these ideas:

ID 1 "I felt that I did not get better when I stayed at home. It seemed not to help me recover. Differently, in the hospital, doctors and nurses take care of me and help me. I will get well either slowly or quickly. It will be quick. When I have a pain and call them, they come to take care of me." # "In the hospital..., oh no, at my house, I could receive help from my wife and son. In this hospital, I receive help from the doctors and nurses.... I live in the hospital similar to how I live in my house. When it gets dark, they remind and help me by serving dinner and cleaning my body."

ID 8 "Focusing on the comfort, the hospital is not like the house. This is because I am ill; so, I need to be admitted to this hospital. If I stay in my house, I am free

to do anything. This is the difference." # "I can say that the hospital is like my house. In my room, I can do everything."

ID 12 "Differently, at home, I sometimes need to help myself a lot. This was because my wife needed to go to work. She did not do anything besides working in garden. She might go somewhere. I needed to be at home alone and help myself. In summary, I am comfortable when staying at the hospital." # "Uh-huh, the hospital and my house are the same. The similarity between the hospital and my house is convenience. The restrooms, including the toilets and bathroom, are convenient."

## Summary

Thai older patients in this study were mostly 68 years ( $SD = \pm 6.15$ ) and had little education. They mostly were diagnosed with lung cancer at an advanced stage or stage IV (or in metastasis). The PPSv2 mean recorded by the researcher was 48.99 (SD $= \pm 8.38$ ) statistically, or about 50, adjusted following the rule of the PPSv2 scores, with each score in increments of 10. The findings of this study were divided into two main sections.

First, based on the findings of the quantitative study, the comfort outcomes of Thai older patients treated for advanced cancer were between moderate and almost high comfort levels of the HCQ (Patient) (M = 4.29,  $SD = \pm .50$ ) and between moderate and fairly high levels of the VRSs (M = 6.25,  $SD = \pm 2.09$ ). In addition, the findings supported the notion that the HCQ (Patient) and the VRSs had sufficient psychometric property – concurrent validity (r = .56, p = .00) – to assess the comfort of patients dying of cancer.

The additional findings were established by analyzing the HCQ (Patient)-item scores; the five lowest-score items related to the four contexts of discomfort, and the five highest-score items related to spiritual comfort, which showed that religious and

spiritual activities could promote comfort or transcendence of Thai older patients with advanced cancer to get comfort although they still faced their discomfort.

Lastly, the qualitative study yielded three domains (here, *two domains* are pertinent to Comfort Theory): *Discomfort* and *Comfort*, and one *Additional domain*. First, the *Discomfort* domain covers four contexts: *Physical-physiological*, *Psycho-spiritual*, *Socio-cultural*, and *Environmental discomfort*. The second domain – *Comfort* – consisted of three types of comfort: *Relief*, *Ease*, and *Transcendence* as well as one new type of comfort – *Inadequate comfort*. Nurses focused on providing physical-physiological relief, whereas relatives mostly provided psychological-spiritual relief. However, almost all or all participants still needed to comfort themselves to relieve their discomfort, especially seeking transcendence through religious and spiritual activities.

The final category, the *Additional domain*, included *Intervening variables* of discomfort and comfort, *Nursing comfort care*, *Nurses* (including other healthcare personnel), *Improvement for comfort care*, and *Comparison between the hospital and the house* of the participants.

In summary, most Thai older patients with advanced cancer still experienced discomfort during hospitalization. Nurses (including other healthcare personnel), families, and the participant's self (as the HSBs) provided comfort care collaboratively. In addition, comfort care was provided by other patients. However, the comfort care provided was not sufficient to support Thai older patients with advanced cancer to meet their ultimate end-of-lives comfort needs. This evidence is of the greatest importance for nurses who are concerned with high-quality nursing comfort care.

## **CHAPTER V**

### **DISCUSSION AND CONCLUSIONS**

This study used between-method triangulation (combining quantitative and qualitative studies) to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand. This chapter presents the discussion and conclusion of the results of this study. The presentation consists of eight sections: (a) discussion of procedural challenges and instruments; (b) discussion of demographic data and results; (c) discussion of quantitative data and results; (d) discussion of the qualitative data and results (*Discomfort, Comfort,* and *Additional domains*); (e) discussion of triangulation confirmation; (f) conclusions; (g) implication (nursing practice, nursing education, and nursing administration and health care policy); and (h) limitations and recommendations for future research.

### **Discussion of Procedural Challenges and Instruments**

### **Discussion of Procedural Challenges**

Several obstacles occurred during the procedure of the data collection. These problems related to the period of time to start the data collection, the atmosphere or nature of ordinary hospital wards and the hospital policy (--the LOS used as a criterion of the hospital accreditation), and the potential subjects themselves. These influences made the time of the data collection longer and needed to increase the total number of participants of this study finally (N = 111) more than the number planned (N = 100) in order to obtain 20 participants for the interview procedure.

First, the period of time to start collecting data was the time after the big and long Thai holidays, called Songkran festival, in April of every year. Generally, many people preferred to stay at home (in their hometowns) to cerebrate with their family members or to provide an opportunity for their children to perform the traditional respect or gratefulness to their parents or the elderly. Thus, many patients and the elderly patients who were being admitted in the hospital desired and requested to be discharged if possible. On the other hand, those who stayed at home likely postponed seeing doctors or coming to a hospital if possible. As a result, the number of the admitted patients was fewer than usual, which caused the number of potential participants in the first month of data collection to be only 10.

Next, the data were collected in ordinary wards where there were many patients so that there was over crowding. In addition, nursing care was provided by team nursing care and was perceived as too busy by their patients. They had less time to identify potential subjects for this research as conceived by this research design. In addition, many nurses did not still understand sufficiently how to apply the Palliative Performance Scale version 2 (PPSv2) tool as part of the research design. How to consider cutting off each suitable PPSv2 score appropriate to each patient's condition was a major issue of many nurses, who needed more skills and practice. This might be because the hospital was in the initiation of establishing palliative care and of developing the PPSv2 tool into practice. However, only the researcher finalized the PPSv2 score of every potential subject who would be enrolled in this study. Furthermore, the researcher frequently needed to request and remind nurses to use the Letter for Invitation to Participate in the Research Study. Similarly, the study of La Monica (2008) found that the invitation forms for that study were abandoned by nurses in busy wards if she was not in the field.

In addition, most elderly patients preferred to be invited and informed about the study verbally rather than reading it by themselves. This event might be explained because these patients were elderly and had impaired vision. In addition, by the general nature of the elderly, they typically liked to have someone to talk with them. These factors explained why the Letter for Invitation to Participate in the Research Study was often ignored.

Another important obstacle involved the hospital policy and accreditation. The length of stay (LOS) was used as a criterion for evaluating the hospital accreditation. It influenced the consideration (under the patient safety) to discharge patients. Consequently, most patients whose symptoms were improved or while waiting for test results or whose courses of chemotherapy were over might be discharged more quickly than that in the past. As a result, the admission period of time of cancer patients was shorter or less than one week, such as in the chemotherapy wards (in the medical department). In contrast, one of the inclusion criteria of this study indicated that the subjects had to be admitted at least for one week (or seven days) or more. Most participants who met the PPSv2 criterion [=  $\leq 60\%$ ] were admitted to this study in the second week of the hospitalization [n = 67, f = 60.4%] and on the seventh day of the admission [n = 26, f = 23.4%] or its mean was 10.98 days [ $SD = \pm 5.00$ ]). As a result,

many Thai older patients with advanced cancer as potential subjects were discharged before the first approach or collecting data.

Regarding the participants, there were several factors involved. First, most participants in this group were the patients who were seriously ill and vulnerable. As a result, collecting the data for each participant had to take a longer time (range = 20-85min or M = 39.05 min,  $SD = \pm 11.70$  for the quantitative study and range = 24-48 min or M = 37.25 min,  $SD = \pm 7.09$  for the qualitative study). Another challenge, some of the every fifth participants in this study agreed to participate in only the quantitative study, but did not want to participate in the qualitative study because of several reasons. These were related to their deteriorated conditions, for example, too tired or too old to talk for a longer time. In addition, some of them were worried and scared to be interviewed and recorded. Thus, although they consented to participate in the quantitative study, they refused to be included or could not participate in the qualitative study. As a result, the interviews had to be postponed. Similarly, the studies of Ryan (2005) and Tamburini et al. (2003) as well as other studies of London et al. (2005) and Mystakidou et al. (2007) encountered these types of problems related to the subjects' condition deterioration and/or refusal. The subjects in this current research were excluded from recruitment into the qualitative portion.

These challenges forced the researcher to continue to collect data in order to obtain 20 participants for the qualitative study as designed. This issue yielded the number of participants in the quantitative study from 100 in the plan up to 111. As a result, the time of data collection had to be extended from four months to five months.

### **Discussion of Instruments**

For this study, three instruments (the PPSv2, HCQ [Patient], and VRSs) were used and tested: the reliability of the PPSv2 and HCQ (Patient) and concurrent validity between the HCQ (Patient) and VRSs. The findings revealed that the HCQ (Patient) and VRSs had sufficient psychometric property—concurrent validity--to assess comfort conceptually on the elderly patients with advanced cancer. In addition, the equivalence reliability—coefficient alpha-of the HCQ (Patient) was .885 (in the pilot study, N = 20) and .898 (in full study, N = 111). This finding is consistent with the findings of previous studies (Devon et al., 2007; Dowd, 2006; Dowd et al., 2007; Kolcaba, 1992, 2003; Novak et al., 2001; Siegle, n.d.). However, as the PPSv2 was a one-item question, it could not be tested for the equivalence reliability. The test-retest method needed to be applied. Similar to the explanation in the Chapter IV, to test the reliability of the PPSv2, both the PPSv2 scores measured by the researcher and ward nurses were used. Based on the result, the PPSv2 scores had a high significant correlation (Pearson correlation [r] =.768) which qualified the tool to assess the prognosis or survival of individual dying patients. This is consistent with the previous studies of Ho et al. (2008, August 4) and Lau et al. (2006).

In summary, the PPSv2, HCQ (Patient), and VRSs had psychometric properties for verifying the results of this study and for use in a future study. The HCQ (Patient) and the VRSs can be used to assess comfort; the PPSv2 qualifies it to be used to assess current conditions and estimate survivals of dying patients, especially elderly patients.

#### **Discussion of Demographic Data and Results**

This study had 111 participants; the number of males and females were almost equal. Most of them were married (n = 72, f = 64.9%). The range of their age was 60-83 years old (M = 68 years,  $SD = \pm 6.15$ ) which supported the report of the Institute for Population and Social Research, Mahidol University (2007) which stated that the major group of Thai elderly were between 60-79 years old. It was also similar to the statement of the Bureau of Empowerment for Older Persons (2004), of Thailand, that reported that 87% of Thai elderly had at least one chronic disease. The most frequent type of cancer of these participants was lung cancer. It was consistent with the previous study of Vatanasapt et al. (2002) about controlling cancer in Thailand which found that lung cancer was the most prevalent in males (47.8%) and females (37.4%) in the northern region of Thailand which was the same location of the setting for this current research. Kamnerdsupaphon, Srisukho, Sumitsawan, Lorvidhaya, and Sukthomya (2008) also studied cancers in the north of Thailand, focusing on cancer patients (the range of their ages = 1-98 years) in the hospital, the same as the setting of the current study. They reported that, in 2005, lung cancer was the primary diagnosis for both male (19.8%) and female 14.1% patients. In the present study, most patients were diagnosed in stage IV with metastasis. This finding could be supported by their PPSv2 scores (assessed by the researcher) that were 30-60 (M = 49.01,  $SD = \pm 8.31$ ), whose mean was 48.99 or almost equal to 50. This result could be supported and explained by the interpretation of the PPSv2 scores that most participants were in the dying process. Ninety-five percent of them had the survival time of only six months or less (Lau et al., 2006).

In addition, approximately, 98.2% of these participants were Thais and Buddhists, the main religion of Thailand. They mostly were educated at a low level. Furthermore, most of these participants were retired (n = 47, f = 42.3%) and had to stop their working because of their illness (n = 42, f = 37.8%). Most of them were poor and needed financial support. The main financial supports for them arose both the 500-Baht subsidy per month for the cost of living (= \$ 16, approximately, calculated based on the currency rate about 30 Baht per dollar) and the 30-Baht via the Gold Card for the hospital costs from the Thai government paid only the first time or at the first of each admission. Most of them had no other regular income (n = 32, f = 28.8%). Some of them received the financial support from relatives, but not always and regularly. Consequently, the data revealed that 81 participants (72.9% of all) had low total income--from 0-2,000 Baht monthly. The main characteristics of the participants of this study were similar to those of Haseen, Adhikari, and Soonthorndhada (2010) whose participants (n = 30,427) were aged 60 years or more and involved self-health assessment of Thai elderly. They reported that most of their participants were 60-69 years old (53%), married (59.3%), educated only at the primary/elementary school (72%), and had low incomes, less than 30,000 Baht per year or 2,500 Bath per month (50.6%).

In summary, almost all participants of this study were Thai younger elders and Buddhists. They had low education, were poor, could not work, and had insufficient finances for themselves and their families. Most participants were seriously ill and in the metastatic stage of lung cancer.

#### **Discussion of Quantitative Data and Results**

Based on the quantitative data, comfort as experienced by 111 Thai older patients was assessed by two tools: the HCQ (Patient) and VRSs. The findings revealed that the comfort level of most participants of this study was between moderate and almost high comfort measured by the HCQ (Patient) (M = 4.29,  $SD = \pm .50$ ) and was moderate to fairly high comfort measured by the VRSs (M = 6.25,  $SD = \pm 2.09$ ) although the qualitative findings showed that most of them still experienced discomfort in four contexts: physical-physiological, psycho-spiritual, socio-cultural, and environmental. On the HCQ (Patient), they also reported that they had inadequate comfort, when some requested nursing care for comfort or enhanced comfort. This study is inconsistent with the work of Novak et al. (2001) who found that dying patients, as hospice clients, had a comfort-score mean measured by the HCQ (Patient] of 5.16 ( $SD = \pm 28.56$ ) which was higher than that of the current study (M = 4.29 (SD = $\pm$ .50). This finding may be explained by the different qualities of palliative care system between two countries: Thailand and USA. In Thailand, palliative care has just been developed in the past several years; whereas in USA, it has been developed since 1974. Care for cancer diseases received the first model of the palliative-care development (Elisabeth, 2003; Hospice Association of America, 2006). Consequently, palliative care in the USA, which has developed and improved for a longer period of time, can provide quality palliative and comfort care to a greater degree. There was no evidence from any previous study related to comfort and Thai older patients or Thai cancer patients in the extant literature. This current study is the first time using the HCQ (Patient) and the

VRSs for Thai cancer patients, especially for the older patients with advanced cancer. However, the possible explanations for these current results (comfort levels from moderate to almost high and to fairly high) may be the followings:

1. Most patients were poor and usually had insufficient means to promote their well being. Most of them often compared and stated that being in the hospital was better than staying at their houses. Examples were found in the views of distressing symptoms, providing care for them, and general hospital life, illustrated by the statements of ID 6, 13, or 20 shown on the theme—*Comparison between the Hospital and the House*. In addition, the statement of ID 7 reflected similar comparison below.

ID 7 "It is not the same. I feel lonely because I needed to stay alone at my house. I have only two dogs and one television as my friend. I needed to help myself for eating. Differently, the hospital provides care and here has friends for talking which relieves my loneliness. There is the happiness, differently (from the house)."

Regarding the view about the distressing symptoms of most participants, these

distressing symptoms were relieved by nursing care and medical treatment during the

admission. As a result, these participants reflected that their conditions were better than

those at their home, such as the ID 1 who expressed that he was so proud of being

admitted and receiving nursing care which helped him to eat better.

ID 1 "I proud of myself to receive the comfort care, such as providing food. Such the Ovaltine sometimes is given to me. At home, although I have food, it is not the same as the food of the hospital. They care for me. They give me the food every mealtime.... They give me the liquid. I drink it gradually; that helps me be happy."

Thus, undoubtedly, most of them perceived that they were more comfortable or

felt comfort during the hospital admission. There was only one participant whose

diagnosis was the intrahepatic cholangiocarcinoma (ICCA) with metastasis. He was very weak and experienced abdominal distension causing dyspnea and the need for oxygen inhalation. His comfort score from the HCQ (Patient) was low (3.14, rating 1-6) and from the VRSs was 0 reflecting "No comfort at all". Regretfully, the researcher knew from his wife that he died about two weeks after participating in the study

2. Ninety eight percent of the participants were Buddhists. Most of them applied Buddhist beliefs and practice to transcend themselves to enhance comfort although their distressing symptoms existed. This evidence was found in 17 participants in the qualitative study. Likewise, the quantitative study showed by five highest-score items of the HCQ (Patient), (items 46, 7, 35, 9, and 10 [see Table 14]), that the participants whose health behaviors included religious or spiritual activities could transcend themselves to experience high comfort.

In summary, most participants experienced comfort between moderate and almost high or fairly high levels during their hospitalization which was not expected by the researcher.

### **Discussion of Qualitative Data and Results**

The discussion of this section consisted of two main domains that emerged from the data: *Discomfort* and *Comfort*, supporting the *Comfort theory of Kolcaba*. A last domain emerged was called the Additional domain which also related to Intervening variables of comfort or discomfort, Nursing comfort care, Nurses (including other healthcare personnel), Improvement for comfort care, and Comparison between the hospital and the house. However, previously, they also were cited and explained as comfort variables by Kolcaba (2003).

## **Discussion of Discomfort**

Based on the interview data, the findings showed that every participant inevitably experienced discomfort covering four contexts: *Physical-physiological*, *Psycho-spiritual*, *Socio-cultural*, *Environmental discomfort*, supporting the Comfort theory of Kolcaba (2003) and consistent with the previous studies of Dunne et al. (2005), Larsson and Wijk (2007), Lin et al. (2000), and Mako et al. (2006).

## **Physical-Physiological Discomfort**.

First, the discussion focused on the *Physical-physiological discomfort* experienced by every participants of this study (N = 20, f = 253). Most of these related to distressing symptoms, deficits of ADLs or disability strategies, and needs of hygiene care. The findings supported the previous reports by the National Comprehensive Cancer Network (2007) and Stuart (1999) which emphasized the clinical symptoms and treatment needs of advanced cancer patients, Tamburini et al. (2003) focusing on better hospital service about meals and cleaning, and Vallerand et al. (2007) who reported the ADL needs of 10 patient-caregiver dyads: dressing, taking a bath, walking down the driveway, getting out of bed, eating a meal, etc.). However, in the current study, the important finding was that discomfort from distressing symptoms was the most prevalent among these participants. The first top 10 of these were as shown in Table 24. Sleep disturbance and pain demonstrated the highest frequencies (n = 18, f = 54; n = 17, f = 49, respectively); so they are presented here for discussion. Between the two themes: sleep disturbance and pain of this study, the frequency of sleep disturbance was higher. This finding is inconsistent with the previous studies which mostly mentioned that pain symptoms were the most significant, such as the study of Stromgren et al. (2001) which found pain in 80% of 56 advanced cancer patients, whereas sleep disturbance was only 42%. In addition, Evans and Hallett (2007) found that pain was the big problem of dying patients and Teunissen et al. (2007) also found that pain was the first physical symptom of 95% of advanced cancer patients in the study. Similarly, Steinhauser et al. (2000) found that 93% of their participants (N = 340) mentioned their pain as one of the important factors at the end of life but did not cite their sleeplessness. However, when considering the current findings with its more details, pain also was mentioned in the category of *Inadequate comfort* (n = 5, f = 15). If the frequencies of pain from two sources were combined, its total will be higher the frequency of the sleep disturbance. Both sleep disturbance and pain were the most distressing symptoms of these Thai older patients with advanced cancer.

In addition, the study revealed that sleep disturbance and pain related to each other. When considering the causes of sleep disturbance, the findings showed that sleep disturbance also related to anxiety and noise. Therefore, three of these symptoms were the most common causes of sleep disturbance (worries [n = 7, f = 17], pain [n = 5, f = 13], and noise [n = 4, f = 5]). However, these findings were supported by Nagel, Markie, Richards, and Taylor (2003) who found that pain, anxiety, and noise pollution were major factors of sleep disturbance. They were also consistent with the study of Hugel, Ellershaw, Cook, Skinner, and Irvine (2004, April) and of Ersser et al. (1999).

Hugel et al. (2004, April) studied the causes and management of insomnia through a retrospective audit (as part of the regional audit program) in 74 patients who were admitted to palliative care units in Merseyside. They used the questionnaire consisting of 15 questions developed by reviewing the literature. They found that 52 patients (72%) had sleep disturbance which developed as insomnia after cancer diagnosis (n = 39, f = 75%). They further revealed that 31 of the patients with insomnia (60% of insomnia cases or 48.5% of all participants) reported that pain which occurred by lack of effective control was the cause of their sleep disorder and 19 patients (36%) mentioned their worries as the main cause of the insomnia.

Similarly, the research of Ersser et al. (1999) was conducted to study sleep quality and pattern of 41 patients aged 60 years or over admitted to a community hospital (rehabilitation wards) or to one of two nursing homes in the same area, by triangulation method. They summarized the findings that pain, discomfort, the need to go to toilet, and the external disturbance—noise—were the main causes of sleep disturbance of their subjects.

### **Psycho-Spiritual Discomfort**.

The *Psycho-spiritual discomfort* was reported to include the top 10: worry and/or fear, worry (solely), impact on the meaning of life, need spiritual support, discomfort relating to hope, fear (solely), missing family members/relatives, sympathy/pity with nurses or relatives, suffering/distress from the illness, and loneliness. The most prevalent of these discomforts was *worry and fear* concepts (see Table 28). The review of literature referred to or mentioned just the term of anxiety, not the term of worry. There was no article found that related to worry and end-of-life, dying, or advanced cancer patients. A new study of Luctkar-Flude, Groll, Woodend, and Tranmer (2009) was reviewed. The authors studied causes of fatigue of 328 cancer subjects (*M* of age = 72.6,  $SD = \pm 5.6$ ) and reported that worry was one of the top five symptom prevalence causing fatigue; however, they did not indicate any other information about the worry in their study.

Consequently, the concepts of worry and anxiety had to be reviewed about their differences carefully. As a result, both anxiety and worry have close meaning and correlate closely. There were several explanations for their definitions. For example, Hunt, Wisocki, and Yanko (2003, p. 548) explained that worry was, "uncontrollable and negatively affect-laden thoughts and images". And, worry also was a pathological and clinical phenomenon of generalized anxiety (Graham, 2003, September; Hunt et al., 2003). Additionally, Hirai et al. (2008) defined anxiety in cancer patients as, "a negative state of mind" and "intrusive and unpleasant anxious thoughts...." (p. 1172). Interestingly, Hirai et al. (2008) and Stober and Joormann (2001) summarized similarly that worry, anxiety, and depression related to each other closely. Conceptually and functionally, their concepts are not the same. Worry can develop into anxiety and, finally, as depression. In addition, in the Thai language, the two terms used for worry and anxiety are pronounced very similarly (kungwol = worry and witok kungwol = anxiety) and are typically defined as nearing the same meaning. They were also used alternatively as having the same meaning in the interview process of this study. Thus,

for this discussion, the terms of anxiety identified in previous studies and of worry cited as the theme in this study are assumed to have the same meaning.

Returning to the findings of the current study, all psycho-spiritual discomforts that emerged, as shown in Table 28, were consistent with several previous studies. (Aitini & Cetto, 2006; Barsevick et al., 2006; McClain, 2003, May; Noorani & Montagnini, 2007; Stromgren et al., 2001; Teunissen et al. 2007). For example, Stromgren et al. (2001) found that 47% of 56 advanced cancer patients receiving noncurative treatment experienced anxiety or depression. The study of Teunissen et al. (2007) revealed that many of the 79 hospitalized patients with advanced cancer confronted anxiety (34%), depressed mood (56%) or both of them (29%). Similarly, Lundberg and Rattanasuwan (2007) studied and reported that 133 Thai Buddhist cancer patients receiving radiation therapy (55 men and 78 women) (*M* of age = 53.3 years, *SD* =  $\pm$ 12.9) experienced feelings of anxiety, fear, and depression. Furthermore, the illness impacted the patients' hope, meaning of life, and need for spiritual support (Tang, Aaronson & Forbes, 2004; Mako et al., 2006; McClain, 2003, May; Noorani & Montagnini, 2007; Valker & Limerick, 2007).

More interestingly, the most prevalent of all psycho-spiritual discomfort of this current study was worry and/or fear which mostly related to their cancer illness and symptoms: the worsening of the progress of the illness, non-healing or the recurrence of distressing symptoms: pain, bleeding from the vagina, inability of defecation, facial edema, future conditions, inability of recovery, the period of time for the recovery, non healing of the abdominal wound (because one participant experienced the eviscerations two times), numbness, and sleeplessness. This finding can be confirmed by the quantitative finding that revealed that the reverted score of the 34<sup>th</sup> item of the HCO (Patient) " I think about my discomfort constantly" was the fifth lowest comfort expression (M = 3.17,  $SD = \pm 1.39$ ) as shown in Table 14. Furthermore, the phenomena of worries and/or fear about illness and distressing symptoms can be explained. Physical distressing symptoms were related or could produce psycho-spiritual discomfort. This finding is supported by the statement of Quill and Meire (2006) who stated that the greatest concern and fear of dying patients was uncontrolled or undertreatment of symptoms, such as pain and others. In addition, Noorani and Montagnini (2007) also stated that up to 75% of patients with life-threatening conditions experienced depression which was caused by physical and psychological symptoms. In addition, Barsevick et al. (2006) studied and tested the mediating effect of functional status on the direct and indirect relationship between cancer-related fatigue and depressive symptoms in their cross-sectional study. This study used an experimental design (the controlled group who were provided with healthy diet information [N = 151] and the treatment group who learned skills designed to minimize the impact of fatigue on functioning called the energy conservation and activity management [ECAM] [N = 144]). Their findings showed that the poorer the functional status or the higher level of the fatigue, the higher the degree of depression. In summary, Thai older patients with advanced cancer experienced psycho-spiritual discomfort which mostly was impacted by physical-physiological discomfort.

### **Socio-Cultural Discomfort.**

Most participants did not report or communicate their discomfort to nurses or other healthcare personnel (n = 18, f = 47) and their needs for medical information (n = 14, f = 34).

Regarding the issue of lack of reporting and communicating their discomfort, these participants mostly reasoned that they did not desire to disturb nurses who were working and so busy on their hard work. The participants also believed that they were not brave enough to ask questions or talk. The participants also reported that the nurses did not ask them about their conditions. Of more concern, these participants believed that nurses should ask first rather than waiting for or just answering their questions. Consequently, nurses did not have an opportunity to know the level of discomfort and provide comfort care to help their patients meet their needs or enhance their comfort.

There are several possible explanations for this phenomenon. First, this may be because of insufficient relationship between nurses and their patients to make a conversation or communication between them, including reporting discomfort. This reason can be supported by the theme—*Communication problems of nurses* (of the category—*Nurses (including other healthcare personnel)*—in the *Additional domain)*. Second, these participants were educated at a low level which made them not brave enough to talk and know how to ask. Last, the medical attitude and culture involved need to be considered. Most Thai people, especially villagers, understand and believe that they come to a hospital to receive help from healthcare providers. In addition, one of the common characteristics of people in the north region is that they are hesitant and

worry to request something from others, especially from doctors or nurses who were respected as helpers. Larson and Tobin (2009) examined the evolution and needs for end-of-life conversation from previous literature and stated that shyness, fear of death and dying, cultures of patients and families were as barriers prohibiting end-of-life conversation between patients and healthcare providers. Furthermore, the theme of *Need for medical information* was supported by the additional findings of the quantitative study which reported that the 39<sup>th</sup> item—"*I need to be informed about my condition*"—obtained the third lowest score of comfort (after converting its score).

Interestingly, two phenomena: *No reporting or communicating of existing discomfort* and *Need for medical information* emerged in this study and were related to problems of relationships and communication between nurses and their patients. This finding is consistent with several previous literature reports and studies (Heyland et al.; 2006; Morse et al., 1994; Ryan, 2005; Steinhauser et al., 2000). They were the major problems and the most prevalent findings. Such as the study of Heyland et al. (2006) that revealed the extremely important elements of 434 seriously ill patients and 160 of their families were the same. Those elements related to trust and confidence of doctors for providing care and needs information and communication about the patient's disease. Similarly, Steinhauser et al. (2000) studied of 1, 885 patients as well as their families and healthcare providers. They reported that relationships between patients and healthcare professionals were an important factor of quality of life. In addition, Ryan (2005) interviewed five patients with advanced cancer. These patients revealed that genuine caring, compassionate honesty, effective communication, relationship support,

caring gestures, acknowledging patients by name and remembering, and listening to the losses should be provided as end-of-life care.

In summary, effective relationships and communication between nurse and patients with advanced cancer were important to provide ultimate comfort.

## **Environmental discomfort.**

The last discomfort is *Environmental discomfort*. Most participants focused on the hospital setting. Most of them complained about uncomfortable rooms, especially *noise* which occurred from other patients' talking or shouting, many patients or visitors/relatives of other patients, coming from the outside of the room, the construction, or nursing carts; and insufficient and uncomfortable restrooms. Similar to the finding of Hearson and Sawatzky (2008) who studied sleep disturbance in patients with advanced cancer. They found that noise and the length of time spent for providing nursing care interferred with the quality and quantity of sleep. Nagel et al. (2003) also reported that noise was a major influence on the sleep disturbance of hospitalized elders. They especially cited the noise of verbal interactions among nurses, other staff, and patients, of equipment and the high level of noise from wheels and doors, and so forth. Thus, noise still is an important discomfort which should be of concern of nurses to provide comfort and palliative care for advanced cancer patients.

In summary, every participant of this study experienced discomfort in four contexts of physical-physiological, psycho-spiritual, socio-cultural, environmental discomfort.

## **Discussion of Comfort**

Comfort, which participants of this study received during the hospitalization, was provided by three main groups: nurses (including other healthcare providers such as doctors, a medical student, and practical nurses); relatives of the patients; and the patients themselves by health seeking behaviors (HSBs); as well as other patients in the same room. Comfort care consisted of three types as described in Comfort theory (*Relief, Ease*, and *Transcendence*). One additional comfort category emerged from this study which was named *Inadequate comfort*. This section discusses comfort care providers and types of comfort care. For the purpose of discussion, the *Relief, Inadequate comfort, and Transcendence* types will be discussed first because their definitions reflected that the participants still experienced some discomfort although they received comfort care. The *Ease* category expressing the state of the participant's comfort level will then be discussed.

First, *Relief*, the study found that most nurses dominantly focused on physicalphysiological care. *Relief* was identified as: *Relief from distressing symptoms*, especially pain; *Professional care* (taking care, paying the attention, and helping); *Technical comfort care* (nursing or medical procedures provided professionally, such as administering, providing medications, preparation for the investigation, or wound care); *ADLs support*; and *hygiene care*. However, nurses provided insufficient psychospiritual and socio-cultural comfort. Most concern was identified that environmental relief by nurses was not experienced by all participants. Nursing care did not help to adjust room or hospital environments for comfort. Obviously, patient's relief from nursing care focused primarily on physical-physiological care to relieve distressing symptoms. This care lacked other care, especially, psycho-spiritual care or relief. This finding was supported by the study's theme —*Requesting comfort care* (in the *Additional domain*). This showed that psycho-spiritual care (such as talking, encouragement, spiritual support, etc.) was requested by participants, but nurses were unaware of the needs by patients and the need was not met.

Furthermore, this finding supports the study of Somjai and Chaipoom (2006, September). One of two study objectives was to compare the differences in psychological needs and need-met between 45 Buddhist cancer patients (aged mean = 47 years,  $SD = \pm 7$ ) and 45 Muslim cancer patients (aged mean = 45 years,  $SD = \pm 12$ ). Those demographic data were similar to those of the participants of the current study. The psychological needs were studied based on eight themes: hope, more information, moral support, acceptance, relief of anxiety, economic support, discussion relating to death, and privacy. They found that psychological needs and psychological needs met were high in both groups (M [Buddhist patients] = 3.56 (SD =  $\pm .39$ ) and 3.11(SD =  $\pm$ .37), respectively; M (Muslim patients) = 3.67(SD =  $\pm$ .39) and 3.14 (SD =  $\pm$ .27), respectively (from a 4-point Likert scale). Evidently, the mean score of psychological needs was more than that of psychological needs met in both groups, which reflected that nursing care could not respond to all psychological needs of cancer patients. Petcharat and Baoban (as cited in Somjai & Chaipoom, 2006, September) mentioned that Thai healthcare providers are mostly focused on more physical care but less on psychological care.

Regarding comfort care—*Relief*--from relatives, 14 participants reported that most of their relatives collaborated to provide psycho-spiritual care (f = 36), such as family information, talking and encouraging, or as consultants. They also provided socio-cultural comfort care (f = 40), such as maintaining family relationship and financial support (which was not sufficient). For physical-physiological comfort care, there were only 10 participants who mentioned that their relatives provided it, such as providing food and hygiene care. As with nurses, there was no datum to indicate that the relatives were involved in environmental comfort. Most participants perceived that psycho-spiritual and socio-cultural comfort were mostly provided by their relatives. The finding is consistent with the findings of Lundberg and Rattanasuwan (2007) who studied self-management in Thai Buddhist cancer patients (55 men and 78 women whose aged mean was 53.3 years,  $SD = \pm 12.9$ ) receiving radiation therapy. Their participants revealed that their families, such as husband/wife or children and friends, provided them with *moral support* which was important and made them feel better about the illness. There is a possible explanation, which may help us to understand this finding as it relates to Thai culture, especially in the north of Thailand. Grateful culture is held strongly and carefully by the society, people are pleased to take care and responsibility to help family members if they are ill or need help. More importantly, if these ill family members are parents or other respective elderly, families cannot refuse their responsibility to provide care.

The relatives in the current study accepted the responsibility to visit and provide care for the participants although the hospital policy generally did not offer or allow

them to be with the patients all day. They needed to visit patients two times per day following the hospital visiting time policy (12:00-01:00 p.m. and 03:00-06:00 p.m.). However, these relatives' visits provided patients with psychological support through talking. Obviously, many relatives whose homes were in another province attempted to be as close to patients as possible. Some family members might be in their relatives' houses or rent a cheap house near the hospital. In addition, some of them tried to find some places within the hospital to spend their nights to wait for the visiting times for patients in the next day. They provided care, especially encouragement, spiritual activities, and financial support beyond physical care. When comparing the psychospiritual and socio-cultural support from nurses who were perceived always to be so busy and from their relatives, most participants felt less supports from their nurse than the support from their relatives.

One of the main providers for relief was the individual patient, named the health seeking behaviors (HSBs). Based on the interview data, the analysis showed that every participant had to seek care for comforting him/herself to relieve physical-physiological discomfort (mostly focusing on relieving pain and sleep disturbance); 19 participants expressed their hope (getting well or recovery, able to go home, etc.); and eight needed to support themselves psychologically by other approaches (for example, trying to accept and understand the current situation, seeking information of medicine, encouraging, etc.). This finding is also supported by the findings of the category—*Inadequate comfort*—and the themes—*Ineffective existing comfort care*, *No comfort care responding to specific discomfort*, and *Request comfort care*—of the Additional

domain (see Table 40). These findings reflected that although the participants received some comfort care, there still were some comfort needs or insufficient nursing comfort care, which was consistent with the studies of Petpichetchian (2001). This study found that most Thai cancer patients still faced pain symptoms. Consistently, Teno et al. (2004) reported that dying patients in healthcare settings experienced inadequate pain control, emotional support, and relationship support as well as ineffective communication and symptom management. Curative treatment or traditional care is still provided for dying patients more than palliative care (Plonk & Arnold, 2005) and considering transferring dying patients from curative treatment to palliative care is difficult for physicians or other health professionals in cancer care for the dying (Schonwetter, 1996, May-June; Teno et al., 2004).

As a result of insufficient comfort care, most participants in this study tried to find out or seek possible ways to relieve the distressing symptoms or comfort themselves. Hope was the most important strategy which they used for fulfilling comfort for themselves. In this study, it was found that 19 participants expressed hope for psychological support to decrease/relieve their worries and fear about cancer diseases and symptoms. The future hope of these participants was the most prevalent theme. This finding is consistent with previous studies. For example, Morse et al. (1994) studied and suggested that fostering hope for the future could help patients endure the suffering body by giving more energy and strength. Furthermore, Chi (2007) explained hope of cancer patients based on the finding of the meta-analysis that "Hope is a profound feature of human life and allows the living to keep on living and the dying

to die more easily and with dignity" (p. 416). Hope is often used by cancer patients while facing fear or uncertain situations through religious beliefs and activities as a strategy. This strategy is called *Transcendence* as one type of comfort (Kolcaba, 2003) and was defined in the present study as a statement that reflects the ability of each participant to rise above his/her existing discomfort when they could not be eradicated. Based on the current finding, 17 participants (f = 53) used religious beliefs and activities to transcend themselves to be above their discomfort. Most of them transcended by positive thinking and holding religious beliefs/precepts (illness already occurred, everyone has to die, detachment, karma, and making a conclusion); and/or religious practice (meditation/Samadhi, praying, blessing, vowing, respect/Wai Pra/worship, blessing, and bargaining for longer life to do merit and taking care the children) (see Table 37). Consistent with the previous studies by Morse et al. (1994) who called the poorly controlled mind affected by the illness or discomfort as the betraying mind, she suggested that religious support could help patients to meet comfort needs. Fleming et al. (1987) and Steinhauser et al. (2000) also studied and reported the pertinent result that religious activities, faith, or peace with God was important for advanced cancer patients to meet their spiritual needs. These studies verify that religious activities are related to comfort transcendence. In addition, there are two more Thai studies that are consistent with this finding. The study of Lundberg and Rattanasuwan (2007) examined the selfmanagement of 133 Thai Buddhist cancer patients. Two of five themes in the study reflected self- management relating to Buddhism: religious practice (reciting, praying, and meditation) (34.6%) and acceptance of the situation and doing the best with the

Buddhist doctrines (27.1%). Another study by Soonthornchaiya and Dancy (2006) examined depression and the strategies of coping of 20 Thai elderly immigrants who belonged to the Thai culture by connecting continuously to three Thai temples in Illinois. Practicing Buddhist teaching, meditation (such as acceptance of life with illness, talking with monks, etc.), and going to a temple emerged as the strategies of their coping.

Interestingly, the importance of Buddhism can help patients, including Thai older patients with advanced cancer in this study, to transcend to be with or above their discomfort. The cores of Buddhist teaching are: mindfulness-awareness, universal characteristics, and law of Karma (Panyapatipo, n.d.; Puapanskul, Charumas, & Ngamluck, 2006; Sayadow, n.d.). Mindfulness-awareness teaches how to understand the world, think positively, and consider what is good for life, wisely. Meditation is one approach to practice the mindfulness-awareness Furthermore, everything in the world follows three universal characteristics: impermanence (birth, old age, sickness, and death as inevitable experiences); suffering as the truly natural experience of a body; and non-self (suffering and death as uncontrolled experiences, especially death as the finality of life). Last, everything occurs (including happiness and misery/suffering) by karma. Karma is the results of the past and present actions of humans who are responsible for their own actions. So, the more doing of goodness or merit results in the obtaining more of the good results. All of Buddhist teaching supports dying patients to detach themselves from impermanent things/phenomena, causing sufferings, in the world in order to end those sufferings and/or make a conclusion to accept their stressful

situations with peacefulness, calmness, and contentment. As a result, *Ease* of comfort occurs if the transcendence is achieved.

*Ease* is one comfort type that emerged. Ease was defined by Kolcaba (2003) as a state of contentment reflecting comfort feeling. Ease in this study was defined by the participants as being satisfied, comfort/more comfort/psychological comfort, happiness or warmth, being glad/pleased, being fine/okay/all right, feeling good, and feeling at multiple-type ease (see Table 36). Ease expression was provided by nurses, relatives, the patients themselves, and other patients. However, nurses were the most important providers for ease phenomenon (n = 17, f = 58). *Ease* expressions mentioned most were comfort/more comfort/ psychological comfort (n = 8, f = 13), happiness or warmth (n = 6, f = 10), and disappearance of distressing symptoms (n = 4, f = 5). This finding was consistent with one previous unpublished study on the Palliative Care Project done by the Nursing Division at the study hospital. It reported that 257 dying patients expressed satisfaction with the palliative care provided. Nevertheless, they also suggested that improving nursing care was the thing which they needed most.

One question why *Ease* could emerge under the participants' experiences of *discomfort* in all contexts with other phenomena: *Inadequate comfort, Ineffective existing comfort care, No comfort care responding to specific discomfort, and Request comfort care* needs to be answered. The possible explanations may be the following:

1. Most participants had a positive attitude and belief in capability and expertise of doctors and other healthcare providers in this hospital which was the biggest in the north of Thailand. 2. Most participants had a low education level and did not know about the hospital cultures well. So, it might be hard for them to compare between the ultimate nursing care which should be provided and the nursing care actually received.

3. Most of them were poor, as daily-wage earners. Comparing their lives and symptoms between the hospital and at their houses, they found that they felt more comfort while they were in the hospital.

Beyond comfort care from nurses, relatives, and the HSBs, other patients in the same room were mentioned as helpers who offered *Relief* (n = 7, f = 7) and *Ease* (n = 3, f = 4) such as serving a bed pan, being friends of talking, teaching how to use the electric bell, and so forth. There is no previous literature relating to this phenomenon. However, the possible reasons may be explained as follows:

1. Because of Thai northern culture, most citizens are nice or friendly and prefer to help each other.

2. All participants were admitted in ordinary wards. Each room commonly has several patients, bed by bed. Consequently, they could see and know who needed help and who could help. In addition, it was easy to call for help among patients.

## **Discussion of Additional Domain**

In the Additional domain, there were five themes emerged: Intervening variables, Comfort nursing care, Nurses (including other healthcare personnel), Improvement for comfort care, and Comparison between the hospital and the house.

First, the category—*Intervening variables*—was defined by Kolcaba (2003, 2004) as interacting forces from external stimuli or sources impacting the comfort

perception of patients. In the current study, the *Intervening variables* were defined as two types of variables: *Comfort variables* (n = 8, f = 17) and *discomfort variables* (n = 12, f = 23).

Comfort variables were defined as characteristics of nurses or other healthcare personnel and their care (speaking nicely and kindness, encouragement, paying attention, and good relationship between healthcare personnel and patients); non-cancer diagnosis; correct investigation; safe treatment; characteristics of patients (personality, age, and attitudes); ability of self care; family of the individual patient (ability of earning of families, good financial status or business of family); and culture of a region.

The discomfort variables were defined as status of illness, distressing symptoms (such as pain), medical treatment, inability of self care, individual personality and attitude, aging, and inappropriate weather. The findings about these variables were consistent with the previous studies (Brokel & Hoffman, 2005; Hamilton, 1989; Kolcaba, 2003, 2004; Morse et al., 1994; Ryan, 2005; Steinhauser et al., 2000; Tamburini et al., 2003; Volker & Limerick, 2007). In addition, Danyuthasilpe, Amnatsatsue, Tanasugarn, Kerdmongkol, and Steckler (2009) insisted from their study that cultures influenced beliefs, thinking, and daily behaviors of the elderly in Thai northern area, which could promote healthy being.

Second, the discussion focused on the theme of *Nursing comfort care*. Most concerns were that 14 patients expressed their requests for holistic nursing care—encompassing four contexts--(such as relieving distressing symptoms, encouragement, counseling and more explanation, spiritual support, financial support, and appropriate

weather and room with enough privacy); and that the present nursing care was not always effective (such as some nursing care provided depended on the schedule time [not on their actual needs]). They also reported that nurses could not respond to all their comfort needs, such as, the distressing symptoms in all discomfort contexts. Ineffective nursing care and lacking some nursing care emerged in this study were consistent with the nursing problems identified in previous studies (Brokel & Hoffman, 2005; Dunne et al., 2005; Ryan, 2005; Steinhauser et al., 2000; Tamburini et al. 2003; Volker & Limerick, 2007)

Most interestingly, communication problems of nurses were mentioned by 14 participants. The most important problem of communication was that most nurses talked with them for too short a time and, then, left, which made them not able to ask and report their discomfort. At the same time, nurses did not have a chance to know that their patients had discomfort. Comfort care could not be provided by nurses to respond to their discomfort.

Communication between nurses and patients or their families has become a critical problem for end-of-life care, palliative care, and comfort care. Many researchers were interested and studied this problem formerly, such as Dunne et al. (2005) who found that effective communication among nurses or healthcare personnel helped to decrease conflicts affecting care. On the other hand, its high quality would support all end-of-life patients, their families, and nurses. Ryan (2005) also found that effective communication, relationship support, and lessening the loss were important for end-of-life patients. Especially, consultation and counseling are needed for dying patients and

their families (Bascom, 1997; Quill & Meier (2006). All these findings suggest that communication still is a problem for the existing nursing care for older patients with advanced cancer or other dying patients, including Thai dying patients. Thus, the findings of this study provide support to improve the provision of palliative nursing care and to improve comfort care with effective communication by nurses.

Surprisingly, although most participants still had discomfort, needed comfort care, and viewed existent nursing care as ineffective care, they evaluated the overall of nursing care provided and said that its quality was good. A possible explanation may relate to the participants' characteristics as follows:

1. Most participants were concerned and worried about the impact from sharing their opinions about nursing care. In addition, as the interviewer was a nurse, they did not feel free to comment about it in a negative manner.

2. Most participants were poor and their daily lives or well being were not good, such as they lived in a small house, earning daily wages, and so on. Furthermore, they suffered more from their distressing symptoms while staying at their homes. As a result, they perceived that their illness was better controlled during the hospital admission because of receiving nursing care and help of nurses.

3. Most of them trusted the doctors, nurses, and services of this hospital which they said was the best hospital in the north of Thailand. This positive attitude toward hospital care was presented very strongly in this study.

Regarding the *Nurses* category, some participants commented about personality and behaviors of nurses and accepted that most nurses had good, satisfying, and friendly relationship (n = 6), speaking nicely (n = 10) and good quality for providing care (n = 10)= 10). In addition, 19 participants also agreed together that most nurses have *enough* knowledge for providing care for them. This is because they viewed nurses providing nursing care as a professional who needed a higher level of education. However, three participants reflected that these nurses needed to be trained additionally and continuously (such as special care-assessment and effective communication-[see Table 41]). Their reasons were that nursing care was professional and nursing knowledge developed all the time. Pertinently, 13 of the participants revealed that the overview of nursing care needed to be improved for comfort care and for helping them to meet comfort needs. The Improvement of nursing care emerged and covered four contexts of comfort, especially more attention for care, quick response to comfort needs or to distressing symptoms, speaking nicely and politely to their patients, and providing appropriate environments (such as sufficient electric fans as well as more cleanliness and better or good smell). Existing nursing care had to be improved encompassing all four contexts of comforts: physical-physiological, psycho-spiritual, socio-cultural, and environmental contexts. Nurses also need to improve their knowledge and skills, especially effective communication and counseling. The possible explanation for these findings is that this hospital has just developed palliative care for a few years. It is not easy to change acute-care hospital culture and develop palliative care in a big hospital within a short time. Significantly, the comfort concept has not been mentioned concretely and addressed in nursing practice effectively at this time at this hospital.

Consequently, most dying cancer patients could not have all their needs met sufficiently.

Thus, all problems relating to nurses and nursing care, hospital service, phenomena of patients' needs covering four comfort contexts were consistent with several previous studies. For example, Morse et al. (1994) used phenomenology with patients with life-threatening illness experiencing discomfort. Based on the enriched narratives derived from their patients, the authors found that providing appropriate care would help patients achieve comfort. They also said that the innovation of care capable to assess discomfort and provide comfort was a challenge task of nurses that needed to be done. Furthermore, Brazil et al. (2006) who conducted a cross-sectional research and found that eight best predictors of quality of EOL care covered all contexts of the participants' comfort needs like the findings of the current study. In addition, the current findings are consistent with the findings of the study of Kolcaba, Tilton, and Drouin (2006) who developed the Comfort theory as a unifying framework to enhance the practice environment for nurses of a non-for-profit New England hospital to provide comfort care. They derived the "Comfort Round" (p. 542) from the brain storming and discussion among the nursing-team members, patients, and families. This Comfort Round revealed that comfort needs of their patients also encompassed four contexts which had details similar to the findings of the current study, that is, physical, psychospiritual, socio-cultural, environmental comfort.

In summary, between the themes relating to the categories: *Nursing comfort care* and *Nurses* (including other healthcare personnel) of the current study and the

findings from the previous study, comfort needs of dying patients which were shared by nurses, patients, and families were pertinent and still evident in all contexts.

The last finding is the theme--Comparison between the hospital and the house. Fifteen participants discussed that the hospital and the house were different. There were two differences. That was, either hospital or the house was better or more comfortable in some respects. The better advantages of the hospital were defined as more psychological comfort; more comfort; trustiness and no fear; receiving what the patient wanted; and better environments: more quiet, cleanliness, and readiness; whereas the houses were better in terms of more freedom, less people, not waiting for the restroom, more cleanliness, no annoyance, and less noise. Obviously, for comfort, most of them wanted the hospital to provide comfort as the same as comfort they received from their house. Their preferences of hospital environments-the home-like hospital--are consistent with several previous studies discussing comfort environments of the hospital. The hospital should be arranged like home and should consist of non-chaotic atmosphere, calmness or tranquility, peacefulness, convenience, and sufficient individual privacy and ability to stay with the loved ones (Brokel & Hoffman, 2005; Hamilton, 1989; Kolcaba et al., 2006; Tamburini et al., 2003, Volker & Limeric, 2007). Thus, comfort environment is one issue which nurses should have much concern and manage for their dying patients. This will support these patients to obtain comfort and to die with peacefulness and dignity.

# **Discussion of Triangulation Confirmation**

This study was to explore comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand. Based on the present situation of palliative care in Thailand that has just developed this care in a few hospitals for a few years, knowledge about palliative care, comfort care, or end-of-life care has been limited. Between-method triangulation (consisting of quantitative and qualitative studies) was used for this study to confirm and validate the findings from both resources (see Figure 11). Thus, there are two main findings: quantitative and qualitative findings.

# **Triangulation Confirmation**

| ings                  | Enhanced Comfort<br>(Each care-providing group focused on | providing care differently.)<br>Relief                                  | <b>Physical-physiological comfort</b><br>By <b>nurses</b> (relief from pain)<br>By <b>HSBs</b> (relief from sleep disturbance or<br>pain)                     | <b>Psycho-spiritual comfort</b><br>By <b>relatives</b> (providing family information,<br>talking and encouragement, or as<br>consultants)<br>By <b>HSB</b> s (Hope support or psychological | care)<br>Socio-culturral comfort<br>By relatives (family relationship support or<br>financial support) | <b>Environmental comfort</b><br>By <b>HSB</b> s (acceptance of being together or<br>ability to control external environment) | Ease<br>By nurses (care during the admission,<br>providing food and medications, talking<br>and making a joke, etc.) |
|-----------------------|---|---|---|---|--|--|--|
| Qualitative findings  | Discomfort  | rt Physical-physiological discomfort<br>(sleep disturbance, pain, etc.) | <b>Psycho-spiritual discomfort</b><br>(worry/fear about illness,<br>worry about family,<br>impact on the meaning of life,<br>need of spiritual support. etc.) | Socio-cultural discomfort<br>(no reporting/communicating distressing<br>symptoms, need for medical<br>information, need for financial support,  | etc.)<br>Environmental discomfort<br>(uncomfortable setting: rooms,<br>restrooms, etc.)                | Inadequate comfort<br>Feeling better from:<br>Nursing care (alleviating distressing symptoms)                                | Relatives' care (consolation/support)<br>HSBs (trying to sleep)  |
| Quantitative findings | HCQ (Patient) Moderate-almost                             | VRSv2 high/fairly comfort   | Additional finding Most Discomfort:<br>(Items of HCQ [Patient] -feel uncasiness<br>with changes<br>-drying mouth<br>and skin                                  | -needs of medical<br>information<br>-pain<br>-thinking about<br>discomfort  | Most Comfort<br>Spiritual comfort:<br>-being loved<br>-worthwhile life<br>-confident spirituality      | -belief for peace<br>-meaning of life  |  |

Figure 11. Triangulation Confirmation

**Transcendence** By HSBs (religious beliefs and practice) First, comfort in the quantitative study was measured by two instruments: the HCQ (Patient) and VRSs. The findings indicate that Thai older patients with advanced cancer experienced comfort from moderate to almost high levels from the HCQ (Patient) and from moderate to fairly high levels from the VRSs. This means that these participants did not have all their needs met or still needed more nursing care to obtain optimal comfort.

Furthermore, the data were analyzed additionally for the five items that obtained the lowest and highest comfort level of all participants (see Table 14). The additional finding revealed that items 24, 27, 39, 14, and 34 obtained lowest scores of comfort, from the lowest to higher scores respectively. Clearly, all of these items reflected and supported the thesis that most Thai older patients with advance cancer still experienced discomfort relating to Physical-physiological discomfort: Item 27 (Mouth and skin feel drying) and Item 14 (My pain is difficult); Psycho-spiritual discomfort: Item 24 (I have experienced changes which make me feel uneasy), which this item could be referred to Environmental discomfort because Kolcaba explained directly to the researcher that some items of HCQ (Patient) might be overlapped with each other because comfort care was holistic care; and Socio-culture discomfort: Item 39 (I need to be better informed about my condition). The five highest scores of comfort were the items 10, 9, 35, 7, and 46, from the highest score to the lower one, respectively. All these items related to religion and spirituality of human beings or patients. This finding reflected that both religion and spirituality could promote Thai older patients with advanced cancer to

enhance comfort significantly by transcendence, which might explain the HCQ (Patient) and VRSs scores as not being too low.

Next, regarding qualitative findings, three domains emerged: Discomfort domain, Comfort domain, and Additional domain which consisted of five categories: Intervening variables, Nursing comfort care, Nurses (including other healthcare providers), Improvement, and Comparison between the hospital and the house. Under Discomfort domain, the study found that every participant (N = 20) experienced discomfort on every context which might be on the same, similar and/or different issues among participants. First, the most prevalent discomfort of each context was sleep disturbance and pain (*Physical-physiological discomfort*); worry and/or fear about disease and symptoms, worry (about family, work, or incomes), impact of meaning of life, and needs of spiritual support (Psycho-spiritual discomfort); no reporting/ communicating discomfort, needs of medical information, and financial support (Socio-cultural discomfort); uncomfortable with the setting (the room and restrooms) (Environmental discomfort). These findings support the five lowest-score items in the additional findings (The item 24 [I have experienced changes which make me feel uneasy] could be defined as environment discomfort as well because Kolcaba suggested to the researcher directly that there was overlap among the meaning of some items. This was because of the holistic characteristic of comfort). However, just five items could not cover the most prevalent occurrences when further examining five to ten items. The result showed the level of five more items: 12 (I have difficulty resting) (M = 3.21,  $SD = \pm 1.45$ ; 26 (I would like to see my doctor more often) (M = 3.23,  $SD = \pm 1.39$ );

6 (*I worry about my family*) (M = 3.33,  $SD = \pm 1.55$ ); 5 (*feel bloated*) (M = 3.35,  $SD = \pm 1.60$ ); and 22 (*I am afraid of what is next*) (M = 3.35,  $SD = \pm 1.60$ ). Evidently, these scores were just more than the comfort level 3, not reaching up to comfort level 4. The conclusion is that the comfort needs appearing on the additional finding and the *Discomfort domain* were congruent and confirmed each other.

Focusing on the *Comfort category*, comfort experienced by the participants of this study defined as *Relief, Ease, Transcendence, and Inadequate* comfort. Nurses, relatives, the patient's self (HSBs) were mentioned as comfort providers. Based on the qualitative findings, the most prevalent nursing comfort care was focused on *Physical-physiological relief* to relieve distressing symptoms. Pain management provided the most frequent comfort (That is, there are deficits of care relating to other care aspects). Most *Psycho-spiritual relief* was provided by relatives, such as providing family information, talking and encouragement or as consultants. However, they did not provide a lot of other care. Consequently, the participants had to seek additional comfort care for themselves, especially physical-physiological comfort care (N = 20) focusing on relieving distressing symptoms, mostly as sleep disturbance (n = 16) and pain (n = 13). This finding confirmed the additional finding, especially the item 14 (pain) and 12 (sleeplessness), which reflected that although the participants experienced pain and sleeplessness, they received insufficient nursing comfort care.

Moreover, 19 participants identified hope as a comfort provided by self. Eight of them had to provide psychological care for themselves, such as acceptance and understanding the illness and admitting their situation or seeking information about the illness and treatment from other villagers. These findings confirmed the items 34, 6, and 22 of the additional findings. Most were concerned about transcendent strategies and support, which the participants did not receive from others, especially nurses whose perceived transcendent support was insufficient. As a result, 17 participants had to help and transcended themselves to meet a level of comfort although their distressing symptoms existed. This finding confirmed the finding in the additional finding in the items: 10 (*I know that I am loved*) (n = 5.40,  $SD = \pm .86$ ); 9 (*My life is worthwhile right now*) (n = 5.34,  $SD = \pm .74$ ); 35 (*I feel confident spiritually*) (n = 5.29,  $SD = \pm .76$ ); 7 (*My beliefs give me peace of mind*) (n = 5.16,  $SD = \pm .82$ ); and 46 (*I have found meaning in my life*) (n = 5.14,  $SD = \pm .74$ ), which related to spirituality and transcendence conceptually.

In addition, the findings relating to the category--Inadequate comfort--and the themes of *the Nursing comfort care* in the additional domain, for instance *Ineffective existing comfort care*, *No comfort care responding to specific discomfort*, *Requesting comfort care*, and *Communication problem of nurses* repeatedly confirmed that nursing care still was ineffective and insufficient to help patients with advanced cancer to meet their comfort needs.

However, the qualitative findings reflected the state of contentment—*Ease*-which was mostly expressed as comfort, more comfort, or psychological comfort. Most Ease occurred from nursing care. These findings validated and helped to explain why these participants reflected their comfort on the HCQ (Patient) and the VRSs as almost high or fairly high comfort although they still experienced discomfort. In summary, the findings from the qualitative study could confirm both the results of quantitative study and of the qualitative study itself and provide more useful knowledge and information. When balancing discomfort and the comfort care provided, the overview of findings reflected that the comfort needs of four contexts of Thai older patients with advanced cancer did not meet their comfort needs entirely. Nursing care that was provided was not sufficient and effective. More seriously, nursing care provided was not pertinent to or could not respond to all their comfort needs.

# **Summary of Findings**

This current study was conducted using between-method triangulation consisting of quantitative and qualitative studies to explore comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand, all of its findings are shown in Figure 12.

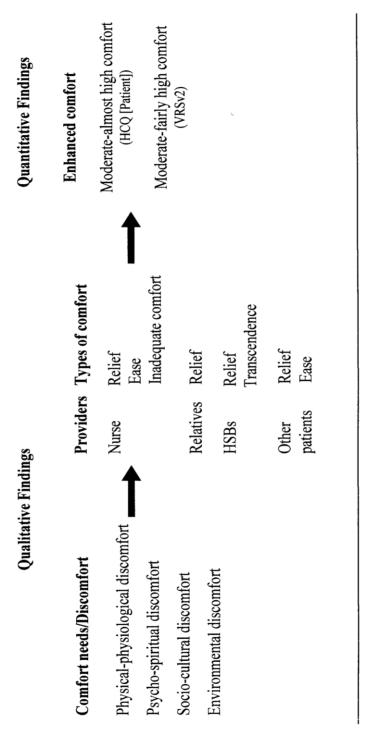


Figure 12. Discomfort and Comfort of Thai Older Patients with Advanced Cancer

First, the findings of the quantitative phase showed comfort levels of all participants from moderate to almost high comfort (M = 4.29,  $SD = \pm .50$ ) (measured by the HCQ (Patient) or from moderate to fairly high comfort (M = 6.25,  $SD = \pm 2.087$ ) (measured by the VRSs). Based on the additional finding, pain, drying of mouth and skin, worry or thinking all the time about conditions, and needs for medical information were reported as the five lowest scores of comfort.

Next, anchored in the findings of qualitative study oriented by the Comfort theory, two domains emerged: *Discomfort* and *Comfort domain*. Unexpectedly, there was one more domain—*Additional domain* emerged. The findings illustrated that discomfort of these participants consisted of four contexts. Each domain revealed the most phenomena: *physical-physiological discomfort* (most distressing symptoms: sleep disturbance and pain); *Psycho-spiritual discomfort* (worry/fear about disease conditions, worry about family, impact on the meaning of life, and need of spiritual support); *Sociocultural discomfort* (no reporting/communicating distressing symptoms, needs of medical information, and needs of financial support); *Environmental discomfort* (the uncomfortable setting), which were congruent with the additional finding of the quantitative study.

Furthermore, *Relief, Ease, Transcendence*, and *Inadequate comfort* emerged in the *Comfort domain*. The comfort providers were nurses (including other healthcare providers), relatives, and the patient's self by the HSBs. Interestingly, other patients in the same room became comfort providers (*Relief* and *Ease*) as well. Regarding *Relief*, the finding also revealed that nurses mostly focused on providing physicalphysiological care whereas relatives collaboratively provided the most of psychospiritual care. Of most concern is that almost all participants needed to seek ways of how to relieve their distressing symptoms with comfort and to transcend themselves as much as they could do, involving physical-physiological care and psycho-spiritual care, with less or insufficient support of nursing care. However, during their admission, 17 of them perceived comfort or more comfort as *Ease* which mostly occurred from comfort care provided by nurses.

Last, the additional domain emerged with themes involving *Intervening variables*, *Nurses* (including other healthcare providers), *Improvement for comfort care*, and *Comparing between the hospital and the house*. These findings supported both the quantitative and the qualitative findings of the study. They provide useful knowledge to improve nursing care for the ultimate comfort nursing care in Thailand.

In conclusion, Thai older patients with advanced cancer admitted to an academic medical-university hospital in Thailand still experienced discomfort on four contexts. However, beyond discomfort and inadequate comfort, some of them also experienced relief and ease, and could transcend themselves by religious and spiritual activities. Nursing care with a comfort goal for dying patients in Thailand has still needs to be improved encompassing four contexts; more especially, special care for distressing symptoms, effective communication, and spiritual care, to help these Thai older patients with advanced cancer to obtain ultimate comfort and finally die with peacefulness and dignity.

### Implications

The aim of this study was to explore and describe comfort as experienced by Thai older patients with advanced cancer in an academic medical-university hospital in Thailand, in which palliative care for dying patients has only been developed as an initial model. The findings of both the quantitative and qualitative design of the study conceptually relating to discomfort and comfort, provide significant knowledge and advantages as a guideline for further developing and improving palliative comfort care in the Thai healthcare system. This development would facilitate nursing practice, nursing education, nursing research, and nursing administration including health care policy.

# **Nursing Practice**

Based on the dominant findings, the quantitative study demonstrated that most patients with advanced cancer enhanced comfort only at moderate to almost high comfort level (by the HCQ [Patient]) or to fairly high comfort level (by the VRSs). Regarding the findings of qualitative study, the crucial discomfort experienced by Thai older patients with advanced cancer related to discomfort of four contexts. These were *Physical-physiological discomfort*: distressing symptoms, especially sleep disturbance and pain, needs of ADLs support, and needs for hygiene care; *Psycho-spiritual discomfort*: worries and/or fear, impact on the meaning of life, need of spiritual support, hopelessness, et cetera; *Socio-cultural discomfort*: no reporting or communicating discomfort of the patients to healthcare providers, need for medical information and need for financial support; and, finally, *Hospital environmental discomfort*: the uncomfortable setting (rooms and restrooms): too many patients, noise, dirty, smell, uncomfortable weather, et cetera.

Considering comfort care provided by nurses, relatives, and the patients themselves (HSBs), including other patients, nursing care mainly provided physicalphysiological comfort care, whereas the psycho-spiritual and socio-cultural comfort care needed to be supported by the relatives or the patients needed to take care for themselves. The patients lacked nursing care supporting religious or spiritual activities for their transcendence which was the significant approach helping them to be above overall discomfort. In addition, while there was environmental discomfort, evidently it was not focused by nurses to be eliminated or relieved intentionally. Thus, nursing care should be improved for effective palliative care and comfort care as the following:

1. There should be the development of nursing standards or guidelines of comfort care covering four contexts of comfort as a holistic care. Comfort guidelines for pain management and for quality of sleep patterns should be the first two priorities to be developed. Nagel et al. (2003) proposed interesting suggestions for sleep promotion which consisted of four strategies: (a) reducing noise, (b) adjusting light suitably, (c) decreasing interrupting factors, and (d) arranging day-time activities. Beyond pain and sleep disturbance, hygiene care should be improved to allow patients to be clean and feel fresh, to help them to meet ultimate physical comfort. In addition, nursing care for elimination (such as serving and keeping a bedpan available and responding to their needs as well as perineum care) is critical because this care is a basic need of a human being.

Lentz and Sherman (2006) suggested standards of nursing palliative care for each setting or organization. They said that these standards should consist of basic and advanced knowledge and skills of palliative care as well as should complete all dimension of holistic care, which encompassed: (a) providing nursing care appropriate to the individual patient's age, culture, and ethnic and sensitive to his/her religion and spirituality; (b) providing a safe environment; (c) educating or orienting both patients and families about the setting; (d) providing continuing care; (e) collaborating with other healthcare resources which offer benefits for patients and with patients' caregivers; (f) providing information; and (g) care with effective communication. Beyond, these dimensions of palliative care for patients and their caregivers, family palliative care needs to be considered and provided.

All of this palliative care framework will help to develop standards or guidelines for nurses to provide comfort care ultimately.

2. Nurses have to recognize and provide psycho-spiritual comfort care such as supporting relatives to provide comfort care and to encourage patients which will relieve worry, fear, hopelessness, et cetera. This is because relatives become important psychological support for the patients with advanced cancer who are dying. In addition, nurses should support religious activities or spiritual practice to provide opportunities for the patients to practice and do merit. Although this hospital setting arranges some religious activities in a few wards, they occurred only sometimes and not regularly, causing the patients to lose some opportunities. Also they may not have time for preparing themselves to participate. This may be because these patients were in ordinary wards and almost all of them did not have relatives with them all the time. In addition, nurses should offer a peaceful room and atmosphere for psycho-spiritual support, such as arranging special zone for dying patients separate from acute or critical patients who need several nursing and medical procedures. If it is possible to have a particular room for an individual, especially, a person facing his/her death, that will be perfect. However, the assessment about what patients need is the most important concern at this time.

3. Nurses, especially those who work in palliative/comfort care, should be trained for psychological care for older patients with advanced cancer or for end-of-life patients. This will help to improve their knowledge and skills to approach and support psychological or spiritual and other aspects of care needed by these patients. For example, Sasatranurak, Nilmanat, Ongphokai, Chuaynukul, & Kongsuwan, (2007, Janurary-February) used a participatory action research to study the results of the training program for 30 nurses--Improving psychological care in medical units (in a tertiary and university hospital, the south of Thailand)—whose content focused on knowledge, skills, and techniques (self understanding and listening skills) to provide psychological care. Their findings showed that nurses should listen to patients more, better understand, and increase positive attitudes to provide psychological care; patients' psychological problems should be clearly recorded and recognized; meanwhile, psychological care should be provided continuously; and patients' and families' satisfaction with nursing care and nurses as counselors would occur as a nursing outcome.

4. Nurses should have approachable personalities and promote good relationships with patients and relatives. The patients will feel comfortable; so it will be easier to report and talk about their discomfort or to ask what they want to know, especially medical information or information of financial resources. Further, providing relatives with comfort care and with communicating professionally and nicely will help them to be stronger and more hopeful to face the loss and grief that will be occurring soon. When families are strong enough, they will be capable to provide comfort care for the patients, especially psychological support. In the current study, relatives or families were important psychological supporters of advanced cancer older patients.

5. Nurses should provide hospital and medical information. That is, nurses should orient their new patients about hospital information such as how to call nurses, where the restrooms are, and so on; and introduce these new patients to other patients. All of these nursing activities can make them more comfortable with the location, room, and other patients. Medical information and the patient's current conditions with diagnosis are important factors which produce patients' worries and sleep disturbance. Thus, nurses need to be concerned and recognize their responsibility to provide this information to patients. More importantly, to provide medical information, nurses have to know the technique of how to provide the information to empower and encourage the patients for possible hope rather than leaving questions for patients to think or worry about. Counseling should be offered to provide medical information that patients need as demonstrated in this study. Nurses who are skillful and effective communicators and counselors are in the best position to take on this role.

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6. Nurses should collaborate and participate in encouraging the multidisciplinary palliative care team to provide ultimate comfort care in each setting. Nurses are the healthcare personnel who work most closely with patients more than other team members. They also better understand individual patient's needs than others. Nursing leaders need to encourage and promote the efforts of staff nurses to desire, create, and address palliative care as a multidisciplinary team focusing on comfort goals. Patients' needs then would be met pertinently and effectively.

7. Hospital environments and patients' rooms should not be ignored by nurses. Based on the current findings, nurses should attempt to eliminate discomfort related to noise, odor, dirt, and crowded rooms and lack of temperature control. Conversely, nurses have to be available to the individual patient to meet his/her needs as much as possible until patients experience ultimate comfort. For example, providing more privacy for personal care, arranging a peaceful and calm atmosphere, promoting feelings of freedom for patients to contact and communicate their discomforts with nurses more easily. There is an interesting suggestion from the study of Rowlands and Noble (2008) who used the phenomenological study to examine the preferred environments of advance cancer patients at a regional cancer centre in the United Kingdom. Rowlands and Noble (2008) found that 12 patients with advanced cancer preferred to keep contact with nurses and staffs. They preferred to be in a small multiple-bed ward where they were able to have contact with others. However, a single cubical unit was preferred when their illness became more critical.

# **Nursing Education**

Nursing education is a critical factor in the future development of palliative and comfort care in Thailand effectively. Thus, nursing professors or nursing faculty become key persons to provide essential concepts and knowledge of palliative care and comfort care in future nurses. This is especially critical if the development of palliative care is to become part of the national healthcare system of Thailand.

1. Nursing colleges and nursing faculty in each university should stimulate and support faculty members to improve their knowledge of palliative care. They may require further study or visiting study in other countries where palliative care is standardized and focuses on comfort, for instance, USA and England.

2. Palliative care and comfort care have to be addressed in the curricula of both undergraduate and graduate levels. Their content should include basic and advanced knowledge relating to palliative care and comfort care. In addition, nursing faculty needs to provide short or long training courses of palliative care for nurses such as symptom management, counseling and effective communication.

3. Nursing faculty or professors who are skilled in palliative care, comfort care, and EBP should collaborate with nurses in practice setting. Initially, nursing faculty or professors may take the role as knowledge supporters or mentors whereas the nurses can exchange their useful clinical experiences and insights to develop palliative care. Finally, both groups can exchange knowledge and skills with each other.

4. Nursing faculty should develop a research team relating to palliative care and comfort care. They also should provide knowledge and promulgate their research

findings as guides for the public to improve its understanding of quality of end-oflife care.

# Nursing Administration and Health Care Policy

Palliative comfort care is a new issue for Thai healthcare system. Although there is evidence that several healthcare settings have developed it into their services, palliative care service is not currently effective. For example, some hospitals mainly provide only religious activities as palliative care or just provide it nearing a death. Hopefully, the findings of this study will help healthcare personnel and administrators to better understand the current situation of palliative care service. Currently there is no difference between the current palliative care nursing and nursing care without palliative care service. Issues that need to be addressed are: insufficient psycho-spiritual comfort care; the barriers to comfort care (such as insufficient pain management, personality of nurses, over-load working conditions of nurses, etc.); and, importantly, what comfort care patients with advance cancer prefer or need (such as effective communication of nurses, psycho-spiritual support, appropriate setting helping them to comfort and transcend themselves, etc.). Consequently, policies supporting palliative and comfort care should be established as follows:

1. Each clinical setting should launch a clear policy supporting the development of palliative care and comfort care as well as putting significant effort to set up a multidisciplinary team, such as doctors, nurses, pharmacologist(s), nutritionist(s), pain specialist(s), nursing counselor, and so forth. 2. Suitable budgets are provided for the palliative and comfort-care development by the hospital administrators and nursing administrators.

3. Hospital administrators should promote healthcare personnel (doctors and nurses) to further study or to obtain training courses relating to palliative care and comfort care.

4. If it is possible, palliative care units providing comfort care as a golden goal should be arranged for dying patients (with or without cancer). An arrangement of appropriate environments for older patients with advanced cancer needs to be supported by the hospital administrators. Based on general characteristics of Thai healthcare system and of hospitals, a one-or two-bed room in each ward should be devoted and organized for older patients with advanced cancer. Furthermore, evidence-based practice (EBP) for comfort environments for these patients should be supported.

5. Nursing administrators or supervisors should support the self study of nurses of EBP to assist them to develop effective palliative care and comfort care measures. Further more, they should support the dissemination of its results and provide rewards for the ones who can provide an excellent EBP nursing care.

6. Nursing supervisors need to support and establish the multidisciplinary team. They should identify nurses who are really interested in providing palliative care and comfort care. Lentz and Sherman (2006) discussed eight standards of professional performance of palliative care nurses. These performances are "Quality of Care" (the ability to develop criteria and evaluate the quality of care provided and its effectiveness); "Performance Appraisal" (clinical practice of an individual palliative

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care nurse should be continuously evaluated as professional care; "Education" (maintenance and improvement of palliative care knowledge relating to current research, scientific findings, and advanced clinical practice); "Collegiality" (ability to develop a peer relationship and coordinate with others as colleagues in both positionsa leader or member); "Ethics" (moral and ethical judgment and interactions with patients and families and with other healthcare personnel); "Collaboration" (collaborating with other healthcare personnel and caregivers to provide palliative care); "Research" (sufficient knowledge and skills to do research and utilize the research findings into practice); and, finally, "Resource Utilization" (providing the most appropriate resources for patients and their families based on safety, effectiveness, and cost) (Lentz & Sherman, 2006, pp. 124-125). However, it is not easy to obtain nurses with all these qualifications, especially during the initial period of development of palliative care of this setting. Thus, nursing supervisors need to convince and support their nurses interested in palliative care and comfort care through further studies and training.

7. Palliative and comfort care training needs to be supported for nurses within and outside clinical settings, such as comfort nursing care, effective communication, distressing symptom management, and so forth.

8. Nursing supervisors have to support coordination between nurses and nursing professors to create EBP atmosphere in their settings because it is a tool to develop palliative care scientifically. For example, EBP should be addressed in the organization's objectives and mission. In addition, EBP should be a criterion in job descriptions to promote a career-ladder for nurses to trigger them to be interested in and accept the EBP as essential to excellent nursing practice.

9. Nursing supervisors shall put efforts into having sufficient numbers of palliative care nurses appropriate to the number of patients who need palliative care.

10. Palliative care and comfort care for non-advanced/advanced cancer patients or non-cancer dying patients need to be pushed as part of a national healthcare policy in order to receive a sufficient budget to develop palliative care networks among community healthcare centers, palliative care or hospice centers, and hospital settings on a continuing basis. Thai government should support having palliative care or hospice units in clinical settings and communities because dying patients desire to spend their lives at the end with their family under a home-like atmosphere.

# Limitations and Recommendations for Future Research

This current study had several limitations. In order to develop palliative care effectively and/or with high quality in Thailand, the following limitations and suggestions for further studies are offered:

1. The current study recruited the participants by the purposive sampling, studying only the elderly group. The findings derived were not generalized. So, discomfort and comfort as experienced by other aged groups of dying patients, such as adolescent or adult patients with advanced cancer, should be studied because dying or death phenomenon occurs in every group of patients.

2. This current study was conducted in only some ordinary wards. It did not cover private wards or special wards in which there are different kinds of dying patients.

Thus, the replicated study, such as—Comfort as experienced by Thai older patients with advanced cancer in intensive care units (ICUs) or in private rooms—should be encouraged.

3. Another limitation of this study was that some interesting issues could not be explored in depth because of three important factors. *First*, the characteristic of the participants who were so seriously ill that this was a barrier for them to talk for a long time. Second, most participants of this study were low educated (at primary-school level) and poor, which caused them to worry about sharing their opinions relating to nursing care or nurses whom they perceived as helpers or caregivers. Thus, the researcher had to spend more time to encourage them to share their experience of comfort and discomfort. Third, during the data collection, there were interruptions from the questions or discussions of other issues from some participants and/or their relatives, from nursing procedures, and from doctor rounds (between medical teachers and students on irregular time schedules). Thus, a future qualitative study is needed and should focus on some themes that emerged in this study. Examples of future studies are presented as follows: psycho-spiritual comfort care, socio-cultural comfort care, and environmental comfort care which were experienced by Thai older patients with advanced cancer; barriers to provide comfort care; communication problem between nurses and Thai older patients with advanced cancer and factors relating to inadequate comfort experienced by Thai older patients with advanced cancer.

4. Based on the current findings, critical issues emerged in four contexts and relating to the comfort of Thai older patients with advanced cancer. These include

effective pain management, promotion of sufficient sleep, worries or fear, effective communication, significant information, financial support, and hospital environmental comfort. Future studies in these areas will assist in the development nursing standards or guidelines for nursing practice.

5. Finally, this current study was conducted in the northern region, as one of four regions in Thailand (the north, east [northeast and eastern part], middle, and south). People or patients in each region have different cultures and beliefs, especially, beliefs about medicine and spirituality. The effective development of palliative care focusing on comfort for a national healthcare system of Thailand needs knowledge pertinent to the actual needs of the individual group in each region. Thus, future research about the comfort of Thai older patients who are at the highest risk of advanced cancer should be supported by the Thai government and studied in every region of Thailand.

# **Summary**

The findings of quantitative and qualitative studies supported each other. They reflected that Thai older patients with advanced cancer admitted to a hospital experienced discomfort encompassing four contexts (physical-physiological, psycho-spiritual, socio-cultural, and environment discomfort). These patients received comfort care from nurses (including some other healthcare providers), their relatives, and themselves, as well as from other patients. However, the care provided could not help them meet all their needs. Especially, nursing care still needs to be improved for quality of comfort care. Research is important to improve quality of nursing comfort care.

Appendices

Appendix A

Palliative Performance Scale Version 2 (PPSv2)

# Date......Time......Ward's name.....Code.....

Victoria Hospice

**PPSv**<sub>2</sub>'s Score.....%

# Palliative Performance Scale (PPSv2)

| PPS<br>Level | Ambulation           | Activity & Evidence of<br>Disease                       | Self-Care                          | Intake               | Conscious Level                 |
|--------------|----------------------|---|------------------------------------|----------------------|---------------------------------|
| 100%         | Full                 | Normal activity & work<br>No evidence of disease        | - Full                             | Normal               | Full                            |
| 90%          | Full                 | Normal activity & work<br>Some evidence of disease      | Full                               | Normal               | Full                            |
| 80%          | Full                 | Normal activity with Effort<br>Some evidence of disease | Full                               | Normal or<br>reduced | Full                            |
| 70%          | Reduced              | Unable Normal Job/Work<br>Significant disease           | Full                               | Normal or<br>reduced | Full                            |
| 60%          | Reduced              | Unable hobby/house work<br>Significant disease          | Occasional assistance<br>necessary | Normal or<br>reduced | Full<br>or Confusion            |
| 50%          | Mainly Sit/Lie       | Unable to do any work<br>Extensive disease              | Considerable assistance required   | Normal or<br>reduced | Full<br>or Confusion            |
| 40%          | Mainly in Bed        | Unable to do most activity<br>Extensive disease         | Mainly assistance                  | Normal or<br>reduced | Full or Drowsy<br>+/- Confusion |
| 30%          | Totally Bed<br>Bound | Unable to do any activity<br>Extensive disease          | Total Care                         | Normal or<br>reduced | Full or Drowsy<br>+/- Confusion |
| 20%          | Totally Bed<br>Bound | Unable to do any activity<br>Extensive disease          | Total Care                         | Minimal to<br>sips   | Full or Drowsy<br>+/- Confusion |
| 10%          | Totally Bed<br>Bound | Unable to do any activity<br>Extensive disease          | Total Care                         | Mouth care<br>only   | Drowsy or Coma<br>+/- Confusion |
| 0%           | Death                | (=);  | -                                  | -                    | -                               |

#### Instructions for Use of PPS (see also definition of terms)

PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.

Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

- PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
- 4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

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#### **Definition of Terms for PPS**

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

#### 1. Ambulation

The items 'mainly sit/lie,' 'mainly in bed,' and 'totally bed bound' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed 'bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'Reduced ambulation' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

#### 2. Activity & Extent of disease

'Some,' 'significant,' and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

#### 3. Self-Care

**Occasional assistance'** means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'Considerable assistance' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

**'Mainly assistance'** is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'Total care' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

#### 4. Intake

Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy. '**Reduced'** means any reduction from that and is highly variable according to the unique individual circumstances. '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

#### 5. Conscious Level

'Full consciousness' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. 'Confusion' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. 'Drowsiness' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. 'Coma' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

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The Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society and replaces the first PPS published in 1996 [J Pall Care 9(4): 26-32]. It cannot be altered or used in any way other than as intended and described here. Programs may use PPSv2 with appropriate recognition. Available in electronic Word format by email request to judy.martell@caphealth.org Correspondence should be sent to Medical Director, Victoria Hospice Society, 1900 Fort St, Victoria, BC, V8R 1J8, Canada Appendix B

Demographic Data Form (DDF)

# Comfort as Experienced by Thai Older Patients with Advanced Cancer

# **Demographic data**

Date......Time......Ward's name.....Code.....

Date of admission......Numbers/Times of admission.....

# Personal data

| 1. Ageyears                                      |  |  |  |  |
|--|--|--|--|--|
| 2. Gender Male Female                            |  |  |  |  |
| 3. Marital status Single Married Widowed         |  |  |  |  |
| Separated Divorced                               |  |  |  |  |
| 4. Ethnicity/Race Thai Chinese others            |  |  |  |  |
| 5. Religion Buddhism Catholic Protestant         |  |  |  |  |
| Muslim Other                                     |  |  |  |  |
| 6. Educational level Not able to read and write  |  |  |  |  |
| Able to read, to write, or both                  |  |  |  |  |
| Elementary school Secondary school               |  |  |  |  |
| Undergraduate level Graduate level               |  |  |  |  |
| Master PhD                                       |  |  |  |  |
| 7. Employment Employed Unemployed                |  |  |  |  |
| Disabled Retired                                 |  |  |  |  |
| 8. Income/month                                  |  |  |  |  |
| 9. Area of residence/address                     |  |  |  |  |
| 10. Caregiver (identify relation to the patient) |  |  |  |  |
| 11. Current social support                       |  |  |  |  |
| 310  |  |  |  |  |

# Clinical Characteristics (from the Medical Record)

| 1. | Medical diagnosisPeriod of time after being diagnosed     |
|----|---|
| 2. | Stage of disease  |
|    | Primary regionSecondary region                            |
| 3. | Comorbidities   |
| 4. | Length of hospital stay of this admission(days or months) |
| 5. | History of treatments                                     |
| 6. | Current main treatments                                   |
|    | Medications such as analgesic and sedative                |
|    | Chemotherapy  |
|    | Radiotherapy  |
|    | Other   |
| 7. | Having ever received palliative care yes no               |

Appendix C

(Hospice) Comfort Questionnaire (HCQ) (Patient)

Date......Time......Ward's name.....Code.....

| Items                 | Strongly<br>Disagree<br>1 | 2 | 3 | 4 | 5 | Strongly<br>Agree<br>6 |
|-----------------------|---------------------------|---|---|---|---|------------------------|
| 1. My body is         |                           | ~ |   |   |   |                        |
| relaxed right now     |                           |   |   |   |   |                        |
| 2. My breathing is    |                           |   |   |   |   |                        |
| difficult             |                           |   |   |   |   |                        |
| 3. I have enough      |                           |   |   |   |   |                        |
| privacy               |                           |   |   |   |   |                        |
| 4. There are those I  |                           |   |   |   |   |                        |
| can depend on when    |                           |   |   |   |   |                        |
| I need help           |                           |   |   |   |   |                        |
| 5. I feel bloated     |                           |   |   |   |   |                        |
| 6. I worry about my   |                           |   |   |   |   |                        |
| family                |                           |   |   |   |   |                        |
| 7. My beliefs give    |                           |   |   |   |   |                        |
| me peace of mind      |                           |   |   |   |   |                        |
| 8. My nurse(s) give   |                           |   |   |   |   |                        |
| me hope               |                           |   |   |   |   |                        |
| 9. My life is         |                           |   |   |   |   |                        |
| worthwhile right      |                           |   |   |   |   |                        |
| now                   |                           |   |   |   |   |                        |
| 10. I know that I am  |                           |   |   |   |   |                        |
| loved                 |                           |   |   |   |   |                        |
| 11. These             |                           |   |   |   |   |                        |
| surroundings are      |                           |   |   |   |   |                        |
| pleasant              |                           |   |   |   |   |                        |
| 12. I have difficulty |                           |   |   |   |   |                        |
| resting               |                           |   |   |   |   |                        |
| 13. No one            |                           |   |   |   |   |                        |
| understands me        |                           |   |   |   |   |                        |
| 14. My pain is        |                           |   |   |   |   |                        |
| difficulty to endure  |                           |   |   |   |   |                        |
| 15. I feel peaceful   |                           |   |   |   |   |                        |
| 16. I sleep soundly   |                           |   |   |   |   |                        |
| 17. I feel guilty     |                           |   | - |   |   |                        |

## **Comfort Questionnaire (Patient)**

## **Cont. Comfort Questionnaire (Patient)**

| Items                          | Strongly<br>Disagree |   |   |   |   | Strongly<br>Agree |
|--------------------------------|----------------------|---|---|---|---|-------------------|
|                                | 1                    | 2 | 3 | 4 | 5 | 6                 |
| 18. I like being here          |                      |   |   |   |   |                   |
|                                |                      |   |   |   |   |                   |
| 19. I am nauseated             |                      | ~ |   |   |   |                   |
| 20. I am able to               |                      |   |   |   |   |                   |
| communicate with               |                      |   |   |   |   |                   |
| my loved ones                  |                      |   |   |   |   |                   |
| 21. This room makes            |                      |   |   |   |   |                   |
| me feel scared                 |                      |   |   |   |   |                   |
| 22. I am afraid of             |                      |   |   | - |   |                   |
| what is next                   |                      |   |   |   |   |                   |
| 23. I have special             |                      |   |   |   |   |                   |
| person(s) who make             |                      |   |   |   |   |                   |
| me feel cared for              |                      |   |   |   |   |                   |
| 24. I have                     |                      |   |   |   |   |                   |
| experienced changes            |                      |   |   |   |   |                   |
| which make me feel             |                      |   |   |   |   |                   |
| uneasy                         |                      |   |   |   |   |                   |
| 25. I like my room to          |                      |   |   |   |   |                   |
| be quiet                       |                      |   |   |   |   |                   |
| 26. I would like to            |                      |   |   |   |   |                   |
| see my doctor more             |                      |   |   |   |   |                   |
| often                          |                      |   |   |   |   |                   |
| 27. My mouth and               |                      |   |   |   |   |                   |
| skin feel very dry             |                      |   |   |   |   |                   |
| 28. I am okey with             |                      |   |   |   |   |                   |
| my personal                    |                      |   |   |   |   |                   |
| relationship                   |                      |   |   |   | + |                   |
| 29. I can rise above           |                      |   |   |   |   |                   |
| my pain                        |                      |   |   |   |   |                   |
| 30. The mood                   |                      |   |   |   |   |                   |
| around here is                 |                      |   |   |   |   |                   |
| depressing<br>31. I am at ease |                      |   |   |   |   |                   |
| physically                     |                      |   |   |   |   |                   |
| 32. This chair (bed)           |                      |   |   |   |   |                   |
| makes me hurt                  |                      |   |   |   |   |                   |
| 33. This view                  |                      |   |   |   |   |                   |
| inspires me                    |                      |   |   |   |   |                   |
| 34. I think about my           |                      |   |   |   |   | +                 |
| discomforts                    |                      |   |   |   |   |                   |
| constantly                     |                      |   |   |   |   |                   |
| constantly                     |                      |   |   |   | 1 | 1                 |

**Cont. Comfort Questionnaire (Patient)** 

| Items                                       | Strongly<br>Disagree | • |   |   | _ | Strongly<br>Agree |
|---|----------------------|---|---|---|---|-------------------|
| 35. I feel confident                        | 1                    | 2 | 3 | 4 | 5 | 6                 |
| spiritually                                 |                      |   |   |   |   |                   |
| 36. I feel good                             |                      |   |   |   |   |                   |
| enough to do some                           |                      | ~ |   |   |   |                   |
| things for myself                           |                      |   |   | 1 |   |                   |
| 37. My friends                              |                      |   |   |   |   |                   |
| remember me with                            |                      |   |   |   |   |                   |
| their cards and                             |                      |   |   |   |   |                   |
| phone calls                                 |                      |   |   |   |   |                   |
| 38. I feel out of                           |                      |   | + | 1 |   |                   |
| place here                                  |                      |   |   |   |   |                   |
| 39. I need to be                            |                      |   |   |   |   |                   |
| better informed                             |                      |   |   |   |   |                   |
| about my condition                          |                      |   |   |   |   |                   |
| 40. I feel helpless                         |                      |   |   |   |   |                   |
| · · · · · · · · · · · · · · · · · · ·       |                      |   |   |   |   |                   |
| 41. My God is                               |                      |   |   |   |   |                   |
| helping me                                  |                      |   |   |   |   |                   |
| 42. This room smells                        |                      |   |   |   |   | :                 |
| fresh                                       |                      |   |   |   |   |                   |
| 43. I feel lonely                           |                      |   |   |   |   |                   |
|   |                      |   |   |   |   |                   |
| 44. I am able to tell                       |                      |   |   |   |   |                   |
| people what I need                          |                      |   |   |   | + |                   |
| 45. I am depressed                          |                      |   |   |   |   |                   |
| 46. I have found                            |                      |   |   |   |   |                   |
|   |                      |   |   |   |   |                   |
| meaning in my life                          |                      |   |   |   |   |                   |
| 47. In retrospect,                          |                      |   |   |   |   |                   |
| I 've had a good life<br>48. My loved ones' |                      |   |   |   |   |                   |
| state of mind makes                         |                      |   |   |   |   |                   |
| me feel sad                                 |                      |   |   |   |   |                   |
| 49. The temperature                         |                      |   |   |   |   |                   |
| in this room is fine                        |                      |   |   |   |   |                   |
| in this room is the                         | L                    |   |   |   |   |                   |

*Note.* Based on the different health culture of between western and Asian countries, the title of the Hospice Comfort Questionnaire (HCQ) (Patient) referred in the study is entitled as the Comfort Questionnaire (Patient) in the Thai-version tool for the process of data collection.

วันที่.....รหัส.....รหัส......รหัส......

แบบสอบถามความสุขสบายของผู้ป่วย (ฉบับภาษาไทย)

คำแนะนำ โปรดแสดงความคิดเห็นที่ตรงกับการรับรู้ หรือรู้สึกของท่านในขณะนี้ที่เกี่ยวกับ ความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในขณะนี้ ในฐานะที่ท่านเป็นผู้ป่วยในที่โรคมีการ ดำเนินก้าวหน้าไปอย่างต่อเนื่อง

ท่านสามารถแสดงความคิดเห็นตามแบบสอบถามข้างถ่างนี้ ซึ่งได้แบ่งระดับความคิดเห็น ออกเป็น 6 ระดับ ได้แก่

ระดับ 1 หมายถึง ไม่เห็นด้วยอย่างมาก

ระดับ 2 หมายถึง ไม่เห็นด้วยมาก

ระดับ 3 หมายถึง ไม่เห็นด้วยเล็กน้อย

ระดับ 4 หมายถึง เห็นด้วยเล็กน้อย

ระดับ 5 หมายถึง เห็นด้วยมาก

ระดับ 6 หมายถึง เห็นด้วยอย่างมาก

|   | ความคิดเห็น       |            |               |               |          |                   |  |  |  |
|---|-------------------|------------|---------------|---------------|----------|-------------------|--|--|--|
|   |                   | ไม่เห็นด้ว | ย             | เห็นด้วย      |          |                   |  |  |  |
| ความสุขสบายของผู้ป่วย   | อย่าง<br>มาก<br>1 | มาก<br>2   | เล็กน้อย<br>3 | เล็กน้อย<br>4 | มาก<br>5 | อย่าง<br>มาก<br>6 |  |  |  |
| 1. ขณะนี้ร่างกายของฉันมีอาการผ่อนคลาย   |                   |            |               |               |          |                   |  |  |  |
| 2. ฉันมีอาการหายใจลำบาก   |                   |            |               |               |          |                   |  |  |  |
| 3. ฉันมีความเป็นส่วนตัวอย่างเพียงพอ   |                   |            |               |               |          |                   |  |  |  |
| 4. ฉันได้รับการพึ่งพาจากบุคคลอื่นเมื่อฉันต้องการ                                  |                   |            |               |               |          |                   |  |  |  |
| 5. ฉันรู้สึกมีก๊าช/น้ำภายในช่องท้อง ซึ่งทำให้ฉันมี<br>อาการแน่น อึดอัด ไม่สุขสบาย |                   |            |               |               |          |                   |  |  |  |
| 6. ฉันมีความวิตกกังวลเกี่ยวกับครอบครัวของฉัน                                      |                   |            |               |               |          |                   |  |  |  |
| 7. ความเชื่อของฉันช่วยให้ฉันมีความสงบสุขทางใจ                                     |                   |            |               |               |          |                   |  |  |  |
| 8. พยาบาลที่ดูแลฉันได้สนับสนุน และให้กำลังใจฉัน                                   |                   |            |               |               |          |                   |  |  |  |

ต่อหน้า 2 แบบสอบถามความสุขสบายของผู้ป่วย

Code.....

|   | ความคิดเห็น       |            |               |               |          |                   |  |  |
|---|-------------------|------------|---------------|---------------|----------|-------------------|--|--|
|   |                   | ไม่เห็นด้ว | ខ             |               | เห็นด้วย |                   |  |  |
| ความสุขสบายของผู้ป่วย   | อย่าง<br>มาก<br>1 | มาก<br>2   | เล็กน้อย<br>3 | เล็กน้อย<br>4 | มาก<br>5 | อย่าง<br>มาก<br>6 |  |  |
| 9. ฉันรู้สึกว่าชีวิตของฉันมีคุณค่าในขณะนี้                          |                   |            |               |               |          |                   |  |  |
| 10. ฉันรู้สึกว่าฉันเป็นที่รักของทุกๆ คน                             |                   |            |               |               |          |                   |  |  |
| 11. ฉันมีความพอใจกับสิ่งแวคล้อมรอบๆตัวฉัน                           |                   |            |               |               |          |                   |  |  |
| 12. ฉันมีความยากลำบากในการพักผ่อน (ไม่สามารถ<br>พักผ่อนได้ตามปกติ)  |                   |            |               |               |          |                   |  |  |
| 13. ฉันกิคว่าไม่มีใกรเข้าใจฉัน                                      |                   |            |               |               |          |                   |  |  |
| 14. ความเจ็บปวดของฉันรุนแรงยากเกินกว่าที่ฉันจะ<br>อดทน              |                   |            |               |               |          |                   |  |  |
| 15. ฉันรู้สึกมีความสุข สงบ  |                   |            |               |               |          |                   |  |  |
| 16. ฉันสามารถนอนหลับได้อย่างสนิทและเพียงพอ                          |                   |            |               |               |          |                   |  |  |
| 17. ฉันกำลังมีความรู้สึกผิด   |                   |            |               |               |          |                   |  |  |
| 18. ฉันชอบอยู่ที่นี้  |                   |            |               |               |          |                   |  |  |
| 19. ฉันมีอาการคลื่นใส้ อาเจียน                                      |                   |            |               |               |          |                   |  |  |
| 20. ฉันมีความสามารถที่จะพูดคุยสนทนากับบุคคลที่<br>ฉันรักได้         |                   |            |               |               |          |                   |  |  |
| 21. ห้องนี้ทำให้ฉันรู้สึกหวาคกลัว                                   |                   |            |               |               |          |                   |  |  |
| 22. ฉันมีความหวาดกลัวในสิ่งที่กำลังจะเกิดขึ้น                       |                   |            |               |               |          |                   |  |  |
| 23. ฉันมีคนที่ให้ความสำคัญ และเอื้ออาทรต่อ<br>ความรู้สึกของฉัน      |                   |            |               |               |          |                   |  |  |
| 24. ฉันเคยมีประสบการณ์การเปลี่ยนแปลงที่ทำให้ฉัน<br>รู้สึกไม่สุขสบาย |                   |            |               |               |          |                   |  |  |
| 25. ฉันรู้สึกห้องนี้มีความเงียบสงบ                                  |                   |            |               |               |          |                   |  |  |
|   |                   |            |               |               |          |                   |  |  |
| 27. ปากและผิวหนังของฉันมีอาการแห้งมาก                               |                   |            |               |               |          |                   |  |  |

# ต่อหน้า 3 แบบสอบถามความสุขสบายของผู้ป่วย

Code.....

|   |              |            | ความก    | าิดเห็น  |     |              |
|---|--------------|------------|----------|----------|-----|--------------|
|   |              | ไม่เห็นด้ว | ย        | เห็นด้วย |     |              |
| ความสุขสบายของผู้ป่วย   | อย่าง<br>มาก | มาก        | เล็กน้อย | เล็กน้อย | มาก | อย่าง<br>มาก |
|   | 1            | 2          | 3        | 4        | 5   | 6            |
| 28. ฉันมีความพึงพอใจกับสัมพันธภาพส่วนตัวของฉัน<br>ที่มีอยู่   |              |            |          |          |     |              |
| 29. ฉันเข้าใจ ยอมรับ และสามารถปรับตัวอยู่กับความ<br>เจ็บปวคค้านร่างกายที่เกิดขึ้นได้                |              |            |          |          |     |              |
| งบบ ภุพพาน ภุพทาน เพ<br>30. บรรยากาศในห้องนี้ให้ฉันรู้สึกซึมเศร้า                                   |              |            |          |          |     |              |
| 30. บรรอ เกาศานหองนาหน่ารูสกษมเศรา<br>31. ฉันกำลังมีความสุขสบายค้านร่างกายในขณะนี้                  |              |            |          |          |     |              |
| 31. ฉนก เสงมความสุขสบายคานรางกาย เนขณะน<br>32. เก้าอี้และเตียงทำให้ฉันบาคเจ็บ (เช่น ปวคเมื่อย       |              |            |          |          |     |              |
| 32. เกายและเดองทาเหน่นบาดเงบ (เช่น บวดเมอย<br>แผลกดทับ และความไม่สุขสบายอื่นๆ )                     |              |            |          |          |     |              |
| 33. สิ่งแวคล้อมและบรรยากาศในที่นี้เป็นแรงกระคุ้น<br>ช่วยทำให้ฉันเกิดกวามรู้สึกดีๆ                   |              |            |          |          |     |              |
| 34. ฉันคิดกังวลอยู่กับความไม่สุขสบายของฉัน<br>ตลอดเวลา  |              |            |          |          |     |              |
| 35. ฉันมีความเชื่อและศรัทธาอย่างแรงกล้าต่อสิ่งที่ฉัน<br>เการพนับถือ                                 |              |            |          |          |     |              |
| 36. ฉํนมีความรู้สึกที่ดีเพียงพอที่จะทำบางสิ่งบางอย่าง<br>สำหรับคัวฉันเอง                            |              |            |          |          |     |              |
| 37. เพื่อนๆของฉันให้กำลังใจฉันโดยการส่งบัตรแสดง<br>กวามกิดถึง หรือโทรศัพท์พูดกุยกับฉัน              |              |            |          |          |     |              |
| 38. ฉันรู้สึกไม่คุ้นเคยกับสถานที่แห่งนี้ (ในห้องพัก/<br>โรงพยาบาล)                                  |              |            |          |          |     |              |
| 39. ฉันต้องการทราบข้อมูลเกี่ยวกับภาวะการเจ็บป่วย<br>และการรักษาพยาบาลที่มากกว่าที่ฉันได้รับในขณะนี้ |              |            |          |          |     |              |
| 40. ฉันรู้สึกว่าฉันไม่ได้รับความช่วยเหลือใดๆ  |              |            |          |          |     |              |
| <ol> <li>41. ฉันคิดว่าสิ่งศักดิ์สิทธิ์ได้กุ้มครองและให้กำลังฉัน</li> </ol>                          |              |            |          |          |     |              |

| ต่อหน้า 4 | แบบสอบถามความสุขสบายของผู้ป่วย |
|-----------|--------------------------------|
|-----------|--------------------------------|

Code.....

|   |              |            | ความเ    | กิดเห็น  |     |              |
|---|--------------|------------|----------|----------|-----|--------------|
|   |              | ไม่เห็นด้ว | ម        | เห็นด้วย |     |              |
| ความสุขสบายของผู้ป่วย   | อย่าง<br>มาก | มาก        | เล็กน้อย | เล็กน้อย | มาก | อย่าง<br>มาก |
|   | 1            | 2          | 3        | 4        | 5   | 6            |
| 42. ห้องที่ฉันอยู่มีบรรยากา <del>ศ</del> สคชื่น ไม่มีกลิ่นเหม็น<br>ใดๆ        |              |            |          |          |     |              |
| 43. ฉันรู้สึกว่าฉันถูกทอดทิ้งและ โดดเดี่ยว                                    |              |            |          |          |     |              |
| 44. ฉันสามารถบอกผู้ที่เกี่ขวข้องว่า อะไรเป็นสิ่งจำเป็น<br>ที่ฉันค้องการ       |              |            |          |          |     |              |
| 45. ฉันรู้สึกซึมเศร้า   |              |            |          |          |     |              |
| 46. ฉันได้ค้นพบความหมายในชีวิตของฉัน (หรือฉัน<br>รู้สึกว่าชีวิตฉันมีความหมาย) |              |            |          |          |     |              |
| 47. เมื่อกิดข้อนไปในอดีตที่ผ่านมา ฉันกิดว่าฉันมีชีวิต<br>ที่ดี                |              |            |          |          |     |              |
| 48. สภาวะจิตใจของบุกคลที่ฉันรักมีส่วนทำให้ฉันรู้สึก<br>แข่หรือมีอาการเลวลง    |              |            |          |          |     |              |
| 49. สภาพอุณหภูมิภายในห้องนี้พอดีและเหมาะสม                                    |              |            |          |          |     |              |

Appendix D

Verbal Rating Scales (VRSs)

Date......Time......Ward's name.....Code.....

Verbal Rating Scale (VRS)Score.....

Please rate your Total Comfort from 0 to 10, using the scale below.

| Place X<br>in best<br>box<br>below |    | The amount of Total Comfort you are experiencing <u>right now :</u> |
|------------------------------------|----|---|
|                                    | 10 | Highest comfort possible  |
|                                    | 9  | Very high comfort   |
|                                    | 8  | Between fairly high and high comfort                                |
|                                    | 7  | Fairly high comfort   |
|                                    | 6  | Between moderate and fairly high comfort                            |
|                                    | 5  | Moderate comfort  |
|                                    | 4  | Between some and moderate comfort                                   |
|                                    | 3  | Some comfort  |
|                                    | 2  | Between a little bit and some comfort                               |
|                                    | 1  | A little bit of comfort   |
|                                    | 0  | No comfort at all   |

Note: Total Comfort includes physical, psychological, spiritual and social aspects of comfort, all combined into one score. วันที่.....รหัส....รหัส.....

คะแนน.....

โปรดเลือกตัวเลขที่แสดงระดับความสุขสบายโดยรวมในขณะนี้ของท่าน

| โปรดกากบาท (x) ตรง<br>หมายเลขที่ครงกับระดับ |    | ระดับความสุขสบายโดยรวมในขณะนี้ของท่าน                          |
|---|----|--|
|   |    |  |
| ความสุขสบายโดยรวมใน                         |    |  |
| ขณะนี้ของท่าน                               |    |  |
|   | 10 | มีความสุขสบายมากที่สุดเท่าที่สามารถเป็นไปได้                   |
|   | 9  | มีความสุขสบายมาก   |
|   | 8  | มีกวามสุขสบายอยู่ระหว่างระดับกวามสุขสบายพอสมกวรและกวามสุข      |
|   |    | สบายมาก  |
|   | 7  | มีความสุขสบายพอสมควร   |
|   | 6  | มีความสุขสบายอยู่ระหว่างระดับความสุขสบายระดับปานกลางและ        |
|   |    | ความสุขสบายพอสมควร   |
|   | 5  | มีความสุขสบายระคับปานกลาง                                      |
|   | 4  | มีความสุขสบายอยู่ระหว่างระดับความสุขสบายบ้างและความสุขสบาย     |
|   |    | ปานกลาง  |
|   | 3  | มีความสุขสบายบ้าง  |
|   | 2  | มีความสุขสบายอยู่ระหว่างระคับความสุขสบายเล็กน้อยและความสุขสบาย |
|   |    | บ้าง   |
|   | 1  | มีความสุขสบายเล็กน้อย  |
|   | 0  | ไม่มีความสุขสบายเลย  |

หมายเหตุ ความสุขสบายโคยรวมได้รวมถึงความสุขสบายด้านร่างกาย จิคใจ สังคม และจิตวิญญาณ ความสุขสบาย ทั้งหมดนี้ถูกรวบรวมและแสดงออกเป็นคะแนนเพียงหมายเลขเดียว Appendix E

Semi-Structured Interview Guide

## Appendix E

 Date......Time......Ward's name.....Code.....

 Semi-Structured Interview Guide

1. In your opinion, please tell me about the nursing care you are receiving for this admission.

Probes:

1. How would you describe the care which you receive from nurses?

2. Can you tell me something that a nurse has done for you that made you feel more comfortable?

3. Is there instance where something was done that made you feel less comfortable?

2. In your opinion, what are your expectations about the care you should be receiving?

## 3. How would you describe nursing care which comforts you?

(The  $2^{nd}$  and  $3^{rd}$  questions will be pursued congruently based on the four contexts

in order to explore what patients' discomfort or comfort is.)

Probes:

1. Physical comfort

1.) Please explain to me how you do *everyday activities of living (such as bath/shower, walking, eating, and ambulation)*.

Please explain to me how you are responded to when you need some assistance.

2.) Please explain to me what your currently *distressing symptoms* are (fatigue, pain, anorexia, nausea/vomiting, constipation, insomnia, etc).

Please explain to me how you relieve this distress.

Who helps you to relieve it? How?

2. Psycho-spiritual comfort

1.) This is a hard time in your life. Please tell me what you are feeling about this situation at this time.

2.) Please tell me what make you *feel most* uncomfortable.

3.) When you are feeling uncomfortable, what do nurses do to help you *feel better or comfortable?*.

4.) Please explain to me what make you feel most *distressed*.

5.) What do you do to relieve these *distress symptoms*, such as fear, fear of future pain, anxiety, grief, loss, depression, insomnia, etc?

Are these distressing symptoms relieved by nurses? How?

6.) Please explain to me how important it is for you to receive support to maintain or continue religious activities. Do these activities bring hope into your life?

7.) How do or could nurses help to bring *hope* into your life?

8.) What is most important to you about what nurses, doctors, and others

in healthcare team are doing to make you comfortable? (For examples, in trust, being nice, offering time for you to question, etc.)

9.) How do you see your future right now?

3. Environmental comfort

1.) In your opinion, please tell me what do you like about this clinical setting (*calm, peace, sound, noise, smell,* etc).

2.) What bother you most about it? How does it not help you to recover or make it worse for you? (In term of *feel upset, frighten, fear, loneliness* etc.)

3.) Is there anything in this setting which you *can control*?

4.) Did you feel as comfortable as when you stay at home? If yes or no, please explain to me.

4. Socio-cultural comfort

1.) How are your family members and friends helping you to be comfortable right now?

2.) What do they do that makes you uncomfortable?

3.) How do you do to maintain the relationship with your

families, friends, and the loved one. How do nurses help you?

4.) How do you do to solve *problems of finance and of other family members?* What worries you most right now?

5.) Please explain to me how you feel about your relationship with your health caregivers, such as the nurses and doctors.

6.) How do you think that nursing care supports your families?

7.) Who do you talk to when feel some stress? How about your feeling after that talking?

- **4. In your opinion, what are the barriers to provide the comfort care for you?** Probe:
  - 1. Please tell me what makes you not receive comfort care as you need. How?

5. In your opinion, how could the nursing care provided be improved for better comfort care?

Probes:

- 1. What is nursing care which you want or need but do not receive?
- 2. In your opinion, please explain to me how nurses can help you to meet

those needs

3. In your opinion, what more (such as knowledge or skills) should nurses know to provide better care at this time in your life?

#### ภาคผนวก E

## แนวทางการสัมภาษณ์เกี่ยวกับ ความสุขสบายของผู้ป่วย

#### (Comfort Semi-Structured Interview Guide) (Thai Version)

 โปรดแสดงความคิดเห็นของท่าน เกี่ยวกับการพยาบาลที่ท่านได้รับขณะที่เข้ารับการรักษาภายใน โรงพยาบาลครั้งนี้

## คำถามย่อย

- 1. โปรดอธิบายการพยาบาลที่ท่านได้รับจากเจ้าหน้าที่พยาบาล
- ท่านสามารถบอกการพยาบาลซึ่งได้รับจากเจ้าหน้าที่พยาบาลที่ช่วยให้ท่านรู้สึกมี ความสุขสบายเพิ่มขึ้น
- 3. มีเหตุการณ์หรือการพยาบาลใดบ้างที่ทำให้ท่านรู้สึกมีความสุขสบายลดลง
- 2. ในความคิดเห็นของท่าน ท่านคาดหวังว่าท่านควรจะได้รับการพยาบาลอะไรบ้าง
- ท่านจงช่วยอริบาย การพยาบาลอย่างไร/แบบใดที่จะทำให้ท่านมีความสุขสบาย

(คำถามข้อ 2 และ 3 เป็นคำถามเกี่ยวกับความสุขสบายและความไม่ความสุขสบาย ซึ่งจะถูกสำรวจ ศึกษาไปพร้อมๆ กัน)

คำถามย่อย

- 1. ความสุขสบายทางด้านร่างกาย
  - โปรดอธิบายกิจวัตรประจำวันที่ท่านสามารถปฏิบัติได้ในขณะนี้ เป็นอย่างไร (เช่น การอาบน้ำ การการเดิน การรับประทานอาหาร และการเคลื่อนไหว ร่างกาย)

โปรดอธิบายในกรณีที่ท่านต้องการความช่วยเหลือ ท่านได้รับการช่วยเหลือหรือ ตอบสนองอย่างไร  โปรดอธิบายขณะนี้ท่านมีอาการเจ็บป่วยทุกข์ทรมานอะไรบ้าง (เช่น อ่อนเพลีย เจ็บปวด เบื่ออาหาร คลื่นไส้/อาเจียน ท้องผูก นอนไม่หลับ เป็นต้น)

โปรดอธิบายท่านบรรเทาอาการเจ็บป่วยทุกข์ทรมานที่เกิดขึ้นอย่างไร ใครได้ช่วยท่านบรรเทาอาการเจ็บป่วยทุกข์ทรมานที่เกิดขึ้น อย่างไร

- 2. ความสุขสบายทางด้านจิตใจ และจิตวิญญาณ
  - ขณะนี้เป็นช่วงเวลาที่มีการเจ็บป่วย และมีความยากลำบากในชีวิตของท่าน ท่านกำลังรู้สึกอย่างไร โปรดอธิบาย
  - โปรดอธิบาย อะไรทำให้ท่านรู้สึกไม่สุขสบายมากที่สุด
  - เมื่อท่านรู้สึกไม่สุขสบายมากในอาการดังกล่าว เจ้าหน้าที่พยาบาลได้ ช่วยเหลือท่านให้มีความรู้สึกดีขึ้น หรือมีความสุขสบายมากขึ้นอย่างไร
  - 4) โปรดอธิบาย อะไรที่ทำให้ท่านรู้สึกเจ็บป่วยทุกข์ทรมานมากที่สุด
  - อะไรที่ท่านปฏิบัติเพื่อช่วยบรรเทาอาการเจ็บป่วยทุกข์ทรมานที่เกิดขึ้น เหล่านี้ (เช่น ความกลัว กลัวความเจ็บปวดที่จะเกิดขึ้น ความวิตกกังวล ความเศร้าโศก ความสูญเสีย อาการซึมเศร้า อาการนอนไม่หลับ เป็นต้น) อาการเจ็บป่วยทุกข์ทรมานที่เกิดขึ้นเหล่านี้ได้รับการบรรเทาจากเจ้าหน้าที่พยาบาล หรือไม่ อย่างไร
  - โปรดอธิบายความสำคัญของการช่วยเหลือสนับสนุนให้ท่านสามารถ ประกอบกิจกรรมทางศาสนาขณะที่รับการรักษาอยู่ในโรงพยาบาล กิจกรรมเหล่านี้มีส่วนทำให้ท่านรู้สึกมีความหวังในชีวิตหรือไม่ อย่างไร
  - เจ้าหน้าที่พยาบาลสามารถช่วยให้ท่านมีความหวังในชีวิตหรือไม่ อย่างไร

- 8) กิจกรรมที่เจ้าหน้าที่พยาบาล แพทย์ และเจ้าหน้าที่อื่น ๆ ในทีมสุขภาพ ให้บริการแก่ท่านเพื่อช่วยส่งเสริมความสุขสบาย ท่านคิดว่ากิจกรรมใดมี สำคัญต่อท่านมากที่สุด (เช่น ความชื่อสัตย์ บุคลิกที่อ่อนโยนและเป็นมิตร การให้เวลาผู้ป่วยในการซักถาม เป็นตัน)
- 9) ขณะนี้ท่านมอง/รู้สึกว่าอนาคตของท่านเป็นอย่างไร
- ความสุขสบายทางด้านสิ่งแวดล้อม
  - ในความคิดเห็นของท่าน สิ่งแวดล้อมใดของโรงพยาบาลที่ท่านชอบ (เช่น ความเงียบสงบ ความสงบทางจิตใจ เสียง กลิ่น เป็นตัน)
  - สิ่งแวดล้อมอะไรที่สร้างความรำคาญรบกวนท่านมากที่สุด สิ่งเหล่านั้นได้เป็น อุปสรรคต่อการฟื้นฟูสุขภาพของท่าน หรือทำให้อาการของท่านเลวลง อย่างไร
  - ในคลินิกแห่งนี้ มีสิ่งแวดล้อมที่ท่านสามารถควบคุมด้วยตนเองหรือไม่
     อะไรบ้าง
  - ท่านรู้สึกมีความสุขสบายเสมือนกับกำลังอยู่ที่บ้านของท่านหรือไม่ ในกรณีที่
     ใช่ หรือไม่ใช่โปรดอธิบายเพิ่มเติม
- 4. ความสุขสบายทางด้านสังคม และวัฒนธรรม
  - สมาชิกในครอบครัวและเพื่อนของท่านมีส่วนช่วยให้ท่านมีความสุขสบาย อย่างไร
  - (ในทางตรงกันข้าม) ท่านทั้งหลายเหล่านั้นทำอะไรบ้างที่ทำให้ท่านไม่มี ความสุขสบาย
  - ท่านทำอย่างไรในการรักษาความสัมพันธ์ที่ดีกับสมาชิกในครอบครัวของท่าน กับเพื่อน และกับคนที่ท่านรัก

เจ้าหน้าที่พยาบาลได้มีส่วนช่วยในการรักษาความสัมพันธ์ที่ดีนั้นไว้อย่างไร

Appendix F

Steps of the Procedures

## Appendix F

#### **Steps of the Procedures**

1. After this study is approved by the Vice Provost and the Dean of Graduate Studies (VP/DGS), Committee for the Protection of Human Research Subjects, The Catholic University of America, and Research Ethics Committee of the Faculty of Medicine, Chiang Mai University, the researcher will approach the director of the Nursing Division/Department, relevant nursing supervisors and the head nurses of each ward that serves older patients with advanced cancer. One of the nursing administrators will work as a coordinator for access to the relevant clinical areas.

2. In relevant wards, older patients with advanced cancer are assessed routinely via the PPSv2 by a registered nurse (RN), especially who is a member of the Palliative Care Team of the setting. The patients who meet the criterion scores of the PPSv2 will be provided with the Letter for Invitation to Participate in the Research Study (Appendix J) and also asked about their interest in the participation by that RN.

3. The RN introduces the purposive patients who are interested in participating in this study to the researcher. The researcher or including the research assistant, who will be trained particular to this study, will introduce herself to the potential subject, as well as his/her families, and invite him/her into the study. Every the fifth participant will be also invited to participant in the qualitative study—to being interviewed.

4. In cases of agreement, the researcher will explain the purpose and the process of this study, as well as the Protection of Human Subjects. Any questions will be answered at this time.

5. The participants, who agree to participate in this study, will sign the Thai Consent Forms (Appendix K or including Appendix L). They will receive a signed copy of the Consent Form (s).

6. The researcher or research assistant (pursuing the data collection of only the portion of the quantitative study) will give a package containing the questionnaires to complete them at that time while the researcher or research assistant is present and available for further questions. In addition, the researcher or research assistant will provide assistance if the participant requests help to fill out the questionnaires in this process, done under the patient self-determination. However, making an appointment at a convenient time may occur, which depends on the patient decision making.

7. Upon completion of the questionnaires, the participants will place the questionnaires in the package, seal, and return them to the investigator.

8. When the package is opened, the researcher will give each participant package an identifying number.

9. Instruments will be scored and data will be analyzed for the results.

10. Only the participants invited for the qualitative study will be further interviewed by the researcher using the Semi-Structure Interview Guide consisting of five open-ended questions with probes. Each interview will be tape-recorded.

11. Content analysis will be used to categorize the themes from each interview.

Appendix G

Program of Training Research Assistants

## Appendix G

## **Program of Training Research Assistants**

This program is to improve knowledge about palliative care/end-of-life care and comfort care as well as communication and counseling skills, and to understand the purpose and process of this study able to reliably, consistently collect data for quantitative portion.

Audiences: Two research assistants (and 10-15 nurses interested in palliative care, especially members of the palliative care team)

#### **Duration of time:** 2 days

## Day 1

1.1 Providing knowledge about palliative care/end-of-life care focusing on eight domains of structure and process of care, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, spiritual, religious, and existential aspects of care, cultural aspects of care, care of the imminently dying patient, and ethical and legal aspects of care (National Consensus Project, 2004)

1.2 Providing knowledge about comfort theory and comfort care (Kolcaba,2003) and how to apply the taxonomic structure of comfort to assess discomforts planand intervene comfort care, and evaluate comfort care provided

## Day 2

1.1 Providing knowledge about counseling strategy for end-of-life patients

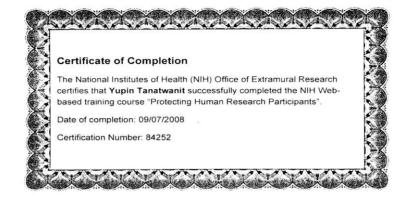
1.2 Explaining the purpose and process of this study (particularly research assistants)

1.3 Explaining the instruments: Hospice Comfort Questionnaire (HCQ)(Patients) and Verbal Rating Scale (VRS) (both English and Thai versions), and how to use them for this study

1.4 Explaining the Protection to Human Rights through the study to the research assistants to rigorously concern them; consisting of the right to self- determination, right to anonymity and confidentiality, right to protection from discomfort and harm, right to privacy (patient's information and data, and medical record kept separate from the questionnaires and interview to prevent identifying an individual patient), and right to protect risks and inconveniences; and to rigorously obtain informed consent(s) by the researcher before the process of data collection.

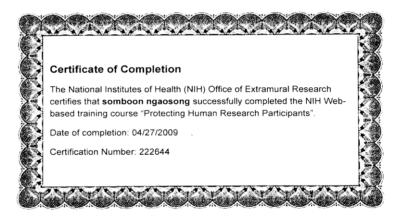
1.5 After completing this training program, the research assistants will be introduced and oriented how to access and learn the NIH Web-Based Training Course "Protecting Human Research Participants" by the researcher. Then, they themselves need to take its quiz for the "Certificate of Completion".

There will be a meeting between the researcher and research assistants after data collection of the first case of each research assistant to assess problems during the procedure and to exchange their resolutions. In addition, the meeting will be addressed periodically to maintain the consistency of procedure among investigators. Protecting Human Subject Research Participants



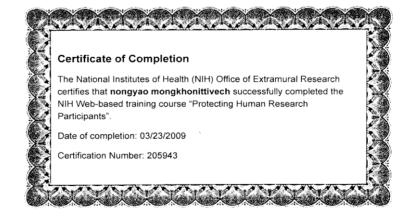
Protecting Human Subject Research Participants

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Protecting Human Subject Research Participants

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Appendix H

Research Participant Information and Consent form

(For Quantitative Component)

English Version



THE CATHOLIC UNIVERSITY OF AMERICA

Office of Sponsored Programs and Research Services Washington, D.C. 20064 202-319-5218

## **Appendix H**

## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM For Quantitative Component

Name of the study: Comfort as Experienced by Thai Older Patients with Advanced Diseases

Investigators: Yupin Tanatwanit, RN, MS, Doctoral Candidate

Supervisor: Sister Mary Elizabeth O' Brien PhD, MSW, MTS, RN, FAAN

**Phone number**: If I have questions about this study, I should call the researcher, Yupin Tanatwanit, at Thai cell phone number.....

## **Description and purpose of the study:**

I am being asked to be in a research study. This research study will describe comfort as experienced by older patients with advanced diseases in an academic medical-university hospital in Thailand. I am being asked to participate as an inpatient diagnosed with advanced diseases of this setting. The purpose of this proposed study is to explore and describe comfort as experienced by Thai older patients with advanced diseases in an academic medical-university hospital in Thailand. This study is being carried out in fulfillment of requirements for a doctoral degree.

## Detailed description of the procedures to be followed

I understand that the participant in this study is voluntary and will start when I sign this Consent Form or I can make an appointment at a convenient time with the investigator. My participation will end when I have completed the booklet of questionnaires given to me by the investigator. In addition, I understand that I may be invited to participate and to be interviewed, which I can determine to participate or not.

I understand that, first, after I complete on this Consent Form, my medical records (medical diagnosis, period of time after being diagnosed, stage of disease, other diseases, length of hospital stay, history of treatment, current treatments, receiving palliative care) will be accessed and recorded by the investigator as part for this study. In addition, it will be used to assess my health status (ambulation, activity and evidence of disease, self-care, intake, and conscious level) which is one of the inclusion criteria of this study. If I qualify to participate in this study, that is, the score is 60% or less, the investigator will ask me about my personal data: age, gender, marital status, race, religion, educational level, employment, income, area of residence, caregiver, and current social support.

Then, I understand that I will be asked to complete the booklet one time in which I will answer questions. I understand that it should take me about 30 minutes to complete the questions. The investigator will be there to answer any questions. The booklet of questions will contain (a) a set of questions of the *Comfort Questionnaires* (*Patient*) and (b) a set of the *Verbal Rating Scale* of comfort which I will determine and answer as my level of comfort. Once I have completed the questionnaires and the Verbal Rating Scale, I understand that the investigator may ask me to confirm my answers which are not clear.

I understand that after answering the questionnaires and the Verbal Rating Scale of comfort, these answered sheets will be collected by the investigator to further study. Then, with my permission, I understand that these answered sheets will be destroyed after approximately five years.

#### Risks and inconveniences, and/or discomforts that may arise:

No medical risks are expected for persons who participate in this study. I may choose not to answer any of the study questions. Also, I can stop the study at any time if the questions make me uncomfortable or distressed, and the investigator who is a registered nurse will psychologically support me or will make a referral to staff for psychological support at a later time. I also understand that the investigator or I may choose to discontinue this participation after our talking.

#### **Benefits that may occur:**

I understand that there is no direct benefit for me for participating in this study. However, my participation may help nurses to better understand and improve the quality of nursing care for other Thai older patients with advanced diseases.

#### **Confidentiality of research records:**

I understand that all identifying information about me in relation to this study will be kept confidential. Any identifying information will be kept separate from the questionnaires. Code numbers will be used on the questionnaires. I or my name will be not connected to the data.

#### **Rights of the subject:**

I understand that I may refuse to participate or discontinue my participation at any time without penalty or loss of benefits to which I am entitled.

I understand that I may request a summary of the results of the research upon completeness

I understand that any information about me obtained as a result of my participation in this research will be kept as confidential as legally possible.

I understand that my research records, just like medical records, may be subpoenaed by court order or inspected by federal regulation authorities.

I have had an opportunity to ask questions about the research and/or my participation in the research, and have received answers to my satisfaction.

I volunteer to participate in this study. I have received a signed copy of this Consent Form.

Subject's signature

Investigator's signature

Date

Date

Any complaints and comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Service, The Catholic University of America, Washington, DC 20064; Telephone: 001-1- (202) 319-5218. In Thailand, you can contact Mrs. Aporn Chairat, as a Head of Nursing, Quality Assurance Unit, Nursing Division, and as the coordinator of this study, office phone number: 053-946649 or cell phone number: 081-6814632. Appendix I

Research Participant Information and Consent form

(For Qualitative Component)

English Version



THE CATHOLIC UNIVERSITY OF AMERICA

Office of Sponsored Programs and Research Services Washington, D.C. 20064 202-319-5218

## **Appendix I**

## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM For Qualitative Component

Name of the study: Comfort as Experienced by Thai Older Patients with Advanced

diseases

Investigators: Yupin Tanatwanit, RN, MS, Doctoral Candidate

Supervisor: Sister Mary Elizabeth O' Brien PhD, MSW, MTS, RN, FAAN

**Phone number**: If I have questions about this study, I should call the researcher, Yupin Tanatwanit, at Thai cell phone number.....

## **Description and purpose of the study:**

I am being asked to be in a research study. This research study will describe comfort as experienced by older patients with advanced diseases in an academic medical-university hospital in Thailand. I am being asked to participate as an inpatient diagnosed with advanced diseases of this setting. The purpose of this proposed study is to explore and describe comfort as experienced by Thai older patients with advanced diseases in an academic medical-university hospital in Thailand. This study is being carried out in fulfillment of requirements for a doctoral degree.

#### Detailed description of the procedures to be followed

I understand this is the second portion of the study. I understand that if I decide to be a participant in this study, it is voluntary and I will start to be interviewed when I sign this Consent Form or I can make the schedule with the investigator to be interviewed later. I understand that the interview consists of a series of open-ended questions which allow me to explain in greater detail my experiences as the inpatient with advanced diseases. With my permission, the interview will be audio-taped approximately 45 minutes. During the interview, I may request that the tape-recorder be turned off at any time if I do not want certain comments to be recorded.

I understand that after completing the interview, all tape recordings will be used only for this study and will be kept confidential. Then, they will be destroyed after approximately five years.

## Risks and inconveniences, and/or discomforts that may arise:

No medical risks are expected for persons who participate in this study. I may choose not to be interviewed or stop the study at any time if the questions make me uncomfortable or distressed, and the investigator who is a registered nurse will psychologically support me or will make a referral to staff for psychological support at a later time. I also understand that the investigator or I may choose to discontinue this participation after our talking.

#### **Benefits that may occur:**

I understand that there is no direct benefit for me for participating in this study. However, my participation may help in better understand and improve the quality of nursing care

for Thai older patients with advanced diseases.

## **Confidentiality of research records:**

I understand that all identifying information about me in relation to this study will be confidential. I understand any identifying information will be kept separate from the interview data in a locked file.

## **Rights of the subject:**

I understand that I may refuse to participate or stop my participation at any time without penalty or loss of benefits to which I am entitled.

I understand that I may request a summary of the results of the research upon completeness

I understand that any information about me obtained as a result of my participation in this research will be kept as confidential as legally possible.

I understand that my research records, just like medical records, may be subpoenaed by court order or inspected by federal regulation authorities.

I have had an opportunity to ask questions about the research and/or my participation in the research, and have received answers to my satisfaction.

I volunteer to participate in this study. I have received a signed copy of this Consent Form.

Subject's signature

Investigator's signature

Date

Date

Any complaints and comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Service, The Catholic University of America, Washington, DC 20064; Telephone: 001-1- (202) 319-5218. In Thailand, you can contact Mrs. Aporn Chairat, as a Head of Nursing, Quality Assurance Unit, Nursing Division, and as the coordinator of this study, office phone number: 053-946649 or cell phone number: 081-6814632. Appendix J

Letter for Invitation to Participate in the Research Study

# Appendix J Letter for Invitation to Participate in the Research Study

The Catholic University of America School of Nursing, Washington D.C., 20064, USA

Dear Patient,

I am a faculty member, Faculty of Nursing, Burapha University, and a professional nurse who had worked in this hospital. As, presently, I am a PhD nursing student at The Catholic University of America. I am interested in providing nursing care, focusing on comfort, for patients with advanced diseases and am willing to improve the quality of this care in Thailand. Thus, the purpose of my study which is conducted is to explore and describe comfort as experienced by Thai older patients with advanced diseases.

The results of this study are expected to reflect the current comfort care provided and comfort needs as well as preferences of patients with advanced diseases. This comfort knowledge will be fundamental as a guide to improve the quality of nursing care for Thai older patients with advanced diseases in this hospital and other healthcare settings in Thailand.

Thus, one nurse of this ward will ask you if you are willing to meet with the researcher or including the research assistant to provide more information about the study which you can use to determine to participate in the study. If you are interested in participating in this study, please inform this nurse about your willingness and available time for the researcher to meet.

Thank you for your interest. I look forward to meeting you.

Sincerely,

Yupin Tanatwanit, PhD nursing candidate, The Catholic University of America

# ภาคผนวก J จดหมายเชิญเข้าร่วมการศึกษาวิจัย

The Catholic University of America School of Nursing, Washington D.C., 20064, USA (ประเทศสหรัฐอเมริกา)

#### ถึง ผู้ป่วย

ดิฉัน นาง ยุพิน ถนัดวณิชย์ เป็นอาจารย์พยาบาล คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา และเป็นพยาบาลวิชาชีพที่เคยปฏิบัติงานที่โรงพยาบาลแห่งนี้ เนื่องจากขณะนี้ดิฉันเป็นนักศึกษา พยาบาลปริญญาเอกที่มหาวิทยาลัยต่างประเทศ (The Catholic University of America) ดิฉันมีความ สนใจการให้บริการการพยาบาลที่มุ่งเน้นความสุขสบายสำหรับผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนิน ก้าวหน้าไปอย่างต่อเนื่อง และมีความตั้งใจที่จะปรับปรุงคุณภาพการพยาบาลดังกล่าว ดังนั้นการศึกษา วิจัยของดิฉันที่กำลังดำเนินการจึงมีวัตถุประสงค์เพื่อศึกษาแบบเจาะลึก และเพื่ออธิบายความสุขสบายที่ ผู้ป่วยได้รับในฐานะที่เป็นผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง

การศึกษาวิจัยครั้งนี้ได้คาดหวังว่า ผลของการศึกษาวิจัยจะสามารถสะท้อนการพยาบาล ความสุขสบายที่ให้บริการในปัจจุบัน และความหมายความสุขสบายที่ผู้ป่วยได้รับและด้องการจากการ รักษาพยาบาลในฐานะที่ท่านเป็นผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างด่อเนื่อง ความรู้เกี่ยวกับการพยาบาลที่มุ่งเน้นความสุขสบายที่ได้จากการศึกษาวิจัยครั้งนี้จะเป็นความรู้หรือข้อมูล พื้นฐานที่ช่วยเป็นแนวทางในการปรับปรุงคุณภาพทางการพยาบาลสำหรับผู้ป่วยสูงอายุที่โรคมีการ ดำเนินก้าวหน้าไปอย่างต่อเนื่อง ที่เข้ารับการรักษาในโรงพยาบาลแห่งนี้ รวมทั้งสถานบริการสุขภาพ อื่น ๆ ในประเทศไทย

ดังนั้น พยาบาลในหอผู้ป่วยแห่งนี้จะเรียนถามท่านว่าท่านมีความสนใจที่จะอนุญาตให้นักวิจัย เข้าพบเพื่ออธิบายข้อมูลเกี่ยวกับการศึกษาวิจัยครั้งนี้เพิ่มเดิมหรือไม่ ทั้งนี้ท่านสามารถนำข้อมูลที่ท่านจะ ได้รับมาช่วยในการตัดสินใจการเข้าร่วมการศึกษาวิจัยครั้งนี้ ถ้าท่านมีความสนใจที่จะเข้าร่วมการ ศึกษาวิจัยครั้งนี้ ขอให้ท่านโปรดแจ้งความประสงค์ของท่านแก่พยาบาล และเวลาที่ท่านสะดวกที่จะให้ นักวิจัยเข้าพบ

ขอบคุณสำหรับความสนใจในการเข้าร่วมการศึกษาวิจัยครั้งนี้ของท่าน และหวังว่าจะได้พบกับ ท่านตามเวลาที่ท่านกำหนด

## ด้วยความนับถือ

นาง ยุพิน ถนัดวณิชย์, นักศึกษาพยาบาลปริญญาเอก The Catholic University of America

Appendix K

Research Participant Information and Consent form

(For Quantitative Component)

Thai Version



#### THE CATHOLIC UNIVERSITY OF AMERICA

School of Nursing Washington, D.C. 20064 202-319-5400 FAX 202-319-6485

#### ภาคผนวก K

## ข้อมูลสำหรับผู้เข้าร่วมการศึกษาวิจัย และหนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัย

## การศึกษาวิจัยเชิงปริมาณ (ส่วนที่ 1)

ชื่อการศึกษาวิจัย ความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในฐานะที่ท่านเป็นผู้ป่วย สูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง หมายเลขโครงการศึกษาวิจัย...... ผู้วิจัย นาง ยุพิน ถนัดวณิชย์

อาจารย์ผู้ควบคุมการศึกษาวิจัย ศาสตราจารย์ ดร. แมรี่ อลิซาเบท โอไบรเอน (Sister Mary Elizabeth O' Brien, PhD, MSW, MTS, RN, FAAN, Professor) ที่ปรึกษาการศึกษาวิจัย ผู้ช่วยศาสตราจารย์ นพ. ห้องสิน ตระกูลทิวากร เบอร์โทรศัพท์ที่สามารถติดต่อได้ ถ้าท่านมีคำถามหรือข้อข้องใจเกี่ยวกับการศึกษาวิจัยครั้งนี้ ท่านสามารถโทรศัพท์ติดต่อกับผู้วิจัย นาง ยุพิน ถนัดวณิชย์ ที่เบอร์......

ท่านได้รับเชิญให้เข้าร่วมการศึกษาวิจัยครั้งนี้เนื่องจากท่านเป็นผู้ป่วยสูงอายุ และโรคของ ท่านได้ดำเนินก้าวหน้าไปอย่างต่อเนื่อง ท่านจะมีโอกาสและเวลาอ่าน (หรือขอให้ผู้วิจัยอ่านเพื่อให้ ท่านรับทราบ) ข้อมูลการศึกษาวิจัยข้างล่างก่อน หากท่านมีข้อข้องใจใด ๆ เกี่ยวกับขั้นตอนการ ศึกษาวิจัยและสิทธิ์ของท่าน ท่านสามารถชักถามจากผู้วิจัยได้ หากท่านดัดสินใจเข้าร่วมการ ศึกษาวิจัยนี้ ท่านจะได้รับสำเนาเอกสารข้อมูลสำหรับผู้เข้าร่วมการศึกษาวิจัยฉบับนี้ และสำเนา หนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัยที่ท่านเซ็นชื่อกำกับเก็บไว้ อย่างละ1 ฉบับ เรารู้สึก ยินดีที่ท่านได้สละเวลาอ่าน (หรือรับฟัง) รายละเอียดดังกล่าวต่อไปนี้

## คำอธิบายและวัตถุประสงค์ของการศึกษาวิจัย

การศึกษาวิจัยครั้งนี้มีความประสงค์ที่จะอธิบายความหมายของความสุขสบายในมุมมอง ของผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง ขณะที่รับการรักษาพยาบาล ในโรงพยาบาลระดับมหาวิทยาลัยทางการแพทย์ ในประเทศไทย ท่านเป็นผู้สูงอายุที่มีคุณสมบัติเข้า ข่ายประชากรของการศึกษาวิจัยนี้ ท่านจึงได้รับเซิญให้เข้าร่วมการศึกษาวิจัยครั้งนี้

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การศึกษาวิจัยครั้งนี้เป็นการศึกษาแบบเจาะลึก โดยท่านจะเป็นผู้บรรยาย ความสุขสบายที่ ท่านได้รับจากการรักษาพยาบาลในขณะที่ท่านรับการรักษาอยู่ในโรงพยาบาลมหาราชนครเซียงใหม่ แห่งนี้

การศึกษาวิจัยครั้งนี้เป็นส่วนหนึ่งของข้อกำหนดสำหรับการสำเร็จการศึกษาในระดับ ปริญญาเอกของมหาวิทยาลัยคาทอลิก ในประเทศสหรัฐอเมริกา

## คำอธิบายรายละเอียดของขั้นตอนการศึกษาวิจัย

การเข้าร่วมการศึกษาวิจัยครั้งนี้เป็นความสมัครใจของท่าน ถ้าท่านมีความพร้อมการศึกษา วิจัยจะเริ่มขึ้นทันทีภายหลังจากที่ท่านได้เซ็นซื่อกำกับในหนังสือแสดงความยินยอมเข้าร่วมการ ศึกษาวิจัย หรือถ้าท่านยังไม่มีความพร้อม ท่านสามารถนัดหมายวันและเวลาที่ท่านสะดวก ในการที่ จะเข้าร่วมการศึกษาวิจัยกับผู้วิจัยได้ในภายหลัง

การศึกษาวิจัยนี้มี 2 ขั้นดอน (ขั้นดอนที่ 1 และ 2) ท่านอาจจะถูกเชิญให้เข้าร่วมการ ศึกษาวิจัยในขั้นดอนที่ 2 ซึ่งเป็นการสัมภาษณ์ แต่ท่านสามารถดัดสินใจได้อีกครั้งว่าจะยินยอมเข้า ร่วมด้วยหรือไม่

สำหรับการเข้าร่วมการศึกษาวิจัย ขั้นดอนที่ 1 หลังจากที่ท่านได้เซ็นชื่อกำกับในหนังสือ แสดงความยินยอมเข้าร่วมการศึกษาวิจัย ผู้วิจัย (หรืออาจรวมผู้ช่วยวิจัย) จะศึกษาข้อมูลทาง การแพทย์ของท่านที่ถูกบันทึกไว้ (การวินิจฉัยโรค ระยะเวลาหลังจากได้รับการวินิจฉัยโรค ระยะ ของโรค โรคอื่น ๆ ระยะเวลาการอยู่โรงพยาบาล ประวัติการรักษาอาการเจ็บป่วย การรักษาอาการ เจ็บป่วยในปัจจุบัน และการได้รับการดูแลแบบประคับประคองภาวะสุขภาพ) เพื่อนำไปเป็นส่วน หนึ่งของการศึกษาวิจัย และนำไปประเมินภาวะสุขภาพของท่าน (ที่เกี่ยวกับ ความสามารถในการ เคลื่อนไหว การปฏิบัติกิจกรรมและการดำเนินไปของโรค การดูแลตนเอง การรับประทานอาหาร/น้ำ รวมทั้งการได้รับสารน้ำ และระดับความรู้สึกดัว) หากผลของการประเมินพบว่าภาวะสุขภาพของ ท่านอยู่ในระดับ 60% หรือน้อยกว่า ถือว่าท่านอยู่ในเกณฑ์ที่จะได้รับเชิญให้เข้าร่วมการศึกษาวิจัย ต่อไป

ต่อจากนั้น ผู้วิจัยจะซักถามท่านเกี่ยวกับข้อมูลส่วนดัว ซึ่งประกอบด้วย อายุ เพศ สถานภาพสมรส ซาดิ ศาสนา ระดับการศึกษา การทำงาน รายได้ เขตพื้นที่ที่อยู่อาศัย ผู้ดูแล และ การสนับสนุนทางสังคมที่ได้รับในปัจจุบัน หลังจากนั้นผู้วิจัยหรือผู้ช่วยวิจัยจะขอให้ท่านตอบคำถาม ซึ่งประกอบด้วย (ก) แบบสอบถามความสุขสบายของผู้ป่วย และ (ข) แบบสอบถามมาตรวัด ความสุขสบาย ท่านอาจจะขอให้ผู้วิจัยหรือผู้ช่วยวิจัยอ่านคำถามให้แทนการอ่านด้วยดัวเอง การ ดอบแบบสอบถามครบสมบูรณ์ทั้งชุดคาดว่าจะใช้เวลาทั้งหมดประมาณ 30 นาที อย่างไรก็ตามเมื่อ

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ท่านดอบคำถามครบสมบูรณ์ ผู้วิจัยหรือผู้ช่วยวิจัยอาจจะมีคำถามเพิ่มเดิมสำหรับคำดอบที่ยังไม่ ชัดเจนเพื่อความถูกต้องสมบูรณ์ของข้อมูล ในขณะที่ท่านดอบคำถาม ผู้วิจัยหรือผู้ช่วยวิจัยจะอยู่ กับท่านดลอดระยะเวลาเพื่อคอยดอบคำถามเกี่ยวกับแบบสอบถามที่อาจจะมีขึ้น

หลังจากที่ท่านได้ตอบคำถามแบบสอบถามความสุขสบายของผู้ป่วย และแบบสอบถาม มาตรวัดความสุขสบายครบสมบูรณ์ หากท่านและผู้วิจัยหรือผู้ช่วยวิจัยไม่มีคำถามใด ๆ อีก เอกสาร บันทึกการตอบคำถามเหล่านี้จะถูกรวบรวมโดยผู้วิจัยหรือผู้ช่วยวิจัยเพื่อดำเนินการศึกษาวิจัยต่อไป ภายหลังจากเสร็จสิ้นการศึกษาวิจัยนี้เอกสารบันทึกการตอบคำถามทั้งหมดเหล่านี้จะถูกเก็บไว้ไม่ เกิน 5 ปี (โดยประมาณ) ก่อนที่จะถูกทำลาย

## ้ความเสี่ยงและความไม่สะดวก และ/หรือความไม่สุขสบายที่อาจจะเกิดขึ้น

การศึกษาวิจัยครั้งนี้คาดว่าไม่มีความเสี่ยงทางด้านการแพทย์ใด ๆ ที่จะเกิดขึ้นกับท่านใน ฐานะผู้เข้าร่วมการศึกษาวิจัย อย่างไรก็ตามท่านอาจจะเลือกที่จะไม่ดอบคำถามบางคำถามได้ หรือ ท่านสามารถที่จะหยุดการเข้าร่วมการศึกษาวิจัยเมื่อใดก็ได้ นอกจากนี้ถ้าคำถามทำให้ท่านรู้สึกไม่ สุขสบายหรือกระทบต่อความรู้สึกและจิดใจของท่าน (เช่น รู้สึกโศกเศร้า) ผู้วิจัยหรือผู้ช่วยวิจัยซึ่ง เป็นพยาบาลวิชาชีพจะเป็นผู้ให้การดูแลช่วยเหลือทางด้านจิตใจของท่านในเบื้องต้น หรืออาจจะ ประสานงานกับเจ้าหน้าที่พยาบาลในหอผู้ป่วยที่ท่านเข้ารับการรักษา เพื่อดำเนินการส่งต่อท่านไป ให้ทีมงานสุขภาพที่เชี่ยวชาญการดูแลช่วยเหลือทางด้านจิตใจต่อไป ตลอดการดำเนินการศึกษาวิจัย หรือภายหลังการสนทนาพูดดุยครั้งนี้ ท่านและ/หรือผู้วิจัยหรือผู้ช่วยวิจัยอาจพิจารณาเลือกที่จะหยุด การศึกษาวิจัยครั้งนี้ก็ได้เช่นกัน

## ผลประโยชน์ที่อาจจะเกิดขึ้น

การเข้าร่วมการศึกษาวิจัยครั้งนี้ ท่านจะไม่ได้รับค่าตอบแทนและผลประโยชน์ ทางตรงใด ๆ อย่างไรก็ตามผลของการศึกษาวิจัยในครั้งนี้จะช่วยให้เจ้าหน้าที่พยาบาลมีความรู้ความเข้าใจ เกี่ยวกับการพยาบาลดีขึ้น และสามารถนำไปสู่การปรับปรุงคุณภาพการให้บริการการพยาบาลที่ มุ่งเน้นความสุขสบายให้กับผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง

## การเก็บรักษาข้อมูลที่ได้จากการศึกษาวิจัยเป็นความลับ

ข้อมูลทั้งหมดที่เก็บเพื่อการศึกษาวิจัยครั้งนี้จะถูกเก็บเป็นความลับ ข้อมูลใด ๆที่เกี่ยวข้อง และสามารถอ้างถึงตัวท่านจะถูกเก็บแยกจากแบบสอบถามและเก็บไว้ในตู้ไส่กุญแจ เลขรหัสถูก นำมาใช้แทนบนแบบสอบถามทุกฉบับ ข้อมูลที่ได้จากท่านและชื่อของท่านจะไม่ถูกเชื่อมโยงติดต่อ ถึงกันได้

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### สิทธิของผู้เข้าร่วมในการศึกษาวิจัย

ท่านอาจจะปฏิเสธหรือหยุดเข้าร่วมการศึกษาวิจัยได้ตลอดเวลาโดยไม่มีการถูกลงโทษใดๆ และปราศจากการสูญเสียผลประโยชน์อันพึงจะได้ใดๆ

ท่านอาจจะร้องขอบทสรุปที่เสร็จสมบูรณ์แล้วของการศึกษาวิจัยในครั้งนี้

ข้อมูลใด ๆ ที่เกี่ยวข้องกับดัวท่านอันเกิดจากผลของการเข้าร่วมการศึกษาวิจัยในครั้งนี้จะถูก เก็บเป็นความลับตามที่กฎหมายด้านจริยธรรมการศึกษาวิจัยระบุ

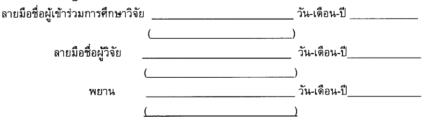
ข้อมูลและการบันทึกใด ๆ ในการศึกษาวิจัยครั้งนี้ที่เกี่ยวข้องกับตัวท่าน (ดังเช่น ข้อมูลทาง การแพทย์ที่ถูกบันทึกไว้) อาจจะถูกร้องขอนำไปใช้ทางราชการโดยคำสั่งศาล หรือถูกตรวจสอบโดย ผู้มีอำนาจทางกฎหมายของรัฐบาลกลางในประเทศสหรัฐอเมริกา (ซึ่งเป็นไปเพื่อการปกป้องสิทธิ มนุษยชนในการเข้าร่วมการศึกษาวิจัย)

ท่านจะได้มีโอกาสที่จะถามคำถามเกี่ยวกับการศึกษาวิจัยและ/หรือการเข้าร่วมการศึกษา วิจัย และจะได้รับคำตอบจนเป็นที่พอใจ

เมื่อท่านอาสาสมัครเข้าร่วมการศึกษาวิจัยในครั้งนี้ท่านจะได้รับสำเนาหนังสือ แสดงความ ยินยอมเข้าร่วมการศึกษาวิจัยพร้อมลายเซ็นของท่านเพื่อเก็บไว้เป็นหลักฐาน 1 ฉบับ

## ส่วนแสดงความยินยอม

โดยการลงนามในหนังสือยินยอมฉบับนี้ ท่านยอมรับว่าท่านได้อ่านเอกสารฉบับนี้แล้ว และ ได้รับคำอธิบายเกี่ยวกับการศึกษาวิจัยนี้ รวมถึงได้รับคำตอบเกี่ยวกับข้อสงสัยต่าง ๆ ที่ท่านมีจาก นักวิจัยแล้ว ท่านได้ตกลงใจที่จะเข้าร่วมในการศึกษาวิจัยนี้ ท่านมีสิทธิที่จะถอนตัวจากการ ศึกษาวิจัยนี้ได้ทุกเมื่อ โดยไม่มีผลต่อการรักษาในอนาคต โดยการลงนามนี้ท่านไม่ได้สละสิทธิ์โด ๆ ที่ท่านพึงมีทางกฎหมาย



คำร้องเรียนและวิจารณ์ใดๆ เกี่ยวกับการเข้าร่วมการศึกษาวิจัยครั้งนี้ของท่าน ควรส่งตรง ไปที่เลขานุการ คณะกรรมการจริยธรรมการศึกษาวิจัยเพื่อปกป้องสิทธิมนุษยชน (Committee for

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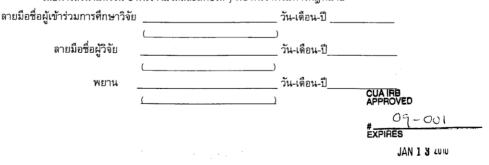
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หนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัย (CONSENT FORM) การศึกษาวิจัยเชิงปริมาณ (ส่วนที่ 1)

ข้าพเจ้า นาย/นาง/นางสาว......ขอให้ความยินยอมของตนเอง ที่จะเข้าร่วมในการศึกษาวิจัยเรื่อง ความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในฐานะที่ท่าน เป็นผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง ข้าพเจ้าได้รับข้อมูลและ คำอธิบายเกี่ยวกับการศึกษาวิจัยนี้แล้ว ข้าพเจ้าได้มีโอกาสซักถามเกี่ยวกับการศึกษาวิจัยนี้และได้รับ คำดอบเป็นที่พอใจแล้ว ข้าพเจ้ามีเวลาเพียงพอในการอ่านและทำความเข้าใจกับข้อมูลในเอกสารนี้อย่าง ถี่ถ้วน และได้รับเวลาเพียงพอในการดัดสินใจว่าจะเข้าร่วมการศึกษาวิจัยนี้หรือไม่ ผู้วิจัยมีความยินดีที่จะ ให้คำดอบต่อคำถามใด ๆ ที่ข้าพเจ้าอาจจะมีได้ ตลอดระยะเวลาการเข้าร่วมการศึกษาวิจัยครั้งนี้ ผู้วิจัย รับรองว่าจะเก็บข้อมูลเฉพาะที่เกี่ยวกับตัวข้าพเจ้าเป็นความลับ และจะเปิดเผยได้เฉพาะในรูปที่เป็นสรุป ผลการวิจัย และผู้วิจัยจะได้ปฏิบัติในสิ่งที่คาดว่าจะไม่ก่อให้เกิดอันตรายต่อร่างกายหรือจิตใจของข้าพเจ้า ดลอดการศึกษาวิจัยนี้ นอกจากนี้ผู้วิจัยได้รับรองว่า เมื่อใดก็ตามถ้าคำถามทำให้ข้าพเจ้ารู้สึกไม่สุขสบาย หรือ กระทบต่อความรู้สึกและจิตใจของข้าพเจ้า ผู้วิจัยซึ่งเป็นพยาบาลวิชาชีพจะเป็นผู้ให้การดูแลช่วยเหลือ ทางด้านจิตใจของข้าพเจ้าในเบื้องต้น หรืออาจจะประสานงานกับเจ้าหน้าที่พยาบาลในหอผู้ป่วยที่ข้าพเจ้า เข้ารับการรักษาอยู่ เพื่อดำเนินการส่งต่อข้าพเจ้าให้กับทึมงานสุขภาพที่เชี่ยวชาญการดูแลช่วยเหลือ ทางด้านจิตใจช่องไป

ข้าพเจ้ายินยอมเข้าร่วมการศึกษาวิจัยโดยสมัครใจ และสามารถที่จะถอนดัวจากการศึกษาวิจัยครั้ง นี้เมื่อใดก็ได้ ทั้งนี้โดยไม่มีผลกระทบต่อการรักษาพยาบาล ที่ข้าพเจ้าจะได้รับในฐานะที่ข้าพเจ้าเป็นผู้ป่วย และในกรณีที่เกิดข้อข้องใจหรือปัญหาที่ข้าพเจ้าต้องการปรึกษากับผู้วิจัย ข้าพเจ้าสามารถติดต่อกับผู้วิจัย ....นาง ยุพิน ถนัดวณิชย์...ได้ที่เบอร์โทรศัพท์......หรือ ผู้ประสานงาน...นาง อาภรณ์ ชัยรัด (หัวหน้าพยาบาล หน่วยงานด้านคุณภาพการพยาบาล ฝ่ายการพยาบาล โรงพยาบาลมหาราชนคร เชียงใหม่) ได้ที่เบอร์โทรศัพท์หน่วยงาน 053-946649 หรือ เบอร์โทรศัพท์มือถือ 081-6814632 โดยการลงนามครั้งนี้ ข้าพเจ้าไม่ได้สละสิทธิ์ใด ๆ ที่ข้าพเจ้าพึงมีทางกฎหมาย



Appendix L

Research Participant Information and Consent form

(For Qualitative Component)

Thai Version



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#### ภาคผนวก L

# ข้อมูลสำหรับผู้เข้าร่วมการศึกษาวิจัย และหนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัย การศึกษาวิจัยเชิงคุณภาพ (ส่วนที่ 2)

ชื่อการศึกษาวิจัย ความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในฐานะที่ท่านเป็นผู้ป่วย สูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง หมายเลขโครงการศึกษาวิจัย...... ผู้วิจัย นาง ยุพิน ถนัดวณิชย์

อาจารย์ผู้ควบคุมการศึกษาวิจัย ศาสตราจารย์ ดร. แมรี่ อลิซาเบท โอไบรเอน (Sister Mary Elizabeth O' Brien, PhD, MSW, MTS, RN, FAAN, Professor) ที่ปรึกษาการศึกษาวิจัย ผู้ช่วยศาสตราจารย์ นพ. ห้องสิน ตระกูลทิวากร

เบอร์โทรศัพท์ที่สามารถติดต่อได้ ถ้าท่านมีคำถามหรือข้อข้องใจเกี่ยวกับการศึกษาวิจัยครั้งนี้ ท่านสามารถโทรศัพท์ดิดต่อกับผู้วิจัย นาง ยุพิน ถนัดวณิชย์ ที่เบอร์.....

ท่านได้รับเชิญให้เข้าร่วมการศึกษาวิจัยครั้งนี้เนื่องจากท่านเป็นผู้ป่วยสูงอายุ และโรคของ ท่านได้ดำเนินก้าวหน้าไปอย่างต่อเนื่อง ท่านจะมีโอกาสและเวลาอ่าน (หรือขอให้ผู้วิจัยอ่านเพื่อให้ ท่านรับทราบ) ข้อมูลการศึกษาวิจัยข้างล่างก่อน หากท่านมีข้อข้องใจใดๆ เกี่ยวกับขั้นตอนการ ศึกษาวิจัยและสิทธิ์ของท่าน ท่านสามารถซักถามจากผู้วิจัยได้ หากท่านตัดสินใจเข้าร่วมการ ศึกษาวิจัยนี้ ท่านจะได้รับสำเนาเอกสารข้อมูลสำหรับผู้เข้าร่วมการศึกษาวิจัยฉบับนี้ และสำเนา หนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัยที่ท่านเซ็นชื่อกำกับเก็บไว้ อย่างละ1 ฉบับ เรารู้สึก ยินดีที่ท่านได้สละเวลาอ่าน (หรือรับฟัง) รายละเอียดดังกล่าวต่อไปนี้

## คำอธิบายและวัตถุประสงค์ของการศึกษาวิจัย

การศึกษาวิจัยครั้งนี้มีความประสงค์ที่จะอธิบายความหมายของความสุขสบายในมุมมอง ของผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง ขณะที่รับการรักษาพยาบาล ในโรงพยาบาลระดับมหาวิทยาลัยทางการแพทย์ ในประเทศไทย ท่านเป็นผู้สูงอายุที่มีคุณสมบัติเข้า ข่ายประชากรของการศึกษาวิจัยนี้ ท่านจึงได้รับเชิญให้เข้าร่วมการศึกษาวิจัยครั้งนี้

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การศึกษาวิจัยครั้งนี้เป็นการศึกษาแบบเจาะลึก โดยท่านจะเป็นผู้บรรยาย ความสุขสบายที่ ท่านได้รับจากการรักษาพยาบาลในขณะที่ท่านรับการรักษาอยู่ในโรงพยาบาลมหาราชนครเซียงใหม่ แห่งนี้

การศึกษาวิจัยครั้งนี้เป็นส่วนหนึ่งของข้อกำหนดสำหรับการสำเร็จการศึกษาในระดับ ปริญญาเอกของมหาวิทยาลัยคาทอลิก ในประเทศสหรัฐอเมริกา

# คำอธิบายรายละเอียดของขั้นตอนการศึกษาวิจัย

การศึกษาวิจัยนี้เป็นขั้นดอนที่ 2 เป็นการสัมภาษณ์โดยผู้วิจัย การเข้าร่วมการศึกษาวิจัย ของท่านในขั้นดอนนี้ยังคงเป็นความสมัครใจของท่าน ถ้าท่านมีความพร้อมในการเข้าร่วมการ ศึกษาวิจัย การสัมภาษณ์จะเริ่มขึ้นทันทึภายหลังจากที่ท่านได้เซ็นชื่อกำกับในหนังสือแสดงความ ยินยอมเข้าร่วมการศึกษาวิจัย หรือถ้าท่านยังไม่มีความพร้อม ท่านสามารถนัดหมายวันและเวลาที่ ท่านสะดวกในการที่จะเข้าร่วมการศึกษาวิจัยกับผู้วิจัยได้ในภายหลัง

การสัมภาษณ์ประกอบด้วยชุดคำถามปลายเปิด ซึ่งเปิดโอกาสให้ท่านได้อธิบายรายละเอียด มากขึ้นเกี่ยวกับความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในฐานะที่ท่านเป็นผู้ป่วยสูงอายุ ชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง และอยู่ในฐานะผู้ป่วยในของโรงพยาบาลแห่งนี้ ภายใต้การอนุญาตของท่าน การสัมภาษณ์จะถูกอัดเทปเป็นระยะเวลาประมาณ 45 นาที ทั้งนี้ ระหว่างการสัมภาษณ์ท่านอาจจะขอให้หยุดการอัดเทป ณ. ช่วงเวลาใดก็ได้ถ้าท่านไม่ด้องการให้ เนื้อหาการสนทนาบางส่วนนั้นถูกอัดเทป

ภายหลังการสัมภาษณ์ ข้อมูลการสัมภาษณ์ที่ถูกอัดเทปไว้จะถูกนำไปใช้เฉพาะการ ศึกษาวิจัยครั้งนี้เท่านั้น และจะถูกเก็บไว้เป็นความลับ ภายหลังจากเสร็จสิ้นการศึกษาวิจัยนี้ข้อมูล การสัมภาษณ์ทั้งหมดเหล่านี้จะถูกเก็บไว้ไม่เกิน 5 ปี (โดยประมาณ) ก่อนที่จะถูกทำลาย

## ้ความเสี่ยงและความไม่สะดวก และ/หรือความไม่สุขสบายที่อาจจะเกิดขึ้น

การศึกษาวิจัยครั้งนี้กาดว่าไม่มีความเสี่ยงทางด้านการแพทย์ใด ๆ ที่จะเกิดขึ้นกับท่านใน ฐานะผู้เข้าร่วมการศึกษาวิจัย อย่างไรก็ตามท่านอาจจะเลือกที่จะไม่ดอบคำถามบางคำถามได้ หรือ ท่านสามารถที่จะหยุดการเข้าร่วมการศึกษาวิจัยเมื่อใดก็ได้ นอกจากนี้ถ้าคำถามทำให้ท่านรู้สึกไม่ สุขสบายหรือกระทบต่อความรู้สึกและจิดใจของท่าน (เช่น รู้สึกโศกเศร้า) ผู้วิจัยซึ่งเป็นพยาบาล วิชาซีพจะเป็นผู้ให้การดูแลช่วยเหลือทางด้านจิดใจของท่านในเบื้องด้น หรืออาจจะประสานงานกับ เจ้าหน้าที่พยาบาลในหอผู้ป่วยที่ท่านเข้ารับการรักษา เพื่อดำเนินการส่งต่อท่านไปให้ทีมงานสุขภาพ ที่เชี่ยวชาญการดูแลช่วยเหลือทางด้านจิตใจต่อไป ดลอดการดำเนินการศึกษาวิจัยหรือภายหลังการ สนทนาพูดดุยครั้งนี้ ท่านและ/หรือผู้วิจัยอาจพิจารณาเลือกที่จะหยุดการศึกษาวิจัยครั้งนี้ก็ได้เช่นกัน ผัวคัดงงย

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## ผลประโยชน์ที่อาจจะเกิดขึ้น

การเข้าร่วมการศึกษาวิจัยครั้งนี้ ท่านจะไม่ได้รับค่าตอบแทนและผลประโยชน์ทางตรงใด ๆ อย่างไรก็ตามผลของการศึกษาวิจัยในครั้งนี้จะช่วยให้เจ้าหน้าที่พยาบาลมีความรู้ความเข้าใจ เกี่ยวกับการพยาบาลดีขึ้น และสามารถนำไปสู่การปรับปรุงคุณภาพการให้บริการการพยาบาลที่ มุ่งเน้นความสุขสบายให้กับผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง

## การเก็บรักษาข้อมูลที่ได้จากการศึกษาวิจัยเป็นความลับ

ข้อมูลทั้งหมดที่เก็บเพื่อการศึกษาวิจัยครั้งนี้จะถูกเก็บเป็นความลับ ข้อมูลใด ๆที่เกี่ยวข้อง และสามารถอ้างถึงดัวท่านจะถูกเก็บแยกจากแบบสัมภาษณ์และเก็บไว้ในดู้ใส่กุญแจ เลขรหัสจะถูก นำมาใช้แทนบนแบบสัมภาษณ์ทุกฉบับ ข้อมูลที่ได้จากท่านและชื่อของท่านจะไม่ถูกเชื่อมโยงดิดต่อ ถึงกันได้

#### สิทธิของผู้เข้าร่วมในการศึกษาวิจัย

ท่านอาจจะปฏิเสธหรือหยุดเข้าร่วมการศึกษาวิจัยได้ตลอดเวลาโดยไม่มีการถูกลงโทษใด ๆ และปราศจากการสูญเสียผลประโยชน์อันพึงจะได้ใด ๆ

ท่านอาจจะร้องขอบทสรุปที่เสร็จสมบูรณ์แล้วของการศึกษาวิจัยในครั้งนี้

ข้อมูลใด ๆ ที่เกี่ยวข้องกับดัวท่านอันเกิดจากผลของการเข้าร่วมการศึกษาวิจัยในครั้งนี้จะถูก เก็บเป็นความลับตามที่กฎหมายด้านจริยธรรมการศึกษาวิจัยระบุ

ข้อมูลและการบันทึกใด ๆ ในการศึกษาวิจัยครั้งนี้ที่เกี่ยวข้องกับตัวท่าน (ดังเช่น ข้อมูลทาง การแพทย์ที่ถูกบันทึกไว้) อาจจะถูกร้องขอนำไปใช้ทางราชการโดยคำสั่งศาล หรือถูกตรวจสอบโดย ผู้มีอำนาจทางกฎหมายของรัฐบาลกลางในประเทศสหรัฐอเมริกา (ซึ่งเป็นไปเพื่อการปกป้องสิทธิ มนุษยชนในการเข้าร่วมการศึกษาวิจัย)

ท่านจะได้มีโอกาสที่จะถามคำถามเกี่ยวกับการศึกษาวิจัยและ/หรือการเข้าร่วมการศึกษา วิจัย และจะได้รับคำตอบจนเป็นที่พอใจ

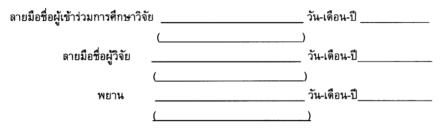
เมื่อท่านอาสาสมัครเข้าร่วมการศึกษาวิจัยในครั้งนี้ท่านจะได้รับสำเนาหนังสือ แสดงความ ยินยอมเข้าร่วมการศึกษาวิจัยพร้อมลายเซ็นของท่านเพื่อเก็บไว้เป็นหลักฐาน 1 ฉบับ

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## ส่วนแสดงความยินยอม

โดยการลงนามในหนังสือยินยอมฉบับนี้ ท่านยอมรับว่าท่านได้อ่านเอกสารฉบับนี้แล้ว และ ได้รับคำอธิบายเกี่ยวกับการศึกษาวิจัยนี้ รวมถึงได้รับคำตอบเกี่ยวกับข้อสงสัยต่าง ๆ ที่ท่านมีจาก นักวิจัยแล้ว ท่านได้ตกลงใจที่จะเข้าร่วมในการศึกษาวิจัยนี้ ท่านมีสิทธิที่จะถอนตัวจากการ ศึกษาวิจัยนี้ได้ทุกเมื่อ โดยไม่มีผลต่อการรักษาในอนาคต โดยการลงนามนี้ท่านไม่ได้สละสิทธิ์โด ๆ ที่ท่านพึงมีทางกฎหมาย



คำร้องเรียนและวิจารณ์ใด ๆ เกี่ยวกับการเข้าร่วมการศึกษาวิจัยครั้งนี้ของท่าน ควรส่งตรง ไปที่เลขานุการ คณะกรรมการจริยธรรมการศึกษาวิจัยเพื่อปกป้องสิทธิมนุษยชน (Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Service, The Catholic University of America, Washington, DC 20064) เบอร์โทรศัพท์ 001-1-202-319-5218 ส่วนในประเทศไทยท่านสามารถดิดต่อ นางอาภรณ์ ชัยรัด หัวหน้าพยาบาล หน่วยงานด้าน คุณภาพการพยาบาล ฝ่ายการพยาบาล โรงพยาบาลมหาราชนครเชียงใหม่ ซึ่งเป็นผู้ประสานงานใน การเก็บข้อมูลเพื่อการศึกษาวิจัยครั้งนี้ เบอร์โทรศัพท์หน่วยงาน 053-946649 หรือ เบอร์ โทรศัพท์มือถือ 081-6814632

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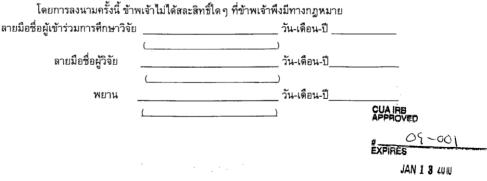
## THE CATHOLIC UNIVERSITY OF AMERICA

<u>School of Nursing</u> Washington, D.C. 20064 202-319-5400 FAX 202-319-6485 หนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัย (CONSENT FORM)

#### การศึกษาวิจัยเชิงคุณภาพ (ส่วนที่ 2)

ข้าพเจ้า นาย/นาง/นางสาว...... ขอให้ความยินยอมของตนเอง ที่จะเข้าร่วมในการศึกษาวิจัยเรื่อง ความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในฐานะที่ท่าน เป็นผู้ป่วยสูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง ข้าพเจ้าได้รับข้อมูลและ คำอธิบายเกี่ยวกับการศึกษาวิจัยนี้แล้ว ข้าพเจ้าได้มีโอกาสซักถามเกี่ยวกับ การศึกษาวิจัยนี้และได้รับ ดำตอบเป็นที่พอใจแล้ว ข้าพเจ้ามีเวลาเพียงพอในการอ่านและทำความเข้าใจกับข้อมูลในเอกสารนี้อย่าง ถี่ถ้วน และได้รับเวลาเพียงพอในการดัดสินใจว่าจะเข้าร่วมการศึกษาวิจัยนี้หรือไม่ ผู้วิจัยมีความยินดีที่จะ ให้คำตอบต่อคำถามใด ๆ ที่ข้าพเจ้าอาจจะมีได้ตลอดระยะเวลาการเข้าร่วมการศึกษาวิจัยกรั้งนี้ ผู้วิจัย รับรองว่าจะเก็บข้อมูลเฉพาะที่เกี่ยวกับดัวข้าพเจ้าเป็นความลับ และจะเปิดเผยได้เฉพาะในรูปที่เป็นสรุป ผลการวิจัย และผู้วิจัยจะได้ปฏิบัติในสิ่งที่คาดว่าจะไม่ก่อให้เกิดอันตรายต่อร่างกายหรือจิตใจของข้าพเจ้า ตลอดการศึกษาวิจัยนี้ นอกจากนี้ผู้วิจัยได้รับรองว่า เมื่อใดก็ตามถ้าคำถามทำให้ข้าพเจ้ารู้สึกไม่สุขสบาย หรือ กระทบต่อความรู้สึกและจิดใจของข้าพเจ้าให้กับก็มงานกับเจ้าหน้าที่พยาบาลในหอผู้ป่วยที่ข้าพเจ้า เข้ารับการรักษาอยู่ เพื่อดำเนินการส่งต่อข้าพเจ้าให้กับทึมงานสุขภาพที่เชี่ยวชาญการดูแลช่วยเหลือ ทางด้านจิตใจต่อไป

ข้าพเจ้ายินยอมเข้าร่วมการศึกษาวิจัยโดยสมัครใจ และสามารถที่จะถอนตัวจากการศึกษาวิจัยครั้ง นี้เมื่อใดก็ได้ ทั้งนี้โดยไม่มีผลกระทบต่อการรักษาพยาบาล ที่ข้าพเจ้าจะได้รับในฐานะที่ข้าพเจ้าเป็นผู้ป่วย และในกรณีที่เกิดข้อข้องใจหรือปัญหาที่ข้าพเจ้าด้องการปรึกษากับผู้วิจัย ข้าพเจ้าสามารถติดต่อกับผู้วิจัย ....นาง ยุพิน ถนัดวณิชย์...ได้ที่เบอร์โทรศัพท์......หรือ ผู้ประสานงาน....นาง อาภรณ์ ชัยรัต (หัวหน้าพยาบาล หน่วยงานด้านคุณภาพการพยาบาล ฝ่ายการพยาบาล โรงพยาบาลมหาราชนคร เชียงใหม่) ได้ที่เบอร์โทรศัพท์หน่วยงาน 053-946649 หรือ เบอร์โทรศัพท์มือถือ 081-6814632



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Letters of Permission



## THE CATHOLIC UNIVERSITY OF AMERICA

Office of the Dean of Graduate Studies 116 McMahon Hall Washington, DC 20064 Tel: 202-319-5247 FAX: 202-319-6174

February 18, 2009

Ms. Yupin Tanatwanit 2121 Columbia Pike, #411 Arlington, VA 22204

Dear Ms. Tanatwanit:

Upon the recommendation of the appropriate reviewing bodies, the Dean of Graduate Studies has reviewed your request for approval of doctoral dissertation topic and committee. Your request was approved on **February 18, 2009** and you may proceed with your dissertation research.

A copy of your approved proposal is being forwarded to you herewith. It is understood that you will conduct your research as outlined in your proposal, and that any substantial changes in your research, or any changes in topic/title or in committee, are subject to the approval of the Dean of Graduate Studies. Any such requests should be made using the appropriate form from the site noted below.

Please keep in mind that in accordance with arrangements made recently by your academic dean, your oral defense and final deposit of your approved dissertation must be completed no later than the end of the **Spring 2013** semester.

The Office of Graduate Studies publishes a handbook \* on the preparation of the doctoral dissertation manuscript. It is very important that you have a copy of this handbook, since it discusses university guidelines and contains important information regarding style, format, and other issues related to the preparation and deposit of the final dissertation manuscript. If you have not already done so, you should arrange to obtain a

Ms. Yupin Tanatwanit

copy of this handbook from 116 McMahon Hall. Forms concerning the publication and copyrighting of the dissertation are also available. However, as these forms are revised periodically, they should be obtained only as you approach completion of your manuscript in preparation for defense and deposit.

If you have any questions or require assistance, please feel free to contact me.

We wish you success with your research and look forward to receiving your completed dissertation.

Sincerely,

Mary Elwood

Mary Elwood Assistant to the Dean Office of Graduate Studies

Enclosures

cc: Dean Nalini Jairath, School of Nursing Sr. Mary Elizabeth O'Brien, Major Professor, School of Nursing

\* The Doctoral Dissertation Handbook is now available online at our website: www.graduatestudies.cua.edu.



## THE CATHOLIC UNIVERSITY OF AMERICA

Office of Sponsored Programs and Research Services Washington, D.C. 20064 202-319-5218

February 6, 2009

T

Ms. Yupin Tanatwanit 2121 Columbia Pike, #411 Arlington, VA 22204

Dear Ms. Tanatwanit:

Your research project titled "Comfort as Experienced by Thai Older Patients with Advanced Diseases," was certified by the Committee for the Protection of Human Subjects (CPHS) as meeting the requirements of the Federal regulations governing protection of human subjects.

CPHS will maintain a copy of your submission on file. You are obligated to follow the research protocol and procedures for obtaining informed consent as you have specified. If you wish to initiate any changes in the research protocol or the informed consent procedure, you should submit this request to CPHS in writing.

Please use the stamped and dated consent forms that accompany the approval letter.

This approval expires on January 13, 2010. If the project continues beyond one year, please resubmit your materials for renewal in a timely fashion so that your research may continue uninterrupted.

Good luck with your research.

Sincerely,

hlph sh-

Ralph Albano Secretary Committee for the Protection of Human Subjects

cc: Sr. Mary Elizabeth O'Brien

### Request to Renew an Approved Protocol The Catholic University of America Institutional Review Board for the Protection of Human Subjects

Please complete this form and return it to the Office of Sponsored Research. Send the original and one copy.

Investigator(s)' Name: \_Ms \_Yupin Tanatwanit\_

Protocol Title: Comfort as Experienced by Thai Older Patients with Advanced Cancer

Original approval date: 2/10/09

THE FOLLOWING ITEMS ARE REQUIRED FOR APPROVAL (If the research covered by this renewal is limited to data analysis, please answer questions 1 and 4 only.)

- 1. Number of subjects accrued: 11 Subjects\_\_\_\_
- 2. Additional anticipated number of subjects for period covered by this renewal: \_--
- 3. Please attach the following:
- 4. A copy of the current consent form(s)
- 5. A summary of progress to date, including findings.
- 6. For research with more than minimal risk or research that provides and evaluates behavioral or psychological interventions, a summary of recent literature related to the research topic. (Federal policy requires that investigators inform subjects of important new information that might affect their willingness to participate in the research. This information may be findings of this research or of that carried out by others.)
- 7. A description of any adverse events or unanticipated problems involving risks to subjects and proposed solutions, any withdrawal of subjects from the research, or complaints about the research. Adverse events include required reporting of suspected child abuse to authorities.

**INVESTIGATOR'S CERTIFICATION** 

Please check one and supply the appropriate information:

 $[\sqrt{1}]$  I (We) hereby certify that the research will be conducted in accordance with the currently approved protocol, including approved amendments.

Signature of Principal Investigator and Faculty Advisor (if applicable)

Date: 41/10 .

[] Changes have been made to the protocol. Attached are 1) a memo describing the changes, and 2) a copy of the most recently approved protocol with the changes in **bold-faced** type.

Signature of Principal Investigator and Faculty Advisor (if applicable)

Date:

Approved

hlip

Date: 2/20/10

IRB Chair or Expedited Reviewer or Human Protections Administrator (Circle One)



Faculty of Medicine Chiang Mai University Chiang Mai 50200 THAILAND Tel: 66-53-946144 Fax: 66-53-217144

April 3, 2009

Office of the Dean of Graduate Studies 116 McMahon Hall Washington, DC 20064, USA

Dear Dean of the Office of Graduate Studies,

Regarding to the request of Sr.Mary Elizabeth O' Brien, PhD, RN, FAAN, the advisor of Ms.Yupin Tanawanit, a candidate in the School of Nursing, for approval of The Research Ethics Committee of the Faculty of Medicine, Chiang Mai University (REC FOM-CMU) for research project titled "Comfort as Experienced by Thai Older Patients with Advanced Cancer"

I am pleased to inform you that the research project was certified by the REC FOM-CMU on April 3, 2009 and Ms.Yupin is authorized to begin data collection immediately. The length of time of the research project will be as specified in the certificate issued by the REC.

Please note that, If Ms.Yupin wish to initiate any changes in the research protocol or the consent documents; she should submit the request to the REC FOM-CMU in writing prior implementing any changes.

Sincerely,

O. Wantachit

(Associate Professor Niwes Nantachit , M.D.) Dean of the Faculty of Medicine



No. 104/2009

Name of Ethics Committee : Research Ethics Committee 3,

Faculty of Medicine, Chiang Mai University

Address of Ethics Committee : 110 Intavaroros Rd., Amphoe Muang, Chiang Mai, Thailand 50200

Principal Investigator : Yupin Tanatwanit

The Catholic University of America School of Nursing

**Protocol title:** Comfort as Experienced by Thai Older Patients with Advanced Cancer **Study code :** 09MAR191013

Sponsor : -

| Documents filed                                       | Document reference             |
|---|--------------------------------|
| Research protocol                                     | - Version 3 date 18 March 2009 |
| Informed consent documents /Patient information sheet | - Version date 3 April 2009    |
| Questionnaire   | - Version 3 date 18 March 2009 |
| Case Report Form                                      | - Version 3 date 18 March 2009 |
| Principal Investigator Curriculum vitae               | - Version date 18 March 2009   |

Opinion of the Ethics Committee/Institutional Review Board : PLS. CHECK ONE

✓ Approval

Conditional approval (Specify on space below)

.....

**DECISION :** By expedited review process

Date of Approval : April 3 , 2009 Expiration Date: July 2 , 2010

This Ethics Committee is organized and operates according to GCPs and relevant international ethical guidelines, the applicable laws and regulations.

Signed : ? Midagrangt

(Emeritus Professor Panja Kulapongs, M.D.)

Chairperson, Faculty of Medicine

signed: N. Vantachul

(Associate Professor Niwes Nantachit, M.D.)

Dean, Faculty of Medicine



เอกสารเลขที่ 104/2552

## เอกสารรับรองโครงการวิจัยในมนุษย์

ชื่อคณะกรรมการจริยธรรมการวิจัย : คณะกรรมการจริยธรรมการวิจัย ชุดที่ 3 คณะแพทยศาสตร์ มหาวิทยาลัยเซียงใหม่

ที่อยู่ : 110 ถนนอินทวโรรส ตำบลศรีภูมิ อำเภอเมือง จังหวัดเซียงใหม่ 50200

ชื่อหัวหน้าโครงการวิจัย : นางยุพิน ถนัดวณิชย์

สังกัด : The Catholic University of America School of Nursing

ชื่อเรื่องโครงการวิจัย : ความสุขสบายที่ท่านได้รับจากการรักษาพยาบาลในฐานะที่ท่านเป็นผู้ป่วย

สูงอายุชาวไทยที่โรคมีการดำเนินก้าวหน้าไปอย่างต่อเนื่อง

Study code: 09MAR191013

ผู้ให้ทุนวิจัย : -

| เอกสารที่รับรอง                               | ฉบับที่รับรอง                     |
|---|-----------------------------------|
| โครงการวิจัย                                  | - ฉบับที่ 3 วันที่ 18 มีนาคม 2552 |
| หนังสือแสดงความยินยอม / ข้อมูลสำหรับอาสาสมัคร | - ฉบับที่ 3 เมษายน 2552           |
| แบบสอบถาม                                     | - ฉบับที่ 3 วันที่ 18 มีนาคม 2552 |
| แบบบันทึกข้อมูล                               | - ฉบับที่ 3 วันที่ 18 มีนาคม 2552 |
| อัดตประวัติส่วนตัวหัวหน้าโครงการ              | - ฉบับวันที่ 18 มีนาคม 2552       |

กระบวนการพิจารณาโครงการวิจัย : เร่งพิเศษ (Expedited Review)

ผลการพิจารณา: คณะกรรมการจริยธรรมการวิจัย ได้พิจารณาแล้ว มีมติ

- [√] เห็นชอบให้ดำเนินการวิจัยในขอบเขตที่เสนอได้
- [] เห็นชอบให้ดำเนินการวิจัยได้ภายใต้เงื่อนไขข้างท้าย

อนุมัติ ณ วันที่ 3 เดือน เมษายน พ.ศ. 2552 มีผลถึงวันที่ 2 เดือน กรกฎาคม พ.ศ. 2553

คณะกรรมการฯ ชุดนี้จัดตั้งและดำเนินการตาม GCPs และแนวทางจริยธรรมสากล กฎหมายและ ข้อบังคับที่เกี่ยวข้อง

(ศาสตราจารย์เกียรติคุณ นายแพทย์ปัญจะ กุลพงษ์) ประธานคณะกรรมการจริยธรรมการวิจัย

VB ลงชื่อ : 

(รองศาสตราจ<del>ารย์ นา</del>ยแพทย์นิเวศน์ นันทจิต) คณบดีคณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่

ห้อง 442, MP Place Apartment, 20 ชอขจำปี ค. สุเทพ อ. เมือง จ. เชียงใหม่ 50200 เบอร์โทรศัพท์ มือถือ...085-7069955.....

วันที่ 7 เมษายน พ.ศ. 2552 งานอุงการ ฝ่ายการพยาชาตั รับที่ 475 เรื่อง ขอความอนุเคราะห์ในการเก็บข้อมูลเพื่อการศึกษาวิจัย เรียน ผู้อำนวยการ โรงพยาบาลมหาราชนครเชียงใหม่ คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่

ดิฉัน นาง ยุพิน ถนัดวณิชย์ ดำแหน่งผู้ช่วยสาสตราจารย์ ระดับ 8 คณะพยาบาลสาสตร์ มหาวิทยาลัย บูรพา ซึ่งลาศึกษาค่อในระดับปริญญาอก สาขาพยาบาลสาสตร์ ณ. School of Nursing, The Catholic University of America ประเทศสหรัฐอเมริกา ขณะนี้กำลังศึกษาอยู่ในขั้นตอนของการทำ Dissertation ในหัวข้อ "Comfort as Experienced by Thai Older Patients with Advanced Cancer" โดยมี วัดฉุประสงค์เพื่อศึกษาแบบเงาะลึกเกี่ยวกับ ความสุขสบายของผู้ป่วยสูงอายุชาวไทยที่ได้รับการวินิจฉัยโรคมะเร็ง ในระยะลุกลาม ขณะที่รับการรักษาพยาบาลในโรงพยาบาลระดับมหาวิทยาลัย ในประเทศไทย (เอกสารฉบับที่ 3) เพื่อนำผลการศึกษามาพัฒนาคุณภาพการบริการสุขภาพโดยเฉพาะการบริการกรดูแลแบบประกับประกองภาวะ สุขภาพที่มุ่งเน้นการดูแลความสุขสบายของผู้ป่วยเป็นสำคัญ ตามกรอบทฤษฎีความสุขสบาย (Comfort Theory) ของ Kolcaba (เอกสารฉบับที่ 4) (ซึ่งการดูแลความสุขสบายเป็นแนวคิดที่ได้รับการยอมรับจากนานาประเทศให้ เป็นวัตฉุประสงค์หลักของการดูแลแบบประกับประกองกาวะสุขภาพ)

ในการนี้โรงพยาบาลมหาราชนครเซียงใหม่ คณะแพทยศาสตร์ มหาวิทยาลัยเซียงใหม่ ซึ่งได้ให้ ความสำคัญและริเริ่มการบริการแบบประคับประคองภาวะสุขภาพแก่ผู้ป่วย โดยเฉพาะผู้ป่วยในภาวะสุดท้ายของ ชีวิต จึงถือได้ว่าเป็นหน่วยงานที่มีศักยภาพอย่างสูงที่สามารริเริ่มให้บริการคังกล่าว อีกทั้งยังเป็นแหล่งข้อมูล ทางด้านวิชาการที่สำคัญอย่างยิ่งต่อการศึกษาวิจัย ดั้งนั้นเพื่อให้การศึกษาวิจัยครั้งนี้บรรจุตามวัตอุประสงค์ อันจะ เป็นประโยชน์ต่อการพัฒนาคุณภาพการบริการสุขภาพดังกล่าวข้างต้นต่อไปในประเทศไทย ดิฉันในนามผู้วิจัยจึง ประสงค์ที่จะคำเนินการศึกษา และเก็บข้อมูล ในโรงพยาบาลมหาราชนครเซียงใหม่ คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่ โดยระยะเวลาขึ้นกับจำนวนกลุ่มตัวอย่างที่ต้องการทั้งสิ้น 100 ราย ซึ่งถูกพิจารณาและ กำหนดตามระเบียบการวิจัย รายละเอียดตามโครงร่างการศึกษาวิจัย (เอกสารฉบับที่ 3) ทั้งนี้ผู้วิจัยจะเริ่มขั้นตอน การเก็บข้อมูลตาม Appendix F (เอกสารฉบับที่ 3) ทันทีที่ได้รับอนุญาตให้เข้าแหล่งข้อมูลเพื่อดำเนินการเก็บ ข้อมูลภายในหอผู้ป่วยที่ให้บริการการรักษาพยาบาลแก่ผู้ป่วยโรคมะเร็ง (ได้แก่ หอผู้ป่วยในงานการพยาบาล ยายุรศาสตร์ ศัลยศาสตร์ โอร์โธปิดิกส์ สูติ-บรีเวช โสตฯ (หู-คอ-จมูก) และทั่วไป โดยผู้บิสัยให้เรียนเซิญ นางอากรณ์ ขัยรัต (หัวหน้าหน่วยประกันคุณภาพการพยาบาล ฝ่ายการพยาบาล โรงพยาบาลมหาราช นครเชียงใหม่) โดยผ่านทางฝ่ายการพยาบาล ให้เป็นผู้ประสานงานตลอดระยะเวลาที่คำเนินการเก็บข้อมล

บัตนี้โครงการศึกษาวิจัยนี้ได้รับการพิจารณาและผ่านความเห็นชอบจาก Institutional Review Boards (IRBs) of the Vice Provost and the Dean of Graduate Studies (VP/DGS), the Committee for the Projection of Human Research Subjects, The Catholic University of America (18, 10 กุมภาพันธ์ 2552) และจาก Research Ethics Committee of the Faculty of Medicine, Chiang Mai University (7 เมษายน 2552) ซึ่งเป็นหน่วยงหนุของท่านเป็นที่เรียบร้อยแล้ว และพร้อมที่จะ ดำเนินการเก็บข้อมูลตามขั้นตอน ทันทีภายหลังจากได้รับการอนูเคราะห์และอนุญาตจากท่าน

ดังนั้นจึงเรียนมาเพื่อขอความอนุเคราะห์และขออนุญาตดำเนินการเก็บข้อมูล ทั้งนี้ได้แนบเอกสาร โทรงการศึกษาวิจัย และเอกสารอื่นๆ ที่เกี่ยวข้อง ดังนี้

- งคหมายขอความอนุเคราะห์และขออนุญาตคำเนินการเก็บข้อมูล
  - 1.1 จดหมายจากผู้วิจัย
  - 1.2 จดหมายจากอาจารย์ที่ปรีกษาของผู้วิจัย
- จดหมายรับรองจาก

2.1 The Institutional Review Boards (IRBs) of the Vice Provost and the Dean of Graduate Studies (VP/DGS), The Catholic University of America

2.2 The Committee for the Protection of Human Research Subjects, The Catholic University of America

2.3 The Research Ethics Committee of the Faculty of Medicine, Chiang Mai University

โครงการศึกษาวิจัย (เอกสารฉบับที่ 3)

4. กรอบแนวคิดการศึกษาวิจัย--ทฤษฎีความสุขสบาย (Comfort Theory) (เอกสารฉบับที่ 4)

 5. ข้อมูลสำหรับผู้เข้าร่วมการศึกษาวิจัย และหนังสือแสดงความยินขอมเข้าร่วมการศึกษาวิจัย (เอกสาร ฉบับที่ 5) ซึ่งได้รับการพิจารณารับรองจากคณะกรรมการในข้อ 2 ได้จัดแนบมากับเอกสารในข้อ 2) ฉบับภาบาไทย (ได้รับการรับรองและประทับตราจากคณะกรรมการในข้อ 2.2)

5.1 การศึกษ เวิจัยเชิงปริมาณ (ส่วนที่ 1) (ภาคผนวก K)

- 5.2 การศึกษาวิจัยเชิงคุณภาพ (ส่วนที่ 2) (ภาคผนวก L)
- 6. Grand Chart (เอกสารฉบับที่ 6)

7. อื่นๆ

7.1 จดหมายอนุญาตให้ใช้เครื่องมือจาก Dr. Downing, Micheal (สำหรับ PPS) และ Dr. Kolcaba, Kathy

7.2 จดหมายรับรองการตรวจสอบหนังสือข้อมูลและหนังสือแสดงความยินยอมเข้าร่วมการศึกษาวิจัย จาก Dr. Wanant, Wanida

7.3 The "Certificate of Completion" รับรองผู้วิจัยใด้ผ่านการทดสอบ The "Protecting Human Research Participants" จาก The National Institutes of Health (NIH) 7.4 จดหมายจากคณบดีคณะแพทยศาสตร์รับรองจะอนุเคราะห์ให้เก็บข้อมูล ในกรณีที่โครงร่างการ ศึกษาวิจัยได้รับการรับรองจากคณะกรรมการทางด้านจริยธรรมการวิจัย

7.5 จดหมายจาก ผู้ช่วยศาสตราจารย์ นพ. ท้องสิน ตระกูลทิวากร ในฐานะที่ปรึกษางานวิจัย

้จึงเรียนมาเพื่อโปรคพิจารณา จักขอบพระคุณอย่างสูง

ด้วยความนับถืออย่างสูง - Sursing (นางขพิน ถนัควณิชย์)

(นารขุพน ถนัควณชย) นักวิจัย และนักศึกษาพยาบาลปริญญาเอก School of Nursing, The Catholic University of America

เอียน ทั่งหนังงางกรังรับสายกรรม กรรม กระ โปรงพิจารณะเพื่อจะได้นำเสนอกณาสัตอไป

ורחשליה בשצעתי ההערוחטילי カカルのうや

16 100 52

เรียน คณบดี ผ่าน ผอ. และ รองฯ บุญเฉลา OND 19,4 Munit (ดร. ลัดดาวัลย์ สิงท์ค่าฟ) รองทั่งหม่ายไวยการพบาบาล 9 1 1292

CINC'S2

# **RE:** News

From: Kathy Kolcaba (kathykolcaba@yahoo.com) Sent: Tuesday, January 22, 2008 2:36:55 AM To: yupin tanatwanit (ytanat@hotmail.com)

You can use all of my instruments without permission, Yupin, since they are on my web site and thus, in te "public domain." Good luck, and I'll wirte you when I get the gift you sent.

Dr. K

--- yupin tanatwanit <ytanat@hotmail.com> wrote:

> > Dear Dr. Kolcaba > Thank you so much for your powerpoint. It will > > be useful for me to better understand your theory > and to apply it in the right way in my dissertation > and, later, in practice. > For my dissertation, do you permit me to use > your tool? What will I need to do for the process of > the permission? > Again, thank you. > > > Yupin > > > > > Date: Mon, 21 Jan 2008 09:18:11 -0800> From: > kathykolcaba@yahoo.com> Subject: Re: News> To: > ytanat@hotmail.com> >

And I think Comfort Theory is > just the right tool to> guide palliative care - in > the US or Thailand. I am> attaching a presentation I> did for Summa in Akron,> when they developed their > palliative care unit.> Thanks for writing Yupin.> > Dr. K> --- yupin tanatwanit <ytanat@hotmail.com>

> wrote:> >> Dear Dr. Kolcaba> >> This message > would like to let you know the> > updated news which > I have just received from one> > nursing supervisor. > It is that the palliative care> > and end-of-life > care in the hospital to which I> > always refer are > going well--excellent soon. It has> > concretely, > systematical collaboration between> > nurses and > doctors under its policy. > > > This hospital not > only becomes the good> > model for other hospitals > in the north but also for> > hospitals in other > region such as in the north-east> > region and > central region. In addition, a few nurses> > and

> supervisors become known speakers to share ideas> >> how to set up these services. Hence, the PC is > added> > in medical curriculum. The PC becomes one > service> > system in this hospital. >> >> I hope > it will be useful for Thai patients.>> I am really > so glad.>>> Yupin> >> >>>>

Windows Live Hotmail Print Message

## RE: Permission for the figures

From: **Kathy Kolcaba** (kathykolcaba@yahoo.com) Sent: Sunday, September 12, 2010 8:43:56 PM To: yupin tanatwanit (ytanat@hotmail.com)

For your dissertation you don't need any copyrights from Springer. In a Journal you do need permission, and your Journal editor will guide you. Kathy

Dr. Kathy Kolcaba Associate Professor (Emeritus) The University of Akron Owner/Consultant: THE COMFORT LINE www.TheComfortLine.com 165 South Franklin St. Chagrin Falls, OH 44022 (H) 440-247-3319 (C) 440-655-2098 (FAX) 440-247-1104

--- On Fri, 9/10/10, yupin tanatwanit <ytanat@hotmail.com> wrote:

From: yupin tanatwanit <ytanat@hotmail.com> Subject: RE: Permission for the figures To: "Kathy Kolcaba" <kathykolcaba@yahoo.com> Date: Friday, September 10, 2010, 8:00 PM

Dear Dr. Kolcaba,

Do you mean the publication in a Journal or you mean for the dissertation?

Thank you so much.

Yupin

Date: Fri, 10 Sep 2010 16:37:19 -0700 From: kathykolcaba@yahoo.com Subject: Re: Permission for the figures To: ytanat@hotmail.com

Yupin, I am happy you are progressing with your dissertation. Any figures you need for publication, you need to contact Springer for permission. Until you publish your findings, I don't think this is necessary. You have my permission to use anything you want to! Kathy

Dr. Kathy Kolcaba Associate Professor (Emeritus) The University of Akron Owner/Consultant: THE COMFORT LINE www.TheComfortLine.com 165 South Franklin St. Chagrin Falls, OH 44022

# FW: From PhD. student of the Catholic University of America

From: Tanatwanit, Yupin 57TANATWANIT (57TANATWANIT@cua.edu) ासू, Sent:

Friday, September 26, 2008 5:06:40 PM To: ytanat@hotmail.com

From: Downing, Michael (Dr) [mailto:Michael.Downing@viha.ca] Sent: a. 26/9/2551 11:59 To: Francis Lau; Tanatwanit, Yupin 57TANATWANIT Subject: RE: From PhD. student of the Catholic University of America

#### Hello Yupin

1. It is nice to meet you and I am glad you are interested in palliative care. What city is the Catholic University of America located?

2. You are most welcome to use PPS and this email is official approval for you. I am not in the office today but can send you the Microsoft Word copy of PPSv2 and the instructions for it if you like.

3. However, we are also currently working with some staff at Maharaj Nakorn Chiang Mai hospital. Ladarat Sapinun is the nurse coordinator along with Dr Hunsa, Dr Bussayamas, Dr Laddawan and others. Are you connected with them as well?

4. We have translated PPSv2 into Thai and have called it PPS Suandok. There is an ethics review underway to do a validity and reliability study. They are developing a palliative care program in the hosptial using several tools: PPS, POS (Palliative Outcome Score) and ESAS (Edmonton Symptom Asssessment Scale).
5. I can put you in contact with Ladarat if you would like as she is the main person working in the nursing division in coordinating this.
Please write back to let me know more about your plans and if we can connect

Please write back to let me know more about your plans and if we can connect your work with some of the above. Best regards, Michael

From: Francis Lau [mailto:fylau@uvic.ca] Sent: Fri 9/26/2008 8:09 AM To: Tanatwanit, Yupin 57TANATWANIT Cc: Downing, Michael (Dr) Subject: RE: From PhD. student of the Catholic University of America

Hello Yupin, thanks for your email. I have forwarded your email here to Dr. Michael Downing who is the creator of PPS at Victoria Hospice. I will leave it to him to reply to you about the logistics of using the PPS tool that he has created and refined over the years.

Thanks -francis

Francis Lau PhD, Associate Professor School of Health Information Science, University of Victoria P.O. Box 3050 STN CSC, Victoria, BC, Canada V8W3P5



Faculty of Medicine Chiang Mai University Chiang Mai 50200 THAILAND Tel: 66-53-946144 Fax: 66-53-217144

August 20, 2008

Patricia C. McMullen, PhD, JD, CNS, CRNP Associate Provost for Academic Administration The Catholic University of America 620 Michigan Avenue, NE Washington, DC 20064 USA

Dear Dr. McMullen

I, Dr. Hongsin Trakultivakorn, Assistant Professor, am the Associate Dean and a member of the Faculty of Medicine at Chiang Mai University in Thailand. I am interested in palliative care and have developed this care for Thai dying patients in the hospital of the Faculty of Medicine, Chiang Mai University. Based on current research policies at Chiang Mai University, a researcher who wants to study in this organization needs to have a consultant who is a faculty member.

In this case, I am writing to verify that I am pleased to serve as a consultant on Mrs. Yupin Tanatwanit's dissertation research study, entitled "End-of-Life Comfort as Experienced by Thai Older Advanced Disease Patients". I do so hope that my support will help her study proceed as expected. Hopefully, the findings of this study will provide useful knowledge that will improve the quality of care given to dying patients in the Thai healthcare system.

Please feel free to contact me if you have any questions or need more information.

Respectfully,

Hoy & Tuskelling

Dr. Hongsin Trakultivakorn Assistant Professor Faculty of Medicine, Chiang Mai University Email: hongsin@mail.med.cmu.ac.th Telephone: +66-53-946144