<u>**ORIGINAL ARTICLE**</u>

PHENOMENOLOGICAL STUDY OF MUSLIM NURSES' EXPERIENCES DURING END-OF-LIFE DECISION MAKING

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ABSTRACT

Nurses' dilemma during EOL decision making can influence quality of End-of-Life (EOL) care and increase dissatisfaction for nurses and the patient's family. Muslim nurses' thoughts and feelings while delivering care in EOL decision making have not been described and understood. This study examines the significance of Muslim, Intensive Care Unit (ICU) nurses' lived experience during their involvement in EOL decision making. The research was conducted at an intensive care unit (ICU) of a government hospital in Indonesia. Fourteen nurses were chosen as participants after meeting the inclusion criteria: Muslims with at least three years of experience in the ICU and experienced in end-of-life decision-making processes in an ICU. Data were gathered through in-depth interviews. The result was then transcribed and analyzed by using van Manen's hermeneutic phenomenological approach. Trustworthiness was established by Lincoln and Guba's criteria. Van Manen's four lifeworlds of body, time, relation, and space were reflected in these subjects. The interview data analysis revealed four key themes shared by all participants: dilemma, uncertainty, receiving an overwhelming role, and evading the process. The findings of this study showed that nurses who are involved in EOL decision-making would experience psychological and spiritual difficulties while providing care to their patients.

Keywords: Critical care; end-of-life; muslim nurse; phenomenology

INTRODUCTION

Many patients admitted to the Intensive Care Unit (ICU) would have undergone life-prolonging treatments and are already in serious conditions. In comparison with other hospital units, the ICU has the greatest death rate (Romain & Sprung, 2016). Roughly 20% of all ICU patients are lifeless when they receive treatment. ICU deaths could occur unexpectedly, but the majority of deaths would occur after the treatment of choice has been postponed or withdrawn (MengJie et al., 2016). As a result, making end-of-life (EOL) decisions is an important part of ICU nursing practice.

As nurses spend more time with patients and families compared to other healthcare practitioners, it is common practice for nurses to share the role of advocate and support a peaceful death for patients during the EOL decision-making process. As a result, they would have the role of aiding the family in dealing with the unfortunate circumstance (Nunez et al., 2015). Nurses are expected to be able to give advice and assistance to the patients' families during EOL decision-making process by using more understandable language than a physician (Kongsuwan & Matchim, 2013). These views make the EOL decision-making process a stressful experience for both the patients' families and the ICU staff.

In the ICU, the EOL issue is acknowledged as a source of stress and conflict. Therefore, imposing religious views that oppose this type of decision-making process can exacerbate these tensions (Fassier & Azoulay, 2010). No study regarding Muslim nurses' lived experiences and

involvement in the EOL decision-making process in the ICU has been conducted before. Therefore, their thoughts and feelings while providing care in EOL decision-making have not been documented and comprehended. Thus, the aim of this study is to reflect the significance of Indonesian Muslim nurses' lived experience in EOL decision-making in the ICU.

METHOD

Study design
A hermeneutic approach to phenomenology was used to analyze and interpret the descriptions of the nurses' experiences with their involvement in the EOL decision-making process in the ICU. In particular, the 1990 van Manen descriptions of the four lifeworlds were used to structure the meanings of the experiences, namely: lived body, lived relationality, lived spatiality and lived temporality.

Informants
Participants who fulfilled the inclusion criteria: Muslim, have worked for at least three years in the ICU, and willing to share their experience, were selected by the purposive sampling method. The number of participants in this study was based on data saturation (when adding more participants to the study does not result in additional perspectives or information). Therefore, this study had 14 participants.

Data collection
This research was conducted at an ICU in Central Java, Indonesia, in 2016. The data for this study was gathered through in-depth interviews with semi-structured questions. In this study, the interviews were conducted in a consultation room that was suitable and pleasant for the interview procedure. When a participant's response was brief or vague, the researcher asked further interview questions to allow them to elaborate on their response. The participants were expected to answer questions within 45 minutes to 1 hour. At the conclusion of each interview, the researcher reminded the participants of a second meeting to review the results of the study to ensure that the findings represent the participants' statements. The interview was performed in the Indonesian language. Each participant had a code to substitute their identity.

Trustworthiness
The trustworthiness in this study was tested against four criteria, namely credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985).

Data analysis
Van manen's approach was used to analyze and interpret the data obtained. The researchers conducted a manual study of the data by using the highlighting technique. Words, phrases and statements illustrating the experiences of nurses involved in the EOL decision-making process in the ICU were recorded. These statements were then separated and evaluated for thematic meanings. A thematic category was then created to group essential ideas with the same meaning.

Ethical consideration
The Institutional Review Board and Ethics Committee of Faculty of Nursing, Prince of Songkla University, Thailand approved this study (Number. MOE 0521.1.05/2738).

RESULTS

In this study, all of the participants are Muslim. There were a few more female nurses (57%) than male nurses (43%). The participants' average age was 35 years old and more than half (57%) of the participants were in the range of 31-40 years. Most of the nurses were married (71%) and has an associate's degree in nursing (71%). Their average work experience in the ICU was 9 years and ranged from 1-10 years (71%) and 11-20 years (29%). All of the participants in this study did not have any experience regarding EOL decision-making training. The findings from the analyzed and interpreted data were then examined by using the fundamental thematic structure of lifeworlds, which consist of lived body, lived time, lived relation, and lived space (Van Manen, 1990).

Lived Body
The term "lived body" refers to a person's physical presence that conceals some parts of their personality. A living body can conceal or reveal truths that explain phenomenological events that occur on the inside (Van Manen, 1990). In this context, when Muslim nurses in the ICU are faced with making EOL decisions, they would engage their bodies to help them make such decisions.

Thematic category: dilemma
The participants expressed how conflicted they were between following their Muslim values by not stopping the patient's care, or following their duty as a nurse by stopping the patient's therapy based on the family's choice. Even though the participants and patient's family members shared the same faith, this dilemmatic situation frequently arise when the participants disagreed with the patient's family members about the patient's order of care during the EOL decision-making process. This complex scenario might lead to nurse dissatisfaction during the EOL decision-making process. These were the explanations given by the participants:
"I don't want to remove or stop the life support machine because it's a big responsibility. It's a dilemma that many healthcare teams face in the ICU, (to choose) between the patient's condition and our faith or beliefs." [P 6]
"I feel like I'm in a dilemma when I need to reduce the FiO2 because it's against my beliefs…from the point of view of my religion, it can be a problem for me." [P 11]
"It's a dilemma, because we know that the machine actually cannot heal the patient, we are only prolonging the patient's suffering." [P 12]

Lived Time
The temporal being in the world, which is governed by sentiments, psychological situations, and dimensions of the present, past, and future, is referred to as lived time (Van Manen, 1990). Subjective perceptions and experiences might influence the participants' perspective of their temporal manner of being during the EOL decision-making process.

Thematic category: uncertainty
In this context, uncertainty refers to the ambiguity regarding the sense of time the participants feel when participating in EOL decision-making, as it is uncertain when the patient's family members may make decisions. The participants explained that they would always be facing uncertainty when the patient's family members could not decide whether to stop or continue treatment due to a variety of factors. These factors include waiting for other family members who live in other cities or the family's fear of being accused of murder if they decided to stop the treatment. This uncertainty indicates that the EOL decision-making process is fluid and might shift back and forth to meet the demands of the family. This is because the family could always consider another choice and reconsider their decision. The

participants were unsure of how long they should wait before receiving the final decision. They have provided some of their thoughts on this subject, shown below:

"The patient's family often feels confused when deciding on whether they should stop or continue the machine…this uncertainty can put us in a difficult position, so we just continue the treatment while they are still thinking. It may take a long time before the family makes a decision." [P 9]

"Some families may say that they cannot decide because they still have to wait for their family members from another city. This condition puts me as a nurse in a state of uncertainty because I would have to wait several days…I don't really know how long I should wait and what I should do during the waiting time." [P 4]

"…sometimes the patient's family would tell me that they have difficulty deciding whether they want to continue or stop, even when the patient does not have any chance to survive. Honestly, that puts us in an uncertain situation, and I feel confused as to what I should do during this time of waiting for their decision..." [P 8]

"…If the family still refuses to decide, that causes me as a nurse and also the patient to be in an uncertain condition." [P 9]

Lived Relation
The term "lived relation" refers to the bonds that people form with those who share their interpersonal space (Van Manen, 1990). Every person may form an opinion about other people, which can be confirmed through their interaction with them.

Thematic category: Receiving an overwhelming role
Unpleasant conditions have occurred when the participants were forced to perform in the position of other healthcare providers. This may make people feel uncomfortable while they participate in the EOL decision-making process. The participants provided these explanations in the following excerpts:

"…we need to learn more; I mean all of us including the medical doctors. We should understand our own role during this process. I don't know, but maybe the doctors actually understand their roles and they just pretend that they don't." [P 5]

"…the doctor should be the person who stops the machine because they have the competencies for that…but they just ordered the nurse to be the executor all the time and as you can imagine, I don't feel comfortable during this process." [P 4]

"Honestly, I feel uncomfortable doing something like this (discussing the situation alone with the family) as it is actually part of the doctor's duty..." [P 11]

Lived Space
Lived space represents the environment or terrain where individuals have experiences and find themselves during daily events (Van Manen, 1990). In this context, the participants' perceptions of space might impact their presence in the EOL decision-making process.

Thematic category: Evading the process
Evading the process refers to a participant's desire to avoid the EOL decision-making process. The participants believed that EOL decision-making is a process that God forbids, and that their participation in it will cause them to sin since they have disobeyed God's commands. The participants believed that their participation would have an impact on the patients' life or death, which they believe to be entirely God's will.

"… I choose to avoid this process (EOL decision-making) because when the family decides to stop the machine, it's

contrary to my beliefs and I will choose to maintain to support for the patient with a ventilator machine instead of stopping the treatment."
[P 3]

"…when a family decides to stop the machine that is supporting the patient and if they ask me to stop the machine on their behalf, of course I will refuse because it is like I am killing the patient." [P 11]

DISCUSSION
It is not uncommon for a nurse to encounter a predicament when participating in the EOL decision-making process. According to Karnik & Kanekar (2017), healthcare practitioners may have diverse views on the EOL decision-making process with a patient or the patient's family. This problem could be created by the family members' unrealistic expectations of care or by the nurse's incompetence (Adams, 2013). Nurses with a diploma and no EOL training comprise the majority of the participants in this research. Due to their limited competencies, the participants' lack of knowledge and training will affect their perceptions during the EOL decision-making process, causing them to be dominated by their beliefs. Due to their lack of knowledge and training, the participants tended to be more concerned with their own feelings than with their abilities. This situation could lead to a dilemma if the nurse disagrees with the family because of their lack of necessary skills to deal with such a situation. This finding was also consistent with other studies, which found that nurses who lack EOL decision-making training and knowledge will feel unprepared and rely solely on their feelings rather than knowledge during their involvement (Adams, 2013; Mani, 2017).

The theme of being in uncertainty represents the participant's perception during their involvement in the EOL decision-making process as they cannot predict when the decision would be made by the family and how long they should have to wait. Similar studies have found that when the patient's family had to make an EOL decision, they often struggled because they thought their decision would make them responsible for the patient's death (Nunez et al., 2015; Ranse, 2014). Therefore, a nurse in the ICU should recognize that EOL decision-making is a continuous process, so they would allow enough time for the relatives to accept the patient's condition and fully understand the situation during the EOL decision-making process. This was similar to a study which found that a family would often want to rethink their decision several times before making a final decision (Sinuff et al., 2015). However, the nurse should be aware that while waiting for the family's decision, the patient may be receiving unnecessary treatment and suffering. In this study, the nurses stated that they felt uncertain after the family made a decision. The nurses questioned how long and how deeply they should be involved in the EOL decision-making process. This uncertainty could have been caused by ambiguous EOL decision-making guidelines (Efstathiou & Walker, 2015). Clear guideline is needed to clarify this issue.

The theme of receiving an overwhelming role represents the participant's condition when forced to take on the role of another healthcare provider. The participants in this study stated that they frequently had to accept the role of another healthcare provider. This finding was similar to previous studies, who found that the roles of nurses and other healthcare providers, such as doctors, frequently overlapped during the EOL decision-making process, despite the fact that they have different responsibilities (Adams, 2013). This may have been created by a lack of

clear guidelines regarding the assignment of roles for this procedure, causing the participants to take on the roles of other healthcare providers. This finding is also in line with a previous study, who found that during the EOL decision-making process, doctors frequently failed to perform their duty of clearly explaining the EOL decision-making process to the family, and instead delegating this difficult task to the nurse (Davatgar, 2016). These ambiguous responsibilities for healthcare providers during the EOL decision-making process are often prompted by the doctor's choice, level of experience, or seniority within the team (Flannery, Ramjan, & Peters, 2017). Further guidelines which include specific assign roles for each healthcare provider specific tasks in the EOL decision-making process is needed.

Moreover, overwhelming tasks causes job satisfaction among ICU nurses to decrease and is linked to burnout. Furthermore, despite playing a significant role in the EOL decision-making process, the participants stated that they did not receive the respect they deserved from the patients' families. Even though nurses strived to conduct their jobs along with all the responsibilities associated, they frequently did not receive adequate respect from the patients' families because they believed that nurses were the doctor's subordinates (Tao, Ellenbecker, Wang, & Li, 2016).

For lived space, the theme "evading the process" represents the participants' desire to avoid the EOL decision-making process. The participants in this study stated that they did not want to be engaged in the EOL decision-making process because they believed it would have an impact on the patient's death and it would be a violation of God's prerogative. A similar conclusion was revealed in a Brazilian study which found that nurses in the ICU often felt uneasy when they had to participate in the EOL decision-making because they thought that they would be implicated in the process of hastening the patient's death (Baliza et al., 2016). Even nurses in the ICU who have the chance to engage in EOL decision-making processes tend to choose not to do so due to the emotional strain, preferring to leave the decision to the physician (Velarde-Garcia et al., 2017). The nurses opted to distance themselves from the family when making EOL decisions in order to minimize family disputes that could lead to a medical lawsuit (MengJie et al., 2016).

Conversely, a study conducted in Turkey, found that all of their sampled ICU nurses expressed a strong desire to be included in the EOL decision-making process and expressed disappointment if the physician made a choice without consulting them (Badır et al., 2015). This disparity might be due to educational differences and a lack of nurse competency regarding the EOL decision-making process in the ICU in other parts of the world. This study was conducted with purposive sampling method in a type B government hospital; therefore, the result cannot be generalized for other Indonesian nurses who work in different level healthcare hospital and this is a limitation of the results of this study. Recruiting participant from different setting could be important in further research.

CONCLUSION AND RECOMMENDATION
The participants in this study used their religious beliefs to justify their participation in the ICU EOL decision-making processed. They explained their dilemma, which made them want to avoid participating in this process. Moreover, they felt overwhelmed by their role in this process and this only added to their feelings of uncertainty and distress. Their lack of understanding of EOL decision-making led them to

believe that their religion strictly forbids them from participating in EOL decision-making. This was not the case in other countries with well-developed EOL decision-making education and guidelines, such as Iran and Turkey, despite the fact that they share the same religion as the participants in this study. The participants' lack of knowledge and training in the EOL decision-making process also contributed to their lack of competency and self-confidence in their roles. A nurse's lack of knowledge and competency may lead to misunderstandings, thereby causing them to lose confidence and avoid EOL decision making. Further research is needed to develop a practical guideline for improving EOL care in the ICU.

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