NURSES’ SPIRITUAL DISTRESS DURING END OF LIFE DECISION MAKING: A PHENOMENOLOGICAL STUDY

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Abstract

Objectives: This study describes the meaning of Muslim nurses’ lived experience during their involvement in End of Life (EOL) decision making in Intensive Care Unit (ICU)

Methods: This study was conducted in an ICU of a government hospital in Central Java, Indonesia. Fourteen nurses were recruited as participants after they met the inclusion criteria: Muslims, working at least three years in the ICU, and willing to share their experience. Data were collected using in-depth interviews. Van Manen’s hermeneutic phenomenological approach was used to analyze the data transcription.

Results: Experiences of nurses’ involvement in EOL decision making revealed four thematic categories. Feeling spiritual distress, understanding family’s feelings as a killer, respecting privacy, and continuing time of caring. These themes reflecting van Manen’s four lived world of body, time, relation, and space.

Conclusions: This study described the meaning of Muslim nurses’ EOL decision making in ICU and influence nursing policies regarding education in EOL decision making in ICU settings.

Keywords: hermeneutics, terminal care, decision making, Islam


INTRODUCTION

ICU has the highest mortality rate compared to other hospital units. Approximately 20 percent of all ICU patients were dead when they received ICU care [1]. Some cases of ICU mortality occur suddenly, but most occur after the decision to withdraw or withhold treatment [2].

In this situation, the families of patients see nurses as more supportive and caring for the patient than other health care providers. Critical nurses are expected to be involved in EOL decision-making by providing information and advice [3]. Nurses are also expected to be able to help patients’ families by providing guidance and support to families during EOL decision-making by using a more understandable language than a medical doctor [4]. ICU nurses are also often emotionally involved with patients and their families after taking care of the patient over time, and this could increase their emotional stress [5]. Nurses in the ICU often feel that they are unable to provide optimal care to dying patients and are disappointed by their lack of knowledge and skills for EOL decision-making [6]. These high expectations cause EOL decision making to become a stressful condition for nurses in ICU.
Muslims in Indonesia has an interesting characteristic compared to Muslims in another country in the world. In Indonesia, Islam appears to have a powerful role in some health-related events that Indonesia is a secular country [7]. Nurses in ICU often feel they have full responsibility for the condition of their patients, and this perception tends to make them susceptible to stress and depression [8].

Muslim nurses’ thoughts and feelings while delivering care in EOL decision making have not been described and understood because from the literature review the study of Muslim nurses living experience in EOL decision-making in the ICU has not been conducted. The aim of this study is therefore to describe the meaning of the experience of Muslim nurses involved in EOL decision-making in ICU Indonesia.

**METHODS**

**Research Design**

A hermeneutic approach to phenomenology was used to analyze and interpret the descriptions of nurses’ experiences of involvement in EOL decision making in ICU. In particular, the 1990 van Manen descriptions of the four life-worlds were used to structure the meanings of the experiences, namely: body, relationality, spatiality and temporality.

**Sample and setting**

This study was conducted at the ICU in Central Java, Indonesia, in 2016. The ICU featured a patient’s bed divided by modesty curtains. The full ICU capacity is 20 people. There is no special room for consultation between family and health care, or for the patient to die peacefully.

**Data Collection**

This research used an in-depth interview with semi-structured questions as a method of data collection. The interview in this study was performed in a consulting room that was suitable and comfortable for the interview process. The researcher used the interview questions to allow participants to expand on their responses when the participant’s response was brief or vague. Participants were expected to answer questions within 45 minutes to 1 hour. At the conclusion of each interview, the researcher will remind the participants of a second communication to review the results of the study to ensure that the findings represent the importance of the participant. The interview was performed in the Indonesian language. Each participant had a code number to recognize.

**Data Analysis**

Methodology was used to evaluate and interpret the results [9]. The researchers carried out a manual study of the data using the highlighting technique. Words, phrases and statements illustrating the experiences of nurses involving in EOL decision making in ICU have been recorded. These statements have been separated and evaluated for thematic meanings. Essential themes that had the same meaning were grouped as a thematic category.

**RESULTS**

**Lived Body**

The lived body refers to a physical appearance that covers some of the components of an individual. The living body may cover or reveal a truth that may provide explanation for the phenomenal reality that occurs within the body. **Thematic category: Feeling spiritual distress.** Spiritual distress is an unpleasant feeling caused by a disturbance in the religious belief or faith of the participants while taking part in the decision-making process of the end-of-life. The spiritual distress of the participants included feeling sad, guilty, and frustrated. The end-of-life decision making...
often made the participants involve in the process to stop or continue patients’ life support with machine technologies of care. This may contradict the Islamic belief of the nurse, especially concerning regard to Allah’s privilege as God to decide patient death. The participants also explained that their role in making end-of-life decisions often violated the rules of God that made them got sin as a result.

I think, it is violated Islamic law, regardless whether the process is correct or not…we should tawakkal (give our maximum effort and surrender to Alloh for the result) to Alloh. When we decide to withdraw the treatment, it shows that we violate God’s order to tawakkal... [P 4, L 125-127]

They ask me to remove the ventilator, but I refuse it...I will not withdraw that ventilator machine. Finally patient’s family agree to remove the machine by themselves. After this situation, I felt very worry, so I went to do taubah pray (specific praying to ask forgiveness from Alloh), and pray to God to forgive me and my sins. [P 5, 96-101]

During the end-of-life decision, the participants often felt guilty and moral burdens when the family finally decided to stop the support machine because it was against God’s command. They felt that they were responsible for the condition of the patient, and that they would be asked of God for responsibility.

I feel burden when we should remove patient’s supporting machine because I should bear very big responsibility in the presence of God... I feel anger inside my heart, maybe little bit frustration because maybe I will get sin.[P 6, L 121-123]

Instinctively when we stop the machine and then we saw that patient die after couple of minutes, it’s like we precede patient’s destiny and same like we kill the patient…moreover in ICU we provide total care, that’s make me think that nurse have full responsibility for patient’s condition... I will get sin for that and it became moral burden for me. [P 13, L 83-89]

When this process (EOL decision making) started I feel an extreme discomfort… I don’t want to get this job because I feel guilty, I will get sin because I involved in patient’s dying process. [P4, L 128 - 133]

Lived Relationality

Lived relationality refers to connection of individuals maintain with others in who live in the same interpersonal space [9].

Thematic category: Understanding family’s feeling as a killer.

Understanding the family’s sense of killing is a participant's sense of compassion for the family that appears as they witness the family’s difficulty and confusion in making end-of-life decisions. The participant explains that they understood that the family often had difficulty and confusion because they were afraid that they would be blamed as a murderer when they made a decision. Participants explain this theme in the following excerpts,

...some family member refuse to make a decision to withdraw the supporting machine because they afraid they will be blamed as a killer...I can imagine their difficulty, I feel sorry for them. [P 10, L 49-51]

...we explain to the family that the family will have responsibility to stop the machine, not the doctor nor the nurse. After they get the explanation, many of them change their decision to give patient minimal therapy instead withdraw the supporting machine. I know this is not easy for them. [P 13, L 14-17]

The family afraid that they will be blamed if they decide to stop the machine, it is sound like they kill the patient…they must be confused because they just want to make the best decision for patient.[P 13, L 19-21]

Lived Spatiality

Live space relates to the part of the environment or ecosystem where people observe and strive to define themselves during their day-to-day interactions [9].
Thematic category: Respecting privacy

Privacy is a right for family members of patients during their time to make decisions on patients’ care as the health of the patient has diminished. Participants understood that it was important to prepare a family privacy area by closing a curtain and permitting the family to stay for a while next to the patient’s bed to help them make the decision and to accept a decision. Allowing the family to spend time with the patient is also necessary to help the family deal with the fact when the patient’s condition is getting worse. Participants explain the following in the excerpts,

When we told the family that the patient condition is getting worst we also close the curtain around them… we understand patient’s family need privacy during this difficult process before finally they will make a decision. [P 5, L 85-86]

…family which refuse to accept patient’s condition can start crying and hug the patient, they not allowing us to do anything. At this moment we understand that they need space for alone and impossible to us starting discussion. So we prepare the curtain for the room. [P 7, L 45-49]

Another participant explain that respecting family’s privacy is useful to enhance spiritual support for patient. The participant explain in excerpt as follow,

…some family want to stay near patient so they can read Quran before they make a decision… I will allow it because I know the family want to close with the patient when patient’s condition is getting worst. [P 10, L 25-28]

Lived Temporality

Lived time refers to temporal being in the world which determined by feelings and psychological conditions and consist of dimension of future, present, and past [9].

Thematic category: Continuous time of caring.

Continuous care during EOL decision-making refers to the provision of care from the first time that end-of-life decision-making is started until the patient’s family decides and remains until the patient reaches a peaceful death. This continuous support was given to the entire family, consisting of physical, psychological and spiritual support. Participants recognize that EOL decision-making was a complicated process and the participant also believed that continuing care was essential in helping the family to make a decision.

Nurses should be able to maintain high quality care from the beginning (EOL decision making), I mean we have responsibility to accompany the family and support them from the beginning of the process until finally the patient died. [P 2, L 91-92]

Another participants in this study explained as follows,

We have specific role to accompany patient’s family from the very beginning of this process (EOL decision making) such as give psychological support for family and we should be ready if patient’s family has some issue to be clarified during this time… [P 6, L 63-65]

We have role to accompany the family from the beginning (EOL decision making), clarify all information which confusing them, and support them psychologically and spiritually when they want to make a decision. [P 9, L 68-70]

Communication with the patient’s family should be maintain continually to ensure they know and understand patient’s progress in the ICU (during waiting family’s decision), because in the ICU family restricted to meet the patient. [P 8, L 73-76]

DISCUSSION

The feeling of spiritual distress, which represent participants unpleasant due to spiritual disturbance during their involvement in EOL decision making. The spiritual distress in this study is caused by their role, which is contrary to the Islamic belief of nurses. The spiritual disruption of this nurse may affect the feelings and treatment of nurses during their participation in EOL decision-making [10]. Participants mention that they felt they were responsible for
the deaths of patients and sometimes feel that they like killing a patient by engaging in EOL decision-making. This difficulty can increase when finally the final decision is to withdraw the treatment, even though they are not the person who stop the treatment but they still feel guilty due to involve in patient’s death [5]. A different perspective was explained who said that ICU Muslim nurses in Iran had no spiritual distress when they were involved in EOL decision-making. This disparity may be caused by the different level of nurse education and the lack of experience [11].

The theme understanding family’s feeling as a killer represent participant’s feeling of compassionate to the family due to family’s difficulty and confusion during make a decision because they afraid will be blame as a killer. Study mention that the family often feeling guilty and regret due to sense of responsibility for their decision [12]. Study also mention similar finding which explain that patient’s family feel that their decision during EOL decision making can be classified as making patient’s die, and this role make them endure emotional discomfort due to responsibility for patient’s death [13]. The emotional barrier of the family, such as anxiety and depression when involved in EOL decision-making, may be problematic due to possible biases that may influence decisions based on patient benefit [14].

The theme respecting privacy represent participant’s appreciation to prepare privacy space for the family to stay with the family during their decision making. A study indicated that the family wants to be able to stay with the patient during the critical condition of the patient and did not need any interest from nurses and other health care providers during that time [15]. Supporting family privacy for staying with patients during EOL decision-making is important for providing spiritual care to patients, although nurses often feel disturbed by family presence when providing care to patients [16]. Preparing space for family privacy during EOL decision-making can help the family deal with the situation and reduce the suffering of the family, which is essential in evaluating family preference throughout EOL decision-making [17].

The theme in lived temporality is continuous time of caring. This theme represent participant’s preference to delivering continuous care to the family during EOL decision making. When patient’s condition is getting worst, the EOL decision making usually will be initiated by the doctor. When the decision-making process for EOL begins, nurses are expected to be able to provide medical literature as strong evidence to the family and to maintain discussion by using good communication skills from the outset, particularly on sensitive issues [12], [18]. Furthermore, the long-term presence of nurses to accompany patients and families during EOL decision-making could also reduce family anxieties and increase their confidence [19]. Continuous support by the nurse is crucial to clarifying the issues and the ambiguity of the information, or even providing a presence can be important to the family during this difficult time [2], [20]. The role of nurses in the delivery of care continues even when decisions are taken. They have a duty to help the patient reach a good death and to maintain the emotional support of families while at the same time helping the family to create positive memories of family remembrance [18].

This research reflects an information regarding Muslim Nurses lived experience during their involvement in EOL decision making. The meaning of their experiences are “feeling spiritual distress during their continuing caring while understanding family’s feeling and privacy for the process”. The finding of this study show that lack of knowledge and information could trigger problem for the nurses. Furthermore, specific education and training regarding EOL decision making tailored for Muslim nurses in ICU are critical. Further study is recommended to develop a practical guideline to enhance palliative and EOL care in ICU.

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REFERENCES


