

# 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, THAILAND

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## ABSTRACT:

**Background:** Although palliative care provides benefits to healthcare system, good management practice of palliative care is not broadly analyzed 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. Healthcare providers are expected to have more knowledge related to palliative care, good perception and provision of care to maintain patients' quality of life. This study aimed to describe the level and identify the most influential factors of healthcare providers to knowledge, perception and provision of palliative care.

**Method:** This study was a cross-sectional descriptive quantitative research based on surveying 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. In order to obtain all the formation, 227 health provides were participated in the data collection process.

**Result:** The average of sum scores of the participants was 19 meant they had good knowledge ( $\bar{x} = 18.97$ , S.D. = 2.11). However, most participants incorrectly answered on palliative care in patients with heart disease ( $n=111$ , 49.1%). The most influential factors of healthcare providers to the level of palliative care knowledge 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). 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 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). For the most influential factors of healthcare providers' demography to the level of provision of palliative care significantly were position of work ( $p = 0.029$ ) and palliative care education ( $p = 0.002$ ) ( $p < 0.05$ ).

**Conclusion:** 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 the needs and also policy planning to provide good quality of palliative care.

**Keywords:** Palliative care (PC); Palliative care knowledge; Perception of palliative care; Provision of palliative care; Healthcare providers (HCP)

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## INTRODUCTION

Palliative care (PC) aims to improve patients and their families' quality of life when facing any

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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]. PC is becoming one of the major public health issues due to the increasing number of world population due to the development of technologies. People would live longer up to 65 years old and the world tends to be an aging society. Aging population burden with chronic illness, such as heart disease, stroke, diabetes, dementia etc. Those factors caused disability, suffer from pain or depression and lack quality of life. Several researches [2-7] have defined the effectiveness of PC are associated with reduction in use of non-benefit ICU treatments and length of ICU stay, reduce family anxiety, distress and posttraumatic stress disorder after 3 months patient's death and/or conflict over the care goal. Although PC could gain benefits of healthcare system, the good management of PC is not broadly done to all kinds of illnesses.

Not only patients with cancer but patients with chronic illnesses as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), dementia or cerebrovascular disease [8, 9] 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. Patients with chronic illnesses are characterized by uncertainty of illness trajectories, uncertainty in progress and extended disease timelines and stresses [10]. PC should be applied for those patients from the early process of care but, generally, PC 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.

Knowledge is an important factor to success in the goal of PC. This consequently improves the outcomes of healthcare for the patients in several kinds of chronic and terminal stage of illness [11, 12]. Although many medical educational institutions contain palliative care as a subject for the medical students, many healthcare providers (HCP) have inadequate palliative knowledge for providing care in terminal illness patients [13]. Other researches [14, 15] found that HCP have lack of knowledge and skill training are the barriers to provide PC. Some physicians has limited experiences in PC as well. The PC program should be improved in term of continuity of medical education program as a key of

health care policies.

The provision of PC should be integrated by interdisciplinary care team. Previous researches [16-18] defined that the appropriate PC from the HCP could improve health service outcomes both in the patients and the caregivers. However, the particular concerns in providing PC in patients with non-malignant, life-threatening disease are the longer course of disease and their less predictable in illness trajectory [19]. 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 [20]. Moreover, there are other sensitive obstacles for HCP in PC; for example, the ethical and legal dilemma in PC is controversy among HCP, 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 [21]. Sometimes, patients are given many medical procedures in the terminal stage of illness which are not helpful, hasten life and oppose to their desires. HCP should have knowledge to give appropriate care to relief suffering, understand the patients' preference and forgive conflict [22]. These issues would challenge physicians and care team to provide proper PC related to the needs of patients and families.

Although PC is considered as one of the most important public health issues, there were rare formal studies on knowledge and perception of HCP in Thailand. The objective of this study is to describe the perception of PC in HCP in private hospital to provide proper PC in patients with chronic-illness, life-limiting disease. The results of this study could use to improve PC program, apply for PC education and provide continuity of PC to the community.

## **METHODS**

### **Design**

This study was a cross-sectional descriptive quantitative research based on surveying study to identify knowledge, perception and provision of PC by Thai HCP in private hospital to non-cancer, life-limiting and chronic illness patients.

### **Participants**

There were 236 healthcare practioners participated in the data collection process. Medical doctors,

registered nurses, technical nurses, nurse assistants, pharmacologist, physical therapists who worked in a private hospital in Bangkok, Thailand whose ages were between 18-60 years old and had work experiences at least for 1 year, were included. Medical specialist as surgeon, pediatric physicians, dentist were excluded. Study area was selected by using purposive sampling technique. The participants were selected by using the name list of healthcare providers who were suitable for the inclusion criteria, then the researcher chose the total numbers of sample size by calculating from Yamane's formula [23], then used the stratified random sampling technique to select the proportional size of participants divided by their occupations. Last but not least, the researcher used simple random sampling technique to recruit participants until the total number fits to the required sample sizes.

### Study instruments

The measurement tools were designed to answer research questions, which includes HCP knowledge level, perception and provision of PC in patients with non-cancer, chronic-illness and life-limiting disease are and what factors of HCP's demographics influence to knowledge, and provision of PC. The hypothesis of the study is HCP have low level of knowledge, perception and provision of PC and PC education is the most influential factor of HCP's demographics that effect to their knowledge and provision of PC.

The measurement tools of this surveying were questionnaires which divided into 5 sections for measuring HCP's knowledge, perception and provision of PC.

The tool for testing PC knowledge was adapted from the physical-therapy in palliative care-knowledge, attitudes, beliefs and experiences scale (PTiPC-KABE Scale), developed by Kumar, et al [24], the Palliative Care Knowledge Test (PCKT), developed by Nakazawa, et al. [25] and by reviewing of the literatures by the researcher. The questionnaire are included philosophy of PC and symptoms management. The researcher also added some questions about the trajectory of illness in the questionnaire to define HCP's knowledge of PC in the patients with non-cancer, life-limiting and chronic illness. This tool was 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 result of the test for reliability of the internal

consistency of this questionnaire was 0.708 which is acceptable. This part contains 23 questions and the answer is true or false.

The tool for testing perception of PC was developed by the researcher based on reviewing of literature and adapted from the PTiPC-KABE Scale. It is used to evaluate HCP's perception of PC. The contents in the questionnaire are included HCP's perception of PC which contain the aspects of healthcare organization and policy, knowledge and training, communication, facilities and teams, financial issues, ethic and legal issues and community. The Cronbachs' alpha coefficient was used to assess internal consistency. The result of the testing was 0.741 which was acceptable. There were 30 questions which all items were coded as Likert-type items scored on a five-point scales which were "strongly agree", "agree", "neutral", "disagree", "strongly disagree".

The tool for testing provision of PC modified from the Caring Behaviors for Dying Patient Scale (CDPs), developed by Daodee [26]. The Cronbachs' alpha coefficient was used to assess internal consistency. The result of the testing was 0.983 which was acceptable. There were 45 questions and all items were coded as Likert-type items scored on a five-point scales which were "never", "seldom", "often", "usually" and "always".

The questionnaires were sent to the 236 HCPs that distributed to various in-patient general wards or intensive care unit. To avoid bias and to maintain participant's autonomy, the researcher used coding and decoding during data collecting and analysis. Each questionnaire used at least 20-30 minutes to complete and it was sent back by enclosed envelope with the researcher's address written on.

### 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 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. Descriptive statistics as frequency and percentage were used to assess the sample characteristics of the participants and the participants' knowledge PC. Mean and standard deviation were used to assess the perception and the provision of PC.

**Table 1** The mean, standard deviation and level of the perception of PC, 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

### Ethical consideration

This study was approved for ethical conduct by the Ethical Committee of the Academic Institution. The approval code was E.025/2559 and approved on 28 October 2016. All participants were given explanation from the researcher and consented form was written. For the data collection, all participants were represented by coding and the results of this study were shown in statistical outcomes. The researcher would terminate the study if there were any evidences of harmfulness in physical or psychological consequences to the participants or there were claims of disrespectful of their confidentiality.

### RESULTS

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

The acquired sample size includes 219 female (96.5%) and 8 male participants (3.5%). Most participants aged between 25-35 years old (n=113, 49.8%). Registered nurses are the most numbers of participants (n=120, 52.9%), followed by practical nurses (n=88, 38.8%) and physical therapists (n=7, 3.1%). Buddhist is the majority characteristics of the participants (n=199, 87.7%). They had worked for less than 5 years (n=87, 38.3%) and had never had PC education (n=73, 32.2%). The participants who have PC education have had for 1-5 years (n=70, 30.8%). 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%).

#### The results of palliative care knowledge

For the results of PC knowledge, the

questionnaire contains 23 items on the principle of PC and symptom management. The average of sum knowledge scores of the participants was 19. The lowest score of knowledge test was 8, whereas the highest score was 23. Most participants had answered correctly about palliative care is the integration of the physical, psychological, social and spiritual aspects of care (n=225, 99.1%) and answered incorrectly about palliative care in patients with congestive heart failure (n=111, 49.1%). The factors of HCP's demographics that had the most influences to the level of palliative care knowledge statistical significantly were age (p= 0.04) and position of work (p =0.001) (p < 0.05).

#### The results of the perception of palliative care

The aspects that had the most effect to PC 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 PC should be provided by multidisciplinary care team ( $\bar{x}$  = 4.35, S.D. = 0.622). However, the aspect that had the least effect to PC was "knowledge and training" ( $\bar{x}$  = 3.35, S.D. = 0.361) and they had perceived that PC is against the value of medical treatments ( $\bar{x}$  = 2.58, S.D. = 0.886), Table 1.

#### The results of the provision of palliative care

The results of the provision of PC in HCP, according to Watson's curative factors of caring behavior in the theory of caring, had shown that 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 behavior that HCP 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), Table 2.

**Table 2** 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

For the factors of healthcare providers' demography that influences the level of provision of palliative care statistical significantly were position of work ( $p = 0.029$ ) and palliative care education ( $p = 0.002$ ) ( $p < 0.05$ ).

## DISCUSSION

### Palliative care knowledge

Although in this study, most participants have never had PC education ( $n=73$ , 32.2%) or have PC education less than 5 years ( $n=70$ , 30.8%), they had answered correctly the integration of the physical, psychological, social and spiritual aspects of care ( $n=225$ , 99.1%) but had answered incorrectly about PC in patients with heart disease ( $n=111$ , 49.1%). From these results, it can be discussed that HCP have knowledge about the broad principle of PC and symptom management but have lack of knowledge in PC for patients with non-cancer, life-limiting and chronic illness. It is because some disease such as CHF and COPD 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. HCP might not determine exactly to provide curative or palliative care. This is conforming from the study of Ziehm.et.al [27] about PC for patients with heart failure. The author have also found that HCP were lacking of knowledge on content as well as measurement of PC, poor communication, unclear responsibilities of role and difficulty about initiate PC for patients with heart failure.

For the factors of HCP's demography that influences the level of PC knowledge, 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 and nurses have been trained about symptom management and the principle of PC in their medical and nursing education, therefore they can apply to patients who need PC in patients. Pharmacists and physical therapists are the multidisciplinary care team who can also provide PC 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 PC knowledge of the healthcare providers. Fadare, et al. [28] defined that different HCP defined the principle of palliative care differently. Pharmacist more likely defined PC as pain management than doctor and nurse. Doctor defined incorrectly that PC is about geriatric medicine. Nurse more likely defined PC is about prolonged life. Thus each healthcare providers have some knowledge based on their role and responsibility.

For the age of HCP, it could be discussed that knowledge could be grown when experience increases. It is tacit knowledge that people are able to improve if they have more experience as well as training in term of skill. Symptoms management is one of the thing that HCP should know and be trained to provide for all patients, not only for who need PC.

### Perception of palliative care

From the results, the organization and its policies have the major influence for HCPs. Organization would provide policies to improve clinical outcome and gain more clients' satisfaction which responds accordingly to national health policies or quality assurance institute. For the best

quality outcomes, multidisciplinary care team should collaborate with PC. Only health practitioners are unable to effectively accomplish the PC's without the assistance of other supportive system.

For the perception of PC, it can be discussed that HCP 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 PC is not for to cure but to relieve pain or suffering. Insufficient PC knowledge and training affect HCPs 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 PC because HCP's duty is saving life. If HCP does not provide aggressive care, it will be against the principle of medical terms, ethical or legal issues. Patients and families may perceive that HCP abandoned them and induce sue later. Thus, adequate PC knowledge and training is essential to avoid these problems. To explore and achieve 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. Patients with these conditions need PC in the same level of patients with cancer but it is difficult for HCP 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 [29] and Farrell [30] found that many HCPs 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.

#### **Provision of care**

From the study, the provision of PC is in high level ( $\bar{x} = 3.92$ , S.D. = 0.670). HCP 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.

HCP in this study reached the lowest mean score in Watson's theory of caring [31]

“Transpersonal teaching-learning”. For this curative 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 HCP cannot spend adequate times for patients and family because their workload. It also needs 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 HCP provides 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. HCP who has 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 HCP's demography that influences the level of provision of PC, it can be discussed that work has influence provision of PC. HCP who has different position of work provide PC 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 PC patients. For the PC education, the theory of caring has been adapted for palliative education. HCP who has palliative care education would has known about the theory of caring and could be applied for their provision of care. It is also shown in this study that PC knowledge correlated to the provision of PC ( $t=0.261$ ,  $p= 0.000$ ) ( $p<0.05$ ). Thus, PC education is important to improve the outcome of the provision of care.

#### **CONCLUSION**

HCP in private hospital have PC knowledge, perception and provision of PC in moderate or high level. However, they have lack of PC knowledge for patients with non-cancer, life-limiting and chronic disease. PC knowledge and training especially communication skill is important for HCP to cope with the patients and families. It is recommended to explore needs and plan for goal of care and provide the best quality of PC for them.

#### **LIMITATION OF THE STUDY**

PC is becoming one of the major public health problems but the studies of PC is limited and do not broadly scope in various aspects. Studies of

perception and provision of PC are rare and needed to be reviewed from previous 10 years. Moreover, there is no study about healthcare providers' barriers in provision of PC in Thailand.

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