NURSE’S ROLES IN PATIENTS-FAMILY DECISION MAKING FOR PALLIATIVE PATIENTS IN INDONESIA AND MALAYSIA

EXECUTIVE SUMMARY

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 require 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%. Both Malaysia and Indonesia also has an increase in the number of patients receive palliative care. The limited of palliative care services especially for cancer patient can affect the late in palliative care management such as late in decision making. Decision making is one of the crucial process that every patients with life threatening health problems need to overcome. Usually patients, family and physician will involve in the decision making process which also known as shared decision making. However, during the process, there will be difference perspectives and preferences. 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.

The research objective is to explore the nursing roles in preparing the palliative patients and family in decision making of palliative care plan in Indonesia and Malaysia. The study will be conducted in qualitative method with the phenomenology approach. Purposive sampling will be used for the participants’ selection because it helps in selecting the participants who have a lot experience in the study area to be interviewed. The the sample size of this study will be 12 participants from two different study settings. Each study setting will recruit three palliative nurse and three physician. The study will be conducted within March until May 2020 at two places (PKU Muhammadiyah Yogyakarta Hospital (PKU) Indonesia and Tunku Fauziah Hospital (HTF) Malaysia. The data from the in depth interview will be transcribed and verbatim then it will be analyzed. This study will use thematic analysis data by using the interpretative phenomenology analysis (IPA). Approvals for this study will be sought from Ethical Committee of Universitas Muhammadiyyah Yogyakarta Indonesia and National Medical Research Register (NMRR). Then, the ethical clearance also should be gained from the ethical committee of

HTF and PKU. Then, verbal informed consent will be obtained from the participants before the interview's date appointed while on the date of the interview, the signed informed consent will be attained.

STUDY BACKGROUND

Palliative care is one of the treatment that is provided to the patients especially for patients who had been diagnosed with terminal health problem(1,2). 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 require 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%.

Both Malaysia and Indonesia also has 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 (3,4). 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 (5).

The increment of terminal health problems causes the demand of in need palliative care increases. However, the facilities provided are unmet. In 2011, World Palliative Care Alliance (WPCA) maps Indonesia's palliative care services in the third category which means isolated provision of palliative care (6,7). 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 (8).

The limited of palliative care services especially for cancer patient 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 (9). Decision making is one of the crucial process that every patients with life threatening health problems need to overcome. Fasten the decision making will fasten the palliative care management which will increase the level of satisfaction(10). 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(11). However, during the process, there will be difference perspectives and preferences (12). 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 (13). (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 (14). Other than that, nurses also have unclear role in decision making process which usually being neglected in the interdisciplinary decision making discussion (15). The same situation also happens for palliative nurses in Malaysia and Indonesia. Thus, the objective of this research is to explore the nursing roles in preparing the palliative patients and family in decision making of palliative care plan in Indonesia and Malaysia.

LITERATURE REVIEW

A. Palliative Care

Palliative care service's history begin in 19th century with the interest in organizing arrangement for end of life care which also known in older term as hospice care (16,17). The palliative care and hospice had different function during 21st century era (17). Palliative's care goals are to prevent and relieve the palliative patients' sufferings and providing support for the best quality of life for the patients and their family regardless of their stage of illnesses and therapies (18). This model of palliative care is the expansion of the traditional model where enhancing the quality of life threatening patients and their family by optimizing their function in the community become the goals of care. Then, helping them with decision making and providing the opportunities that may help in growing their personal values. The palliative care also involves the assessment and the treatment of symptoms, support the decision making and matching the treatment to the needs and the goals of care from the palliative patients and family. It is divided into three categories; primary, secondary and tertiary

(19).

The primary palliative care which also known as palliative approach level consists the involvement of all the general healthcare providers. This level provide the palliative patients meet their needs comprehensively and satisfactorily without referring to the specialists. The treatment also includes the discussion in making decision based on their preferences care to ensure they receives the holistic approach which including the pain assessment and advanced care plan with the basic of palliative care (16, 19, 20).

The secondary palliative care which also known as general palliative care where there is an involvement of expertise in treating life threatening diseases with good basic of palliative care for example oncologists and geriatrics (20). However, palliative care are not their main focus of services. This level of palliative care is available in the hospital settings and community settings.

While, the tertiary palliative care is a referral that involves the specialists of palliative care. This level of care is offered by proactively address the palliative patients' symptoms and the effects towards the patients and their caregiver and family quality of life (1,20). Consultation and care will be provided by the greater degree trained healthcare professionals to meet the needs of the palliative patients (21).

B. Decision Making

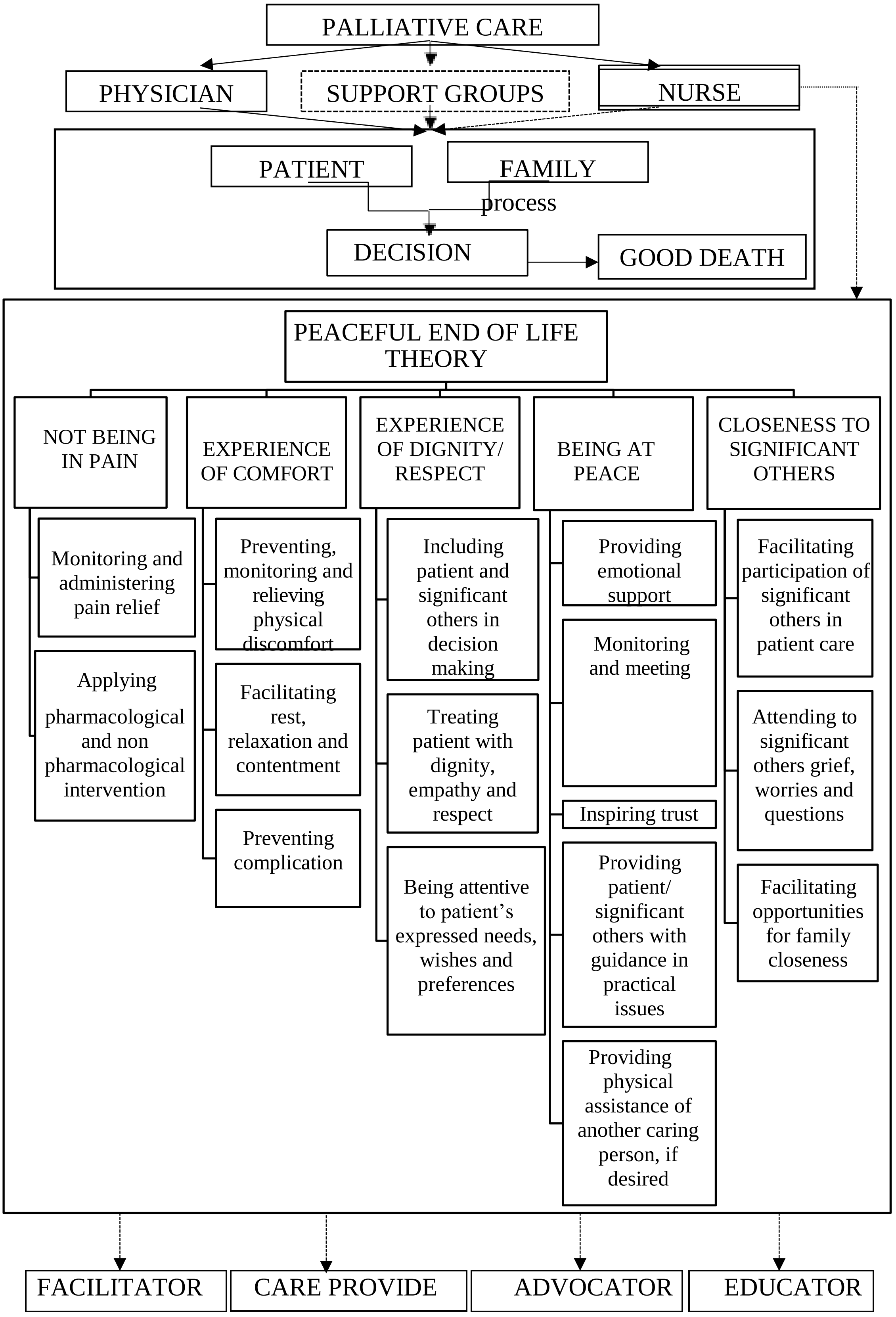
Decision making in palliative care is crucial because it involves symptoms-oriented care either it is provided based on demand or based on standard (22). Making decision for palliative care is very difficult because it involves the taboo words of 'giving up', 'giving in' and 'not fighting (23. Therefore, many cases which had been delays in confirming the decision reported.

Thus, in delivering the short prognosis of the dying patients to the patients and their family members requires good communication skills (24, 23, 19, 25). either it is among the healthcare providers or the communication between healthcare providers and the palliative patients and family. Other than communication skills, the consideration of the time for the discussion is also should not be overlooked (24).

Delaying in decision making will delay the assistance from the healthcare providers which then will affect the treatment that are unwanted, futile and costly (26, 27). The effect will not only shown within the palliative patients and healthcare providers but, it also affects the palliative family too, either it affects the physical or psychological or spiritual especially in the bereavement outcome (19).

As in Asian countries have multi cultures, the decision making process usually based on the patients culture. For example, in the Southeast Asian who mostly are Confucians preferred the physicians- patients decision making as the belief of a good doctor has a heart of a parent. While for Japanese, the preference is on family-physicians decision making (28). In Malaysian, the decision usually has been handled based on physicians' preferences. Some of the physicians prefer they make decision because they know the best about patients' condition and state. However, most of the physicians choose shared decision making as the method in decision making though it is still new in Malaysian medical environment. The physicians able to be facilitators and guidance for the palliative patients and family members (29). In Indonesia, there is no articles has been found discussing on the type of decision making used in the process. Malaysia and Indonesia is multicultural countries with different religions, races and beliefs. While, in the East Asian countries which involve the Japan, Taiwan and Korea, the autonomy in decision making had been given to the patients because it has been considered as the patients' right to decide (30).

C. Theoretical Framework



RESEARCH METHODOLOGY

The study will be conducted in qualitative method with the phenomenology approach. The phenomenology able to help in providing the data which is descriptive, reflective and interpretive from different real experience of different informants. Purposive sampling will be used for the participants' selection because it helps in selecting the participants who have a lot experience in the study area to be interviewed. Therefore, the collected data will be more explainable, explicable and justifiable. While for the sample size, it will be based on the saturation data that will be collected. Guest suggested that data can be saturated if the sample is more than twelve persons (31). Therefore, the sample size of this study will be 12 participants from two different study settings. Each study setting will recruit three palliative nurse and three physician.

For palliative nurses, the inclusion criteria should be; 1) has been a registered nurse with more than two years of working experience, 2) must have minimum of a diploma level of education as it is the basic qualification of a nurse and 3) able to speak either Bahasa Malaysia, or English, or Indonesia. While for the exclusion criteria, the palliative nurses does not received any palliative care training within six months of working.

For the physician recruitment, the inclusion criteria should be; 1) have working experience for more than two years and 2) able to speak either Bahasa Malaysia or English or Indonesia. However, for the physician who does not receive any palliative care training within six months of working will be excluded as the participant for this study. The study will be conducted within March until May 2020 at two places (PKU Muhammadiyah Yogyakarta Hospital (PKU) Indonesia and Tunku Fauziah Hospital (HTF) Malaysia.

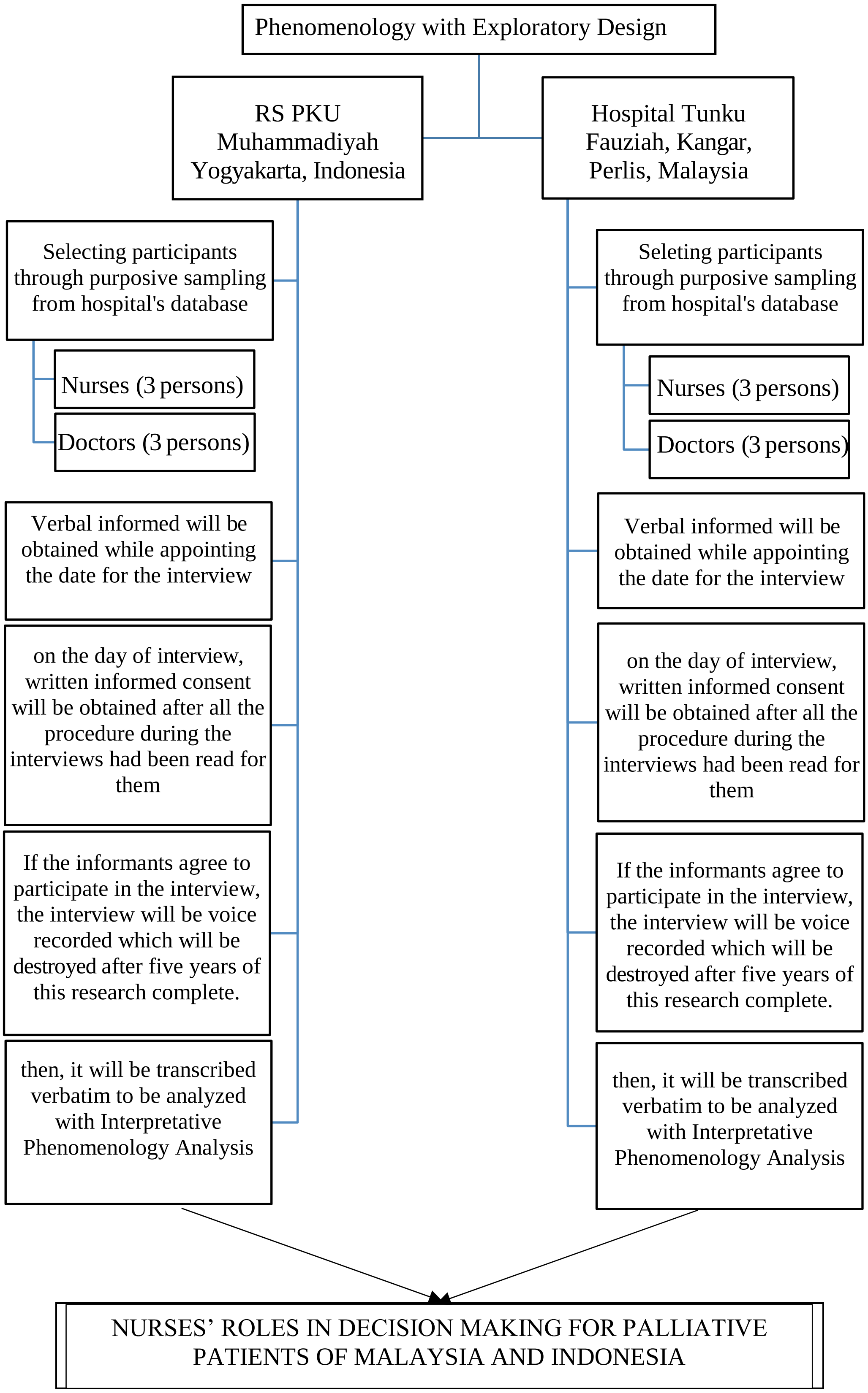
The research will be conducted within sixth months. The participants/ informants will be selected from the database of HTF and PKU. Then, they will be contacted through email and phone to set the date for the interview and obtained their verbal informed consent of participating in this study. The data will be collected through in depth interview because it promotes the freedom for the participants to freely argue with other participants within the group discussion to enhance the result. Furthermore, in depth interview helps researcher to gain valuable information from the participants and the data collected will be fast, flexible and elaborative because the amounts of data can be gained in one interview.

The interview will be tape recorded. The informants can ask for their personal information and study data only. They cannot access other informants' personal information and study data. The information that were collected from this research project will be kept private. Any information about the informants will have a number on it instead of their name. Only the researchers will know what their code number and it will be locked up with a lock and key. The collected data will be destroyed after three years of this study complete.

The data from the in depth interview will be transcribed and verbatim then it will be analyzed. This study will use thematic analysis data by using the interpretative phenomenology analysis (IPA) (32).

Approvals for this study will be sought from Ethical Committee of Universitas Muhammadiyyah Yogyakarta Indonesia and National Medical Research Register (NMRR). Then, the ethical clearance also should be gained from the ethical committee of HTF and PKU. Then, verbal informed consent will be obtained from the participants before the interview's date appointed while on the date of the interview, the signed informed consent will be attained.

The Research Design Protocol



Research Team

No	Name	Institution	Task
1	Dr. Titih Huriah	Master Nursing UMY	- Head of research - Prepare a research proposal - Develop research instrument - Analysis data - Compile research report - Compile publication manuscripts
2	Sutantri, Ph.D	School of Nursing UMY	- Research member - Prepare a research proposal - Analysis data - Compile research report - Compile publication manuscripts
3	Rosnani Binti Sarkarsi	Kulliyah in Nursing IIUM Malaysia	- Research member - Prepare a research proposal - Instrument validation - Compile research report - Compile publication manuscripts
4	Madihah Binti Abdullah	Student Master in Nursing UMY	- Research member - Prepare a research proposal - Analysis data - Compile research report - Compile publication manuscripts

Research Schedule

No	Nama Kegiatan	2019		2020						
		11	12	1	2	3	4	5	6	7
1	Prepare a research proposal	X								
2	Submit for research ethic		X							
3	Develop research instrument		X	X						
4	Research permission			X						
5	Coordination with the research location			X						
6	Data collection				X	X	X			
7	Data analysis							X		
8	Compile research report								X	
9	Compile publication manuscripts									X

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