

HEALTHCARE PROVIDERS' KNOWLEDGE AND PERCEPTION IN THE PRO-
VISION OF PALLIATIVE CARE IN PATIENTS WITH NON-CANCER LIFE-
LIMITING CHRONIC DISEASE IN A
PRIVATE HOSPITAL IN BANGKOK, THAILAND

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จุฬาลงกรณ์มหาวิทยาลัย

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ความรู้ และการรับรู้ของบุคลากรทางการแพทย์เกี่ยวกับการดูแลแบบประคับประคองในผู้ป่วยโรค
เรื้อรังที่ไม่ใช่มะเร็งและมีระยะเวลาของการมีชีวิตจำกัดในโรงพยาบาลเอกชนในกรุงเทพมหานคร
ประเทศไทย



วิทยานิพนธ์นี้เป็นส่วนหนึ่งของการศึกษาตามหลักสูตรปริญญาสาขารณสุขศาสตรมหาบัณฑิต
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น้ำผึ้ง ปรินญาคุณ : ความรู้ และการรับรู้ของบุคลากรทางการแพทย์เกี่ยวกับการดูแลแบบประคับประคองในผู้ป่วยโรคเรื้อรังที่ไม่ใช่มะเร็งและมีระยะเวลาของการมีชีวิตจำกัดในโรงพยาบาลเอกชนในกรุงเทพมหานคร ประเทศไทย (HEALTHCARE PROVIDERS' KNOWLEDGE AND PERCEPTION IN THE PROVISION OF PALLIATIVE CARE IN PATIENTS WITH NON-CANCER LIFE-LIMITING CHRONIC DISEASE IN A PRIVATE HOSPITAL IN BANGKOK, THAILAND) อ.ที่ปริกษาวิทยานิพนธ์หลัก: รศ. ดร.รัตนา สำโรงทอง, อ.ที่ปริกษาวิทยานิพนธ์ร่วม: ศ. นพ. จิตร สิทธิอมร, 73 หน้า.

แม้ว่าการดูแลแบบประคับประคองจะช่วยเพิ่มประโยชน์ต่อระบบการดูแลผู้ป่วย แต่การจัดการการดูแลแบบประคับประคองที่ดียังไม่ได้รับการปฏิบัติต่อผู้ป่วยทุกกลุ่มโรค การศึกษาวิจัยนี้มีจุดประสงค์เพื่อศึกษาความรู้ การรับรู้ และการให้การดูแลแบบประคับประคองของบุคลากรทางการแพทย์ในผู้ป่วยที่มีโรคเรื้อรังที่ไม่ใช่มะเร็ง และมีภาวะความมีชีวิตอยู่อย่างจำกัด และศึกษาปัจจัยส่วนบุคคลที่มีผลต่อความรู้และการให้การดูแลแบบประคับประคอง การศึกษาวิจัยนี้เป็นการวิจัยเชิงพรรณนาแบบตัดขวางเพื่อสำรวจความรู้ การรับรู้ และการให้การดูแลแบบประคับประคองในผู้ป่วยที่มีโรคเรื้อรังที่ไม่ใช่มะเร็ง และมีภาวะความมีชีวิตอยู่อย่างจำกัด โดยทำการศึกษานักวิชาการทางการแพทย์ในโรงพยาบาลเอกชนแห่งหนึ่ง ได้แก่ แพทย์ พยาบาล เภสัชกร และนักกายภาพบำบัด จำนวน 227 คน ผลการศึกษายืนยันพบว่า จากแบบสอบถามความรู้เกี่ยวกับทฤษฎีการดูแลแบบประคับประคองและการจัดการอาการรบกวน จำนวน 23 ข้อ ผู้เข้าร่วมวิจัยมีคะแนนอยู่ในระดับดี ($\bar{x} = 18.97, S.D. = 2.11$) โดยได้คะแนนความรู้ต่ำสุดคือ 8 คะแนน สูงสุดคือ 23 คะแนน ผู้เข้าร่วมวิจัยเกือบส่วนใหญ่ (49.1%) ตอบคำถามคิดเกี่ยวกับการดูแลแบบประคับประคองในผู้ป่วยโรคหัวใจล้มเหลว ปัจจัยส่วนบุคคลของบุคลากรทางการแพทย์ที่มีผลต่อความรู้ อย่างมีนัยสำคัญทางสถิติคือ อายุ ($p = 0.04$) และบทบาทหน้าที่ ($p = 0.001$) ($p < 0.05$) ด้านการรับรู้ของผู้เข้าร่วมวิจัย ประเด็นที่ผู้เข้าร่วมวิจัยรับรู้ว่ามีผลต่อการดูแลแบบประคับประคองมากที่สุดคือ ประเด็นด้านจริยธรรมและกฎหมาย ($\bar{x} = 4.18, S.D. = 0.648$) และองค์กรและนโยบาย ($\bar{x} = 4.17, S.D. = 0.584$) ผู้เข้าร่วมวิจัยเห็นด้วยมากที่สุดว่าการดูแลแบบประคับประคองต้องได้รับความร่วมมือจากทีมสหสาขาวิชาชีพ ($\bar{x} = 4.35, S.D. = 0.622$) ด้านการรับรู้เกี่ยวกับการตัดสินใจเพื่อการดูแล ผู้เข้าร่วมวิจัยเห็นด้วยมากที่สุดว่าการดูแลแบบประคับประคองจะต้องกระทำร่วมกันระหว่างผู้ป่วยและครอบครัวและบุคลากรทางการแพทย์ ($\bar{x} = 4.37, S.D. = 0.583$) ด้านการให้การดูแลแบบประคับประคองพฤติกรรมที่บุคลากรทางการแพทย์ปฏิบัติมากที่สุดคือ ให้การดูแลผู้ป่วยอย่างอ่อนโยน ($\bar{x} = 4.48, S.D. = 0.693$) แต่ได้ให้การสนทนากับผู้ป่วยเรื่องจุดมุ่งหมายในชีวิตและชีวิตหลังความตายในระดับน้อย ($\bar{x} = 2.80, S.D. = 1.350$) ปัจจัยส่วนบุคคลของบุคลากรที่มีผลต่อการให้การดูแลอย่างมีนัยสำคัญทางสถิติ คือ บทบาทหน้าที่ ($p = 0.029$) และการศึกษาด้านการดูแลแบบประคับประคอง ($p = 0.002$) การศึกษาวิจัยนี้สามารถสรุปได้ว่า ความรู้ การร่วมมือของทีมสหสาขาวิชาชีพ และการฝึกฝนทักษะการให้การดูแลแบบประคับประคอง มีความสำคัญต่อบุคลากรทางการแพทย์ เพื่อให้สามารถค้นหาความต้องการและวางแผนเป้าหมายการดูแลแก่ผู้ป่วยและครอบครัวได้อย่างมีคุณภาพที่สุด

สาขาวิชา สาธารณสุขศาสตร์

ปีการศึกษา 2559

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NUMPUENG PRACHYAKOON: HEALTHCARE PROVIDERS' KNOWLEDGE AND PERCEPTION IN THE PROVISION OF PALLIATIVE CARE IN PATIENTS WITH NON-CANCER LIFE-LIMITING CHRONIC DISEASE IN A PRIVATE HOSPITAL IN BANGKOK, THAILAND. ADVISOR: ASSOC. PROF. RATANA SOMRONGTHONG, Ph.D., CO-ADVISOR: PROF. CHITR SITHI-AMORN, Ph.D., 73 pp.

Although palliative care could gain benefits of healthcare system, the good management of palliative care is not broadly done to all kinds of illnesses. Patients with chronic illness have impaired quality of life and emotional well-being but have less obtainment of palliative care. This study aimed to assess the knowledge, perception and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting diseases and to explore the socio demographic factors associate to knowledge and provision of palliative care. This cross-sectional descriptive study was conducted in one selected private hospital. 227 healthcare providers including doctors, nurses, pharmacists and physical therapists were recruited, self-administration questionnaires were used for data collection. For the results of palliative care knowledge, the questionnaire contains 23 items about the principle of palliative care and symptom management. The participants had good knowledge ($\bar{x} = 18.97$, S.D. = 2.11, Min = 8, Max = 23). Almost half of the participants (49.1%) had answered incorrectly about palliative care in patients with congestive heart. The factors of healthcare providers' demography that associate to the level of palliative care knowledge statistical significantly were age ($p = 0.04$) and position of work ($p = 0.001$) ($p < 0.05$). In their perception, the aspects that had the most effect to palliative care were ethic and legal issues ($\bar{x} = 4.18$, S.D. = 0.648) and organization and policy ($\bar{x} = 4.17$, S.D. = 0.584). They also mainly agreed that palliative care should be provided by multidisciplinary care team ($\bar{x} = 4.35$, S.D. = 0.622). For the perception of decision making, the participants mainly agreed that palliative care should have jointly established between patients and family and healthcare team ($\bar{x} = 4.37$, S.D. = 0.583). For the provision of palliative care, the behavior that healthcare providers mainly performed is providing care gently ($\bar{x} = 4.48$, S.D. = 0.693) but had less conversation about the aims of life and the life after death with patient ($\bar{x} = 2.80$, S.D. = 1.350). For the factors of healthcare providers' demography that associate the level of provision of palliative care statistical significantly were position of work ($p = 0.029$) and palliative care education ($p = 0.002$) ($p < 0.05$). It could be concluded that palliative care knowledge, cooperation of multidisciplinary care team and training palliative care skill are important for healthcare providers to cope with the patients and families. It is to explore needs and plan for goal of care and provide the best quality of palliative care for them.

Field of Study: Public Health

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Student's Signature

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หนังสือรับรองจริยธรรมการวิจัย

โครงการวิจัยเรื่อง	HEALTHCARE PROVIDERS' KNOWLEDGE AND PERCEPTION IN THE PROVISION OF PALLIATIVE CARE IN PATIENTS WITH NON-CANCER LIFE-LIMITING CHRONIC DISEASE IN THE PRIVATE HOSPITAL IN BANGKOK
หัวหน้าโครงการวิจัย	นางสาวน้ำผึ้ง ปรัชญาคุณ
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โครงการวิจัยเรื่องนี้ได้รับความเห็นชอบจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ วิทยาลัยเซนต์หลุยส์ โดยได้ผ่านการพิจารณาการวิจัยในมนุษย์แบบเร่งรัด เรียบร้อยแล้ว

ให้ไว้ ณ วันที่ 28 ตุลาคม 2559

(ดร.ชูเกียรติ จากใจชน)

ปฏิบัติหน้าที่แทนประธานคณะกรรมการจริยธรรมการวิจัย
วิทยาลัยเซนต์หลุยส์

เมตตาภาวณอยู่ที่ใด พระเจ้าสถิตที่นั่น
Wherever compassion exists God exists

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Chapter 1

Introduction

1.1. Background and rationale

Palliative care aims to improve patients and their families' quality of life when facing with any life-threatening illnesses, providing cares to relieve pain and other distressing symptoms, including integration of psychological and spiritual aspects of care and regarding dying as a normal process.^[1] Palliative care is becoming one of the major public health issues. It is because of increasing of world population due to the development of technologies. The numbers of patients with non-communicative diseases are rising according to health determinants have changed. The predicted most common causes of death by 2020 are heart disease, cerebrovascular disease, chronic respiratory disease, respiratory infection disease and lung cancer.^[2] The pattern of disease has changed and the life expectancy of population has extended. People would live longer up to 65 years old and the world tends to be an aging society. Many of aging population burden with chronic illness, such as heart disease, stroke, diabetes, dementia etc.,. These illnesses cause people disability, suffer from pain or depression and lack quality of life. Large amount of cost spending for the treatments and caring may affect families and caregivers in financial and emotional problems. Moreover, public governments are burdened with increasingly elder population who live alone. Therefore it needs effective strategies to provide enough facilities or healthcare centers for them.

Several researches^[3-8] have defined the effectiveness of palliative care are associated with reduction in use of non-benefit ICU treatments and length of ICU stay, decreased the duration of mechanical ventilator, reduce family anxiety, distress and posttraumatic stress disorder after 3 months patient's death and/or conflict over the care goal. Although palliative care could gain benefits of healthcare system, the good management of palliative care is not broadly done to all kinds of illnesses. Many researches emphasized approaching palliative care on the patients with cancer who are predicted not more than 6 month-longed life despite cancer is not the first rank of dying in the most population. Patients with other chronic illnesses as congestive heart failure, chronic obstructive pulmonary disease, dementia or cerebrovascular disease^[9, 10] are also burdened with suffering from their symptoms that are incurable and have lost quality of life since limitation of activities that could lead to be psychological problems later. Palliative care should be applied for those patients from the early process of care but, generally, palliative care is frequently applied when the patients' prognosis are poor and impossible to treat, thus, these problems lead more difficulties for the clinicians to discuss with the patients and families about failure of treatments.

Patients with chronic illnesses are characterized by uncertainty of illness trajectories, uncertainty in progress and extended disease timelines and stresses.^[11] The Center for Disease Control stated that chronic diseases are the most common, costly and preventable of all health problems. They are also the leading causes of disability and death in the USA.^[12] Although palliative care has aims to relieve suffering from pain or symptoms and improve patient's quality of life, patients with chronic illness have significantly impaired quality of life and emotional well-being that more often provided in patients with cancer and they do not receive holistic care that is appropriate to their needs.^[13-15] Patients with chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) are suffered from symptoms burden which impair their activities in daily living in physical, emotional and social functioning equivalently to those who have malignant disease but less have offered specialist palliative care service.^[16-18] Many of patients with chronic illness die in institutional forms of care with little support provide in the community despite of preference of death at home. The reason that patients die in the hospital with unwillingness are unexpected deterioration of treatment or investigations, family cannot cope with home care and late presentation precluding transfer.^[19, 20]

The provision of palliative care should be integrated by interdisciplinary care team. The healthcare providers, for example physicians and nurses, have the major roles in providing quality palliative services for the patients. Physicians provide medical cares including symptoms management and continue appropriate application of disease-modifying therapy.^[21] Nurses often have closer relationship with patients and their families and can provide some sources of important information to help physician about decision-making in medical treatment.^[22] Several researches^[23-25] defined that the appropriate palliative care from the healthcare providers could improve caring outcomes both in the patients and the caregivers.

The provision of palliative care in patients with non-malignant diseases must be based on their needs which the physiological and psychological needs are different from those in patients with cancer. The physical symptoms burden are included pain, breathlessness, fatigue, nausea, constipation and limitation of activities which lead to psychological problems as depression and anxiety.^[26-33] The chronic and progressive nature of non-malignant and life-threatening illness may impact to patients' daily life and their self-perception and spiritual aspects. Although there is no evidence of treating depression can reduce morbidity and mortality in patients, the appropriate management of pharmacotherapy with selective serotonin re-uptake inhibitors as well as psychotherapy and spiritual contentment might help to relieving the symptoms.^[34]

The particular concerns in providing palliative care in patients with non-malignant, life-threatening disease are the longer course of disease and their less predictable in illness trajectory.^[35] The prognosis of heart failure is poor, 38% of patients are dead within 1 year of diagnosis and 60% are dead within 5 years, 50% of the patients have sudden death.^[36, 37] Patients with COPD have the five-year survival rate around 72-78% from diagnosis but falls to 24-30% with severe disease.^[38] The pattern of diseases are likely gradual decline, punctuated by episodes of deterioration and exacerbation, often triggered by infection as well as environment factors, and

eventually seemingly unexpected death.^[39, 40] Many physicians are unwilling to discuss with patients and family about advanced treatments including mechanical ventilation, intubation and palliative care strategies that sometimes lead to inappropriate and unwanted treatments.^[41] However, decision-making between physicians with patients and families may be complicated. Some patients feel uncomfortable to discuss about their mortality.^[42] and some have not received enough information about their prognosis and medical management. The opinions in preferred place of care and death are also different. Some patients would like to die at home and other patients are concerned that dying at home might cause too much stress upon their families. Some families' members deny the prospective of the beloved one dying there.^[43, 44] These issues would challenge physicians and care team to provide proper palliative care related to the needs of patients and families.

Although palliative care must be a public policy of primary healthcare system, it is difficult to approach early palliative care in every level of care. Some obstacles occur as barriers between healthcare providers with patients and families, For example, less communication about place to die or do not attempt to resuscitation orders for patients who have chronic disease with families in the early stage of illness may be avoided by clinicians who have lack of communication skill. When palliative care is needed, effective communication between the healthcare providers, the patients and the families is important to success goal of care but discussing about dying is not easy at all. Slort (2011)^[45] defined some obstacles in communication that could be difficult tasks for general practitioners to approach palliative care to their patients. Those factors include the difficulty of dealing other former doctors in delaying diagnosis and confront with strong demands from the relatives. These findings contrasted from patient views of general practitioners in palliative care. Patients concerned that healthcare providers do not explain many issues clearly enough, express them too much hopeless, being irritate and not being clear in patients opinion about euthanasia. Lenhurr (2012)^[46] defined some more about the difficulty of communication in palliative care, The location in general wards that surround with other patients are not appropriate to talk about dying. Moreover palliative care is a sensitive issue. It is difficult for clinicians, patients and families to talk about. To decrease difficulties of communication, Clayton et al ^[47] suggested that balancing of hope with honesty in communication with end-of-life patient is important for healthcare providers to practice this skill in palliative care.

Knowledge is one of the most important factors to success in the goal of palliative care as well. Palliative care education could improve the outcomes of caring for the patients in several kinds of chronic and terminal stage of illness.^[48, 49] Although many medical educational institutions contain palliative care as a subject for the medical students, many healthcare providers have inadequate palliative knowledge for providing care in terminal illness patients.^[50] Some researches^[51, 52] defined that healthcare providers have lack of knowledge and skill training are the barriers to provide palliative care. Some physicians has limited experiences in palliative care as well. The palliative care program should be improved and added in the continuing medical education program as a key of health care policies.

There are other sensitive obstacles for healthcare providers in palliative care. The ethical and legal dilemma in palliative care is controversy among healthcare providers, patients and families. Patient has the self- autonomy in the decision-making relating to his/her own health and medical treatment including the right of an individual to die in natural death without the administration of artificial life support procedures.^[53] Sometimes, it would lead patient and physician to the decision of euthanasia which is inhibited in many countries. Moreover, the patients are given many medical procedures as mechanical ventilation, defibrillation in the terminal stage of illness which are not helpful, hasten life and oppose to their desires. Healthcare providers should have knowledge to give appropriate care to relief suffering, understand the patients' preference and forgive conflict.^[54] The complementary of palliative care and medical ethics would give protection and gain satisfaction to the patients and families.

In Thailand, National Health Commission of Thailand declared the National Strategic plan on Health Promotion for Good Death 2013-2016^[55] to specify the strategies and the direction in provision of palliative care for Thai citizens. The goal of the strategy is to provide quality of life and good death for all Thai people with terminal stage of illness. The strategic plans are (a) to improve the education and attitude of end-of-life care and good death, and to promote of palliative care, (b) to develop, administrate, standardize and cover the provision of palliative care in healthcare system, (c) to develop the supplementary system for the management of palliative care. After the strategic plans are approved by Councils of Ministers, they would be available to apply in the healthcare system as in the funding management or the administration of care. However, to the achievement of goal of service plan, the plan should be announced both to all levels of the healthcare system and the citizens and establish the cooperation among other involved organizations.

The Thai Palliative Care Society and Medical Schools Palliative Care Network, (MS-PCARE) underneath the support of Thai Health Promotion Foundation and National Health Security Office explored the palliative care service and human resources from all public hospital in Thailand in 2012. There were 61% of all public hospital (537/882) and some private hospitals replied back the exploration questionnaire forms, it was found that 60% (321/536) of all replied public hospital had palliative care service in their institution with specialist in palliative care at least 147 healthcare providers. Most of them had short-course of general palliative care education but it was also found that almost 25% of these healthcare institutes have no specialist in palliative care.^[56] Although there are 93^[57] private hospitals in Bangkok, only 5 from 18 private healthcare institutes in this exploration announced the provision of palliative care in their services. This numbers of private hospitals are very few when compare with public hospitals despite the annual amounts of patients in private hospital are around 43 million patients per year.^[58] and according to Thailand National Hospital Accreditation Authority, the provision of palliative care and end of life care are quality indicator for hospital care,^[59] Thus, Healthcare providers in the private hospital are one of the main role in providing palliative care for these patients. If the palliative program is provided effectively in the private hospital, it could distribute quality of care to chronic illness population and decrease expenses of public hospitals in medical facilities and resources.

This study would like to describe the perception of palliative care in healthcare providers in private hospital to provide proper palliative care in patients with chronic-illness, life-limiting disease. The results of this study could use to improve palliative care program, apply for palliative care education and provide continuity of palliative care to the community

1.2. Research Questions

- What are the levels of healthcare providers' knowledge, perception and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease regarding to patients and families' needs in physical, psychological, social and spiritual aspects?
- What factors of healthcare providers' demographics, as gender, age, position of work, religion, working experiences, palliative care education and palliative care experiences, do influence to knowledge and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease?

1.3. Research objectives

- To access healthcare providers' knowledge, perception and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease regarding to patients and families' needs in physical, psychological, social and spiritual aspects.
- To identify the most influential factors of healthcare providers' demographics to knowledge and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease.

1.4. Research Hypothesis

- Although palliative care is an important public health issue and should be delivered to all kinds of illness patients, healthcare providers have low level of knowledge, perception and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease.
- Palliative care education is the most influential factor of healthcare providers' demographics that effect to their knowledge and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease.

1.5. Operational Definition

Palliative care

Refer to palliative care service, based on the definition of palliative care of World Health Organization (WHO, 2002), providing to the patients after being diagnosed as the non-cancer, life-limiting and chronic illness patients.

Healthcare providers

Include general medical doctors, registered nurse, practical nurses, nurse assistants, pharmacologists, physical therapists who work in selected private hospital, involve general wards and intensive care unit.

Non-cancer, life-limiting and chronic illness patients

Refer to the clinical conditions of patients that are diagnosed from the physicians and included in the trajectory 2 and 3 of illness criteria which are incurable and would decline and be predicted for poor progressive prognosis of disease. In this study, non-cancer, life-limiting and chronic illness patients are patients with heart disease (for example CHF, MI, CAD etc.), chronic pulmonary disease (e.g. COPD) and the deterioration of brain function disease (e.g. Dementia, Alzheimer's disease and CVA etc.).

Palliative care Knowledge

Refer to the basic knowledge of palliative care including philosophy, trajectories of illness and symptom management which are provided to the patients with non-cancer, life-limiting and chronic illness.

Perception

Refer to the healthcare providers' recognition of providing palliative care to the patients with non-cancer, life-limiting and chronic illness in term of their roles in healthcare team, the facilitators and obstacles that affect to the delivery of palliative care service including healthcare organization and policy, knowledge and training, communication, financial issues, ethic and legal issues, facilities and team and community.

Decision making for suggestion with patients and families

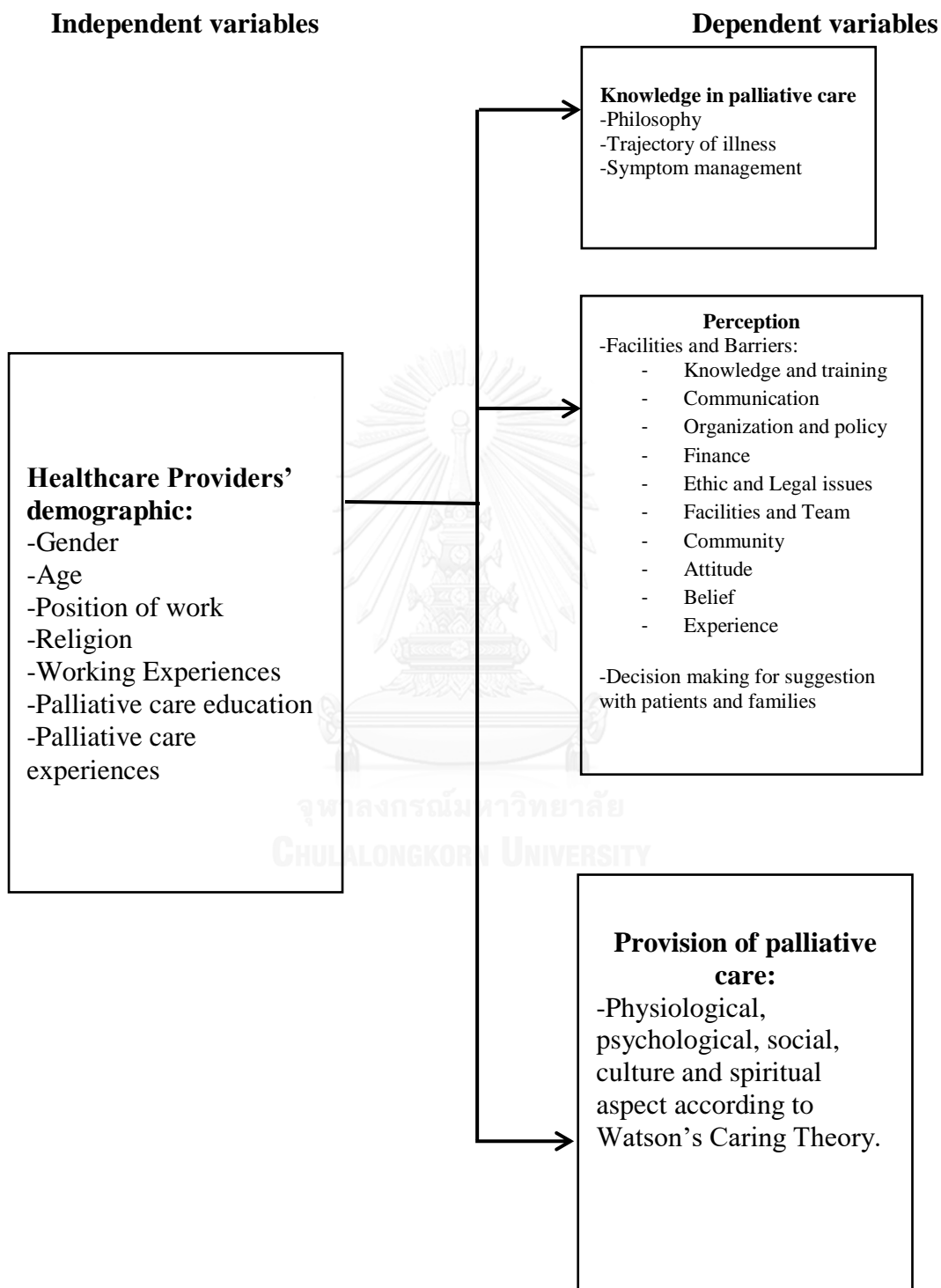
Refer to healthcare provider's perspective to provide suggestion in decision-making of medical care for patients with non-cancer, life-limiting and chronic disease and their families. It includes the essential ethical principles and the aspect of medical care choices regarding to patient and family's needs.

Provision of palliative care

Refer to WHO's definition of palliative care and the caring behaviors that healthcare providers provide to patients and families which based on the Watson's caring theory. The caring behaviors factors are included 1) Humanistic-altruistic system of value 2) Faith-hope 3) Sensitivity to self and others 4) Helping-trusting, Human care relationship 5) Expressing positive and negative feelings 6) Creative problem-solving caring process 7) Transpersonal teaching-learning 8) Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment 9) Human needs assistance 10) Existential-phenomenological-spiritual forces



1.6. Conceptual Framework



Chapter2

Review of related literatures

2.1. Definition of palliative care

Palliative care is defined by WHO^[1] as an approach to improve the quality of life in patients and their families who are confronting with life-threatening condition by prevention or relieving of suffering from pain and other physical, psychological and spiritual problems. It includes:

1. Providing relieving from pain or other symptoms.
2. Regarding dying as a normal process.
3. Intension not prolonged death.
4. Integration of psychological and spiritual aspects of patient care.
5. Providing supportive facilities to help patients to maintain quality of live as much as possible until death.
6. Encourage the families to cope with suffering from patient illness.
7. Providing team approach to define the needs of patients and families.
8. Should be applied in the early course of treatments and combined with other curative treatments.

Delivery palliative care for patients with non-cancer, life-limiting and chronic disease ^[60, 61]

Palliative care can be provided to all ranges of care settings and models of health structure, including hospital-based care and home-based care. It can be provided in specialists as well as general setting. Palliative care should be comprehensively delivered by multidisciplinary care teams, working together to define treatment goals and care plan with patient and family. However, palliative care for patients with non-cancer, life limiting and chronic disease is not simple such chronic illnesses are complex and uncertainty. Patients with non-cancer, life-limiting and chronic disease may have frequent times of illness exacerbation and it tends to deteriorate. The illness condition would decline and patient would have suffered for long period of illness or disability and diminished functioning. Palliative care should be delivered along the courses of treatment. Early of the course, patients may need either curative care or palliative care as treating symptoms, and in the late stage of illness, aggressive treatment may not necessary but patients mostly need palliative care for relieving symptoms and providing support.

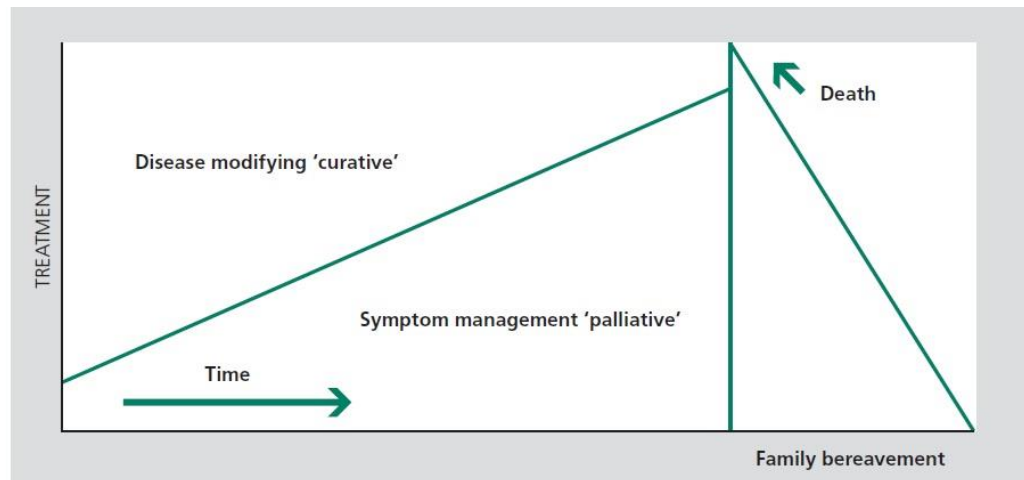


Figure 1 Trajectory model of palliative care

Source: Irish Hospice Foundation, 2008

2.2. Level of provision of palliative care ^[62]

2.2.1. Level one: palliative care approach

The principle of palliative approach, for example the supportive treatment, communication skill with patient and family or palliative care plan management etc., should be the core education and practices for all healthcare providers. The aims of palliative care approach are to promote physical and psychological well-being of patients with progressive or advanced disease without referral to palliative care specialist unit either in the hospital or community level. The palliative care approach should be integrated its principle knowledge and practice in all level of healthcare education.

2.2.2. Level two: general palliative care

Palliative care in this level is provided to patients with life-threatening condition or aggressive needs by expertise of healthcare professionals who have additional education or training experience in palliative care. The intermediate level of palliative care experts are available in the hospital or community setting but they are not full time staffs.

2.2.3. Level three: specialist palliative care

The specialist palliative care (SPC) service are limited to provide only palliative care in patients with more complication or intensive demanding care needs. The core speciality is provision of advanced palliative care which is required greater degree of training, staffs or other resources. The healthcare professionals are interdisciplinary team, under the direction of consultation physicians in palliative care

medicine. The SPC is available either in primary healthcare service and inpatient palliative care department or developing as the center of excellence which provides palliative care education and training program or researches of palliative care.

2.3. Illness Trajectories and palliative care ^[63]

Discussion about prognosis with the families about patients in life threatening condition is sometimes difficult because healthcare providers may not predict the certain life expectancy of their patients. The typical illness trajectories can aid them to plan the provision of care by providing a broad timeline of life and patterns of specific type of patient's prognosis in their probably needs toward death.

Typical illness trajectories have been described in 3 different types of progressive chronic illness, cancer, organ failure and frail elderly or dementia trajectory.

2.3.1. Trajectory 1: Short period of evidence decline, typical cancer

This trajectory is reasonable and predictable decline in physical health over the period of time that will be in a week, month or, in some patients, year. Patient's health condition deteriorate continuously in the few last month of life, usually occur with most weight loss, reduction of performance status and impair self-care ability. The palliative care program in this trajectory has aim to provide comprehensive service in relieving symptoms in the late week or month of life.

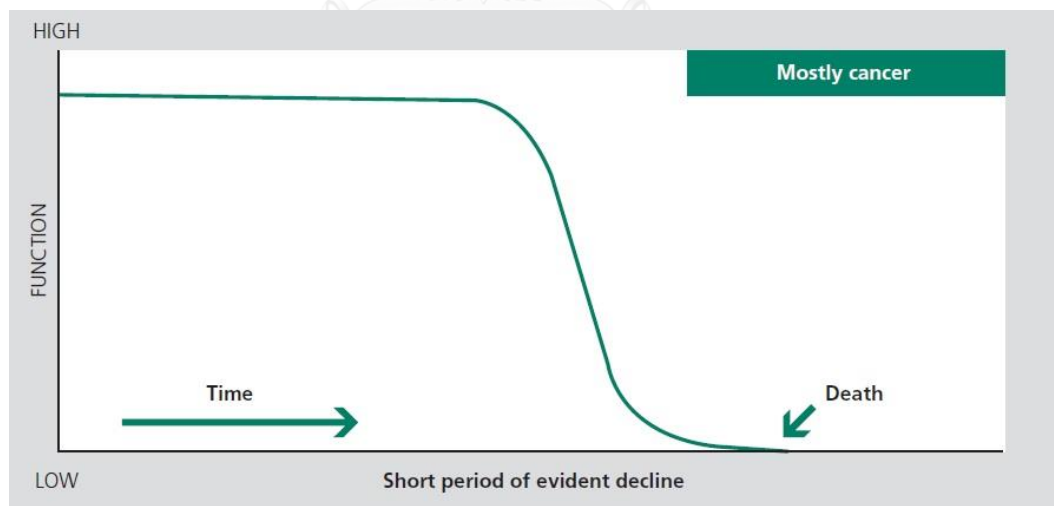


Figure 2 Short period of evidence decline, typical cancer

Source: Irish Hospice Foundation, 2008

2.3.2. Trajectory 2: Long term limitation with intermediate serious episodes

Patients in this trajectory are such as patients with heart failure and chronic lung disease. Health conditions of these patients are not certain. The diseases have remained for a long period of time with occasional acute and severe exacerbation. Patients in this trajectory generally admit in the hospital and receive intensive treatments. Each exacerbation can lead to death and although patients survive, the gradual deterioration in health and functional status is typical declining after each exacerbation. The timing of death is unpredictable.

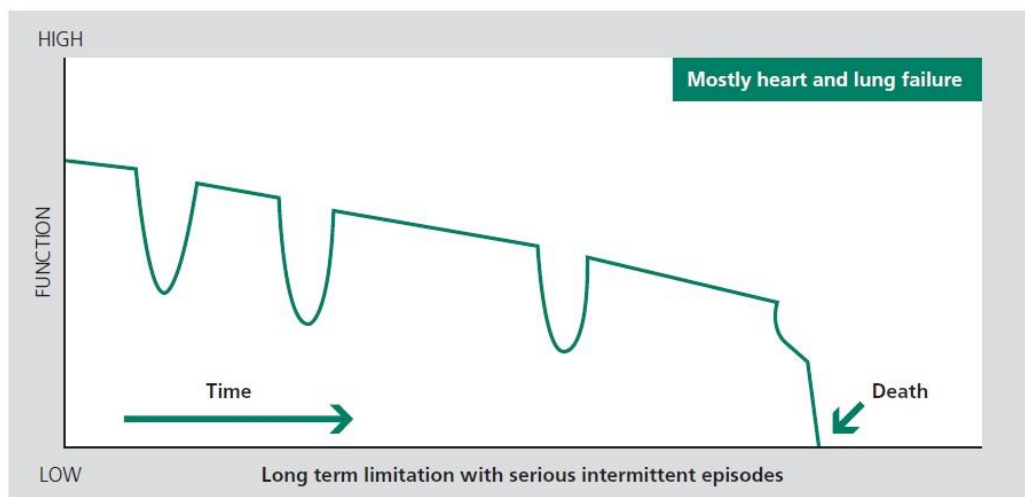


Figure 3 Long term limitation with intermediate serious episodes

Source: Irish Hospice Foundation, 2008

2.3.3. Trajectory 3: prolonged dwindling

Patients in this trajectory are likely to die of their old age with deterioration of brain failure (such as Alzheimer's or other dementia) or generalized frailty of multiple organ failure. Patients will lose cognitive or physical functioning in slowly progressive but the short-cut of death may occur with other diseases, for example fractured neck of femur or pneumonia.

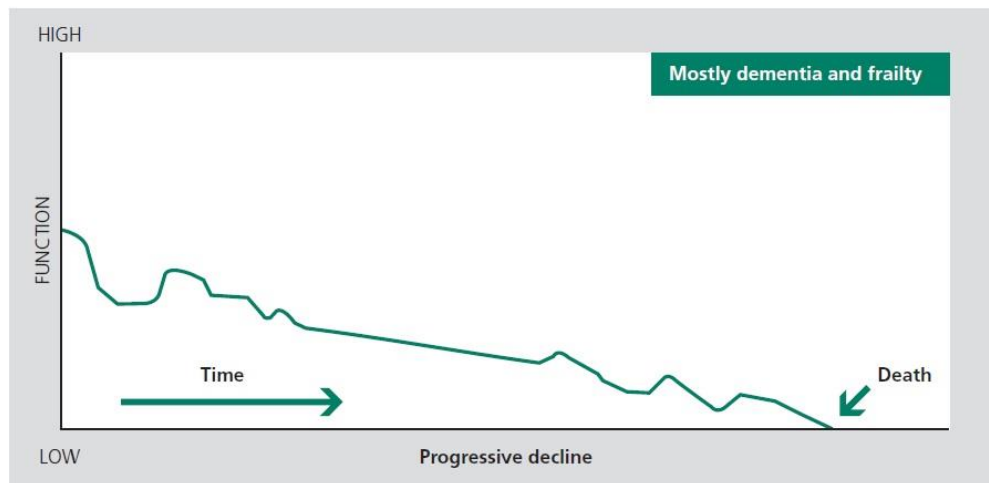


Figure 4 Prolonged dwindling

Source: Irish Hospice Foundation, 2008

2.3.4. Clinical Implications of illness trajectories

Illness trajectories can help healthcare providers to plan suitable care for their patients and families. Physicians may predict the timeframe of disease progression and discuss with them in some sensitive issues such as resuscitation and patient's "living will". It can also decrease patient and family's stress or worry about sudden death and they tend to accept death with less aggressive.

2.3.5. Service planning and development implication

The specific illness trajectory may use to establish the healthcare policies and services for the patients. It can lower the number of patient admission in the hospital and provide the patients die in the place they prefer.

2.3.6. Limitation of illness trajectories

The typical illness trajectories provide a conceptual framework of disease progression but it is not suitable for all patients. Some patients, their conditions are

more than one trajectory, for example patients with stroke may have death suddenly when diseases immediately occur and left disabilities remain for long time if they survive. Healthcare provider should decide the potential care map of individual patient. Moreover, there are also more than one dimension of needs. The illness trajectories describe physical progression of illness toward death but psychological, emotional, spiritual and social need in each patient is different. Patients with cancer may suffer from psychological, spiritual and emotional distress in the beginning of diagnosis but will be less in the final stage of illness. Patients with heart failure and chronic lungs disease may have spiritual distress throughout the trajectory meanwhile their physical conditions decrease. Patients with dementia would loss in ability of daily living, social withdrawal and emotional distress. Other dimensions of needs should be provided in patient care plan as well.

2.4. Palliative care for chronic illness, life-limiting non malignancy disease.

According to the pattern of disease is changing, people live longer beyond 65 year of age and die with non-communicative disease, chronic illness, life-limiting non malignancy disease increasingly which cause a wide range of physical, psychological and social problems.

Chronic disease such as dementia, Chronic obstructive pulmonary disease (COPD) and heart failure are the major causes of disability and effect on the individual's physical and psychological well-being, employment, family life and self-esteem over a prolong period. There are several evidences ^[64-67] defined that patients who have chronic disease have similar palliative care needs to those patients with cancer.

Symptom burden of disease

In this study, the researcher has a specific focus on patients with chronic illness with life-limiting non malignancy disease such as COPD, heart failure and deterioration of brain function (dementia, Alzheimer's disease and Cerebrovascular accident (CVA)). It is actually helpful to outline the burden of disease and general characteristic to guide the role of palliative care performance. It is also acknowledged that patients with these illnesses commonly present with co-morbidities which need to be considered when introducing palliative care.

Chronic obstructive pulmonary disease (COPD)

COPD is the progressive disease of the airways. Some people have rapid decline in lung function which may lead to early death, whereas some people have gradual, progressive decline of lung function after the exacerbation that its severity and frequency would increase fatal and the possibility of death.

Patients with advanced COPD experience the symptoms which include severe breathlessness on minimum exertion, cough and sputum production, which tend to cause sleep problems, loss of appetite, fatigue, depression, impair of abilities in daily

living, social isolation and anxiety. The prolonged period of disease with intermittent exacerbation can also effect on their family and caregivers in quality of life. The palliative care these patients need is the same quality of palliative care of those patients with lung cancer received.

The uncertainty of illness trajectory and identifying whether an exacerbation may fatal, physicians may confront the difficulty of the communication with the family. Discussion about end-of-life issues would be careful depend on individual needs. Physician should provide specific information about disease in advanced stage and intensive treatments that the patient would have to help them consider about this issues and the appropriate time of the conversation might be the first review after discharge.

Dementia

Patients with dementia would suffer from impairment of memory, intellect, judgment, insight and loss of social skills. The illness trajectory will decline, gradual slowly. The life expectancy of patients with dementia is generally thought to 5-29 years.

The end stage of dementia, patients would be burdened with increasing memory loss, confusion and disorientation, loss of ability or desire communication, impair of self-cared. The patients may have behavior change such as aggression, loss of abilities of swallow and eat independently, accompanied by loss of appetite. Other complications include delirium, incontinence, pain, recurrent infection, restlessness and agitation. Symptoms that are existing co-morbidities of dementia are such as heart failure, diabetes and infections such as pneumonia and septicemia are the most frequent cause of death.

There is study suggested that patients with end-stage dementia need the care as same as patients with advance cancer but more long duration. In the final stage of dementia, patient will not particularly express their preference by words and this phase takes long duration and difficult to identify. There are some researches shown that these patients did not really received benefits of palliative care because healthcare staffs did not recognize the progressive nature disease.

Heart failure

Heart failure is the symptom that heart cannot maintain sufficient cardiac output and oxygenation delivery throughout every organ. The illness trajectory of heart failure is described as a slowly decline with occasional rapid deterioration leading to acute hospital admission. Half of the patients with heart failure will die in four year whereas half of severe heart failure will die in a year.

Patients with advance heart failure are burdened with the uncertainty of illness trajectory which lead to high level of physical, functional and emotional distress. At the final phase of patients dying from heart failure, the physical and psychological symptoms are as same as the patients dying with advance cancer which includes weakness, pain, fatigue, dyspnea, insomnia, depression, anxiety, anorexia, constipation,

nausea and vomiting. Patients with advance heart failure may have poor quality of life. There are some study shown that lack of end-of-life discussion was a source of fear and anxiety for both patients and caregivers.

2.5. Provision of palliative care

2.5.1. The Theory of caring

Palliative care is aimed to diminish suffering and improve patients' quality of life. The most principle of palliative care is caring more than curing to offer patients and families in physical, psychological and spiritual needs. The use of Watson's theory of human caring was found to be an appropriate model not only in nursing but also for multidisciplinary care team to directly provide good palliative care to the patients.^[68]

Implementation of the Jean Watson's Caring Theory ^[69-75]

Jean Watson's Caring theory is either philosophy or theory of nursing which has been developed since 1979, emphasized on human care and the transpersonal relationship between nurses and patients and their families. Watson believed that caring is the basis of humanity and nursing is the human caring science. The goal of nursing based on her theory is to help patients reach a higher degree of harmony within mind, body and soul which lead patients to the self-healing in a person

According to Watson's Theory, the major components in her theory are (a) the carative factors (b) the transpersonal caring relationship and (c) the caring occasion/caring moment.

A. The carative factors

Watson defined "the carative factors" as the core of nursing, attempt to "honor the human dimension of nursing's work and the inner life world and subjective experiences of the people we serve". The carative factors are included 10 elements as below;

- Humanistic-altruistic system of value
- Faith-hope
- Sensitivity to self and others
- Helping-trusting, Human care relationship
- Expressing positive and negative feelings
- Creative problem-solving caring process
- Transpersonal teaching-learning
- Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment
- Human needs assistance
- Existential-phenomenological-spiritual forces

Later, the word “carative factors” was changed to “Caritas”, which originated from the Greek vocabulary, means cherish and giving love attention. The elements of clinical Caritas process are;

- Practice of loving kindness and equanimity within context of caring consciousness.
- Being authentically present, and enabling and sustaining the deep belief system and subjective life world of self and the one-being-cared-for.
- Cultivation of one’s own spiritual practice and transpersonal self, going beyond ego self, opening to others with sensitivity and compassion.
- Developing and sustaining a helping-trusting, authentic caring relationship.
- Being present to, and supportive of, the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared-for.
- Creative use of self and all ways of knowing as part of the caring process; to engage in artistry of caring-healing practices.
- Engaging in genuine teaching-learning experience that attends to unity of being and meaning, attempting to stay within other’s frames of reference.
- Creating healing environment at all levels (physical as well as non-physical), subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated.
- Assisting with basic needs, with an intentional caring consciousness, administering “human care essentials,” which potential alignment of mind, body, spirit, wholeness, and unity of being in all aspects of care; tending to both the embodied spirit and evolving spiritual emergence.
- Opening and attending to spiritual-mysterious and existential dimensions of one’s own life-death; soul care for self and the one-being-cared-for.

B. The Transpersonal Caring Relationship

This theory emphasized on the relationship between patients and nurse to go beyond ego to higher “spiritual” caring for the patients. Transpersonal caring relationship depends on

- The nurse’s moral commitment in protecting and enhancing human dignity as well as the deeper/higher self. Respect or love for the person, give the honoring to patients and families’ needs, wish, routine and rituals
- The nurse’s caring consciousness communicated to preserve and honor the embodied spirit.
- The nurse’s caring consciousness and connection having the potential to heal since experience, perception and intention connection are taking place. Maintain balance of inner harmony. Caring patients with heart-centered, honoring wholeness of mind-body-spirit in self and each other.

The nurse's caring consciousness is essential for the connection and understanding of the other's perspective. This approach focus on the uniqueness of both patients and nurses, and also mutuality between two individuals which is the basis of relationship. The goal of the transpersonal caring relationship are to protecting, enhancing and preserving the person's dignity, humanity, wholeness and inner harmony.

C. The Caring occasion/caring moment

According to Watson's theory, a caring occasion is the moment, focus on space and time, when the nurse and another person come together in an occasion and the human caring created. Both persons, with their unique phenomenal field, have the possibility to come together in a human-to-human transaction. A phenomenal field is the person's frame of reference or the totality of human experience consisting of feelings, bodily sensation, thoughts, spiritual beliefs, goals, expectations, environment considerations and meaning of one's perceptions. All of these are based on one's past life history, one's present moment and one's imagined future.

Not simply a goal for the caring, it also insisted that the nurse needs to be aware of one own consciousness and authentic presence of being in a caring moment with the patients. Moreover, both the one cared-for and the one caring can influenced by the caring moment through the choices and actions decided within the relationship, thereby, influencing and becoming part of their own life history. The caring occasion becomes "transpersonal" when "it allows for the presence of the spirit of both-then the event of the moment expands the limits of openness and has the ability to expand human capability."

Although caring is the main principle of palliative care, many healthcare providers could not respond to patients and families' needs in psychological and spiritual needs. ^[76] Daodee S. (2008) ^[77] had studied the caring behavior of Thai nurse and it was found that the caring behavior and communication skill of these healthcare staffs should be improved to respond appropriately to patients and family needs.

2.5.2. Symptoms management in palliative care ^[61, 78, 79]

2.5.2.1. Physiological problems

Patients in life- threatening condition have severity of prognosis which causes deterioration of health and suffering. The symptoms which frequently occur are such as pain, dyspnea, nausea and vomiting, fatigue, depression etc. the symptom management in palliative care has aims to provide patient's highest quality of life. Accurate and meticulous assessment is necessary that should address both non-physical and physical issues. The palliative care in difficult issues may need several approaches which should combine multidisciplinary team and reassess continuously.

Pain

Pain is the common symptom occurs in patients with end-of-life phase and causes them suffering. It could happen to patients with several conditions, not only in cancer and the management of pain can be difficult. The accurate diagnosis of the cause and mechanism of pain can precede effective treatment.

The successful relief of pain is generally required regular dose and appropriate time interval management between each dose. Give the patients sufficient dose to prevent recurrent of pain before the next dose is due. Healthcare providers should provide information and explanation of medication to the patients and caregivers as well for relieving the anxiety.

Morphine sulphate is the “Gold Standard” medication for both cancer and end-stage condition. The drug administration of Morphine is generally provided to the patient in oral form, may combine with other drugs, for example co-analgesics include non-steroidal anti-inflammatory drugs (NSAIDs), anti-convulsants, anti-depressants, benzodiazepines and corticosteroid. If patients have swallow or absorbance problem (such as dysphagia, gastric stasis, uncontrollable nausea and vomiting and impair consciousness), physicians should consider other routes (subcutaneous injection). The opioides side effects include constipation, nausea and vomiting, drowsiness, respiration distress. Healthcare providers should reassess and provide appropriate management of opioids.

Nausea and vomiting

Nausea and vomiting are the common symptoms in palliative care and difficult control. There are multiple causes and required more than one drug to cope with. Healthcare providers should detect all possible causes and consider the appropriate management. Anti-emesis drugs are required if patients have uncontrollable nausea and vomiting. Moreover, dietary and environment management are also used to relieve the symptoms.

Dyspnea (Breathlessness)

Dyspnea is the common and most distressing symptoms for the patients and family when end-of-life stage approaches. It occurs commonly in advanced cancer, cardiorespiratory and neurological disease. There are multiple causes regarding to physical and psychological factors. Healthcare providers should not emphasize only one dimension but analyze other possible causes and determine appropriate solutions for each patient. Some non- medication therapies are such as high positioning, oxygen therapy, physical therapy, drainage of ascites or effusion and complement therapy should be considering as combination with medication but in the final stage of end-of-life, these therapeutic method may not work. Some drugs such as opioids or sedative medicines (e.g. benzodiazepines) are required.

Fatigue

Fatigue is the symptom of tiredness, lack of energy, difficulty concentrating and lack of motivation. It can be caused by either illness or treatments (such as medications), or by poor eating or sleeping pattern. However, there are a few medical interventions for these symptoms. The most effective medications for fatigue are likely dexamethasone or other steroids which could improve patient's symptoms in a few days or weeks but the consideration of drug usage should be careful because of their unwanted side effects. However, non-medical intervention will be effective. Healthcare providers should observe and report fatigue, encourage healthy dietary and plenty of fluid intake, and manage to support in suitable physical training and sleep pattern would be helpful.

Constipation

Constipation involves infrequent, incomplete and difficult bowel movement, caused by underlying disease, drugs such as opioids or antidepressants, inactivity, a low-fiber diet or low fluid intake. It can cause patients discomfort from abdominal pain and bloating. Laxatives or peripheral opioid antagonist methylnaltrexone are effective options for treatment of opioid-induced constipation. Other non-medical interventions are such as eating adequate high fiber diet and drinking enough fluid and increase physical activities will help to prevent constipation.

2.5.2.2. Psychological problems

Patients with end-of-life phase may confront with psychological problems because they face with the diagnosis of incurable disease and limited prognosis. Anxiety and depression are the major psychological problems in palliative care. There are some researches^[80, 81] defined that inadequate healthcare providers and the more amounts routine workloads cause staffs have not enough time to provide palliative care to patients with life-threatening condition. The lack of confidence in palliative care and communication skills are also the healthcare providers' problems to provide sufficient palliative care. The patients are required to have psychological treatments to restore quality of life for the rest of their lifespan.

Anxiety

Anxiety is the feelings of apprehensive, fear and dread. It interrupts sleep pattern in the night and causing tiredness during the day. This can lead to other physical symptoms such as dizziness, nausea, shortness of breath and diarrhea. Benzodiazepines is a good medication to relieve insomnia. It will also use as the treatment of dyspnea and other symptoms that may be augmented by anxiety.

Depression

Some patients with advanced disease suffer from depression. It involves loss of pleasure and interest in activities. Depressed patients may isolate themselves from

others and feel hopelessness and helplessness. Mirtazapine is an essential drug for relieving depression, anxiety and panic attack. However, antidepressants may have some side effects such as dry mouth and constipation which patients will feel discomfort. The use of antidepressants should be careful balancing of effectiveness and side effects.

Delirium

Agitation and confusion can lead the stress not only on the patients but also the caregivers and healthcare staffs. Patients will have problems with attention and understanding, disorientation, rambling or unclear speech and reduce of ability in activities. There are some conditions of disease and treatments that can be caused of delirium. Neurological cause may include seizure, brain ischemia or bleeding, brain metastasis. Other causes are such as the usage of drugs or alcohol, fever infection, electrolyte imbalance or dehydration can trigger and aggravate delirium. Neuroleptic medication such as haloperidol and levomepromazine can be used to seduce and reduce delirium and agitation.

Medication and counseling can relieve psychological problems but other non-medical interventions are also important which can help patients deal with their mental status. Healthcare providers should find some strategies to provide emotional support. Some alternative options are such as music therapies, relaxation therapies, mind-body therapies, animal-assisted therapies, health-promotion program and changing environment could be applied and integrated with medication for more effectiveness of psychological treatments.

2.5.2.3. Social, Culture and spiritual aspects ^[82]

Family

“Family” in palliative care does not mean only the blood-bonded relationship, it is also involved ones who patient significantly loved with that includes friends, neighbors or work colleagues. Their support and education are important. The patients are not individually treated in their problems and symptoms but the families are involved as well. Losses suffered would be effected to the families’ emotions and experiences. Although the family members have as same cultural, spiritual and psychological backgrounds as patients, they have their own needs, expectation and rights.

The communication with family members are tough, especially in the hopeless topics. The diagnosis of terminal illness is traumatic to everyone. Families need help as the patients either. Neutrality is important and healthcare providers should aware and offer enough information and help them coping with hopelessness.

Culture

Healthcare providers should be aware of the patients and families' beliefs, values and respects when providing palliative care even they are not the same as healthcare providers own. The culture, ethnic or religion are associated with:

- Expression and meaning of pain and suffering.
- Attitude toward life and death.
- Beliefs about causes of illness.
- Choice of healer and treatment regimen
- Belief about afterlife
- The value of human life and the body
- Expression of loss and grief
- Death rituals including preparation for burial, funeral practices or memorial services, customs for disposing of the body and mourning rites.

Spiritual aspect

Spiritual support is important to many people at the end of life and it should be the part of palliative care service. Spiritual aspect is not only the religion but also include patients and families' beliefs and values. It would help patients and families to be at peace at the end of life. Healthcare providers should have respectfulness and openness on their individuality.

2.6. Decision making in palliative care ^[83]

Decision making is difficult in patients with non-cancer, life-limiting and chronic illness because of the uncertainty of illness prognosis. It is hard to clarify clinical outcomes and be sensitive to discuss with patients and families about the implementation of appropriate treatments. Healthcare providers may confront with ethical dilemma and legal issues which finally lead them to provide useless and unwanted cares to the patients. The relevant ethical principles are needed to be reviewed and understood clearly. It will help healthcare providers to aim the goal of care regarding to patients' and families' needs.

2.6.1. The essential ethical principles

There are four important principles of ethical consideration of treatments procedures for decision making that are included respect for autonomy, non-maleficence, beneficence and justice.

Respect for autonomy

It means the individual's right or ability to decide for himself/herself, according to beliefs, values and life plan. Respect for autonomy in medical practice defines that patients have unique rights and ability to decide for their own medical cares although they are incompetent in any aspects of their lives, for example in managing in financial affairs, patients would still be capable to understand their clinical issues and make their own decision which, sometimes, may be opposite to the course of treatments that is recommended by healthcare providers. Autonomy happens when patients intentionally act, with understanding and without forced or influence.

Respect for autonomy depends on truth-telling, right to the conveying accurate information of the fact and the situation and the determination of their choices of cares. It recognizes that patients may perceive the components of situation differently from healthcare providers do. The prognosis and clinical outcomes of patient with non-cancer, life-limiting and chronic illness may be not predictable, gentle truth-telling and exchange of accurate information about illness status, medical options, planned care and expectation is essential.

Although respect for autonomy is important, it needs other ethical principles to be combined for consideration in medical decision making and it does not mean there is no limitation, for example, the decision making of euthanasia is still not allowed in many countries. Respect for autonomy is based on the moral thought, cultural practice and legal precedent.

Non-maleficence

This principle means "one ought not to inflict evil or harm". Causing unnecessary physical or psychological pain from performing tests, procedures, history-taking or physical examination or even insensitive truth-telling are violations to the principle of non-maleficence.

Any provisions of medical cares should be suitable, especially in dying patients. They must not be overtreated or undertreated. Continued aggressive life-prolonging treatment or unnecessary and unwanted, unrequested or uninformed withhold or withdraw treatments that is not suited to patients' needs or wishes may be violation of this principle.

Beneficence

The concept of this principle defines that "one ought to prevent or remove evil or harm, and do or promote good". Healthcare providers should deliver care to promote patient's and family's quality of life including the effective treatments of pain and other symptoms. It also includes sensitive interpersonal support and acknowledgement patients and families to be respected and valued as unique human being.

Justice

The concept of justice is fairness or what is deserved by people. It defines what people are legally entitled and what they can claim. At the social level, justice is described as the policy or the distribution of the goods or service. Dying patients are equally able to access to medical care as same as other patients. Justice is also served to limit autonomy which the individual needs or desires may not be allowable because of contradiction to the social norm. Decisions or actions that may seem morally or appropriate to the individual person may not allowable because it is risk to other members in the society, for example, decision of euthanasia for the terminal or serious illness patients is prohibited even though they wish or attempt for this therapies. Cardiopulmonary resuscitation to the patients with terminal stage of cancer who have cardiac arrest due to the dying phase of illness is also against the principle of justice.

2.6.2. Medical decision-making in the care of patients with non-cancer, life-limiting and chronic illness

Goals of care are established by patient and family with healthcare providers together. Consideration of the goal is upon patient's illness, experience, goals and plans. In the process of decision making, moral principles are as important as the decision achievement. Healthcare providers should offer patient and family various treatment options which relate to their abilities in either life prolongation goal or non-life prolongation goal. Full supportive care is still essential in both paths. Renegotiation of goals should occur if patient's illness condition changes significantly either improvement or deterioration.

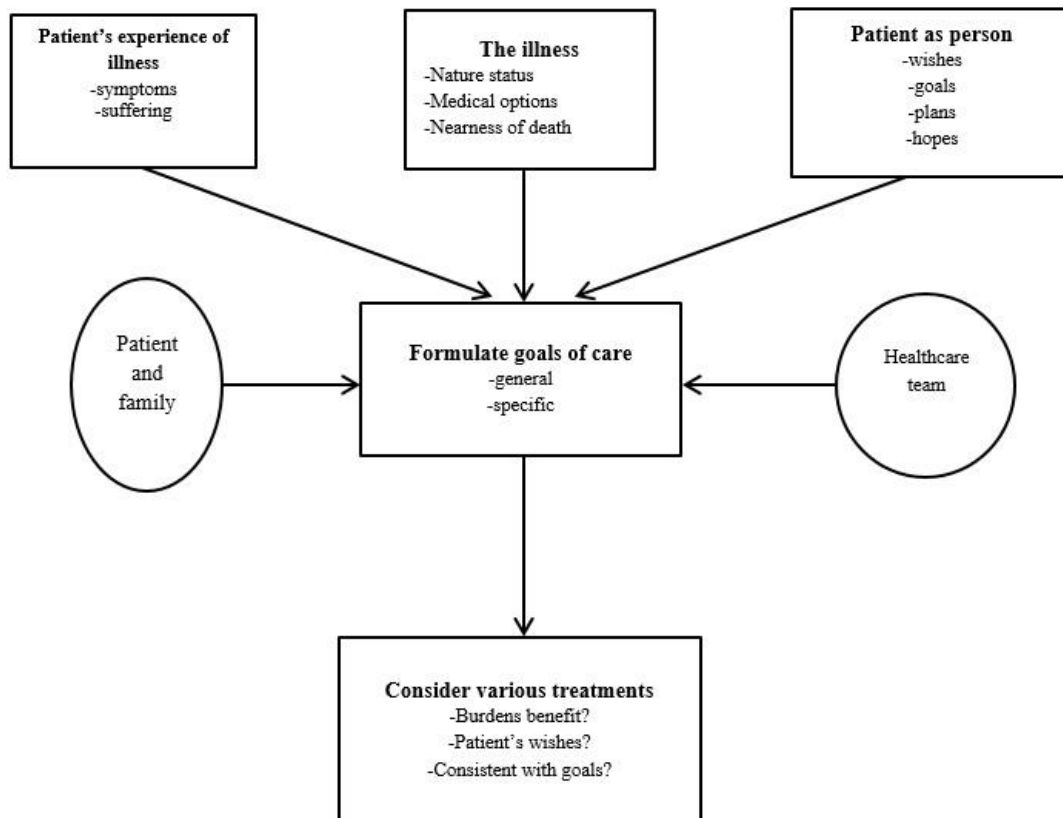


Figure 5 Medical decision making with dying patient

Source: Latimer J. 1991

Non-initiation or Cessation of treatment

The patient who is competent would have capacity to voluntary participation in decision making of his/her own medical cares through the process of informed consent. Patient has right to be given information and accept or refuse the course of treatments regarding to his/her beliefs, values or views. If the patient has lack of the ability of his/her autonomy, the representative of patient would be sought. Usually, family would hold that position because family would know well what patient's expressed prior wishes are.

If discussion with family does not successfully reveal patient's wishes, healthcare providers would describe about the benefits and the burdens of proposed treatments to the family, then healthcare providers, family, ethic committees and sometimes courts would weigh for the burdens and the benefits and attempt to determine for proper cares to them. Sometimes, it would be controversy because all participants weight burdens and benefits of cares differently and hardly to decide. For example, withholding or withdrawing of artificial feeding or hydration for terminal illness patient is difficultly considerable.

Cessation of treatments must also be considered for either competent patients, who request therapies to be stopped, or non-competent patients, who unable to do so. It sometimes causes psychologically and emotionally problems for healthcare providers, patient and family. If patients have received only a few benefits from the treatment, it should not be started from the beginning. In fact, the treatments are once started may be stopped if all participants are received accurate information about actual burdens and benefits and agree to discontinue treatments.

Continued treatment

Treatment is continued when it is compatible with the goals of care. Such goals are based on illness status, the range of possible treatments and patient's wishes and the burdens and the benefits involved. Open negotiation before starting a trial of treatment can allow for its cessation if the outcomes are not as expected. A course of therapy should be alterable.

The ethical consideration of a particular decision should be judged in the clinical condition. For example, it would be wrong ethically to withhold potentially beneficial treatment from non-competent patient if it obviously occurs that it gains more benefits than its burdens or it is clear that patient would choose to have. On the other hands, although patient refuses treatments, it should be renegotiate if the decision is not well informed or patient has lack capacity to decide.

Decision making for patient should be individual and not necessary to apply for the others. Such decision should not be made categorically on the basis of policies, protocols or generalizations about age or diagnosis. It should be particularly based on patient's situation and clearly exchanged information among patient, family and healthcare providers.

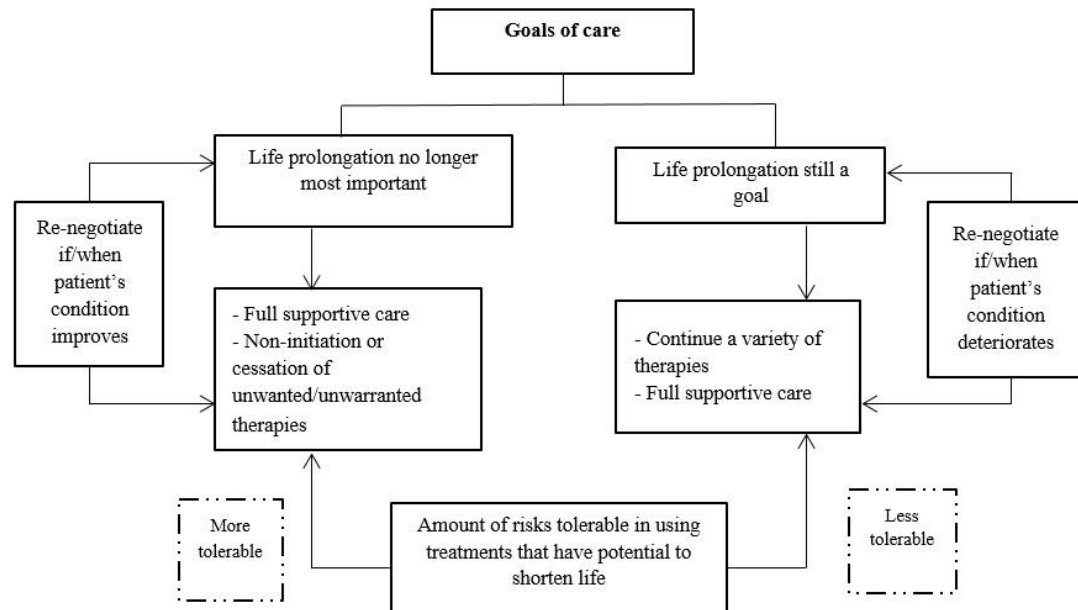


Figure 6 Potential paths to care

Source: Latimer J. 1991

2.7. Perception of palliative care

2.7.1. Multidisciplinary roles in palliative care ^[84]

Palliative care should be provided by multidisciplinary care teams. It is important to clarify definition of roles and responsibilities of each healthcare provider in the care team. It will improve the collaboration of interdisciplinary model and reduce misunderstanding regarding protocols, procedures, responsibilities and authority.

Physician

Physician provides the assessment of the physical and mental condition of client and the diagnosis, treatments and prevention of any diseases, disorder or dysfunction.

Physician is usually the first healthcare provider that patient requires health care, support and information. Physician provides continuous cares to patient over their lifetime including acute medical treatments or in long term care, early intervention and counseling to reduce risk or development of harm from illness.

Physician also coordinates to other healthcare team members to approach the management of the illness in patient and family. Physician performs the role of advocate to assist patients to navigate through the complex healthcare system to obtain the best care in the most effective cost.

Physician helps patient to explore the definition of problems and sets goals of care in a manner that respect to patient's autonomy, empower them and make decision in their best interests.

Nurses

The roles of nurse are the assessment and the promotion of health, the provision of care by supportive, preventive, therapeutic, palliative and rehabilitative in order to maintain patient's optimal function.

All nursing practice is based on the principles of primary health care. Although either registered nurses or practical nurses are similarly entitled, there are some differences in the depth and the width of knowledge, in the competency and authority, and the expectation for clinical performance. Registered nurses are able to autonomously provide nursing care to patients whose needs defined not clearly or changing. Practical nurses are independent to care for patients whose needs are well controlled or stable and well defined.

Nurses have the closest relationship with the patients and families than other healthcare providers. Nurses will help patients and family to identify their decisions of their own interests. Nurses also collaborate with other healthcare providers to manage good care for their patients and families or refer care to community healthcare teams regarding to their needs.

Pharmacist

Pharmacists are the healthcare providers who are medication experts. The practice of pharmacy are compounding and dispensing of drugs, the provision of non-prescription of drugs and the provision of information relate to drug use. When physicians have complexity of drug-related needs, pharmacists will join in multidisciplinary teams to help the challenge of optimizing drug use. Pharmacists also communicate with physicians to help patients achieve the maximum benefits and prevent the medication errors or adverse drugs reaction.

Physiotherapist

Physiotherapists are experts in physical rehabilitation. The practices of physiotherapy are the assessment of physical function and the treatment, rehabilitation and prevention of physical dysfunction, injury or pain. Physiotherapists are able to evaluate pain and movement patterns, muscle and joint function, cardiorespiratory status, reflexes and sensation. Physiotherapists provide plan treatment programs which include education, exercise program, manual therapy, modality to improve physical movement, injury prevention and reduce pain for patients.

2.7.2. Facilitators and Barriers of palliative care ^[85]

There are many facilitators and barriers that can affect the provision of quality palliative care for patients with non-cancer, life-limiting and chronic illness.

Healthcare Organization and policy ^[2]

Healthcare organizations such as hospitals and academic healthcare centers consist of interdisciplinary care teams to provide patient's safety and quality of care.^[86] All care team members have to coordinate and communicate with either professional care team members or other non-professional staffs to manage and deliver effective cares. Healthcare organizations have to establish institutional policies, protocols, models or guidelines of palliative care which emphasis on the needs of patients and families including symptoms management and other supportive cares for all healthcare members to implement. Healthcare organization should offer services and invest in the funding of full range of effective palliative care to ensure that patients and families are able to access to the care they need. Healthcare organization should coordinate to the community networks or other referral healthcare organizations to maintain continuity of palliative care for patients and families according to their wishes in the place of care or death. Healthcare organization should also promote the palliative care education and training for healthcare members and need to develop cultures and working practices for healthcare professionals that allow the best use of palliative care skills including the spending of sufficient times with patients and families and using the effectiveness of all available resources.

Knowledge and training

Lack of knowledge and training in palliative care among healthcare providers could decrease the good quality of palliative care. The knowledge as pain and symptoms management may affect to physical care to patients. Training could encourage healthcare providers to manage with some psychological support. Without effective training, healthcare providers cannot communicate clearly with the patients about the prognosis and care. Although there are some short training courses in palliative care available for healthcare providers, many healthcare providers have inadequate palliative knowledge for providing care in terminal illness patients.

Communication

The lack of proper communication among healthcare providers with patients and families means that patients and their families are not able to manage the kind of care regarding to their preferences. One possible reason of failure communication is the uncertainty of illness until the prognosis is poor. It is not easy to decide the appropriate time to discuss with patients and families about the dying, death and preferred options

of care. Advanced care planning at the early stage of illness could help healthcare providers discuss with patients and families for the appropriate caring management.

Facilities and Teams

Lack of healthcare staffs and small amount of service time could affect the delivery of good quality provision of palliative care. Sometimes it is difficult to provide effective palliative care if the doctors or nurses are busy from their duties. Some physical environments would be the obstacles to provide palliative care, for example the limitation of acute care setting in general wards with surrounded by many patients in emergency situation, it means the ideal of peaceful and dignified death for patients and their families is rarely possible.

Financial issues

Palliative care would not effective if patients and families worried about cost expenses. Healthcare providers should identify the financial needs, particularly with families who have to deal with poverty, unemployment and poor housing. To cope with this issue, healthcare providers should manage of the referral of caring system.

Ethic and legal issues

Patient has the self- autonomy in the decision-making relating to his/her own health and medical treatment including the right of an individual to die in natural death without the administration of artificial life support procedures. Sometimes, it would lead patient and physician to the decision of euthanasia which is inhibited in many countries. Moreover, the patients are given many medical procedures as mechanical ventilation, defibrillation in the terminal stage of illness which are not helpful, hasten life and oppose to their desires. Healthcare providers should have knowledge to give appropriate care to relief suffering, understand the patients' preference and forgive conflict. The complementary of palliative care and medical ethics would give protection and gain satisfaction to the patients and families.

Community

Policy makers internationally would like to integrate palliative care to the home and community because many patients prefer to be cared at home. Community based care is often less expensive than hospital care.^{[87] [88]} Adopting palliative care in home based care can help patients to die at home regarding to their wishes by implementing plans to avoid unnecessary transfers due to predictable health crisis.^[89] The community based palliative care should be the coordination of the core group of family carers, care workers, healthcare professionals and volunteers.^[79] The roles of this health care team are to manage symptoms, provide education, coordinate care and provide additional and enhanced support, services and care in the community setting.^[90]

When implementing community based palliative care, advanced care plans, which include patient's preference of future care or treatment options that were previously discussed with healthcare team and family so that patient could make a choice, should be documented, known, understood and current. Advanced care plan should provide advice to the carer about the staff and support devices available especially after hours. Plans should be identified the sign and symptom when patient's condition is changing and approaching to the death and provide support information about what to do and who to be contacted when the death has occurred. Healthcare team should also deliver continuity of bereavement care for the family after patient's death.

2.8. The factors of healthcare providers' demographics to palliative care

Healthcare providers have important roles for providing effective palliative care for patients and families. However, there are some factors of healthcare providers' demographics that influence the quality of care which the researcher would like to identify in this study.

Gender

Gender influences to the attitude of caring. Male nurses and female nurses providing care differently. Male nurses had been characterized as protector when there was confrontational interaction with the patients. Female nurses had spent more time with patients than male nurses had. Male nurses had lower satisfaction when they perceived spending time with patients. Patients also perceived that female nurses had more natural tendencies to care than male nurses but male nurses have showed little emotional actions than female nurses. Moreover, male nurses had asked to care for aggressive patients or avoided caring interaction that might be interpreted as sexual. However, the relationship between male and female healthcare providers for providing palliative care has less of evidences.

Age

Age is personal factor that influences to the attitudes and behaviors. People with different age have different needs and experiences. Human could have development in physical, intelligent, emotional and social capabilities in each period of ages. When people get older, they would have learnt and experienced that effect to their thought and behavior and would gain more efficacy of working.

Religion

Every religion has the thought of death similarly. Death is the natural phenomena that happen to everybody. Buddhist emphasizes that people should have conscience in death and the last moment of life is the way to be free from evil therefore people should always be prepared for dying and remind of goodness. Roman Catholic believes that death is the path of life and people would rebirth with God in heaven after death. Muslim believe that faith in life after death is important. Palliative care has aim to reduce suffering and prepare patients and family for good death, thus palliative care should be apply for all religions.

Position of work

Healthcare providers have different roles in providing palliative care for patients and families. Doctors provide medication, investigation and exploring for the goal of care. Nurses provide care and have the closest relationship with patients and families. Pharmacists provide advices of medication and drug management and physical therapists provide exercise program to relieve symptoms and suffering.

Working experience

Working experience is an important factor of care. When people have more practices, it could gain more work efficiency. Experience could gain more skill and consideration. People would have learnt from their experiences to solve the problems and manage their proper plan for the future. Healthcare providers who have more working experiences could gain more effectiveness in their work than who have less working experience.

Palliative care education

Palliative care education is one of the most important factors to provide effective palliative care for patients and families. Palliative care education could gain more confidence of healthcare providers. Palliative care includes the principle of palliative care and communication skill could encourage healthcare providers to explore patients and families' needs and provide proper care according to their desires.

Palliative care experiences

Palliative care experiences effect to healthcare providers in their attitude and behaviors. When healthcare providers have learnt and practiced their palliative care skills, it would gain more confidence to provide appropriate cares for patients and families. Palliative care also emphasizes on caring more than curing. When healthcare providers have experience of caring for palliative care patients, it would help them define the meaningful quality of care and prepare for good death.

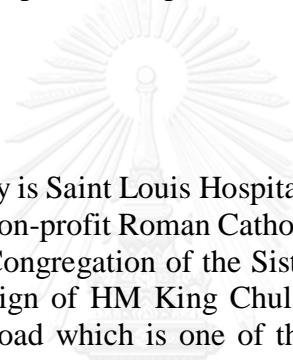
Chapter 3

Research Methodology

3.1. Research Design

This study is cross-sectional descriptive quantitative research based on surveying study to identify knowledge, perception and provision of palliative care by Thai healthcare providers in private hospital to non-cancer, life-limiting and chronic illness patients.

3.2. Study Area



The area of this study is Saint Louis Hospital where is a general private hospital in Bangkok. It is a general non-profit Roman Catholic hospital where has been founded and administrated by The Congregation of the Sisters of Saint Paul de Chartres since 1898, in the time of the reign of HM King Chulalongkorn. Saint Louis Hospital is located on South Sathorn road which is one of the most important business area in Bangkok and legally registered for attendance of 412 in-patient department beds. This hospital has been certified for many quality assurance awards such as ISO9002, ISO14001 and Hospital Accreditation (HA). The philosophy of this hospital is "Where there's mercy, there's the God" with the declared vision of "We are committed to being a leader of hope in healing and pastoral care." It is organized with the majority of medical specialization. There are a lot of clients have been satisfied and trusted in its services and staffs. In 2014, the total numbers of patients who were admitted in in-patient department were 2,093, there were 453 patients admitted with non-cancer, life-limiting and chronic illness such as chronic obstructive disease (COPD), heart disease and dementia or there were about 21.63% of all admitted patients in Saint Louis Hospital. These patients and their families need to be provided palliative care approach, therefor healthcare providers in this institution should understand the meaning and deliver the good service of palliative care to the patients and families upon their needs.

3.3. Study Population

The study populations of this study are healthcare providers, as general medical doctors, registered nurses, practical nurses, nurse assistants, pharmacologist, physical therapists who work in this hospital, involve outpatient department, general wards and intensive care unit. The inclusion criteria and exclusion criteria are as below

Inclusion Criteria

- Male and female age between 18-60 years old.
- Healthcare providers such as general medical physicians, registered nurse, practical nurses, pharmacologists, physical therapists who have worked in private hospital, involve outpatient department, general wards and intensive care unit for at least 1 year.

Exclusion Criteria

- Non-Thai healthcare providers.
- Physicians who are specialist as surgeon, pediatric physicians, Dentist etc.

Discontinuation Criteria

- Participants who deny to answer the questionnaires or unwilling to join the research.

Termination criteria for the study

This research would be terminated if there were any evidences of harmfulness in physical or psychological consequences to the participants or there were claims of disrespectful of their confidentiality.

3.4. Sampling Technique

The researcher selects the private hospitals by using purposive sampling technique according to the aims of the study to define healthcare providers' knowledge, perception and provision of palliative care for patients with non-cancer, life-limiting and chronic illness where Saint Louis Hospital has served for these patients around 450-500 patients per year. This hospital also has been addressed palliative care service in its major policies. After selecting this hospital, the researcher would select the samples by using the name list of healthcare providers who are suitable for the inclusion criteria, then the researcher chooses the total numbers of sample size of participants by calculating from Yamane's formula (Yamane et al.¹⁹⁶⁷)^[91], then use the stratified random sampling technique to select the proportional size of participants divided by their occupations. After that, the researcher uses sample random technique to recruit the participants until the total numbers of selected samplings are fit to the required sample sizes.

3.5. Sample & Sample size

In this study, the researcher selects all healthcare staffs in the name list as the research sample which include:

15 general medical doctors
 246 registered nurses
 172 technical nurses
 114 nurse assistants
 15 pharmacologists
 17 physical therapists

The total numbers of healthcare providers in this research is 579.

Then the researcher uses Yamane's formula to calculate for sample size. As formula below:

$$n = \frac{N}{1 + N\theta^2}$$

For: n = the sample size
 N = the population size
 θ = Allowable error; the acceptable error for this study is 0.05

The research finds the population size from the total number of healthcare providers in Saint Louis Hospital which are 579 people then use this number in the formula.

$$n = \frac{579}{1 + 579[(0.05) \times (0.05)]} \cong 236.56 \cong 236$$

The sample size of this study is 236 people.

Then the researcher divides the proportion of sample sizes by using the stratified random sampling technique using the formula bellows:

$$n_i = \frac{N_i}{N} * n$$

For n_i = the total numbers of the proportional sample size
 N_i = the population size of divided group of participants
 N = the total numbers of population sizes
 n = the total numbers of sample sizes

From this formula, the sample size of each group of participants is

General medical doctors:	$n_i = \frac{15}{579} * 236 \cong$	6	people
Registered nurses:	$n_i = \frac{246}{579} * 236 \cong$	100	people
Technical nurses:	$n_i = \frac{172}{579} * 236 \cong$	70	people
Nurse assistants:	$n_i = \frac{114}{579} * 236 \cong$	47	people
Pharmacologists:	$n_i = \frac{15}{579} * 236 \cong$	6	people
Physical therapists:	$n_i = \frac{17}{579} * 236 \cong$	7	people

Then, the researcher uses sample random technique to recruit the participants until the total numbers of selected samplings are fit to the required sample sizes.

3.6. Measurement Tools

The measurement tools of this surveying are questionnaires which divided into 5 sections for measuring healthcare providers' knowledge, perception and provision of palliative care. All tools are reviewed to ensure the correct contents and usability for the study by 3 experts of palliative care and translated backwardly and forwardly from English into Thai.

3.6.1. Measurement tool for knowledge

The tool is adapted from the physical-therapy in palliative care-knowledge, attitudes, beliefs and experiences scale (PTiPC-KABE Scale), developed by Kumar, et al.^[92] and the Palliative Care Knowledge Test (PCKT), developed by Nakazawa Y. et al. (2009)^[93]. It is used to improve and evaluate the palliative care educational program that is not only suitable for physicians but is also used to evaluate nurses and multidisciplinary care team for their knowledge of palliative care. The contents in the questionnaire are included philosophy of palliative care and symptoms management. The researcher also added some questions about the trajectory of illness in the questionnaire to define healthcare providers' knowledge of palliative care in the patients with non-cancer, life-limiting and chronic illness. It would be translate in Thai and revise for appropriate usage by expert discussion.

- *Reliability and validity*

This tool would be tested for reliability and validity. It was approved by 3 experts for content validity. The Kuder-Richardson formula 20 (KR-20) was used to assess internal consistency. The acceptable results of the test for reliability for KR-20 index for internal consistency of this questionnaire was 0.70.

3.6.2. Measurement tool for Perception

The tool is developed by the researcher based on reviewing of literature and adapted from the PTiPC-KABE Scale. It is used to evaluate healthcare provider's perception of palliative care. The contents in the questionnaire are included healthcare providers' perception of palliative care which contain healthcare organization and policy, knowledge and training, communication, facilities and teams, financial issues, attitude, belief, experience, ethic and legal issues and community. It would be translate in Thai and revise for appropriate usage by expert discussion.

- *Reliability and validity*

This tool was approved by 3 experts for content validity. The Cronbachs' alpha coefficient was use to assess internal consistency. The acceptable results of the test for reliability for the Cronbachs' alpha coefficient for internal consistency of this questionnaire was 0.70.

3.6.3. Measurement tool for Decision-making

The tool is developed by the researcher based on reviewing of literature. It is used to evaluate healthcare provider's perception in the decision-making for palliative care to patients with non-cancer, life-limiting and chronic illness. The contents in the questionnaire are included healthcare providers' perception of the essential ethical principles and the aspect of medical care regarding to patient and family's needs. It would be translate in Thai and revise for appropriate usage by expert discussion.

- *Reliability and validity*

This tool was approved by 3 experts for content validity. The Cronbachs' alpha coefficient was use to assess internal consistency. The acceptable results of the test for reliability for the Cronbachs' alpha coefficient for internal consistency of this questionnaire was 0.70.

3.6.4. Measurement for provision of palliative care

The instrument for this section is adapted from the Caring Behaviors for Dying Patient scale (CDPs), developed by Daodee S.(2008)^[77]. This instrument is used for exploring and evaluating the caring behaviors of Thai nurses, based on the Watson's Caring theory. This instrument is in Thai version that is suitable and can be modified for Thai healthcare providers. This instrument is included 45 Likert-type items scored on a five-point scale.

- *Reliability and validity*

This tool was approved by 3 experts for content validity. The Cronbachs' alpha coefficient was use to assess internal consistency. The acceptable results of the test for reliability for the Cronbachs' alpha coefficient for internal consistency of this questionnaire was 0.70.

The researcher combined and modified all items in the questionnaire to suit for the non-cancer, life-limiting and chronic illness patients and divided into 5 sections as below;

Part 1 are the characteristic and demographic information of healthcare providers included age, gender, position of work, religion, working experience, palliative care education and palliative care experiences.

Part 2 is the questionnaire about knowledge of palliative care. The questionnaires contain with items about principles of palliative care, symptoms management including drug usage and trajectories of illness. The answers are true and false.

Part 3 is the questionnaire about perception of palliative care. The questionnaires contain items about healthcare providers' perception of palliative care which contain healthcare organization and policy, knowledge and training, communication, facilities and teams, financial issues, attitude, belief, experience, ethic and legal issues and community. All items are codes as Likert-type items scored on a five-point scales which are "strongly agree", "agree", "neutral", "disagree", "strongly disagree".

Part 4 is the questionnaire about perception of decision making of palliative care. The questionnaires contain items about healthcare providers' perception of the essential ethical principles and the aspect of medical care regarding to patient and family's needs. All items are codes as Likert-type items scored on a five-point scales which are "strongly agree", "agree", "neutral", "disagree", "strongly disagree".

Part 5 is the questionnaire about provision of palliative care. The questionnaires contain some items about palliative caring for the patients based on the Watson's Caring theory. All items are codes as Likert-type items scored on a five-point scales which are

"never" means the participants have never provided palliative care according to the questionnaire.

"seldom" means the participants have provided palliative care according to the questionnaire less than 2 times per week.

"often" means the participants have provided palliative care according to the questionnaire 2-4 times per week.

“*usually*” means the participants have provided palliative care according to the questionnaire 5-7 times per week.

“*always*” means the participants have provided palliative care according to the questionnaire more than 7 times per week.

3.7. Validity and Reliability

The instruments of this research are reviewed to ensure the correct contents and usability for the study by 3 experts of palliative care by testing content validity and use the edited questionnaires to test 37 multidisciplinary healthcare providers in Saint Mary Hospital in Nakhon Ratchasima province, which this hospital has similar healthcare policy and environment to Saint Louis Hospital. The Cronbach’s alpha score is used to test for internal consistency. The acceptable point is .70. After the instrument was corrected and usable, then the researcher applied the questionnaires to the participants in Saint Louis Hospital.

Instrument reliability

After the questionnaires were reviewed by 3 experts and corrected for the valid contents, the researcher used them to the pilot group for testing reliability of the instrument. The sample size of the pilot group was calculated in the same proportion of the sample size of the study. The total number of the pilot group was 37 cases which included 1 doctor, 17 registered nurses, 1 pharmacists and 1 physical therapist. For the data collection of the practical nurses, the researcher had to collect the total numbers of 17 practical nurses instead of 10 practical nurses and 7 nurse assistants because according to the pilot hospital policy, there were no nurse assistants in that hospital.

Internal consistency reliability was assessed for all parts of the questionnaires. The acceptable point of the Cronbach’s alpha coefficient is 0.70. Some items of this instrument which significantly indicated a low level of the internal consistency reliability were removed until the Cronbach’s alpha coefficient was in the acceptable point. The Cronbach’s alpha coefficient of the questionnaire for part 2, part 3, part 4 and part 5 were 0.708, 0.741, 0.848 and 0.983.

3.8. Data Collection

The questionnaires are sent to the 236 healthcare providers in Saint Louis Hospital that distributed to various in-patient general wards or intensive care unit. To avoid bias and to maintain participant’s autonomy, the researcher use code and decoding during data collecting and analysis. Each questionnaire uses at least 20-30 minutes to complete and it would be sent back by enclosed envelope with the researcher’s address written on.

3.9. Data Analysis (statistics)

The statistical analysis computer program for this study is SPSS statistical package (version 22, IBM Corporation, NY, USA). It is used for calculating all variables in this study.

Part1 use descriptive analysis as frequency and percentage to assess all characteristics and demographic information.

Part 2-5 use coding and descriptive analysis as mean to measure central tendency and standard deviation to describe dispersion. The one-sample Kolmogorov-Smirnov Z test is used to test the normality of distribution. The non-parametric statistics are used in this study because the total numbers of some samples size of participants are less than 10. The Mann-Whitney U test and the Kruskal-Wallis test are used to test all samplings for significantly difference of all variables.

3.10. Ethical Consideration

This study has to be approved by Saint Louis Hospital Administrators and Ethical committee of Saint Louis College before conducting to the participants. All questionnaires are not used as a part of treatment guideline or have an effect on medical treatments for the patients. The healthcare provider's personal data is confidentially preserved. All participants are given verbal and written information about the aims and method of this study and sign informed consent.

3.11. Risk management

Although it is apparently less possibility of risk in the research, the risk management protocol is reviewed. The most important issue is confidentiality. The research uses codes and decode to represent the participants. All the questionnaires would be sent back with enclosed envelopes. If there were claims of disrespectfulness of participants' confidentiality, the research would be terminated and the participants would receive some penalties but not more than 10,000 Baht per case.

3.12. Limitation

Palliative care is becoming one of the major public health problems but the studies of palliative care is limited and do not broadly scope in various aspects. Studies of perception and provision of palliative care are rare and needed to be reviewed from previous 10 years. Moreover, there is no study about healthcare providers' barriers in provision of palliative care in Thailand.

3.13. Expected benefits and Application

The study is to define healthcare providers' knowledge, perception of provision in provision of palliative care in non-cancer, life-limiting and chronic illness patients. It is not only patients with cancer who need palliative care but it is also useful for other chronic illness patients who suffer from their long- term and incurable diseases. The outcomes of this research could be applied for developing palliative care program, for examples, it is to improve palliative care education and training program in the hospital or develop health policy for distributing palliative care program to the community.

3.14. Obstacles and strategies to solve the problems

Difficulty of cooperation with the healthcare providers

Many healthcare providers may not cooperate with the researcher. Their responsibility forces them to spend their most time for curing patients. Moreover, they may not want to answer some questions about their actions in palliative care that is the blame of giving up for their treatments or caring, therefore, many healthcare providers are not willing to join the research. On the other hand, palliative care emphasized on caring for dying people that contrast with their major tasks which for curing patient to survive. Palliative is not modern issue about medical investigation but it mostly concerns about psychological and moral topics that the healthcare providers may not be interested in.

Strategies to solve the problems:

- Inform the aims and method of the research to the healthcare providers before conducting data. Preserving their personal data as confidential along the research process.
- Use brief, less numbers but simply and cover all main contents questionnaires to spend less of their time.
- Provide the participants some adequate times when they are available to answer the questions.

Lack of supportive budget

Many researches in Thailand are emphasized on medical treatment and investigation to cure patients from disease but palliative care is about caring to maintain quality of life for dying people that is less important than help patients to survive despite

patients with chronic illness tend to gain more in the future. It needs more supportive resources to improve palliative care program but some budgets are not available.

Strategies to solve the problems:

- Making research account. Listing strictly income and outcome of budget for the research.
- Use available resources with the most efficiency and find other alternative resources to apply instead.
- Searching for some supporting resources such as funding from inner or outer the country to use for the research.

3.15. Administration and Time schedule

Research/Project Activities	Time Frame (Month)					
	1	2	3	4	5	6
Literature review	→					
Tool development for data collection		→				
Field preparation and Ethical Consideration			→			
Data collection (Questionnaires)				→		
Data analysis					→	
Report Summarize					→	
Publication						→

After the research proposal has been finished, it would be sent to College of Public Health Ethical Committee for approval, then, it would be launched for surveying. The consent forms are prepared and the researcher will reach the administrators of the selected hospital to ask for permission. When receive allowance, the surveying will be done. If there are some obstacles occur, the researcher would solve them in the best and most appropriate way, record and learn to apply for the future.

3.16. Budget

List	Cost (Baht)	
Incomes:		
-Researcher	15,000.00	-
-Other fund	0.00	-
Outcomes:		
-experts	-	5,000.00
-Transportation	-	1,000.00
-Stationary	-	1,000.00
-Meal (Food and Drink)	-	1,000.00
-Printing	-	2,000.00
-Miscellaneous	-	2,000.00
Total	15,000.00	12,000.00



Chapter 4

Results

This chapter discusses about the results from the statistical data analysis of the study. The purposes of the statistical data analysis is to answer the following questions:

- What are the levels of healthcare providers' knowledge, perception and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease regarding to patients and families' needs in physical, psychological, social and spiritual aspects?
- What factors of healthcare providers' demographics, as gender, age, position of work, religion, working experiences, palliative care education and palliative care experiences, do influence to knowledge and provision of palliative care in patients with non-cancer, chronic-illness and life-limiting disease?

4.1. Data analysis

The data of the study were analyzed by using updated SPSS version 22 with the level of significance at 0.05. All variables were tested for normality of distribution by using One-Sample Kolmogorov-Smirnov test. The results of Kolmogorov-Smirnov Z for the variables are in table 1 with p value is 0.000 ($p > 0.05$), thus the data of this study were not normal distribution. The non-parametric statistics as Mann-Witney U test and Kruskal- Wallis H test were used to analyze all variables according to the research questions.

Table 1: The variable analysis for the normality of distribution

Sample Characteristic	Test value	P value
Gender	0.540	0.000
Age	0.294	0.000
Position of work	0.287	0.000
Religion	0.523	0.000
Work experience	0.229	0.000
Palliative care education	0.209	0.000
Palliative care experience	0.227	0.000

4.2. Sample characteristics

The questionnaires were sent to 236 participants. However, 9 participants were missing and did not return the questionnaires back, therefore, the total numbers of participants who consented in this study were 227.

For the data collection of practical nurses, the researcher had to collect 88 practical nurses and 1 nurse assistant instead of the total- planned numbers of samples size of participants because according to the hospital policy, there were a few nurse assistants in the hospital.

Descriptive statistics as frequency and percentage were used to assess the sample characteristics of the participants.

Table 2: The frequency and percentage of the sample characteristics of participants (n=227)

Sample Characteristic	n	%
Gender		
male	8	3.5
Female	219	96.5
Age		
18-24 yrs.	44	19.4
25-35 yrs.	113	49.8
36-45 yrs.	45	19.8
46-55 yrs.	22	9.7
56-60 yrs.	3	1.3
Position of work		
Doctor	6	2.6
Nurse	120	52.9
Practical nurse	88	38.8
Nurse assistant	1	0.4
Pharmacist	5	2.2
Physical therapist	7	3.1
Religion		
Buddhist	199	87.7
Christian	28	12.3
Muslim	0	0
Others	0	0
Work experience		
< 5 yrs.	87	38.3
5-10 yrs.	55	24.2
11-15 yrs.	32	14.1
16-20 yrs.	25	11
21-25 yrs.	18	7.9
>25 yrs.	10	4.4

Sample Characteristic	<i>n</i>	%
Palliative care education		
Never	73	32.2
< 1 yr.	44	19.4
1-5 yrs.	70	30.8
> 5 yrs.	40	17.6
Palliative care experience		
Never	26	11.5
< 1 yr.	43	19.0
1-5 yrs.	71	31.4
> 5 yrs.	86	38.1

From table2, it is able to describe the sample characteristics for each topic as below

Gender: Female is the majority characteristic of all participants in the study (n=219, 96.5%). Male participants are 8. (n=8, 3.5%)

Age: The most participants in the study are in the range of age 25-35 years old (n=113, 49.8%). Followed by the participants with the range of age 36-45 years old (n=45, 19.8%) and 18-24 years old (n=44, 19.4%).

Position of work: The most participants in this study are nurses (n=120, 52.9%). Followed by practical nurses (n=88, 38.8%) and physical therapists (n=7, 3.1%)

Religion: Buddhist is the majority characteristics of the participants (n=199, 87.7%). Followed by Christian (n=28, 12.3%). There are no Muslim and other religions in this study.

Work experience: The most participants have worked for less than 5 years (n=87, 38.3%). The second length of work experience is 5-10 years (n=55, 24.2%).

Palliative care education: Most participants have never had palliative care education (n=73, 32.2%). The participants who have palliative care education have had for 1-5 years (n=70, 30.8%).

Palliative care experience: Although most participants have never had palliative care education, the most participants have palliative care experience for more than 5 years (n=86, 38.1%) and 1-5 years (n=71, 31.4%)

4.3. The results of palliative care knowledge.

The researcher had corrected and applied the questionnaire of palliative care knowledge from the physical-therapy in palliative care-knowledge, attitudes, beliefs and experiences scale (PTiPC-KABE Scale), developed by Kumar et al.(2011), the Palliative Care Knowledge Test (PCKT), developed by Nakazawa Y. et al. (2009) and by reviewing of the literatures. There were 23 items in this questionnaire with the answer of true and false. Descriptive statistics as frequency and percentage of correct and incorrect responses were used to assess the participants' knowledge in palliative care. The results for each item after testing are as below table.

Table 3: The frequency and percentage of correct and incorrect responses of palliative care knowledge, divided by items. (n=227)

Questions	Correct answer	Correct		Incorrect	
		n	%	n	%
1. Palliative care provides relief from pain and other distressing symptoms.	<i>True</i>	6	2.6%	221	97.4%
2. Palliative care considers life and regards dying as a complicated natural process.	<i>False</i>	39	17.3%	187	82.7%
3. Palliative care intends to hasten or postpone death.	<i>False</i>	27	11.9%	200	88.1%
4. Palliative care integrates the physical, psychological, social and spiritual aspects of patient care.	<i>True</i>	2	0.9%	225	99.1%
5. Palliative care offers a support system to help patients die as early as possible.	<i>False</i>	15	6.6%	212	93.4%
6. Palliative care offers a support system to help family cope during the patient's illness.	<i>True</i>	7	3.1%	220	96.9%

Questions	Correct answer	Correct		Incorrect	
		<i>n</i>	%	<i>n</i>	%
7. Palliative care help family members to adjust of the grief in their own bereavement.	<i>True</i>	17	7.5%	210	92.5%
8. Healthcare providers in palliative care team will assess and provide counseling to patient and family individually.	<i>True</i>	8	3.5%	219	96.5%
9. Palliative care will not enhance quality of life.	<i>False</i>	41	18.1%	186	81.9%
10. Palliative care does not influence the course of illness.	<i>True</i>	106	46.7%	121	53.3%
11. Palliative care is applicable early in the course of illness	<i>True</i>	16	7%	211	93%
12. Palliative care should combine with other therapies that are intended to relief pain and suffering, such as chemotherapy or radiation therapy, and patient needed to understand and manage distressing clinical complications.	<i>True</i>	22	9.7%	205	90.3%
13. Palliative care should be only provided for patients who have no curative treatment available.	<i>False</i>	90	39.6%	137	60.4%
14. Long-timed use of Morphine in palliative care often induces addiction.	<i>False</i>	70	30.8%	157	69.2%

Questions	Correct answer	Correct		Incorrect	
		<i>n</i>	%	<i>n</i>	%
15. Use of morphine does not influence survival time.	<i>True</i>	75	33%	152	67%
16. There is no route except central venous or skin patch for patient unable to maintain a peripheral intravenous route.	<i>True</i>	35	15.5%	191	84.5%
17. The typical illness trajectories can aid healthcare providers to discuss with patients and their families about the prognosis and to plan the proper provision of care.	<i>True</i>	5	2.2%	222	97.8%
18. Patients with chronic obstructive pulmonary disease (COPD) need less palliative care than patients with lung cancer need.	<i>False</i>	70	31%	156	69%
19. The end-of-life discussion in patients with terminal state of heart failure may be a source of fear and anxiety for either patients or families.	<i>False</i>	115	50.9%	111	49.1%
20. The provision of fiber diet and adequate fluid intake and appropriate activities such as exercise would relief constipation.	<i>True</i>	5	2.2%	222	97.8%
21. Alternative therapies such as musical therapy, meditation, pet therapy,	<i>False</i>	67	29.6%	159	70.4%

Questions	Correct answer	Correct		Incorrect	
		<i>n</i>	%	<i>n</i>	%
health promotion program and changing patient's room environment cannot relief psychological problem as well as medication.					
22. Patient has right to indicate advance directive or living will to inform healthcare provider to provide medical treatments as patient's desires when end-of-life time comes.	<i>True</i>	19	8.4%	20.8	91.6%
23. In Thailand, Euthanasia is illegal.	<i>True</i>	66	29.3%	159	70.7%

To summarize the overall results of palliative care knowledge testing, descriptive statistics as minimum score, maximum score, mean score and percentage of correct responses were used to assess the palliative care knowledge of all participants. Modified Bloom's cut off point^[94] were used to classify the level of palliative care knowledge with the score of 18.4-23 (80%-100%) of correct response meant a high level or good knowledge, 11.5-18.39 (50%-79%) of correct response meant a moderate level or satisfactory knowledge and less than 11.5 (50%) of correct response meant low level or poor knowledge. The results is shown in table4

Table 4: The minimum score, maximum score, mean score and standard deviation of correct responses of the sum of palliative care knowledge test. (n=227)

	Min.	Max.	Mean	S.D.	Level
Total scores	8	23	18.97	2.11	High

From table 3-4, the average of sum knowledge scores of the participants is 18.97 which is in high level ($\bar{x} = 18.97$, S.D. =2.11). The minimum score of the test is 8 and the maximum score is 23. If we examine each item of the questionnaire, the item that has the highest correct response is "Palliative care integrates the physical, psychological, social and spiritual aspects of patient care." (n=225, 99.1%) and the item

that has the lowest correct response is “The end-of-life discussion in patients with terminal state of heart failure may be a source of fear and anxiety for either patients or families.” (n=111, 49.1%).

To answer the research question and to investigate hypothesis of the study, the Mann-Whitney test and the Kruskal-Wallis test are used to assess the difference of the median score of the test in each variable. The results of the test are in the table 5-6.

Table 5: The result of the difference of the median score of the variable and the palliative care knowledge test. Used the Mann-Whitney test. ($p > 0.05$)

Sample Characteristic	N	Mean Rank	Test value	P value
Gender				
Male	7	112.64	499.50	0.347
Female	180	93.28		

From table 5, The result of the difference of the median score of palliative care knowledge test in male and female, test value is 499.50, P value is 0.347 ($p > 0.05$) which means the median score of palliative care knowledge test in male and female is not significantly different at α is 0.05 ($p > 0.05$).

Table 6: The result of the difference of the median score of the variable and the palliative care knowledge test. Used the Kruskal-Wallis test test. ($p < 0.05$)

Sample Characteristic	N	Mean Rank	χ^2	df	P value
Age					
18-24 yrs.	38	81.12	10.006	4	0.04
25-35 yrs.	93	90.26			
36-45 yrs.	38	100.54			
46-55 yrs.	16	125.75			
56-60 yrs.	2	134.50			
Position of work					
Doctor	6	152.00	19.680	5	0.001
Nurse	99	101.17			
Practical nurse	73	77.54			
Nurse assistant	1	34.50			
Pharmacist	4	137.38			
Physical therapist	4	101.38			
Religion					
Buddhist	167	94.46	0.116	1	0.733
Christian	20	90.15			
Muslim	-	-			
Others	-	-			

Sample Characteristic	N	Mean Rank	χ^2	df	P value
Work experience					
< 5 yrs.	74	81.93	8.082	5	0.152
5-10 yrs.	44	97.60			
11-15 yrs.	27	96.11			
16-20 yrs.	23	112.02			
21-25 yrs.	14	104.61			
>25 yrs.	5	116.90			
Palliative care education					
Never	57	84.98	5.971	3	0.113
< 1 yr.	34	104.57			
1-5 yrs.	64	88.99			
> 5 yrs.	32	108.84			
Palliative care experience					
Never	22	76.82	4.272	3	0.234
< 1 yr.	30	100.45			
1-5 yrs.	63	89.38			
> 5 yrs.	72	100.60			

From table 6, The result of the difference of the median score of palliative care knowledge test in the participants with different age has Chi-square value of 10.006, df is 4 and p value is 0.04 ($p < 0.05$) and the participants with different position of work has Chi-square value of 19.680, df is 5 and p value is 0.001 ($p < 0.05$). It could be examined that there are significant differences of the median score of palliative care knowledge test in the participants with different age and different position of work at α is 0.05 ($p < 0.05$).

4.4. The results of the perception of palliative care

The instrument was adapted from the physical-therapy in palliative care-knowledge, attitudes, beliefs and experiences scale (PTiPC-KABE Scale), developed by Kumar et al.(2011), and by reviewing the literatures. There were 30 questions in this part. The questionnaires contain substances about healthcare providers' perception of palliative care which involved healthcare organization and policy, knowledge and training, communication, facilities and teams, financial issues, attitude, belief, experience, ethic and legal issues and community. The grouping of question numbers by substances were

- Knowledge and training: question number 1,12,21,23
- Communication: question number 15, 18
- Organization and policy: question number 8, 14
- Finance: question number 29
- Ethic and legal issue: question number 30
- Facilities and team: question number 5, 7, 19, 20, 24, 27, 28
- Community: question number 4, 6, 25, 26

- Attitude: question number 3, 9, 13, 17, 22
- Belief: question number 16
- Experience: question number 2, 11

All items were coded as Likert-type items scored on a five-point scales which were “strongly agree”, “agree”, “neutral”, “disagree”, “strongly disagree”. The scoring of negative statement questions included question number 3, 17, 21, 25, 26 were inverted the scales. Modified Bloom’s cut of point were used to classify the level of perception with the score of 4.00-5.00 (80%-100%) of mean perception scores meant a high level or positive perception, 2.50-3.99 (50%-79%) of mean perception scores meant a moderate level or neutral perception and less than 2.50 (less than 50%) of mean perception scores meant low level or negative perception.

Descriptive statistics as mean and standard deviation are used to assess the perception of palliative care. The results for each item after testing are as below table.

Table 7: The mean, standard deviation and level of the perception of palliative care, divided by grouping of substances. (n=227)

Substances	Mean	S.D.	Level
Knowledge and training	3.35	0.361	Moderate
Communication	3.77	0.635	Moderate
Organization and policy	4.17	0.584	High
Finance	3.84	0.737	Moderate
Ethic and legal issues	4.18	0.648	High
Facilities and team	3.93	0.401	Moderate
Community	3.48	0.573	Moderate
Attitude	3.57	0.534	Moderate
Belief	3.95	0.727	Moderate
Experience	3.71	0.915	Moderate
Total	3.69	0.324	Moderate

From table 7, the perception of palliative care in terms of healthcare providers’ role, knowledge and training, facilities, team and barriers of palliative care, divided by grouping of items, are moderate level ($\bar{x} = 3.69$, S.D. = 0.324). The highest mean score

of the perception is in “Ethic and legal issues” ($\bar{x} = 4.18$, S.D. = 0.648), followed closely by “organization and policy” ($\bar{x} = 4.17$, S.D. = 0.584). The lowest mean score of the perception is in “knowledge and training” ($\bar{x} = 3.35$, S.D. = 0.361).

The results of the perception of palliative care could be separated to each item as shown in the table below.

Table 8: The mean, standard deviation and level of the perception of palliative care, divided by items. (n=227)

Questions	Mean	S.D.	Level
1. Palliative care is as important as curative care in patients with non-cancer, life-limiting and chronic illness.	3.84	0.932	Moderate
2. I have had experiences of providing palliative care to dying patients and families.	3.98	0.973	Moderate
3. I feel a sense of personal failure when patient dies.	3.55	1.133	Moderate
4. There is support for palliative care for non-cancer, life-limiting and chronic illness patient in society.	3.31	0.806	Moderate
5. The healthcare staffs support palliative care for patients with non-cancer, life-limiting and chronic illness in my workplace.	4.17	0.689	High
6. The environment of my workplace is ideal for providing palliative care to the patient and family.	3.96	0.760	Moderate
7. My workplace is adequately staffed for providing the needs of non-cancer, life-limiting and chronic illness patients requiring palliative care and their families.	3.54	0.837	Moderate
8. In my workplace, families/relatives are involved in decisions about their patients.	4.09	0.738	High
9. My previous experiences of providing palliative care to dying patients have been rewarding.	3.56	1.031	Moderate

Questions	Mean	S.D.	Level
10. When patients are dying in my workplace, providing pain relief is a priority for me.	3.80	0.878	Moderate
11. I am often exposed to death in my workplace environment.	3.44	1.208	Moderate
12. Palliative care is necessary in healthcare education.	4.22	0.705	High
13. When a patient dies in my workplace, I have sufficient time to spend with the family.	4.14	0.739	High
14. There are policies or guidelines to assist in the delivery of palliative care in my workplace.	4.24	0.728	High
15. In my workplace, when a diagnosis with a likely poor outcome is made, patients/relatives are informed of palliative care options.	3.93	0.798	Moderate
16. In my workplace, the team expresses its options, values and beliefs about providing palliative care to patients.	3.95	0.727	Moderate
17. Caring for dying patient is traumatic for me.	2.87	1.129	Moderate
18. I have received education that assists me to support and communicates with patients/relatives of dying patients.	3.60	0.748	Moderate
19. All members of the healthcare team in my workplace agree with and support palliative care when it is implemented for dying patient.	3.85	0.644	Moderate
20. In my workplace, the staffs go beyond what they feel comfortable with in using technological life support.	3.73	0.683	Moderate
21. In my workplace, staffs are asked by patients/relatives to continue life-extending care beyond what they feel is right.	2.77	1.183	Moderate
22. My personal attitudes about death affect my willingness to deliver palliative care.	3.73	0.915	Moderate

Questions	Mean	S.D.	Level
23. Palliative care is against the value of medical treatments.	2.58	0.886	Moderate
24. When a patient dies in my workplace, counseling is available if I need it.	3.84	0.737	Moderate
25. There is a belief in society that patients should not die, under any circumstances.	3.80	0.966	Moderate
26. Curative care is more important than palliative care in the healthcare environment.	2.85	1.163	Moderate
27. Palliative care should be provided by multidisciplinary care team.	4.35	0.622	High
28. As a member of healthcare team, I know my exact role in support of palliative care.	4.04	0.619	High
29. Patients/relatives who have financial problems should be offered palliative care as an option.	2.69	0.988	Moderate
30. I have concerned about ethical dilemma and ethical issues to provide palliative care to my patient and family.	4.18	0.648	High

From table 8, the highest mean score of the perception of palliative care for each item is in “Palliative care should be provided by multidisciplinary care team” ($\bar{x} = 4.35$, S.D. =0.622), followed by “There are policies or guidelines to assist in the delivery of palliative care in my workplace” ($\bar{x} =4.24$, S.D. =0.728). The lowest mean score of the perception is in “Palliative care is against the value of medical treatments.” ($\bar{x} = 2.58$, S.D. = 0.886).

The perception of palliative care in term of decision making of healthcare providers are also explored. There were 10 questions in this part. The questionnaires contain items about healthcare providers’ perception of the essential ethical principles and the aspect of medical care regarding to patient and family’s needs. All items are positive statement and codes as Likert-type items scored on a five-point scales which are “strongly agree”, “agree”, “neutral”, “disagree”, “strongly disagree”. Modified Bloom’s cut of point were used to classify the level of perception with the score of 4.00-5.00 (80%-100%) of mean perception scores meant a high level or positive perception, 2.50-3.99 (50%-79%) of mean perception scores meant a moderate level or neutral

perception and less than 2.50 (less than 50%) of mean perception scores meant low level or negative perception.

Descriptive statistics as mean and standard deviation are used to assess the results. They are shown in the table below

Table 9: The mean, standard deviation and level of the perception of palliative care in term of decision making of healthcare providers, divided by items. (n=227)

Questions	Mean	S.D.	Level
1. The goal of palliative care decision making is to meet patient's wishes and needs by choosing appropriate treatments.	4.23	0.565	High
2. If my patient is unable to express his/her needs according to illness condition, I will accept relatives to make decision for patient's treatments instead.	4.21	0.644	High
3. I have respected for patient's beliefs, values and life plans although those are different from mine.	4.22	0.643	High
4. Gentle truth-telling and exchange of accurate information about illness status, options, plan care and future expectation is essential for decision making.	4.32	0.555	High
5. If patient and family have to deal with financial affair, they still have full capacity to make their own decision of caring.	4.23	0.659	High
6. Palliative care should be the one caring option to provide for patient who has frequent times of cardiac arrest.	3.64	0.893	Moderate
7. When patient is diagnosed incurable disease, he/she should be informed the choices of either life-prolongation or non-life prolongation care.	4.20	0.647	High
8. Palliative care is necessary in either life prolongation or non-life prolongation goal of cares.	4.09	0.635	High

Questions	Mean	S.D.	Level
9. Renegotiation of goal of care should occur if the patient's condition changes significantly.	4.11	0.657	High
10. Goal of care should be established jointly by patient and family together with healthcare team.	4.37	0.583	High
Total	4.16	0.462	High

From table 9, the perception of palliative care in terms of decision making of healthcare providers, divided by items, are high level ($\bar{x} = 4.16$, S.D. = 0.462). The highest mean score of the perception is in "Goal of care should be established jointly by patient and family together with healthcare team" ($\bar{x} = 4.37$, S.D. = 0.583). The lowest mean score of the perception is in "Palliative care should be the one caring option to provide for patient who has frequent times of cardiac arrest" ($\bar{x} = 3.64$, S.D. = 0.893).

4.5. The results of the provision of palliative care

The instrument for exploring the provision of palliative care was adapted from the Caring Behaviors for Dying Patient scale (CDPs), developed by Daodee S. (2008). There were 45 questions in this part. All items are positive statement and coded as Likert-type items scored on a five-point scales which are "always", "usually", "often", "seldom" and "never". Modified Bloom's cut of point were used to classify the level of provision of palliative care with the score of 4.00-5.00 (80%-100%) of mean provision scores meant a high level or positive behaviors, 2.50-3.99 (50%-79%) of mean provision scores meant a moderate level or neutral behaviors and less than 2.50 (less than 50%) of mean provision scores meant low level or negative behaviors.

All items could be separated into 10 groups according to Watson's carative factors of caring behavior in the theory of caring which were

- Humanistic-altruistic system of value: question number 32, 33, 34, 35, 43
- Faith-hope: question number 27, 39, 40, 44
- Sensitivity to self and others: question number 19, 41, 45
- Helping-trusting, Human care relationship: question number 10, 15, 16, 17, 18, 20, 21, 42
- Expressing positive and negative feelings: question number 22, 23, 24, 25, 26
- Creative problem-solving caring process: question number 28, 29, 30, 31, 36
- Transpersonal teaching-learning: question number 1

- Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment: question number 2, 37, 38
- Human needs assistance: question number 3,4,5,6,7,8
- Existential-phenomenological-spiritual forces: question number 9, 11, 12, 13, 14

Descriptive statistics as mean and standard deviation are used to assess the results which were shown in the table below.

Table 10: *The mean, standard deviation and level of the perception of palliative care in term of decision making of healthcare providers, divided by grouping of items. (n=227)*

Subscales	Mean	S.D.	Level
Humanistic-altruistic system of value	4.23	0.687	High
Faith-hope	3.87	0.830	Moderate
Sensitivity to self and others	3.98	0.790	Moderate
Helping-trusting, Human care relationship	4.06	0.665	High
Expressing positive and negative feelings	3.71	0.872	Moderate
Creative problem-solving caring process	3.90	0.812	Moderate
Transpersonal teaching-learning	3.28	1.420	Moderate
Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment	3.71	0.930	Moderate
Human needs assistance	4.17	0.750	High
Existential-phenomenological-spiritual forces	3.61	0.894	Moderate
Total	3.92	0.670	Moderate

From table 10, the overall results of provision of palliative care, divided by grouping of items, are moderate level ($\bar{x} = 3.92$, S.D. =0.670). The highest mean score of the provision of care is in “Humanistic-altruistic system of value” ($\bar{x} = 4.23$, S.D. = 0.687). The lowest mean score of the provision of care is in “Transpersonal teaching-learning” ($\bar{x} = 3.28$, S.D. = 1.420).

The results of the perception of palliative care could be separated to each item as shown in the table below.

Table 11: The mean, standard deviation and level of the provision of palliative care, divided by items. (n=227)

Questions	Mean	S.D.	Level
1. You cooperate with family to prepare patient's physical, psychological and spiritual conditions before the patient is transferred to die at home as he/she desired.	3.28	1.420	Moderate
2. You clean up and neat environment of patient's room.	3.93	1.113	Moderate
3. You always give patients comfort care.	4.42	0.785	High
4. You let patient do some expected successful activities or task.	4.01	0.950	High
5. You give patient complement when he/she try to do some activities by himself/herself.	4.29	0.859	High
6. You advice family to always come visit patient.	4.09	0.939	High
7. You afford family to participate in caring the patient.	4.24	0.849	High
8. You give family a chance to express their anxiety or fear.	3.96	1.096	Moderate
9. You give patient a chance to join spiritual or religious activities according to his/her belief.	4.11	0.916	High
10. You introduce yourself before giving care to the patient.	3.70	1.069	Moderate
11. You stay with the patient when he/she is dying.	4.07	1.018	High
12. You promote patient to explore the value of past successful or impressive experiences of patient's life.	3.44	1.241	Moderate

Questions	Mean	S.D.	Level
13. You define patient's good points and his/her environment.	3.61	1.081	Moderate
14. You provide patient the conversation about the aims of life and the life after death.	2.80	1.350	Moderate
15. You inform patients before giving care all the time.	4.23	0.879	High
16. You do not quicken doing caring activities for the patient.	3.70	1.218	Moderate
17. When the patient speaks, you listen to him/her carefully.	4.35	0.727	High
18. You behave to the patient with friendly manner.	4.46	0.724	High
19. You listen or talk about patient's belief even it contrast to your belief.	4.14	0.866	High
20. You provide caring to the patient by conversation and touching.	4.28	0.809	High
21. You give patients the promise in what you can actually do.	3.63	1.126	Moderate
22. You stay calm with the patient even he/she undesirably behaves.	3.98	0.924	Moderate
23. You give patient a chance to express his/her feelings both positive and negative way.	4.04	0.926	High
24. You do not blame patient if he/she express their feeling of guilty in his/her past.	3.92	1.120	Moderate
25. You advice patient to forgive himself/herself to the mistakes in the past.	3.38	1.335	Moderate
26. You help patient to understand his/her own feelings by reflecting patient's feelings.	3.25	1.245	Moderate

Questions	Mean	S.D.	Level
27. You provide caring with confidence.	4.34	0.756	High
28. You closely observe patient's abnormal physical conditions.	4.30	0.814	High
29. You can observe patient's grief and anxiety by face and eyes expression.	4.15	0.871	High
30. You provide flexible caring schedule when patient needs.	3.72	1.129	Moderate
31. You consult the specialist to manage with patient's complication.	3.53	1.168	Moderate
32. You provide caring gently.	4.48	0.693	High
33. You let patient express his/her feeling about the treatment.	4.17	0.913	High
34. You stay with the patient when he/she is suffering with agony.	4.05	0.930	High
35. You provide caring without disgusting.	4.38	0.953	High
36. You help patient to succeed in his/her important things when patient alive.	3.79	1.193	Moderate
37. You help patient to participate to other patients who have the same problems.	3.24	1.329	Moderate
38. You provide patient occasion to do whatever patient pleases.	3.96	0.911	Moderate
39. You are interested to find the thing that is belief or hope of the patient.	3.58	1.096	Moderate
40. You provide patient's rightfulness to the choice of treatment regarding to patient's belief.	3.97	1.115	Moderate
41. You observe patient's feelings while providing caring.	4.14	0.819	High

Questions	Mean	S.D.	Level
42. You establish good relationship and feelings between patient and multidisciplinary care team.	4.10	0.889	High
43. You immediately respond to patient's needs.	4.05	0.840	High
44. You always give patient possible hopefulness.	3.59	1.177	Moderate
45. You directly talk with the patient about his/her feelings.	3.64	1.164	Moderate

From table 11, the highest mean score of the provision of palliative care is in “You provide caring gently” (\bar{x} =4.48, S.D. = 0.693). The lowest mean score of the provision of care is in “You provide patient the conversation about the aims of life and the life after death.” (\bar{x} =2.80, S.D. =1.350).

To answer the research question and to investigate hypothesis of the study, the Mann-Whitney test and the Kruskal-Wallis test are used to assess the difference of the median score of the test in each variable. The results of the test are in the table 12-13

Table 12: The result of the difference of the median score of the variable and the provision of palliative care test. Used the Mann-Whitney test. ($p > 0.05$)

Sample Characteristic	N	Mean Rank	Test value	P value
Gender				
Male	8	97.50	744.00	0.469
Female	219	14.60		

From table 12, The result of the difference of the median score of provision of palliative care in male and female, test value is 744.00, P value is 0.469 ($p > 0.05$) which means the median score of provision of palliative care in male and female is not significantly different at α is 0.05 ($p > 0.05$).

Table 13: The result of the difference of the median score of the variable and the palliative care knowledge test. Used the Kruskal-Wallis test test. ($p < 0.05$)

Sample Characteristic	N	Mean Rank	χ^2	df	P value
Age					
18-24 yrs.	44	114.43	1.338	4	0.855
25-35 yrs.	113	115.30			
36-45 yrs.	45	114.40			
46-55 yrs.	22	101.86			
56-60 yrs.	3	141.83			
Position of work					
Doctor	6	133.75	12.462	5	0.029
Nurse	120	120.79			
Practical nurse	88	110.18			
Nurse assistant	1	193.00			
Pharmacist	5	63.70			
Physical therapist	7	53.43			
Religion					
Buddhist	199	114.42	0.066	1	0.797
Christian	28	111.02			
Muslim	-	-			
Others	-	-			
Work experience					
< 5 yrs.	87	118.89	2.375	5	0.795
5-10 yrs.	55	109.35			
11-15 yrs.	32	122.70			
16-20 yrs.	25	101.64			
21-25 yrs.	18	108.19			
>25 yrs.	10	110.55			
Palliative care education					
Never	73	93.90	15.389	3	0.002
< 1 yr.	44	132.05			
1-5 yrs.	70	110.34			
> 5 yrs.	40	137.24			
Palliative care experience					
Never	26	90.83	3.852	3	0.278
< 1 yr.	43	120.40			
1-5 yrs.	71	117.34			
> 5 yrs.	86	113.74			

From table 13, The result of the difference of the median score of provision of palliative care in the participants with different position of work has Chi-square value of 12.462, df is 5 and p value is 0.029 ($p < 0.05$) and the participants with different palliative care education has Chi-square value of 15.389, df is 3 and p value is 0.002 ($p < 0.05$). It could be examine that there are significant differences of the median score

of provision of palliative care test in the participants with different position of work and different palliative care education at α is 0.05 ($p < 0.05$).



Chapter 5

Discussion and Conclusion

This chapter will focus on the result interpretation, the discussion of the consequences, limitation of the study and recommendation for further study.

5.1. Palliative care knowledge

Although in this study, most participants have never had palliative care education (n=73, 32.2%) or have palliative care education less than 5 years (n=70, 30.8%), they had good knowledge ($\bar{x} = 18.97$, S.D. =2.11). The lowest score of knowledge test was 8 and the highest score was 23. Most participants knew about the principle of palliative care and symptom management but had answered incorrectly about palliative care in patients with heart disease (n=111, 49.1%). From these results, it can be discussed that healthcare providers have knowledge about the broad principle of palliative care and symptom management but have lack of knowledge in palliative care for patients with non-cancer, life-limiting and chronic illness. It is because some disease such as congestive heart failure and chronic obstructive pulmonary disease are long term limitation with intermediate serious episodes. The condition of the illness does not predictable. Patients might die in a short period of time or would be better if patients have some medical investigations or interventions. The symptom management in these disease is also different from cancer. Healthcare providers might not determine exactly to provide curative or palliative care. This is conform from the study of Ziehm.et.al (2016)^[95] about palliative care for patients with heart failure. The author have found that healthcare providers have lack of knowledge about content and measure about palliative care, poor communication, unclear responsibilities of role and difficulty about initiate palliative care for patients with heart failure.

For the factors of healthcare providers' demography that influences the level of palliative care knowledge, It could be examined that there are significant differences of the median score of palliative care knowledge test in the participants with different age ($\chi^2 = 10.006$, df = 4, p= 0.04) and different position of work ($\chi^2 = 19.680$, df = 5 and p =0.001) at α is 0.05 (p < 0.05). From these results, it could be discussed that position of work and age have influenced palliative knowledge. For the position of work, doctors and nurses play the main role in palliative care. Doctors provide medical treatments, discuss with patients and families about prognosis and explore the goal of care. Nurses have the closest relationship with patients and families because nurses provide nursing care and be with patients and families most of time. Doctors and nurses have been trained about symptom management and the principle of palliative care in their medical and nursing education, therefor they can apply to patients who need palliative care in patients. Pharmacists and physical therapists are the multidisciplinary care team who

can also provide palliative care for the patients. Pharmacists manage the drug administration and physical therapists provide the physical therapy to relieve pain and other distress symptom. However there are some probable gap in palliative care knowledge of the healthcare providers. Fadare et.al.(2014)^[96] defined that different healthcare providers defined the principle of palliative care differently. Pharmacist more likely defined palliative care as pain management than doctor and nurse. Doctor defined incorrectly that palliative care is about geriatric medicine. Nurse more likely defined palliative care is about prolonged life. Thus each healthcare provider have palliative care knowledge differently accordingly to their roles.

For the age of healthcare providers, it could be discussed that when people get older, they would get more intelligence. Knowledge could grow when experience increases. It is tacit knowledge that people can improve when they have more experience or training in skill. Healthcare providers have to care various patients who have various needs. They have to learn about how to care their patients for the best clinical outcomes. Symptoms management is one of the thing that healthcare providers should know and be trained to provide for all patients, not only for who need palliative care. Moreover, when people get older, they have more different points of view, caring patients who have chronic incurable diseases may complicate. Some medical treatments do not gain benefit and make patients suffering, Therefore healthcare providers should learn about palliative care that help patients more comfort and improve outcomes of caring. It conforms from the study of Poka(2009)^[97]. The author found that the perception of cultural congruent end-of-life care were different between age and nurses who were older had more perception in cultural congruent end-of-life than the younger nurse.

5.2. Perception of palliative care

From the results of the study, healthcare providers' perception in palliative care is in moderate level ($\bar{x} = 3.69$, S.D. = 0.324). In their perception, the aspects that had the most effect to palliative care were ethic and legal issues ($\bar{x} = 4.18$, S.D. = 0.648) and organization and policy ($\bar{x} = 4.17$, S.D. = 0.584). If we consider in subscale sequences, healthcare providers mainly agreed that palliative care should be provided by multidisciplinary care team ($\bar{x} = 4.35$, S.D. = 0.622) and there are policies or guidelines to assist delivery of palliative care in their workplace ($\bar{x} = 4.24$, S.D. = 0.728). The least agreeing of palliative care in healthcare providers is that palliative care is against the value of medical treatments ($\bar{x} = 2.58$, S.D. = 0.886) and knowledge and training ($\bar{x} = 3.35$, S.D. = 0.361). For these consequences, we can discuss that organization and its policies have the major influence for healthcare providers. Organization would provide policies to improve clinical outcome and gain more clients' satisfaction which responds accordingly to national health policies or quality assurance institute. Organization would provide supportive facilities or systems that assist multidisciplinary care team to care for patients. For the best quality outcomes, multidisciplinary care team should

work together because palliative care is the holistic care. Patients and families should need support in physical, psychological and spiritual care. Only doctor or nurse does not complete successfully care. It needs help for other supportive system to achieve goal of care.

For the least perception of palliative care, healthcare providers perceive that palliative care is against the value of medical treatments which conform accordingly to the perception that ethic and legal issues influence the provision of care. It can be discussed that healthcare provider have learnt to cure or care patients for the best clinical outcomes which have aims for patients to be healthy or cure from the illness but the principle of palliative care is not for to cure but to relieve pain or suffering. Insufficient palliative care knowledge and training affect healthcare providers misunderstanding the concept, being worried and do not confident to provide appropriate care for patients. Patients with chronic incurable diseases receive aggressive medical treatments instead of palliative care because healthcare providers' duty is saving live. If healthcare providers do not provide aggressive care, it will be against the principle of medical terms, ethical or legal issues. Patients and families may perceive that healthcare provider abandoned them and induce sue later. Thus adequate palliative care knowledge and training is essential to avoid these problems.

5.3. Perception of decision making

From this study, perception of decision making in healthcare providers is in high level ($\bar{x} = 4.16$, S.D. = 0.462). The participants mainly agreed that palliative care should have jointly established between patients and family and healthcare team ($\bar{x} = 4.37$, S.D. = 0.583). They had the lowest agreeing in "Palliative care should be the one caring option to provide for patient who has frequent times of cardiac arrest" ($\bar{x} = 3.64$, S.D. = 0.893). For these consequences, we can discuss that palliative care is the dynamic participation between patients and families and multidisciplinary care team. To explore and success the goal of care, the cooperation between patients and families and healthcare team should be established especially for the patients with chronic incurable diseases and have occasional serious exacerbation condition as congestive heart failure. Patients with these conditions need palliative care in the same level of patients with cancer but it is difficult for healthcare providers for coping with because it is complicated to predict the prognosis or plan for medical treatments. Patients and families might want to express their worry or fears but the study of Wilkinson (1991)^[98] and Farrell (1992)^[99] found that many healthcare providers have difficulties in communication. The appropriate communication is important to less the conflict between patients or families and healthcare team. It also relieve emotional tension about fears or dying. It should be occurred frequently especially when the condition change significantly or prone to deteriorate.

5.4. Provision of care

From the study, the behavior of healthcare providers to the provision of palliative care is in high level ($\bar{x} = 3.92$, S.D. =0.670). The highest mean score of the provision of care according to Watson's carative factors is in "Humanistic-altruistic system of value" ($\bar{x} = 4.23$, S.D. = 0.687) and the lowest mean score of the provision of care is in "Transpersonal teaching-learning" ($\bar{x} = 3.28$, S.D. = 1.420). If it is considered in subscale sequences, the behavior that healthcare providers mainly performed is providing care gently ($\bar{x} =4.48$, S.D. = 0.693) but less performed in providing conversation about the aims of life and the life after death with patient ($\bar{x} =2.80$, S.D. =1.350).

Jean Watson (2007)^[100] had developed The Theory of Caring which emphasizes on the relationship between caring giver and receiver that always represent as healthcare providers and patients or families. In this theory describes that both caring giver and receiver could feel the power of caring from each other that includes physical, psychological and spiritual aspects. The Theory of caring contains ten carative factors. From the result of the study, healthcare providers reached the highest mean score in formation humanistic-altruistic system of value. It includes kindness, empathy, concern and love for self and others. It is the basic value of human caring and provide the best performance of care. Provide caring gently is in this factor as well. This factor is the most common that all healthcare providers should have and care for one another as human being.

Healthcare providers in this study reached the lowest mean score in Watson's theory of caring "Transpersonal teaching-learning". For this carative factor, its meaning is that learning is not only getting some information but we have to learn something from the others. It also involves the relationship between caring giver and receiver as a teacher for each other. This factor needs readiness and timeliness to achieve the transpersonal teaching-learning but sometimes healthcare providers cannot spend adequate times for patients and family because their workload. It also need communication skill to getting information but in some sensitivity topic as death is difficult conversation. As the lowest mean score of the sequence items is healthcare providers provide patient the conversation about the aims of life and the life after death. In Thailand, according to the culture, death is very sensitive although it is natural event of life. Healthcare providers who have been trained for curing the illness feel uncomfortable to talk about death with patients or family that is against their expectation and hope.

For the factors of healthcare providers' demography that influences the level of provision of palliative care, It could be examined that there are significant differences of the median score of provision of palliative care test in the participants with different position of work ($\chi^2=12.462$, df =5 and p = 0.029) and different palliative care education ($\chi^2=15.389$, df =3 and p =0.002) (p < 0.05). It can be discussed that work has influence provision of palliative care. Healthcare providers who have different position

of works provide palliative care differently. Nurses spend more time caring for patients and families than other healthcare team member and theory of caring is the basic value of nursing practice which should be applied to all patients including palliative care patients.

5.5. Limitation of the study

This study has aim to explore knowledge, perception and provision of palliative care of healthcare providers with different position of work. Some parts of the questionnaires adapted from the palliative care test for some kinds of work as nurses and physical therapist. Thus the researcher had to adjust the contents of the questionnaire to usable for all healthcare provider.

5.6. Recommendation for further study

In this study, there were some interesting notices. For the perception of palliative care in healthcare providers, organization and policies were the most influence for the provision of care to patients and families. Policies has purposes to specify the direction of provision of care. It is important to interpret the policies into plan, monitoring and evaluation of care and distribute the policies to all healthcare providers. One of the most important policies that organization should establish is the policies about human resource management. It includes the human development of knowledge and skill in palliative care and respect for human dignity that would gain more ethical and moral awareness and avoid conflict about misunderstanding of medical treatments between patients and families and healthcare providers.

There were other interesting remarks, for the knowledge of healthcare providers in palliative care in patients with non-cancer, life- limiting and chronic disease especially patients with heart disease, chronic obstructive pulmonary disease or cerebrovascular disease, in this study it was found that healthcare providers have limited palliative care knowledge for them. It is because these diseases are difficult to predict of the prognosis. It is important for healthcare providers to increase their education both in curative and palliative knowledge and practice more communication skills to inform patients and families about benefits, risks and burdens of disease and treatments. It is to avoid of conflicts between patients and families and healthcare providers and decrease the useless of treatments sources. Moreover, healthcare providers should practice communication skills to explore patients and families' needs. It is important for decision making and establish the proper planning to reach patients and families' goal of care and their best quality of life.

For the healthcare providers, in this study, it is interesting that nurses have lower mean rank values of palliative knowledge test than other healthcare providers despite nurses have the closest relationship with patients and families. This result should be apply for palliative care education and training program to improve their knowledge

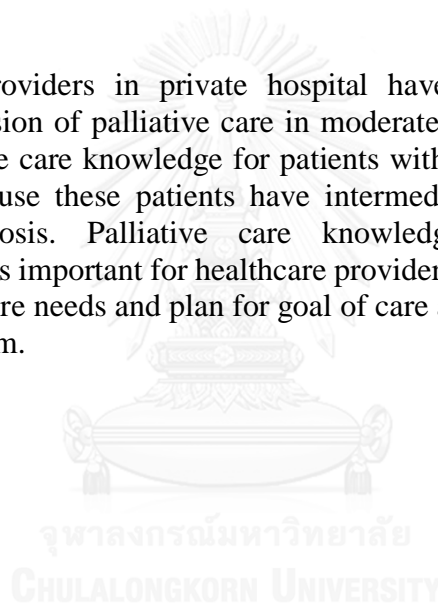
and skills so that nurses can encourage other healthcare providers to provide efficient caring for the best quality palliative care outcomes.

Some groups of participants in this study were small. Qualitative study is suggested to be an alternative study for exploring the actual attitudes and perceptions in palliative care. The results of the study could apply for development for palliative care program.

This study should be applied for other kinds of healthcare institutes as public hospital or medical institution to assess knowledge, perception and provision of palliative care.

5.7. Conclusion

Healthcare providers in private hospital have palliative care knowledge, perception and provision of palliative care in moderate or high level. However, they have lack of palliative care knowledge for patients with non-cancer, life-limiting and chronic disease because these patients have intermediated serious exacerbation or difficulty in prognosis. Palliative care knowledge and training especially communication skill is important for healthcare providers to cope with the patients and families. It is to explore needs and plan for goal of care and provide the best quality of palliative care for them.



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APPENDIX

จุฬาลงกรณ์มหาวิทยาลัย
CHULALONGKORN UNIVERSITY

Appendix A- Questionnaires (English)

Questionnaires for surveying of healthcare providers' knowledge and perception in the provision of palliative care with non-cancer, life-limiting, chronic disease in the private hospital in Bangkok.

Part 1 Sample characteristics

Please write “√” in the form that is mostly same of your characteristics.

1. Gender: Male Female
2. Age: 18-24 yrs. 25-35 yrs. 36- 45 yrs. 46- 55 yrs. 56-60 yrs.
3. Position of work:
 - Doctor
 - Registered nurse
 - Practical nurse
 - Nurse assistants
 - Pharmacologist
 - Physical therapist
4. Religion: Buddhist Christian Muslim Others:.....
5. Working experience:
 - Less than 5 years
 - 5-10 years
 - 11-15 years
 - 16-20 years
 - 21-25 years
 - More than 25 years
6. Palliative care education:
 - Never
 - Less than 1 year
 - 1-5 years
 - More than 5 years
7. Palliative care experiences:
 - Never
 - Less than 1 year
 - 1-5 years
 - More than 5 years

Part 2 the Questionnaire about palliative care knowledge

Please select “true” if the following statement is true and “False” if the following statement is false and write “✓” in the blank space.

No.	Question	True	False	Researcher
1	Palliative care provides relief from pain and other distressing symptoms.			
2	Palliative care considers life and regards dying as a complicated natural process.			
3	Palliative care intends to hasten or postpone death.			
4	Palliative care integrates the physical, psychological, social and spiritual aspects of patient care.			
5	Palliative care offers a support system to help patients die as early as possible.			
6	Palliative care offers a support system to help family cope during the patient’s illness.			
7	Palliative care help family members to adjust of the grief in their own bereavement.			
8	Healthcare providers in palliative care team will assess and provide counseling to patient and family individually.			
9	Palliative care will not enhance quality of life.			
10	Palliative care does not influence the course of illness.			
11	Palliative care is applicable early in the course of illness			
12	Palliative care should combine with other therapies that are intended to relief pain and suffering, such as chemotherapy or radiation therapy, and patient needed to understand and manage distressing clinical complications.			

No.	Question	True	False	Researcher
13	Palliative care should be only provided for patients who have no curative treatment available.			
14	Long-timed use of Morphine in palliative care often induces addiction.			
15	Use of morphine does not influence survival time.			
16	There is no route except central venous or skin patch for patient unable to maintain a peripheral intravenous route.			
17	The typical illness trajectories can aid healthcare providers to discuss with patients and their families about the prognosis and to plan the proper provision of care.			
18	Patients with chronic obstructive pulmonary disease (COPD) need less palliative care than patients with lung cancer need.			
19	The end-of-life discussion in patients with terminal state of heart failure may be a source of fear and anxiety for either patients or families.			
20	The provision of fiber diet and adequate fluid intake and appropriate activities such as exercise would relief constipation.			
21	Alternative therapies such as musical therapy, meditation, pet therapy, health promotion program and changing patient's room environment cannot relief psychological problem as well as medication.			
22	Patient has right to indicate advance directive or living will to inform healthcare provider to provide medical treatments as patient's desires when end-of-life time comes.			
23	In Thailand, Euthanasia is illegal.			

Part 3 the questionnaire about perception of palliative care about healthcare providers' role and barriers in palliative care.

Please select "true" if the following statement is true and "False" if the following statement is false and write "✓" in the blank space.

No.	Question	Level of opinion					Resear cher
		strongly agree	agree	neutra l	disagree	strongly disagree	
1	Palliative care is as important as curative care in patients with non-cancer, life-limiting and chronic illness.						
2	I have had experiences of providing palliative care to dying patients and families.						
3	I feel a sense of personal failure when patient dies.						
4	There is support for palliative care for non-cancer, life-limiting and chronic illness patient in society.						
5	The healthcare staffs support palliative care for patients with non-cancer, life-limiting and chronic illness in my workplace.						
6	The environment of my workplace is ideal for providing palliative care to the patient and family.						
7	My workplace is adequately staffed for providing the needs of non-cancer, life-limiting and chronic illness patients requiring palliative care and their families.						
8	In my workplace, families/relatives are involved in decisions about their patients.						

No.	Question	Level of opinion					Researcher
		strongly agree	agree	neutral	disagree	strongly disagree	
9	My previous experiences of providing palliative care to dying patients have been rewarding.						
10	When patients are dying in my workplace, providing pain relief is a priority for me.						
11	I am often exposed to death in my workplace environment.						
12	Palliative care is necessary in healthcare education.						
13	When a patient dies in my workplace, I have sufficient time to spend with the family.						
14	There are policies or guidelines to assist in the delivery of palliative care in my workplace.						
15	In my workplace, when a diagnosis with a likely poor outcome is made, patients/ relatives are informed of palliative care options.						
16	In my workplace, the team expresses its options, values and beliefs about providing palliative care to patients.						
17	Caring for dying patient is traumatic for me.						
18	I have received education that assists me to support and communicates with patients/relatives of dying patients.						

No.	Question	Level of opinion					Researcher
		strongly agree	agree	neutral	disagree	strongly disagree	
19	All members of the healthcare team in my workplace agree with and support palliative care when it is implemented for dying patient.						
20	In my workplace, the staffs go beyond what they feel comfortable with in using technological life support.						
21	In my workplace, staffs are asked by patients/relatives to continue life-extending care beyond what they feel is right.						
22	My personal attitudes about death affect my willingness to deliver palliative care.						
23	Palliative care is against the value of medical treatments.						
24	When a patient dies in my workplace, counseling is available if I need it.						
25	There is a belief in society that patients should not die, under any circumstances.						
26	Curative care is more important than palliative care in the healthcare environment.						
27	Palliative care should be provided by multidisciplinary care team.						
28	As a member of healthcare team, I know my exact role in support of palliative care.						

No.	Question	Level of opinion					Researcher
		strongly agree	agree	neutral	disagree	strongly disagree	
29	Patients/relatives who have financial problems should be offered palliative care as an option.						
30	I have concerned about ethical dilemma and ethical issues to provide palliative care to my patient and family.						

Part 4 the questionnaire about perception of decision making of palliative care.

Please select “true” if the following statement is true and “False” if the following statement is false and write “✓” in the blank space.

No.	Question	Level of opinion					Researcher
		strongly agree	agree	neutral	disagree	strongly disagree	
1	The goal of palliative care decision making is to meet patient’s wishes and needs by choosing appropriate treatments.						
2	If my patient is unable to expresses his/her needs according to illness condition, I will accept relatives to make decision for patient’s treatments instead.						
3	I have respected for patient’s beliefs, values and life plans although those are different from mine.						
4	Gentle truth-telling and exchange of accurate information about illness status, options, plan care and future expectation is essential for decision making.						
5	If patient and family have to deal with financial affair, they still have full capacity to make their own decision of caring.						

No.	Question	Level of opinion					Resear cher
		strongly agree	agree	neutral	disagree	strongly disagree	
6	Palliative care should be the one caring option to provide for patient who has frequent times of cardiac arrest.						
7	When patient is diagnosed incurable disease, he/she should be informed the choices of either life-prolongation or non-life prolongation care.						
8	Palliative care is necessary in either life prolongation or non-life prolongation goal of cares.						
9	Renegotiation of goal of care should occur if the patient's condition changes significantly.						
10	Goal of care should be established jointly by patient and family together with healthcare team.						

Part 5 The questionnaire about the provision of palliative care

Please write “√” in the blank space of the following statements that correspond to your agreement of the palliative care.

Choose: “Never” if the following item you have never done it.

“Seldom” if the following item you have done less than 2 times per week

“Often” if the following item you have done 2-4 times per week

“Usually” if the following item you have done 5-7 times per week

“Always” if the following item you have done more than 7 times per week.

No.	Question	Level of opinion					Resear cher
		Always	Usually	Often	Seldom	Never	
1	You cooperate with family to prepare patient's physical, psychological and spiritual conditions before the patient is						

No.	Question	Level of opinion					Researcher
		Always	Usually	Often	Seldom	Never	
	transferred to die at home as he/she desired.						
2	You clean up and neat environment of patient's room.						
3	You always give patients comfort care.						
4	You let patient do some expected successful activities or task.						
5	You give patient complement when he/she try to do some activities by himself/herself.						
6	You advice family to always come visit patient.						
7	You afford family to participate in caring the patient.						
8	You give family a chance to express their anxiety or fear.						
9	You give patient a chance to join spiritual or religious activities according to his/her belief.						
10	You introduce yourself before giving care to the patient.						
11	You stay with the patient when he/she is dying.						
12	You promote patient to explore the value of past successful or impressive						

No.	Question	Level of opinion					Researcher
		Always	Usually	Often	Seldom	Never	
	experiences of patient's life.						
13	You define patient's good points and his/her environment.						
14	You provide patient the conversation about the aims of life and the life after death.						
15	You inform patients before giving care all the time.						
16	You do not quicken doing caring activities for the patient.						
17	When the patient speaks, you listen to him/her carefully.						
18	You behave to the patient with friendly manner.						
19	You listen or talk about patient's belief even it contrast to your belief.						
20	You provide caring to the patient by conversation and touching.						
21	You give patients the promise in what you can actually do.						
22	You stay calm with the patient even he/she undesirably behaves.						
23	You give patient a chance to express his/her feelings both positive and negative way.						

No.	Question	Level of opinion					Researcher
		Always	Usually	Often	Seldom	Never	
24	You do not blame patient if he/she express their feeling of guilty in his/her past.						
25	You advice patient to forgive himself/herself to the mistakes in the past.						
26	You help patient to understand his/her own feelings by reflecting patient's feelings.						
27	You provide caring with confidence.						
28	You closely observe patient's abnormal physical conditions.						
29	You can observe patient's grief and anxiety by face and eyes expression.						
30	You provide flexible caring schedule when patient needs.						
31	You consult the specialist to manage with patient's complication.						
32	You provide caring gently.						
33	You let patient express his/her feeling about the treatment.						
34	You stay with the patient when he/she is suffering with agony.						
35	You provide caring without disgusting.						

No.	Question	Level of opinion					Resear cher
		Always	Usually	Often	Seldom	Never	
36	You help patient to succeed in his/her important things when patient alive.						
37	You help patient to participate to other patients who have the same problems.						
38	You provide patient occasion to do whatever patient pleases.						
39	You are interested to find the thing that is belief or hope of the patient.						
40	You provide patient's rightfulness to the choice of treatment regarding to patient's belief.						
41	You observe patient's feelings while providing caring.						
42	You establish good relationship and feelings between patient and multidisciplinary care team.						
43	You immediately respond to patient's needs.						
44	You always give patient possible hopefulness.						
45	You directly talk with the patient about his/her feelings.						

Appendix B - Questionnaires (Thai)

แบบสอบถาม

เรื่อง

“ความรู้และการรับรู้ของบุคลากรทางการแพทย์เกี่ยวกับการดูแลแบบประคับประคองในผู้ป่วยโรคเรื้อรังที่ไม่ใช่ มะเร็งและมีระยะเวลาของการมีชีวิตจำกัดในโรงพยาบาลเอกชนในกรุงเทพฯ”

เรียน ผู้ตอบแบบสอบถาม

แบบสอบถามฉบับนี้เป็นส่วนหนึ่งของการทำวิทยานิพนธ์ ข้อมูลที่ได้จากท่านจะเป็นประโยชน์อย่างยิ่งต่อการทำวิจัย ซึ่งผลจากการทำวิจัยนี้จะเป็นประโยชน์อย่างยิ่งต่อการพัฒนาการจัดระบบการดูแลผู้ป่วยแบบประคับประคอง คำชี้แจงต่อการทำแบบสอบถามมีดังนี้

1. แบบสอบถามนี้ประกอบด้วย 5 ตอน คือ

1.1 ตอนที่ 1 แบบสอบถามข้อมูลส่วนบุคคล

1.2 ตอนที่ 2 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับความรู้ในการดูแลผู้ป่วยแบบประคับประคอง จำนวน 23 ข้อ

1.3 ตอนที่ 3 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับการรับรู้ในด้านบทบาท สิ่งอำนวยความสะดวก และอุปสรรคของการดูแลผู้ป่วยแบบประคับประคอง จำนวน 30 ข้อ

1.4 ตอนที่ 4 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับการรับรู้ในด้านการตัดสินใจในการแนะนำผู้ป่วยและญาติในการดูแลผู้ป่วยแบบประคับประคอง จำนวน 10 ข้อ

1.5 ตอนที่ 5 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับการให้การดูแลผู้ป่วยแบบประคับประคอง จำนวน 45 ข้อ

2. ผู้วิจัยขอรับรองว่า จะเก็บรักษาข้อมูลไว้เป็นความลับ ผลการวิจัยจะนำเสนอในลักษณะภาพรวมเพื่อประโยชน์เชิงวิชาการเท่านั้น จะไม่ก่อให้เกิดผลเสียต่อท่านหรือหน่วยงานของท่านแต่อย่างใด

3. แบบสอบถามนี้ ผู้ตอบคือ แพทย์ พยาบาลวิชาชีพ พยาบาลผู้ช่วย ผู้ช่วยพยาบาล เกษัตริกร และนักกายภาพบำบัด ที่มีอายุระหว่าง 18-60 ปี กรุณาอ่านคำชี้แจงก่อนตอบคำถามและกรุณาตอบทุกข้อคำถาม เพื่อให้ได้คำตอบที่สมบูรณ์ อันจะเป็นประโยชน์อย่างยิ่งสำหรับการวิเคราะห์ที่ได้จริง ผู้วิจัยขอความกรุณาส่งแบบสอบถามกลับที่ฝ่ายการพยาบาล ภายใน 1 สัปดาห์ หลังจากท่านได้รับแบบสอบถามเรียบร้อยแล้ว

ดิฉันหวังเป็นอย่างยิ่งว่าจะได้รับความร่วมมือจากท่านเป็นอย่างดี และขอขอบพระคุณอย่างสูงมา ณ โอกาสนี้

ขอแสดงความนับถือ

น้ำผึ้ง ปรัชญาคุณ

(นางสาวน้ำผึ้ง รัชญาคุณ)

นิสิตหลักสูตรสาธารณสุขศาสตรมหาบัณฑิต

วิทยาลัยวิทยาศาสตร์สาธารณสุข จุฬาลงกรณ์มหาวิทยาลัย

คำถามสำหรับวิจัยเรื่อง “ความรู้และการรับรู้ของบุคลากรทางการแพทย์เกี่ยวกับการดูแลแบบประคับประคองในผู้ป่วยโรคเรื้อรังที่ไม่ใช่มะเร็งและมีระยะเวลาของการมีชีวิตจำกัดในโรงพยาบาลเอกชนในกรุงเทพฯ”

ตอนที่ 1 ข้อมูลทั่วไปของผู้ตอบแบบสอบถาม

คำชี้แจง กรุณาทำเครื่องหมาย “✓” ในข้อที่ตรงกับตัวท่านมากที่สุด

1. เพศ: ชาย หญิง
2. อายุ: 18-24 ปี 25-35 ปี 36- 45 ปี 46- 55 ปี 56-60 ปี
3. อาชีพ:
 - แพทย์
 - พยาบาลวิชาชีพ
 - พยาบาลผู้ช่วย
 - ผู้ช่วยพยาบาล
 - เกสเซอร์
 - นักกายภาพบำบัด
4. ศาสนา: พุทธ คริสต์ อิสลาม อื่นๆ ระบุ.....
5. ประสบการณ์การทำงาน:
 - ต่ำกว่า 5 ปี
 - 5-10 ปี
 - 11-15 ปี
 - 16-20 ปี
 - 21-25 ปี
 - มากกว่า 25 ปีขึ้นไป
6. ระยะเวลาของการศึกษาด้านการดูแลผู้ป่วยแบบประคับประคอง:
 - ไม่เคยได้รับการศึกษาด้านการดูแลผู้ป่วยแบบประคับประคอง
 - น้อยกว่า 1 ปี
 - 1-5 ปี
 - มากกว่า 5 ปี
7. ประสบการณ์การดูแลผู้ป่วยแบบประคับประคอง
 - ไม่เคยดูแลผู้ป่วยแบบประคับประคอง
 - น้อยกว่า 1 ปี
 - 1-5 ปี
 - มากกว่า 5 ปี

ตอนที่ 2 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับความรู้ในการดูแลผู้ป่วยแบบประคับประคอง จำนวน 30 ข้อ
คำชี้แจง กรุณาเลือก “ถูก” หากท่านคิดว่าข้อคำถามที่กำหนดให้ถูกต้อง และเลือก “ผิด” หากท่านคิดว่าข้อคำถามที่
 กำหนดให้ผิด และทำเครื่องหมาย “✓” ลงในช่องว่าง

ลำดับ	ข้อคำถาม	ถูก	ผิด	ผู้วิจัย
1	การดูแลแบบประคับประคองมีจุดประสงค์เพื่อช่วยบรรเทาความเจ็บปวดและอาการ ไม่สุขสบายอื่นๆ			
2	การดูแลแบบประคับประคองถือว่าการตายเป็นกระบวนการทางธรรมชาติที่อยู่ยาก ซับซ้อน			
3	การดูแลแบบประคับประคองมีเจตนาเพื่อเร่งรัดหรือยืดการตาย			
4	การดูแลแบบประคับประคองเป็นการบูรณาการการดูแลทั้งด้านร่างกาย จิตใจ สังคม และจิตวิญญาณ			
5	การดูแลแบบประคับประคองเป็นการดูแลที่ช่วยให้ผู้ป่วยเสียชีวิตโดยเร็วที่สุดเท่าที่จะ เป็นไปได้			
6	การดูแลแบบประคับประคองช่วยให้ครอบครัวผู้ป่วยสามารถเผชิญปัญหาเกี่ยวกับความ เจ็บป่วยของผู้ป่วยได้			
7	การดูแลแบบประคับประคองเป็นการดูแลที่ช่วยให้ครอบครัวผู้ป่วยสามารถปรับตัว ได้ภายหลังการเสียชีวิตของผู้ป่วย			
8	บุคลากรในทีมสุขภาพที่ดูแลผู้ป่วยแบบประคับประคอง จะประเมินและให้คำปรึกษา ผู้ป่วยและครอบครัวตามความต้องการที่จำเป็นแต่ละราย			
9	การดูแลแบบประคับประคองจะไม่เพิ่มคุณภาพชีวิตผู้ป่วยให้ดีขึ้น			
10	การดูแลแบบประคับประคองไม่มีผลต่อการดำเนินโรคของผู้ป่วย			
11	สามารถประยุกต์การดูแลแบบประคับประคองได้ตั้งแต่ระยะแรกของความเจ็บป่วย			
12	สามารถประยุกต์การดูแลแบบประคับประคองร่วมกับการรักษาอื่นๆเช่นการทำเคมี บำบัด การรักษาด้วยรังสี เป็นต้น เพื่อจัดการกับอาการ ไม่สุขสบายต่างๆ โดย จำเป็นต้องต้องให้ผู้ป่วยเข้าใจการรักษาและการจัดการเมื่อเกิดภาวะแทรกซ้อน			
13	การดูแลแบบประคับประคองใช้ในการดูแลผู้ป่วยที่ไม่มีการรักษาที่มุ่งการหายจาก โรคนั้น			
14	การใช้ยาในกลุ่ม กลุ่มมอร์ฟีน เพื่อการดูแลแบบประคับประคองมักจะทำให้ผู้ป่วยเกิด อาการติดยา			

ลำดับ	ข้อความ	ถูก	ผิด	ผู้วิจัย
15	การใช้ยากลุ่ม มอร์ฟีน ไม่มีผลต่ออัตราการรอดชีวิตของผู้ป่วย			
16	ในกรณีที่ไม่สามารถให้ยาทางหลอดเลือดดำส่วนปลายได้ จำเป็นต้องให้ยาทางหลอดเลือดดำส่วนกลาง / แผ่นแปะ			
17	ความเข้าใจต่อการดำเนินโรคของผู้ป่วย ช่วยให้บุคลากรทางการดูแลสามารถสื่อสารถึงการพยากรณ์โรคและการวางแผนการดูแลที่เหมาะสม			
18	ผู้ป่วยที่เป็นโรคปอดอุดกั้นเรื้อรัง (Chronic Obstructive Pulmonary Disease: COPD) ต้องการการดูแลแบบประคับประคองน้อยกว่าผู้ป่วยโรคมะเร็งปอด			
19	การประชุมปรึกษาเพื่อการดูแลผู้ป่วยโรคหัวใจระยะท้ายอาจเป็นสาเหตุหนึ่งที่ทำให้ผู้ป่วยและญาติเกิดความกลัวและความวิตกกังวล			
20	การจัดอาหารที่มีกากใยและให้ผู้ป่วยดื่มน้ำในปริมาณที่เพียงพอ รวมทั้งการเพิ่มกิจกรรมบางอย่างเช่นการออกกำลังกาย สามารถบรรเทาอาการท้องผูก			
21	การบำบัดทางเลือกอื่นๆเช่นการใช้ดนตรีบำบัด การทำสมาธิ การบำบัดด้วยสัตว์เลี้ยง การจัดโปรแกรมการส่งเสริมสุขภาพ และการเปลี่ยนสิ่งแวดล้อมในห้องผู้ป่วย ไม่สามารถช่วยบรรเทาปัญหาด้านจิตใจ เช่นความวิตกกังวล และภาวะซึมเศร้าของผู้ป่วยระยะท้ายได้ดีเท่ากับการใช้ยา			
22	ผู้ป่วยมีสิทธิทำหนังสือแสดงเจตนาไม่ขอรับบริการทางการแพทย์ (Living will) เพื่อให้บุคลากรทางการแพทย์ปฏิบัติตามเมื่อระยะสุดท้ายของชีวิตมาถึง			
23	สำหรับประเทศไทยในปัจจุบัน การทำการุณยฆาตเป็นสิ่งผิดกฎหมาย			

ตอนที่ 3 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับการรับรู้ในด้านบทบาท สิ่งอำนวยความสะดวก และอุปสรรคของการดูแลผู้ป่วยแบบประคับประคอง จำนวน 30 ข้อ

คำชี้แจง กรุณาทำเครื่องหมาย “✓” ลงในช่องว่างหลังข้อความที่ตรงกับความคิดเห็นของท่านตามความเป็นจริงที่สุดเพียงข้อเดียว

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		เห็นด้วยที่สุด	เห็นด้วย	ไม่แน่ใจ	ไม่เห็นด้วย	ไม่เห็นด้วยที่สุด	
1	การดูแลผู้ป่วยแบบประคับประคองในผู้ป่วยที่ไม่เป็นมะเร็งและมีข้อจำกัดในการมีชีวิตจากการป่วยเรื้อรังมีความสำคัญเท่ากับการดูแลที่มุ่งการรักษาให้หายจากโรค						
2	ฉันมีประสบการณ์การดูแลผู้ป่วยและครอบครัวในช่วงเวลาที่ผู้ป่วยกำลังจะเสียชีวิต						
3	ฉันรู้สึกล้มเหลวเมื่อผู้ป่วยที่ฉันดูแลเสียชีวิต						
4	ในชุมชนของฉันมีการสนับสนุนช่วยเหลือในการดูแลแบบประคับประคองในผู้ป่วยที่ไม่ใช่มะเร็งและมีการจำกัดของชีวิตด้วยโรคเรื้อรัง						
5	บุคลากรทีมสุขภาพในที่ทำงานของฉันมีการช่วยเหลือดูแลผู้ป่วยแบบประคับประคองต่อผู้ป่วยซึ่งไม่ได้เป็นมะเร็งที่มีภาวะจำกัดของชีวิตและเจ็บป่วยด้วยโรคเรื้อรัง						
6	สภาพแวดล้อมที่ฉันทำงานเอื้ออำนวยต่อการดูแลผู้ป่วยและครอบครัวแบบประคับประคอง						
7	หน่วยงานของฉันมีบุคคลที่เพียงพอในการดูแลผู้ป่วยและครอบครัวแบบประคับประคอง						
8	ในหน่วยงานของฉัน ครอบครัวและผู้ใกล้ชิดผู้ป่วยมีส่วนร่วมในการตัดสินใจในการดูแลผู้ป่วย						
9	ประสบการณ์การดูแลผู้ป่วยแบบประคับประคองจนถึงเสียชีวิตเป็นเหมือนรางวัลในการทำงานของฉัน						
10	การดูแลผู้ป่วยที่กำลังจะเสียชีวิตในหน่วยงานของฉันถือว่าการจัดการความเจ็บปวดเป็นเรื่องสำคัญ						
11	ในหน่วยงานของฉันมักมีผู้ป่วยเสียชีวิตเสมอ						
12	การดูแลแบบประคับประคองเป็นเรื่องที่จำเป็นในระบบการศึกษาด้านสุขภาพ						

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		เห็นด้วยที่สุด	เห็นด้วย	ไม่แน่ใจ	ไม่เห็นด้วย	ไม่เห็นด้วยที่สุด	
13	เมื่อผู้ป่วยเสียชีวิตในหน่วยงานของฉันทัน ให้เวลากับครอบครัวของผู้ป่วยอย่างเพียงพอ						
14	หน่วยงานของฉันทัน มีนโยบายหรือแนวปฏิบัติเพื่อสนับสนุนการดูแลแบบประคับประคอง						
15	ในที่ทำงานของฉันทัน ผู้ป่วยและครอบครัวจะได้รับข้อมูลการดูแลแบบประคับประคองเป็นทางเลือกเมื่อผู้ป่วยได้รับการวินิจฉัยที่มีแนวโน้มผลลัพธ์ที่ไม่ดี						
16	ในที่ทำงานของฉันทัน ทีมการดูแลสามารถเสนอ ทางเลือก ค่านิยม และความเชื่อในการดูแลผู้ป่วยแบบประคับประคองแก่ผู้ป่วยได้						
17	การดูแลผู้ป่วยที่กำลังจะเสียชีวิตเป็นสิ่งที่เจ็บปวดสำหรับฉันทัน						
18	ฉันทันมีความรู้ในการสื่อสารกับผู้ป่วยและครอบครัวเกี่ยวกับการเสียชีวิตของผู้ป่วย						
19	สมาชิกทีมสุขภาพในที่ทำงานของฉันทันเห็นด้วยและสนับสนุนฉันทันในการดูแลผู้ป่วยแบบประคับประคอง						
20	บุคลากรในที่ทำงานของฉันทันรู้สึกมั่นใจในการใช้เทคโนโลยีเพื่อช่วยชีวิตผู้ป่วย						
21	ในหน่วยงานของฉันทัน การยืดอายุผู้ป่วยให้ยาวที่สุดเป็นสิ่งที่ถูกต้องในการดูแลแบบประคับประคอง						
22	ทัศนคติของฉันทันเกี่ยวกับความตายที่ผลต่อความรู้สึกยินดีที่จะดูแลผู้ป่วยแบบประคับประคอง						
23	หลักการดูแลแบบประคับประคองขัดแย้งต่อค่านิยม ของหลักการรักษาของแพทย์						
24	ในที่ทำงานของฉันทัน มีบริการให้คำปรึกษาตามต้องการเมื่อมีผู้ป่วยเสียชีวิต						
25	ในสังคมเชื่อว่าผู้ป่วยไม่ควรเสียชีวิต ไม่ว่าจะกรณีใดก็ตาม						
26	ในสิ่งแวดล้อม การดูแลสุขภาพ การดูแลเพื่อการหายมีความสำคัญมากกว่าการดูแลแบบประคับประคอง						
27	การดูแลแบบประคับประคองควรเป็นการดูแลร่วมกัน โดยทีมสหสาขาวิชาชีพ						

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		เห็นด้วยที่สุด	เห็นด้วย	ไม่แน่ใจ	ไม่เห็นด้วย	ไม่เห็นด้วยที่สุด	
28	ในฐานะที่เป็นสมาชิกในทีมการดูแลด้านสุขภาพ ฉันรับรู้บทบาทหน้าที่ที่แท้จริงของฉันในการให้การดูแลแบบประคับประคอง						
29	ควรเสนอทางเลือกการดูแลแบบประคับประคองในกรณีผู้ป่วยมีปัญหาเศรษฐกิจ						
30	ฉันตระหนักในประเด็นจริยธรรมในการดูแลผู้ป่วยและญาติแบบประคับประคอง						

ตอนที่ 4 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับการรับรู้ในด้านการตัดสินใจในการแนะนำผู้ป่วยและญาติในการดูแลผู้ป่วยแบบประคับประคอง จำนวน 10 ข้อ

คำชี้แจง กรุณาทำเครื่องหมาย “✓” ลงในช่องว่างหลังข้อความที่ตรงกับความคิดเห็นของท่านตามความเป็นจริงที่สุดเพียงข้อเดียว

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		เห็นด้วยที่สุด	เห็นด้วย	ไม่แน่ใจ	ไม่เห็นด้วย	ไม่เห็นด้วยที่สุด	
1	เป้าหมายของการตัดสินใจเลือกแนวทางการดูแลรักษาที่เหมาะสมในการดูแลแบบประคับประคองคือการตอบสนองความปรารถนาและความต้องการที่จำเป็นของผู้ป่วยให้เหมาะสม						
2	ฉันยอมรับการตัดสินใจของครอบครัวผู้ป่วยในกรณีที่ผู้ป่วยไม่อยู่ในสถานการณ์ที่ตัดสินใจได้ด้วยตนเอง						
3	ฉันเคารพในความเชื่อ คุณค่า และแบบแผนชีวิตของผู้ป่วย แม้ว่ามันจะแตกต่างจากความเชื่อ คุณค่าและแบบแผนชีวิตของฉัน						
4	การบอกความจริงเกี่ยวกับสภาวะการเจ็บป่วยแบบค่อยเป็นค่อยไป ทางเลือก แผนการรักษา และความคาดหวังในอนาคต เป็นสิ่งสำคัญสำหรับผู้ป่วยและครอบครัวในการตัดสินใจการรักษา						

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		เห็นด้วยที่สุด	เห็นด้วย	ไม่แน่ใจ	ไม่เห็นด้วย	ไม่เห็นด้วยที่สุด	
5	เมื่อผู้ป่วยและครอบครัวประสบปัญหาเกี่ยวกับการระงับชีพจร พวกเขาก็ยังคงมีสามารถเลือกและตัดสินใจในการรักษาของพวกเขาเองได้อย่างเต็มที่						
6	การดูแลแบบประคับประคองควรเป็นทางเลือกหนึ่งที่ใช้ในการดูแลผู้ป่วยที่มีภาวะหัวใจวายบ่อยครั้ง						
7	เมื่อผู้ป่วยได้รับการวินิจฉัยว่าเป็นโรคที่รักษาไม่หาย เขาควรจะได้รับข้อมูลเกี่ยวกับทางเลือกในการรักษา ทั้งการรักษาเพื่อเป็นการยืดชีวิตและการรักษาที่ไม่เป็นการยืดชีวิต						
8	การดูแลแบบประคับประคองเป็นสิ่งจำเป็น ทั้งในจุดประสงค์ของการรักษาเพื่อยืดชีวิต และการรักษาที่ไม่เป็นการยืดชีวิต						
9	การเจรจาขึ้นเพื่อหาจุดมุ่งหมายของการรักษา ควรกระทำเมื่อภาวะความเจ็บป่วยของผู้ป่วยมีการเปลี่ยนแปลงอย่างมีนัยสำคัญ						
10	การตั้งจุดมุ่งหมายในการดูแลควรกระทำร่วมกันระหว่างผู้ป่วยและครอบครัวรวมทั้งทีมสุขภาพ						

ตอนที่ 5 แบบสอบถามบุคลากรด้านสุขภาพเกี่ยวกับการให้การดูแลผู้ป่วยแบบประคับประคอง จำนวน 45 ข้อ
คำชี้แจง กรุณาทำเครื่องหมาย “✓” ลงในช่องว่างหลังข้อความที่ตรงกับความคิดเห็นของท่านตามความเป็นจริงที่สุด
 เพียงข้อเดียว

กรุณาเลือก: “ไม่เคย” เมื่อท่าน ไม่เคยกระทำตามข้อความดังกล่าว
 “นานๆครั้ง” เมื่อข้อความดังกล่าว ท่าน ได้กระทำตามต่ำกว่า 2 ครั้งต่อสัปดาห์
 “บางครั้ง” เมื่อข้อความดังกล่าว ท่าน ได้กระทำตาม 2-4 ครั้งต่อสัปดาห์
 “บ่อยครั้ง” เมื่อข้อความดังกล่าว ท่าน ได้กระทำตาม 5-7 ครั้งต่อสัปดาห์
 “สม่ำเสมอ” เมื่อข้อความดังกล่าว ท่าน ได้กระทำตามมากกว่า 7 ครั้งต่อสัปดาห์

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		สม่ำเสมอ	บ่อยครั้ง	บางครั้ง	นานๆครั้ง	ไม่เคย	
1	เมื่อผู้ป่วยต้องการกลับไปใช้ชีวิตที่บ้าน ท่านได้ร่วมมือกับครอบครัวในการเตรียมความพร้อมแก่ผู้ป่วยด้านร่างกาย จิตใจ และจิตวิญญาณก่อนที่จะย้ายผู้ป่วยกลับบ้าน						
2	ท่านจัดสิ่งแวดล้อมในห้องผู้ป่วยให้เหมาะสมกับการดูแลแบบประคับประคอง						
3	ท่านให้การดูแลเพื่อความสุขสบายของผู้ป่วย						
4	ท่านยอมให้ผู้ป่วยได้กระทำกิจกรรมบางกิจกรรมที่คาดว่าผู้ป่วยจะกระทำด้วยตนเองได้สำเร็จ						
5	ท่านชื่นชมผู้ป่วยเมื่อผู้ป่วยสามารถทำกิจกรรมได้ด้วยตนเอง						
6	ท่านแนะนำให้ครอบครัวมาเยี่ยมผู้ป่วยอย่างสม่ำเสมอ						
7	ท่านส่งเสริมให้ครอบครัวมีส่วนร่วมในการดูแลผู้ป่วย						
8	ท่านเปิดโอกาสให้ครอบครัวของผู้ป่วยแสดงออกถึงความวิตกกังวลหรือความกลัว						
9	ท่านเปิดโอกาสให้ผู้ป่วยได้มีส่วนร่วมในการทำกิจกรรมทางจิตวิญญาณหรือศาสนาตามความเชื่อของเขา						
10	ท่านแนะนำตนเองก่อนให้การดูแลผู้ป่วย						

ลำดับ	ข้อคำถาม	ระดับความคิดเห็น					ผู้วิจัย
		สม่ำเสมอ	บ่อยครั้ง	บางครั้ง	นานๆ ครั้ง	ไม่เคย	
11	ท่านเปิดโอกาสให้ครอบครัวและคนสำคัญของผู้ป่วยอยู่กับผู้ป่วยที่กำลังจะเสียชีวิตโดยท่านสนับสนุนอยู่ใกล้ๆ						
12	ท่านส่งเสริมให้ผู้ป่วยได้สำรวจถึงคุณค่าความสำเร็จในอดีต หรือ ประสบการณ์ที่น่าประทับใจในชีวิตของเขา						
13	ท่านสามารถให้ความหมายถึงข้อดีของผู้ป่วยและสิ่งแวดล้อมของเขาได้						
14	ท่านเปิดการสนทนากับผู้ป่วยถึงจุดหมายของชีวิตและชีวิตหลังความตาย						
15	ท่านแจ้งผู้ป่วยรับรู้ก่อนการปฏิบัติการการดูแล						
16	ท่านไม่เร่งรีบในการปฏิบัติการการดูแล						
17	ท่านรับฟังผู้ป่วยด้วยความยินดีและตั้งใจ						
18	ท่านปฏิบัติต่อผู้ป่วยด้วยท่าทีที่เป็นมิตร						
19	ท่านรับฟังหรือพูดคุยกับผู้ป่วยเกี่ยวกับความเชื่อของเขาแม้ว่าจะขัดแย้งกับความเชื่อของท่าน						
20	ท่านดูแลผู้ป่วยด้วยการสนทนาและสัมผัส						
21	ท่านให้ความสำคัญกับผู้ป่วยในสิ่งที่ท่านสามารถจะกระทำได้						
22	ท่านอยู่ในท่าที่สงบแม้ว่าผู้ป่วยจะแสดงอาการที่ไม่พึงประสงค์ออกมา						
23	ท่านเปิดโอกาสให้ผู้ป่วยได้แสดงความรู้สึกทั้งทางบวกและทางลบ						
24	ท่านไม่กล่าวโทษผู้ป่วยเมื่อผู้ป่วยแสดงความรู้สึกผิดในอดีตที่ผ่านมา						

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		สม่ำเสมอ	บ่อยครั้ง	บางครั้ง	นานๆ ครั้ง	ไม่เคย	
25	ท่านแนะนำให้ผู้ป่วยยกโทษให้ตนเองสำหรับความผิดพลาดในอดีต						
26	ท่านช่วยให้ผู้ป่วยสามารถเข้าใจความรู้สึกของตนเองโดยใช้เทคนิคการสะท้อนความรู้สึกของผู้ป่วย						
27	ท่านดูแลผู้ป่วยด้วยความมั่นใจ						
28	ท่านสังเกตอาการความคิดปกติทางร่างกายของผู้ป่วยอย่างใกล้ชิด						
29	ท่านสามารถสังเกตความโศกเศร้าและความวิตกกังวลของผู้ป่วยทางสีหน้าและแววตาได้						
30	ท่านจัดตารางการดูแลผู้ป่วยให้ยืดหยุ่นตามความต้องการที่จำเป็นของผู้ป่วย						
31	ท่านขอคำปรึกษาจากผู้เชี่ยวชาญเพื่อจัดการกับภาวะแทรกซ้อนของผู้ป่วย						
32	ท่านดูแลผู้ป่วยด้วยความนุ่มนวล						
33	ท่านเปิดโอกาสให้ผู้ป่วยได้แสดงความรู้สึกเกี่ยวกับการรักษา						
34	ท่านอยู่กับผู้ป่วยเมื่อผู้ป่วยรู้สึกทุกข์ทรมาน						
35	ท่านดูแลผู้ป่วยโดยปราศจากความรู้สึกรังเกียจ						
36	ท่านช่วยให้ผู้ป่วยประสบความสำเร็จในสิ่งสำคัญของเขา ในช่วงเวลาที่ผู้ป่วยยังมีชีวิตอยู่						
37	ท่านช่วยให้ผู้ป่วยมีปฏิสัมพันธ์กับผู้ป่วยคนอื่นๆที่ประสบปัญหาแบบเดียวกัน						
38	ท่านเปิดโอกาสให้ผู้ป่วยได้กระทำในสิ่งที่ผู้ป่วยพึงพอใจ						
39	ท่านสนใจที่จะค้นหาสิ่งที่เป็นความเชื่อหรือความหวังของผู้ป่วย						

ลำดับ	ข้อความ	ระดับความคิดเห็น					ผู้วิจัย
		สม่ำเสมอ	บ่อยครั้ง	บางครั้ง	นานๆ ครั้ง	ไม่เคย	
40	ท่านให้สิทธิผู้ป่วยในการเลือกการรักษาตามความเชื่อของเขา						
41	ท่านสามารถรับรู้ความรู้สึกของผู้ป่วยขณะดูแลผู้ป่วยได้						
42	ท่านสร้างสัมพันธภาพและความรู้สึกที่ดีระหว่างผู้ป่วยและทีมสหสาขาวิชาชีพ						
43	ท่านตอบสนองความต้องการที่จำเป็นของผู้ป่วยในทันที						
44	ท่านให้ความหวังที่เป็นไปได้แก่ผู้ป่วยเสมอ						
45	ท่านพูดคุยกับผู้ป่วยเกี่ยวกับความรู้สึกของเขาโดยตรง						

ขอขอบพระคุณอย่างสูงในความกรุณาตอบแบบสอบถาม

Appendix C- The name list of thesis experts

Name of experts	Work and Expertise
Dr. Panta Apiruknapanond, Ph.D.	<ul style="list-style-type: none"> - Lecturer of Master degree of Nursing Science and Bachelor degree in Nursing, Saint Louis College. - Had Palliative and End-of-Life Training course, St. Christopher-QELCA program, Cicely Saunders Institute, London, UK, 2016. - Volunteer for promoting palliative and end of life care for nurses, Thai Nurses' palliative and EOL Club.2014-2016
Asst. Prof. Capt. Dr. Wasinee Wiserith, Ph.D.	<ul style="list-style-type: none"> - Lecturer of Faculty of Nursing, Chulalongkorn University, Thailand. - Written some articles about palliative care in Thailand.
Pol. Col. Nantiya Sujirattanavimol, M.D.	<ul style="list-style-type: none"> - Anesthetist of Police General Hospital, Thailand - Counselor of palliative care program in Police General Hospital, Thailand



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หนังสือรับรองจริยธรรมการวิจัย

โครงการวิจัยเรื่อง HEALTHCARE PROVIDERS' KNOWLEDGE AND PERCEPTION IN THE PROVISION OF PALLIATIVE CARE IN PATIENTS WITH NON-CANCER LIFE-LIMITING CHRONIC DISEASE IN THE PRIVATE HOSPITAL IN BANGKOK

หัวหน้าโครงการวิจัย นางสาวน้ำผึ้ง ปรัชญาคุณ

สังกัดหน่วยงาน คณะสาธารณสุขศาสตร์ วิทยาลัยวิทยาศาสตร์สาธารณสุข จุฬาลงกรณ์มหาวิทยาลัย

เลขที่รับรอง E. 025/2559

โครงการวิจัยเรื่องนี้ได้รับความเห็นชอบจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ วิทยาลัยเซนต์หลุยส์ โดยได้ผ่านการพิจารณาการวิจัยในมนุษย์แบบเร่งรัด เรียบร้อยแล้ว

ให้ไว้ ณ วันที่ 28 ตุลาคม 2559

(ดร.ชูเกียรติ จากใจชน)

ปฏิบัติหน้าที่แทนประธานคณะกรรมการจริยธรรมการวิจัย
วิทยาลัยเซนต์หลุยส์

เมตตากรุดมาอยู่ที่นี่ใด พระเจ้าสถิตที่นั่น
Wherever compassion exists God exists

VITA

Miss Numpueng Prachyakoon was born on July 1,1981 in Bangkok, Thailand. Her nationality is Thai. She was graduated for the Bachelor degree of Nursing from Saint Louis College in 2004. She was trained and certificated for Nursing specialty short course program for critical care from Faculty of medicine Ramathiboi Hospital Mahidol University in 2010. For her current woking position, she works as a registered nurse in intensive care unit, Saint Louis Hospital. Her email address is hunnsosweet@hotmail.com.



