

# CHAPTER I

## INTRODUCTION

### A. Study Background

Palliative care is one of the treatments that is provided to the patients especially for patients who had been diagnosed with terminal health problem. Palliative care had been introduced to the medical world since 1990s. Today, palliative care had been seen as important as other departments such as medical department, surgical department and obstetrics and gynecology department. According to World Health Organization (WHO) (WHO, 2015), palliative care is:

An approach that improves the quality of life of patients and their families facing the problem associate with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”

The worldwide prevalence of palliative patients is increasing with the increase of ageing population and incidence of communicable and non-communicable diseases. As in 2008, 20,245,792 out of 54,591,143 deaths requires palliative care which is about 37%. It increases with 70.3% of deaths only caused by non-communicable diseases. For the patients with age above 70 years old, the prevalence living with cardiovascular disease increase to 53.7% while diagnosed with neoplasm is 86.3%. However, Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS) had been

reported decrease in number with 1.91 million cases to 1.03 million cases (Abajobir et al., 2017; Connor & Bermedo, 2014).

Both Malaysia and Indonesia also have an increase in the number of patients receive palliative care. Malaysia records ischemic heart disease which also categorized in cardiovascular diseases as the main cause of death since 2010 until 2012 with the increase in number of accidents from 25.6 % to 36.0% of deaths. Cancer which also enlists as the terminal health problem that in need for palliative care, records the increase in numbers with 11.1% to 15.0% of the deaths (MOH, 2011; World Health Organization, 2015). HIV and AIDS also increases in incidents. While Indonesia also reports that non communicable health problems is increasing. Stroke is the main cause of death in Indonesia since 1990s with the total increases' incident percentage 61.5% with average 2.7% per year. HIV and AIDS case reports also increase from 21.5% cases to 41.2% cases (Budijanto et al., 2017) .

The increment of terminal health problems causes the demand of in need palliative care increases. However, the facilities provided are unmet. Lim (2017) stated that World Palliative Care Alliance (WPCA) maps Indonesia's palliative care services in the third category which means isolated provision of palliative care with the development of palliative care is not well supported and limited in number compare to the size of population. While Malaysia has been mapped in fourth category which means palliative care services are in the mainstream medicine with various types of palliative care services, the awareness of the healthcare professionals and communities, the pain management services

available with morphine and other strong pain relieving medicine, policy has minimal impact to the services, available of training and education and have interest in the national palliative care association concept.

The limited of palliative care services can affect the late in palliative care management such as late in decision making. Decision making is required usually in the transition of the diseases' progress in order to change the goals of care (Docherty et al., 2012). A systematic review conducted by Visser, Deliens, & Houttekier (2014), 90 barriers for decision making in palliative care caused by physicians' lack of attitudes towards palliative patients, knowledge, practice, communication skills and confidence with their own judgment of the patient's condition and prognosis. Late in decision making can cause low in services' satisfaction either for the patients or family or the healthcare practitioners (McDonald et al., 2015; Zimmermann et al., 2014).

Decision making is one of the crucial process that every patient with life limiting health problems need to overcome. Decision making process is very important for them because they do not have much time to be treated with unnecessary and costly treatments. Fasten the decision making will fasten the palliative care management which will increase the level of satisfaction (Patel & Masi, 2015). Palliative care management will help in pain management, relief the sufferings and good death holistically (Attia et al., 2013). Promoting proper care technique to the patients can help them to have good quality end of life which then, help them in achieving the good end of life or *husnul khotimah*.

Usually patients, family and physician will involve in the decision making process which also known as shared decision making (Gramling et al., 2015). However, during the process, there will be difference perspectives and preferences (Caprio, 2016). Therefore, nurses can be the third party between the patients and physician, the family and physician and the patient and the family in helping them for the decision making (Adams et al., 2011).

Nurses facilitate the palliative patients and family with the information about palliative informally, while advocating and supporting the care (Broom et al., 2015). However, nurses being lack of confidence in initiating referral of palliative care, though they know much about the patients. The lack of confidence is due to less of opportunities given to the nurses in decision making as there is nurses –physician communication barriers (Kirby et al., 2014). The same situation also happens for palliative nurses in Malaysia and Indonesia. The nurses had been highlighted the roles in caring for the palliative patients, physically, psychologically, psychosocially and spiritually, but not the roles of nurses in decision making (Beng et al., 2015; Effendy et al., 2015).

## **B. Problem Statement**

Decision making process for nurses had been acknowledge as important because nurses-patient relationship is stronger than physician-patient relationship. Nurses should take action in order to help the patients, family and other healthcare providers especially physicians to make decision. From the early of effective discussion, early effective end of life care plan can be

produced and delivered to the patients that is preferred by the patients and their family.

Thus, what and how the nurses should exactly act effectively and efficiently organized in preparing and helping the palliative patients, family and physicians in decision making process? Are there any differences perspectives for palliative patients, family and physicians in Malaysia and Indonesia?

### **C. Research Objectives**

#### 1. General Objectives

To determine the nursing roles in preparing the palliative patients and family in decision making of palliative care plan in Indonesia and Malaysia.

#### 2. Specific Objectives

- a. To explore the nursing roles in preparing the palliative patients and family in decision making of palliative care plan in Indonesia and Malaysia.
- b. To explore the differences perspectives of palliative care decision making between the palliative patients and family in Indonesia and Malaysia.

### **D. Benefit of the Research**

This study is significant for the improvement of palliative care nursing especially in theoretical and practical area.

#### 1. Nursing Theoretical Area

This research may be able to provide theoretical guidance for nurses especially those who work in palliative care areas that usually deal with human end of life by providing the roles that nurses should play in helping the palliative patients and family to have good quality of end of life. Especially in dealing with the differences' perspectives of the palliative care.

## 2. Nursing Practical Area

This research may be able to highlight the nurses on skills that need to be trained in order to serve the palliative patients and family because breaking and handling bad news requires advanced skills especially communication skills. Effective communication skills are the basic of therapeutic method. Thus, the nurses will be able to handle the palliative patients and family on how to make decision in order to have good quality and peaceful end of life.

## **E. Related Research**

1. Chong, L., & Abdullah, A. (2015). Community Palliative Care Nurses' Challenges and Coping *American Journal of Hospice and Palliative Medicine*.

Method: Qualitative study

Result: For the challenges the nurses faced while dealing with palliative patients, are; 1) communication challenges, 2) inadequate training and knowledge, 3) personal suffering and 4) challenges of the system. While the coping mechanisms are; 1) intrapersonal coping skills, 2) interpersonal

coping strategies and 3) systemic support.

Similarity: Interview had been conducted to the palliative nurses in the community

Differences: The study had been conducted only to the palliative pediatric nurses. My study will explore the differences perspectives between the patients, family and physician and how the roles of nurses to settle the disagreements.

2. Gallagher, A., Bousso, R. S., McCarthy, J., Kohlen, H., Andrews, T., Paganini, M. C., ... Padilha, K. G. (2015). Negotiated reorienting: A grounded theory of nurses' end-of-life decision-making in the intensive care unit.

Method: Qualitative with grounded theory approached

Result: Negotiated reorienting may help in achieving the goal of palliative care services to provide comfortable and and good death. Negotiated reorienting can be achieved through consensus seeking and emotional holding.

Similarity: The differences between patients and physicians derives throughout the process of decision making.

Differences: The study had been done in Brazil, England, Germany, Ireland and Palestine which has different culture and environment with Malaysia and Indonesia.

3. Jerpseth, H., Dahl, V., Nortvedt, P., & Halvorsen, K. (2016). Nurses role and care practices in decision-making regarding artificial ventilation in late

stage pulmonary disease.

Method: Qualitative research design

Result: Nurses usually work in a cure-directed treatment culture which is unclear, unsatisfactory with the valued caring. Lack of interdisciplinary cooperation also can cause in reluctant for making decision.

Similarity: The study explore on how the nurses roles in making decision.

Differences: The study focuses on Chronic Pulmonary Obstructive Disorders (COPD) patients only.

4. Namasivayam, P., Lee, S., O'Connor, M., & Barnett, T. (2014). Caring for families of the terminally ill in Malaysia from palliative care nurses' perspectives.

Method: Qualitative with grounded theory approach

Result: Main problem for nurses to engage with the palliative patients' family is the different expectation in palliative care. Some of the strategies had been list down to help in enaging nurses with the palliative patients' family; 1) prepare the family for palliative care treatment, 2) modifying care and 3) staying engaged.

Similarity: The differences of perspectives about palliative care services derived from the interviews.

Differences: The study only had been done in Malaysia. My stud will compare between Malaysia nd Indonesia who has difference cultures and environment.

5. Walker, A., & Breitsameter, C. (2015). Ethical decision-making in hospice



care.

Method: Qualitative with grounded theory

Result: Nurses work in leeway but ethically relevant. However, nurses should work incorporate the holistically approach to the palliative patients.

Similarity: The roles of nurses in palliative care decision making

Differenes: The study focuses on the ethical problem in the palliative care services while my study will focus on how the nurses should act efficient and effectively to help patients, family and physician to make decision for palliative care treatment.

6. Kristanti, M. S., Setiyarini, S., & Effendy, C. (2017). Enhancing the quality of life for palliative care cancer patients in Indonesia through family caregivers: a pilot study of basic skills training.

Method: Prospective quantitative with pre and post-test design

Result: There is significant changes in the quality of end of life for patient with palliative care when their family as the caregivers have the basic knowledge about caring the palliative patients.

Similarity: The study also explore the family perspectives and basic skills of palliative patients care.

Differences: The study design of this study is quatitative while my study will be done qualitatively.