Muslim Nurses' Lived Experience in Involvement at the End of Life Decision Making in Intensive Care Unit

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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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ชื่อวิทยานิพนธ์ ประสบการณ์ของพยาบาลมุสลิมในการมีส่วนร่วมกับการตัดสินใจในระยะท้ายของชีวิตในหออภิบาลผู้ป่วย
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บทคัดย่อ

การศึกษานี้มีวัตถุประสงค์เพื่ออธิบายความหมายของประสบการณ์ของพยาบาลมุสลิมในการมีส่วนร่วมกับการตัดสินใจในระยะท้ายของชีวิตในหออภิบาลผู้ป่วย (ไอซียู) โดยใช้การศึกษาปรากฏการณ์วิทยาแบบเฮอร์เมนนิวติกส์ ผู้ให้ข้อมูลเป็นพยาบาลของหอผู้ป่วยไอซียู จำนวน 14 ราย และเป็นไปตามเกณฑ์ในการคัดเลือกผู้ให้ข้อมูล คือ เป็นพยาบาลมุสลิมที่ทำงานในหอผู้ป่วยไอซียูอย่างน้อย 3 ปี เก็บรวบรวมข้อมูลโดยการสัมภาษณ์เชิงลึกรายบุคคล วิเคราะห์ข้อมูลของบทสัมภาษณ์โดยใช้วิธีการของแวนมาเนน และสร้างความน่าเชื่อถือของงานวิจัยตามแนวทางของลินคอล์นและกูบา

ผลการศึกษาพบกลุ่มความหมายจำนวน 11 กลุ่มความหมาย และได้สะท้อนภายใต้โลกสี่ใบ ประกอบไปด้วย โลกของร่างกาย โลกของเวลา โลกของความสัมพันธ์ และโลกของสถานที่ กลุ่มความหมายในโลกของร่างกาย ได้แก่ “รู้สึกกลืนไม่เข้าคายไม่ออก” “รู้สึกคับข้องทางด้านจิตวิญญาณ” และ “รู้สึกไร้พลัง” กลุ่มความหมายในโลกของเวลา ได้แก่ “อยู่ในเวลาที่ไม่แน่นอน” และ “การต่อเนื่องเวลาของการดูแล” กลุ่มความหมายในโลกของความสัมพันธ์ ได้แก่ “ได้รับบทบาทที่เกินตัว” “ให้คุณค่าความสามารถในการสื่อสารกับครอบครัว” “เข้าใจความรู้สึกของครอบครัว” และ “เป็นผู้สนับสนุนแก่ครอบครัว” กลุ่มความหมายในโลกของสถานที่ ได้แก่ “เคารพความเป็นส่วนตัว” และ “หลีกเลี่ยงกระบวนการ”

ผลการศึกษาครั้งนี้ให้ความเข้าใจประสบการณ์ของพยาบาลมุสลิมในการมีส่วนร่วมกับการตัดสินใจในระยะท้ายของชีวิตในหอผู้ป่วยไอซียู และสามารถนำไปเป็นข้อเสนอแนะผู้บริหารทางการพยาบาลของโรงพยาบาลในการสนับสนุนนโยบายทางด้านการศึกษาและอบรมเกี่ยวกับการตัดสินใจในระยะท้ายของชีวิตในหอผู้ป่วยไอซียู

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ABSTRACT

This study aimed to describe the meaning of Muslim nurses' lived experience in involvement at the End of Life (EOL) decision making in Intensive Care Unit (ICU). Hermeneutic phenomenological study was used. Fourteen nurses who work in an ICU in Indonesia met the inclusion criteria: being Muslim nurse and have been working in ICU for at least three years. Data were collected using in-depth individual interview. Interview transcriptions were analyzed by using van Manen's approach. Trustworthiness was established following Lincoln and Guba's criteria.

This study found eleven thematic categories and were reflected within four lifeworlds of body, time, relation, and space. Lived body consisted of three thematic categories; 'feeling of dilemma', 'feeling spiritual distress', and 'feeling powerless'. Lived time included of themes 'being in uncertain time' and 'continuous time of caring'. Lived relation were revealed in four thematic categories; 'receiving overwhelming role', 'valuing competency in communication with the family', 'understanding the family's feeling', and 'being a supporter for the family'. Lived space included 'respecting privacy' and 'evading the process'.

The findings of this study provide understanding the lived experience of Muslim nurses in involvement at the end of life decision making in an ICU. These findings can be used to suggest nursing administrators of the hospital to support policies toward education and training regarding EOL decision making in ICU.

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Arif Imam Hidayat

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Chapter 1

Introduction

This chapter presents the background and significance of the problem, objective of the study, research questions, conceptual framework of the study, scope of the study, and significance of the study.

Background and Significance of the Problem

The healthcare team in Intensive Care Unit (ICU) mainly focuses on helping patients to survive the acute threats while preserving and restoring the quality of life (Truog et al., 2008). Many patients are assigned to the ICU when they are in critical condition after undergoing life-prolonging remedies (Romain & Sprung, 2014). ICU has the highest mortality rate in comparison with other units in the hospital. Romain and Sprung (2014) discussed that approximately 20% of all patients in ICU are lifeless when they receive care. Some fatalities in ICU happen all of a sudden but the majority transpires after the decision of treatment is withheld or withdrawn (Ranse, Yates & Coyer, 2012).Hence, end of life (EOL) decision making is an integral element of nursing practice in ICU.

EOL decision making is a process in considering whether some prescriptions and treatments may or may not be used in patients to treat life-threatening illnesses and concerns the patient and their families as well as the healthcare providers. This process has several scheme such as, advance directives (living wills and/or durable power of attorney for healthcare), decision on resuscitative efforts, and the decision to withdraw or withhold remedies such as mechanical ventilation, administration of

fluids and nutritional feedings, dialysis, use of vasopressors, and antibiotic therapy (Thelen, 2005). During EOL decision making, patients' families often experience high anxiety levels because of the patient's fatal status. They equally wish to be involved in all treatment decisions and oftentimes obtain information from the nurse (Limerick, 2007). The latitude of the situation distinguishes the nurse as a supportive and caring agent for the patient more than other healthcare providers. Nurses in critical care are expected to engage in EOL decision making by providing information and advice (Velarde-Garcia et al., 2016).

It is customary for nurses to promote a peaceful death for patients during EOL decision making (Browning, 2010) and share the role of an advocate during EOL decision making because they lavish their time with the patient and families more than any other healthcare provider. Thus, they assist the family to be conscious and handle the ill- fated situation (Hebert, Moore, & Rooney, 2011). Nurses are slated to be able to help patients' families provide direction and support during EOL decision making to synthesize and usie more coherent language than a medical doctor (Kongsuwan & Matchim, 2012). These assumptions cause EOL decision making to develop into a stressful plight not only for patients' families but also for nurses in ICU.

Nurses perceive EOL decision making as a complex and stressful state because it affects the life of their patient and occasionally other patient's life. During the process nurses reflect on the patient's and the family's cultural, social, legal, and religious issues (Borhani, Hosseini, & Abbaszadeh, 2014). A study from Indonesia found that nurses often face dilemma in this situation not only because they must stop life support equipment in one patient, but also giving the life support equipment to

another patient who has a better life-saving prognosis (Setiawan, Chaowalit, & Suttharangsee, 2004). Nurses in ICU are every so often emotionally intricate with patients and families after being compassionate and concerned for a patient over time and that leads to increased emotional stress (McMillen, 2008). Nurses in ICU setting often feel that they miss the mark to deliver optimal care to dying patients and feel disillusioned with inadequate knowledge and EOL decision making skilss (Hillman & Chen, 2008).

Nurse's emotional suffering during their participation in EOL decision making in ICU has positive correlation with burnout syndrome, turnover, and low work satisfaction (Teng, Chang, & Hsu, 2009; Martins & Robazzi, 2009). Nurse's stress can likewise lead to physical and psychological health difficulties, initially from chronic fatigue up to psychological problems (Donovan, Doody, & Lyons, 2013). Similarly, healthcare quality will become a negative effect from nurse's undesirable feelings because nurse's emotional anguish could decrease patient's safety (Teng, Chang, & Hsu, 2009).

Islam always uses three pillars as the basis for Islamic law. Those pillars are the Holy Quran, the Sunnah, and the Ijtihad and must be followed by all Muslim. The highest level of these pillars is The Holy Quran which is a direct word from God (Damghi et al., 2011). God teaches all Muslim by the Holy Quran to follow specific duties from Him (Alloh), and one of the duties for every Muslim is to seek medical care and appropriate medical treatment as much as possible and avoid killing because Muslims believe that healing comes from God. They have a clear obligation to treat their body as a gift from God (Huerta-Alardin, Cruz-Amador, Sternbach, & Varon 2004).

Islam believes that human life is very sacred and God is the only one who can determine a person's life or death (Abu-El-Noor & Abu-El-Noor, 2014). Islam believes that death is an inevitable event for all human beings as the beginning of the life hereafter which is perpetual and infinite. Prophet Muhammad (PBUH) mentioned that people who feel sick and then choose to be patient will receive forgiveness for their sins so they can enter paradise after death. When a Muslim (someone who follows or practices Islam) is dying, their friends and family should come to provide emotional support by reciting The Holy Quran beside the patient until patient's death (Hillman & Chen, 2008).

Muslim in Indonesia has interesting characteristic compare with Muslim with another country in the world. In Indonesia Islam seems have potent role in some health issue event Indonesia is a secular country (Webster, 2013). The influence of Islam can be different with other places such as Iran, Saudi Arabia, or Egypt. Indonesian Muslim greatly influenced by local culture and makes most people define themselves locally instead of nationally. As regards EOL decision making, some people may choose to avoid discussion regarding EOL and believe that God is the only one who can determine life and death. During EOL stage, Muslim patients and their families often choose to avoid sedating drugs which can affect their consciousness to allow the patient can recite the Islamic creed to achieve good death (HealthCare Chaplaincy, 2013).

The Muslim healthcare provider often faces difficulty during their involvement in the EOL decision making since they are retained in a difficult choice whether to withhold or withdraw management as part of the decision making process classified as evil or not (Abu-El-Noor & Abu-El-Noor, 2014). EOL decision making

is still an argument based on the Muslim religious point of view. Nurses in ICU who face this condition continually experience burnout symptoms. They time and again feel that they have full responsibility regarding their patient's condition and this sensitivity tends to make them susceptible to stress and depression (Teixeira et al., 2013).

Nurses' dilemma during EOL decision making can influence quality of EOL care and increase nurse's, patient's as well as family's dissatisfaction. The EOL situation is correspondingly recognized as a basis for stress and conflict in ICU. Inappropriate imposition of religious beliefs in the decision making process can aggravate these conflicts (Fassier & Azoulay, 2010). 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 about Muslim nurses lived experience in involvement at the EOL decision making in ICU has not been piloted. Most studies from the literature review about EOL decision making from the perspective of nurses were led in other countries with different healthcare system and dissimilar culture and religious beliefs from Indonesia, which influence nurses' thoughts and ways of nursing practice regarding EOL decision making.

Nurses are concerned to deliver high quality care to the patient and the patient's family. This condition makes them absorbed in several unique experiences and conditions as lived experience. The lived experiences are the focus of phenomenological inquiry because it can describe the world as total experiences which are circumscribed by the objects, persons, and events encountered in the pursuit of the pragmatic objectives of living (Streubert & Carpenter, 1999). Phenomenology fits this study because it takes into consideration the values of the individual's

experience and their whole being (Reiners, 2012). Hermeneutic phenomenology was used in this study to gain full understanding about this phenomenon by exploring the meaning of Indonesian Muslim nurses' lived experience involved in the EOL decision making.

The evidence regarding Muslim nurses' lived experiences and their involvement in EOL decision making in ICU in Indonesia is necessary as a source of knowledge for further research to increase the quality of EOL decision making in ICU. For that reason, this study aimed to describe the meaning of Muslim nurses' lived experience in their involvement at the EOL decision making in ICU in Indonesia.

Objective of the Study

The objective of this study was to describe the meaning of Indonesian Muslim nurses' lived experience in their involvement at the EOL decision making in ICU.

Research Question

What is the meaning of lived experience of Indonesian Muslim nurses in involvement at the EOL decision making in ICU?

Conceptual Framework of the Study

This study used Hermeneutic phenomenology as a framework to study the Indonesian Muslim nurses' lived experience in involvement at the EOL decision making in ICU. Heidegger, an expert on hermeneutic philosophy, focused on

revealing knowledge which transcends human experience and aimed to understand the meaning of being in the world rather than knowing the world.

Heidegger explains that *Dasein*, or, being in the world, is often taken for granted and easy to be forgotten. People often ignore many important elements that shape our being in the world. These elements need interpretation to be understood, therefore, Heidegger is concerned with uncovering the meaning of hidden phenomena using our preconceptions (Heidegger, 1996).

Heidegger believes that, it is not possible to ignore our previous knowledge and experiences regarding the phenomenon of any given study and we cannot encounter anything without referring to our prior understanding. Heidegger also explains that prior understanding is very important to understand the meaning of phenomenon and interpret it. Hence, researchers cannot remove themselves from the meaning extracted from the phenomenon. Consequently, prior knowledge or preconceived opinions are not bracketed (Heidegger, 1996).

Heidegger explains that specific being and time for each person can create different experiences for them in comparison with another person and, consequently, can initiate different perspectives for each person. Every person has their specific world which cannot be separated from themselves and can be expressed by explaining their own value and significance through process of interpretation (Heidegger, 1999).

In the context of nurses in critical care setting, nurses are over and over again involved in EOL decision making as part of their professional life in the delivery of care to the patient and patient's family. During their involvement in EOL decision making nurse should understand that they also have engagement with ICU setting, other health care providers, patients, and likewise patient's families. Nurses should

deal not only with themselves but also with their environment by means of knowledge and experience. Therefore, nurses in ICU involved in EOL decision making has treasured experience while dealing with circumstances. The lived experience of Indonesian Muslim nurses in involvement at the EOL decision making in ICU can be different from that of other groups of nurses. Therefore, it is important to get clear information regarding their perspective in this specific setting. This is related with *Being* as mentioned by Heidegger.

Hermeneutic interpretive phenomenology was used in this study to understand the lived experience of Indonesian Muslim nurses in their involvement at the EOL decision making in ICU. This phenomenology was used to generate interview questions to gather data utilizing in-depth interviews. Hermeneutic approach also was used to analyze the data to understand the meaning of phenomena and interpret the data which will be transcribed from participant's explanation. Thus, this phenomenology was appropriate to use in this study to explore the meaning of Indonesian Muslim nurses' lived experience during their involvement at the EOL decision making in ICU.

Scope of the Study

The scope of the study includes exploring the lived experience of Indonesian Muslim nurses during their involvement at the EOL decision making in ICU. Their lived experiences are mainly related to their understanding and feeling when they are involved at the EOL decision making in ICU. The concept of EOL decision making in ICU was reviewed to gain understanding about this topic. The Muslim nurses who work in ICU in Margono Soekarjo Hospital in Indonesia were recruited as participants

in this study. The participants were interviewed from December 2016 to January 2017.

Significance of the Study

This study provided knowledge about Indonesian Muslim nurses' lived experience in involvement at the EOL decision making in ICU. The result of this study will be used to gain better understanding on nurses' feelings and thoughts regarding involvement in EOL decision making and how to improve nurses' role and quality of nursing practice regarding EOL decision making. For nursing education, the result of this study can be useful as a source of evidence to learn and highlight nurses' lived experience during their involvement at the EOL decision making especially in Islamic context. Better understanding regarding nurse's role during EOL decision making is useful to prevent misinterpretation. This study is also important in general nursing practice as this study can be used as a reference to address profound understanding regarding nurses' needs and feelings during their involvement in EOL decision making to increase quality of care during EOL decision making in ICU. This study is also vital for nursing research because the findings of this study will be useful for a baseline data for further research related to EOL decision making especially from the nurses' perspective.

Chapter 2

Literature Review

This chapter consists of a literature review which is an important part of the research process. It also creates a bridge from the research questions to the data analysis process. Relevant literature viewed during development of this proposed study is included in this chapter as follows:

1. End of Life (EOL) Decision Making in Intensive Care Unit (ICU)
    1.1 Definition of end of life decision making
    1.2 Issues of end of life decision making in ICU
    1.3 Persons who are involve in end of life decision making in ICU
    1.4 Process of end of life decision making in ICU
    1.5 Nurses' roles in end of life decision making
    1.6 Existing studies of EOL decision making in ICU in other country
    1.7 Factors influencing end of life decision making in ICU
2. Islamic Perspective in EOL
    2.1 Islamic perspective in end of life decision making
    2.2 Existing studies of EOL decision making in Muslim healthcare provider
    2.3 Studies in Indonesia
3. Hermeneutic Phenomenology
4. Summary of Literature Review

End of Life Decision Making in ICU

This section includes definition, types, persons involved in EOL decision making in ICU, process, nurses' role, existing studies of EOL decision making in other countries and factors influencing EOL decision making in ICU.

Definition of end of life decision making. End of life can be defined as a condition of advanced disability when patients are likely to die within the next twelve months (General Medical Council, 2010). People with progressive disease commonly experience certain symptoms in their last 6 to 12 months of their life such as less active, chronic weakness, increasing pain which may be diffuse or in specific area, shortness of breathing, or tingling in the extremity due to nervous problem. When patient in their last days and hours of their life, they activity decreases significantly and have some other specific symptoms such as *Cheyne-Stokes* breathing, coughing due to body fluids which build up in the pharynx, and change of skin color. Some dying patients can experience unusual perception because of sensory change and make them often feel hallucination and delusions (Papadimos et al., 2011).

During EOL stage, decision making regarding treatments for patient can be very common because it is by human nature a process to select some alternatives or to find a solution and expresses one or more specific objectives including a decision about the patient's care (Baliza et al., 2015). Decision making in EOL stage should represent collaborative process which is not only involving nurses, physician, and another health care provider but also include patient and patient's family (NSW Department of Health, 2005).

We can conclude that end of life decision making is a process that healthcare providers, patients, and patients' families go through while considering which treatments will or will not be used during the patient's life-threatening condition (Thelen, 2005).

In short, end of life decision making is a process which is conducted to consider the treatment that will be given or not be given to the patient during the patient's end of life stage.

Issues of end of life decision making in ICU. There are three issues of end of life decision making in intensive care unit consist of advance directives, withholding or withdrawing therapy, and euthanasia.

Advance directives. Advance directives such as living wills and durable power of attorney for healthcare can be made only when patient still in capable condition. This advance directive can give patient chance to communicate their preferences in writing before some critical condition occurs (Thelen, 2005).

Withholding or withdrawing therapy. Withholding or withdrawing life-sustaining therapies, such as dialysis, antibiotic drugs, mechanical ventilation, and administration of fluids and nutritional feedings. The withholding or withdrawing life sustaining therapies can be considered with some circumstances such as, when benefit to the patient has been exhausted, when life sustaining therapy no longer meet treatment goals, or when the topic is rendered by patient to discussed (Papadimos, Maldonado, Tripathi, Kothari, & Roseberg, 2011)

Euthanasia. Euthanasia can be defined as a conscious act of administering medication or other intervention with the intention of causing patient's death (Kranidiotis, Ropa, Mprianas, Kyprianou, & Nanas, 2015; Schuklenk, Van Delden,

Downie, McLean, Upshur, &Weinstock, 2011). Euthanasia is considered illegal in almost all country and unacceptable like assisted suicide event the informed consent is conducted either by patient or patient's family (Schuklenk et al., 2011; Tepehan, Ozkara & Yavuz, 2009). Nurses in ICU believe that euthanasia is an unethical process and against their religious belief (Tepehan, Ozkara, & Yavuz, 2009). Healthcare provider in ICU often have a misconception regarding euthanasia and have difficulty to differentiate between euthanasia and withholding or withdrawing the treatment (Kranidiotis, Ropa, Mprianas, Kyprianou, & Nanas, 2015; Goligher et al., 2017).

Persons involved in end of life decision making in ICU. During end of life decision making, either through advance directives or in supportive roles, the patient or patient's family should work together with healthcare providers including medical specialist, general physician, nurses, and also allied health workers such as spiritual advisors (NSW Department of Health, 2005).

Patient's family. The patient's family is often involved during end of life decision making in ICU, especially when the patient is unable to express their preference. Quinn et al. (2012) explains that the patient's family can be engaged in several informal roles during end of life decision making in ICU such as, primary caregiver, primary decision maker, family spokesperson, out-of-towner, patient's wish expert, protector, vulnerable member, and health care expert.

A patient's family typically starts from the order of spouse, followed by adult children, and then another family member. They will commonly make the decision regarding patient condition in ICU, although this regulation can be different in each country (Cai et al., 2015). The family member who is involved in EOL decision making should be a competent person, meaning they should be capable enough to

understand the condition and consider the information and consequences of the decision that they make (Schunklenk et al., 2011).

***Physician*.** During this process, the physician should be able to respect the patients and their family's autonomy and provide personalized care to the patients by informing them clearly regarding their condition and empower them to communicate their feelings and perspectives about the treatment (The Royal Australian College of Physicians, 2016).

Nurses. Nurses have significant duties during end of life decision making in ICU. Nurses have the role of providing clinical information about patients to the patients themselves or to the patients' families. Nurses also should be able to facilitate a collaborative process between patients' families and healthcare providers during end of life decision making (NSW Department of Health, 2005).

***Spiritual advisor*.** A spiritual advisor is very important during end of life decision making to support the patient and the patient's family when the patient is still alive and continues after the death of the patient (NSW Department of Health, 2005). Spiritual advisors can help when a patient wants to consider advance directives by answering and giving consideration related to how religion might view the end of life decision making and the spiritual advisor also can improve the quality of end of life decision making by facilitating patients and their families to achieve the best possible death in the process by respecting the patient's spiritual and cultural values (The American College of Obstetricians and Gynecologists, 2008).

In short, end of life decision making should involve the patient's family, a healthcare provider, and also allied health workers to ensure the quality of end of life decision making and to respect the autonomy of the patient and the patient's family.

Process of end of life decision making in ICU. The process of EOL decision making is a cyclic process consisting of assessment, disclosure, discussion, and consensus building involving not only a healthcare provider but also the patient and their family. This process can last anywhere from hours to weeks or months.

Assessment. Patients' conditions in ICU often fall into sudden or unexpected deterioration and making complete assessment regarding preferences and values for life sustaining treatments becomes important. Assessment is conducted by a healthcare team and can include a patient's cultural and religious background to avoid inappropriate clinical decision making. Patients' preferences regarding whether they will allow their family to make an EOL decision when it is necessary also should be assessed to avoid role confusion during EOL decision making (NSW Department of Health, 2005).

Disclosure. The patient and the patient's family have the right to get clear and honest information regarding the patient's condition and prognosis. This information should be given by a healthcare provider who is respected as an expert such as physician or nurse (NSW Department of Health, 2005). The good communication between healthcare providers and patients and patients' families can create trust to defuse tension and difficulty during EOL decision making (Norton & Bowers, 2001). Swigart et al (1996) explains that the first step of EOL decision making for a patient's family starts when they seek information regarding the patient's condition from a healthcare provider. Honest information with understandable language can help the patient's family to synthesize the information and the consequences of the decision.

Discussion. Discussion ideally occurs in stages over a period time, when the patient is still competent to decide how appropriate the treatment is. The healthcare

provider should have the same person/s to communicate with the patient and family to minimize inconsistency in explaining the progress of the patient's condition (NSW Department of Health, 2005). Collaboration between healthcare providers is important in this step to support the patient's family with consistent information, change the scope of treatments, and create new expectations (Norton & Bowers, 2001). In this step, the patient's family tries to review the patient's values including evaluating the patient's condition and quality of life to be a decision maker on behalf of the patient when the patient unable to take that role (Swigart et al., 1996). During this process, a meeting between the healthcare provider and the patient's family is crucial to assure that the patient's family has enough understanding regarding the patient's condition. This is important to help the patient's family to reach a consensus, ease burdens surrounding EOL decision making for families, and reduce distress for the patient's family (Cai et al., 2015).

Documentation. The agreed decision about the use of life sustaining treatment during the patient's EOL stage should be documented and delivered to all team members. The summarized decision should consist of several important information such as medical facts including prognosis, persons who were involved in the EOL decision making, patient's wishes if known, goal of the treatments, details about treatments that will be provided and about treatments to be withdrawn or withheld (NSW Department of Health, 2005).

Nurses' roles in end of life decision making. Based on previous studies, the roles of nurses in end of life decision making in ICU are educator, advocator, collaborator, and supporter as explained in the following.

Educator. The educational process during end of life decision making requires nurses to be an educator to clarify all information that the patient's family members need to understand. When a patient's family has good understanding regarding the patient's prognosis, they can be well prepared for the decision making process (Adams, Bailey, Anderson & Docherty, 2011). During the educational process in the end of life decision making, the patient's family can get clear and honest information about the patient's healing possibilities and also possible intervention for the patient (Baliza et al., 2015).

Advocator. Advocating is one of the nurses' roles which is very important to support the decision making process. Nurses can help the patient's family by understanding the implications of decisions, helping the patient's family to speak up about their perception and their confusion regarding the patient's condition. When the patient's families get enough information regarding the patient's condition from an early stage, they tend to make decisions more easily during the decision making process (Adams, Bailey, Anderson & Docherty, 2011).

Collaborator. Nurses should be able to work in a team to fulfill their role as part of a healthcare team. Collaboration between the physician and the nurse is crucial to improve communication between health care professionals and the family during the decision making process (Efstathiou & Clifford, 2011). Good collaboration between healthcare providers is also very important in the decision making process to avoid the emotional burden of providing care and decrease professional distress by receiving support from colleagues (Kryworuchko, Hill, Murray, Stacey, & Ferguson, 2013).

***Supporter*.** Adams, Bailey, Anderson & Docherty (2011) explain that nurses have a role in EOL care by building trust in relationships with family members as they navigate the EOL decision making process and by demonstrating empathy for patients, family members, and physicians. The nurses' role in supportive family care is expected to bring comfort for the patient's family. This can be achieved by have a meeting with the family upon the patient's admission and continuing until the critical condition in order to understand the patient's family's feelings and expectations (Tsaloukidis, 2010).

Existing studies of EOL decision making in ICU in other countries. From reviewing existing studies there are four studies which mention regarding nurses involvement at the EOL decision making in ICU. The first study was a cross-sectional survey study conducted by Langley, Schmollgruber, Fulbrook, Albarran, and Latour (2014) to investigate South African nurses' critical experiences and perceptions of EOL decision making. This study was conducted in South Africa with 149 participants. This study reveals that even though 76% of the total participants mentioned that they were involved in EOL care, a minority (29%) had participated during EOL decision making. This study also mentioned that 62% of participants reported that EOL decision making is a routine practice and 86% of participants believed that EOL decision making should involve the patient's family during the process. More than half of the total respondents (68%) believed that patients should stay in ICU during end of life stage, with the majority (72%) supporting open visiting and the practicing of religious or traditional cultural rituals regarding EOL.

The second study was conducted by Gallagher et al. (2015) to understand nurses' practices in EOL decision making in ICUs in different cultural contexts. This

study used grounded theory to inform data collection and analysis. Interviews were conducted in five countries consisting of Brazil, England, Germany, Ireland, and Palestine with a total of 51 respondents who were all nurses. This study explains that there was consensus regarding the core concept and core practices employed by nurses in ICUs in five countries. Event there is some differences between participants in different country to perceive autonomy, but they agree that nurses should actively involve in EOL decision making. This research also explain that nurse should be able to facilitate patient to achieve good death by focus on need and problem of patient and patient's family instead of treatment and cure in an technology focused environment. The research also mention that further research which discusses about the impacts of nurses' cultural and religious perspective in EOL decision making is crucial to enhance understanding regarding ethical and clinical aspect of EOL decision making.

The third study was a qualitative study conducted by McLeod (2014) in United Kingdom to explore nurses' perceptions of the ethics involved with withholding and withdrawing treatment in intensive care. Six nurses participated in this study choose by using purposive sampling method. This study explain that nurses in intensive care belief that there are three issues that important during withhold or withdraw patient treatment, such as nurses personal set of moral beliefs, their experience, and decision making process. Moral distress and ethical dilemma seems occur when one or more of these factors is does not support each other.

The fourth study was a postal survey study conducted in United Kingdom by Seale (2010) to compare ethnicity and religious faith in the medical and general United Kingdom populations, and their correlation with ethically controversial decision taken when providing care to patient in EOL stage. Total sample in this study

is 3733 person. This study explains that doctor's cultural background and religion have relation with their willingness to take decision in EOL stage. Non-white doctors tend to have more strength religion than white ethnicity. Doctors who considers themselves as a religious person tend to disclose their moral objection to certain procedure so patient can decide to choose another doctor if they want. Further study was needed to get better understanding regarding this issue and also to understand the situation during the involvement of healthcare provider in EOL care.

Factor influencing EOL decision making in ICU

Based on previous studies there are five factors that can influence EOL decision making in ICU. Those factors are knowledge and experience of healthcare provider, patient's condition, families and healthcare provider's belief, communication, and culture as explained in the following.

Knowledge and experience of healthcare provider. Even though the end of life decision making issue is increasing, neither physicians nor nurses have confidence that they are well prepared to help patients and their families at end of life decision making (Thelen, 2005). Lack of knowledge and experience in healthcare providers in ICU can hinder the provision of high quality care for patients and their families during end of life decision making (Velarde-Garcia et al., 2016). Lack of knowledge and experience also can cause nurses to have low self-confidence when dealing with end of life decision making (Raphael et al., 2014).

Patient's condition. During patient's EOL stage, patient's family often consider the EOL decision based on patient's physical appearance, such as facial expression, skin color, and synchrony with the ventilator. Patient's previous condition such as age, athletic activity, and illness history also considered by patient's family

before taking a decision (Boyd et al., 2010). Healthcare provider such as doctor and nurses also considered patient's condition before initiate discussion regarding EOL decision making. Doctor tend to delay the EOL decision making, and both of doctor and nurses reporting that they feel moral distress when they have different perspective about patient's prognosis with the family (Kryworuchko, Strachan, Nouvet, Downar, & You, 2016).

Belief. Religion is one of the factors that can be a barrier for healthcare providers during the end of life decision making process (Borhani, Hosseini, & Abbaszadeh, 2014). End of life decision making is still a controversy based on religious point of view and nurses who face this condition continually can experience burnout symptoms. Healthcare providers in ICU often feel that they have full responsibility regarding their patient's condition and this perception tends to make them susceptible to stress and depression (Teixeira et al., 2013). For patient's family, their belief to God often overrode the information regarding patient's prognosis and think that miracle probably happened through prayer, community support, or the presence of God through the actions of healthcare provider (Kryworuchko, Strachan, Nouvet, Downar, & You, 2016).

Communication. Communication especially between patient's family and healthcare provider is one of the most important factor during end of life decision making. Ineffective communication can induce problems among nurses, physicians, and the patient's families because the information regarding the patient's condition is not clear and often inconsistent (Aslakson et al., 2012). Communication problems also could happen between healthcare providers which have negative impact by inducing

intra-team conflict and could increase the rate of medical errors on patients (Fassier & Azoulay, 2010).

***Culture*.** EOL decision making process is an emotionally issue for patient, patient's family, and healthcare provider. Their coping mechanism often affected by their culture. Culture can gave different effect for the response during EOL decision making and the issues become more complicated when religion are considered (Steinberg, 2011). The healthcare provider must understand the distinction and influence of culture on patient and patient's family behavior by doing comprehensive assessment and respect each subject as individual with his or her own uniqueness (Coolen, 2012; Bullock, 2011; Jackson, Schim, & Duffy, 2000).

Islamic perspective in EOL

This section includes Islamic perspective in EOL decision making, existing studies of EOL decision making in Muslim healthcare provider, and studies in Indonesia.

Islamic perspective in EOL decision making. Muslims believe that every person will experience death as a transition process from one state of existence to the hereafter world which is infinite. Death is an unpredictable and inevitable process that can happen anytime and every Muslim should always be well prepared for death. The time of death is a secret from God, and when that time comes no one can delay that event for one second, nor can they bring it forward even one second (Abu-El-Noor & Abu-El-Noor, 2014).

Muslim believe that God create them to obey and serve him throughout their life. Life and death is God's prerogative and that will not happened but with the permission of God. This make saving a life consider one of highest merit for Muslim, and kill person is one of the biggest sin in Islam (Zahedi, Larijani, & Bazzaz, 2007). Muslims believe that death is a destiny from God and illness is a trial from God. The Prophet said that illness is a process to test a person's faith. It is from God and not to be taken as a punishment so Muslims should face it patiently. At the same time the Prophet also clearly commanded that Muslims must seek for treatment and may not terminate life. Based on this, some Muslim scholars consider that withholding and withdrawing treatment as one form of end of life decision making is not allowed (Abu-El-Noor & Abu-El-Noor, 2014).

Medical treatment is an obligation in order to cure diseases for every Muslim, however, medical management should not be given to the patient if it only prolongs the final stage of terminal illness and cannot cure the patient (Damghi et al., 2011; Huerta-Alardin, Cruz-Amador, Sternbach, & Varon 2004). This is based on a quote by the Prophet that mentions that the Muslim who prays to God when they are sick can choose to ask God to heal their disease or they can be patient and therefore they can go to paradise. Based on this, some Muslim scholars consider medical treatment not to be an obligation when the patient's prognosis is getting worse. Event Muslim believes that life and death only can be decided by God, but it is acceptable to withdraw patient's treatment when healthcare team certain about inevitable death. Thus treatment does not have to provide to only prolong patient's final stage in terminal condition (Zahedi, Larijani, & Bazzaz, 2007).

During EOL decision making, Islam regulates that patient's autonomy is very important and must be respected by healthcare team. The obligation to withhold or withdraw patient's treatment must be based on permitted. This understanding make healthcare provider should accept the decision of capable patient or patient's family as long as the healthcare provider gave comprehensive information regarding patient's condition and consequences of each decision (Padela & Mohiuddin, 2015). Patient and patient's family who involve in this process should be capable to make decision which some criteria such as mature, conscious, and responsible to God for his or her action (Paris & Hawkins, 2015).

The end of life decision based on Islamic perspective is crucial to be understood. Good understanding regarding religious beliefs of the patient and the patient's family can alleviate some of the dilemma that can come during end of life decision making. The dilemma often happens not only for the patient's family but for nurses as well.

Existing studies of EOL decision making in Muslim healthcare provider. From literature review two articles regarding Muslim healthcare perspective in EOL care were found. The first study was a systematic review study conducted by Lari, Goushegir, Madjid, and Latifi (2008). The aim of this study is to perform an original research in spirituality at the end of life in Islamic context by using systematic manner. Total articles which gathered from searching on main database and hand searching are 92 articles and after review process, there are only 5 articles which met with the inclusion criteria, however the researchers in this study decide that only three articles that can be used after careful review. From this study we can get information that patient's spirituality has good effect on patient's coping, and they perceive that

healthcare providers especially nurses are very helpful to help them cope with the problem especially when nurses can understand patient cultural background. On the other hand healthcare providers often feel stress because of their lack of knowledge regarding supporting spiritual care in EOL care. This study also mentions that the evidence regarding Islamic context in EOL is very few (Lari, Goushegir, Madjid, & Latifi, 2008).

A second study was conducted by Badir et al.(2015) to investigate the views and practices of ICU nurses in Turkey on EOL decision making. The total sample in this cross-sectional study was 602 respondents. Almost half of the total respondents (40%) felt withdrawal and withholding treatment were unethical actions. This study also explained that 75.7% of respondents were not directly involved in EOL decision making and 78.4% of respondents believed that the patient's family should be involved in EOL decision making. When the decision to withdraw the treatment is made, the majority of nurses (87.2%) agreed that the patients and their families should be facilitated to fulfill their final religious and spiritual duties.

Studies in Indonesia. Enggune, Ibrahim, and Agustina (2014) conducted qualitative studies regarding nurses' perception toward end of life care to obtain information about how nurses perceive the care of dying patients in Neurosurgical Critical Care Unit. This study involves eight nurses by using a purposive sampling method. This study explains that nurses in ICU often experienced a dilemma during end of life decision making because the discussion about end of life decision making was often too late. Nurses also experienced a dilemma when they allowed the patient's family to accompany the patient. Nurses also often felt disturbed when delivering care to the patient.

Studies that mention nurse lived experience in end of life decision making in ICU in Indonesia are very limited. Thus, it is difficult to understand Muslim nurses' lived experience in end of life decision making in ICU in Indonesia.

Hermeneutic Phenomenology

Phenomenology evolved as a result of a countermovement to the positivist paradigm in 19th century. The positivist assumed that objectivity measured knowledge and was independent of human interaction, while the naturalistic paradigm, which allied closely with phenomenology, assumed that knowledge was achieved through interactions between researchers and participants (Reiners, 2012). The term phenomenology derives from the Greek word *phainomenon*, whose roots are *phaenin* (appear) and *logia* (science or study), therefore, *phaenomenon* means the study of appearance (Kosasih, 2004).

Hermeneutics is a philosophical practice of interpreting all types of interview results aiming to clarify and find deep understanding of some phenomena we engage in rather than arrive at categorical solutions to its inquiries (Magrini, 2012). Hermeneutics or interpretive frameworks within phenomenology are used to deeply understand the meanings and the relation that context and knowledge has with each other.

Hermeneutic was introduced as a philosophy by Martin Heidegger (1889-1976) since he believed that interpretation is necessary to reveal the meaning of some phenomena. He believes that hermeneutics is the essence of human understanding, which consists of our understanding of the everyday world and our interpretation of it (Reiners, 2012). The word hermeneutics is derived from the Greek *hermeneutin*

which originated from the name of the Greek god Hermes, who made the unknowable become knowable through language and writing. First hermeneutics was only used to refer to study and interpretation of texts, but with the contribution of Heidegger and Gadamer, the term is now defined as the theory and practice of interpretation and understanding in different kinds of human contexts (Wilcke, 2002).

Hermeneutics is a philosophy that supports interpretive phenomenological approach through methods that focus on meaning and understanding in some specific context. Hermeneutics phenomenology aims to gather a deeper understanding by opening and understanding the meaning through a process of interpretation which involves reading between the lines and giving attention to what has been underestimated, and to that which has been so taken for granted that is has not been questioned (Wilcke, 2002).

Phenomenal reduction and bracketing is not possible in hermeneutics phenomenology because hermeneutics seeks to discover the meaning of the description. Rather than bracketing our assumptions and preconception, Heidegger maintains that our prior knowledge is an integral part of the process of understanding. Each person is then unique due to their previous experiences (Heidegger, 1996).

Heidegger uses the word pre conception and pre understanding to explain the meaning of a culture (language and practices) that was already set up before we arrived in the world. Pre understanding is a structure of our being-in-the-world it is not something we can eliminate, or bracket, because it is already with us in the world. This makes our pre understanding become an inseparable part of a human being's situation. This common background understanding needs to be brought into focus in order to be understood (Van Manen, 2007).

Heidegger explains that we cannot have the world without the process of interpretation. He broadened hermeneutics by emphasizing the concept of being in the world rather than knowing the world (Reiners, 2012). We can understand after we interpret something based on our experience. That makes us become self-interpreting beings (Dreyfus & Dreyfus, 1987).

Dasein in Being and time was explained as a personal existence in an average everydayness. Zuckerman (2015) explained that the term *Dasein* can seem to refer to the particular identities we live out, the basic understanding of being that gives sense to all of our worldly comportments, the authentic and inauthentic model of existence, or even the possibility of existing at all rather than not.

Warfield (2016) explained that *Dasein* was used by Heidegger to indicate specific situation of human beings. This specific situation means human beings are always involve in a particular context situation in the world such as cultural, socio-economic, and historical. This can be highlighted as we are trap into a world which we do not choose before and we should adapt our understanding in a certain way to agree that we choose to accept this condition. The interpretation is underlying person's understanding which means that every person's interpretation can be unique.

Thus the hermeneutic phenomenology is important as it can help to unveil the phenomena of Muslim nurses in ICU, and also to gain understanding of the Muslim nurses' lived experience and being in end of life decision making in ICU.

This study was using Van Manen's approach to generate data from interview result. Van manen offers a thematic approach to interpret hermeneutic phenomenology, in which the researcher was using and acknowledge his or her prior knowledge, experience, beliefs, and how these may influence the researcher during

the collection, analysis, and interpretation process. Van manen's approach consists of creating texts using hermeneutic reflection in a process of writing and re-writing to develop themes.

Van Manen (1990) explains the structure to approach interpretation of hermeneutic phenomenology and looks into the structure of human lifeworld by using lifeworld existential.This lifeworld can be different between one person and another person. Even one person can have different lifeworld existential at different times. Lifeworld existential consists of lived space (spatiality) as a felt space, lived body (corporeality) refers to the phenomenological facts that every person has a body in the world, lived time (temporality) refers to subjective time, and lived human relation (relationality) refers to the relation that every person maintain with others.

Lifeworld existential was adopted to describe and interpret the phenomena. Lived space is a category to describe human spatial dimensions of their daily experience. Lived body is a phenomenological fact that human being always bodily in the world. Lived time reflect is a temporality subjective time that can be vary between person as opposed to objective time. Lived human relation is the relationship that maintained with other person in the personal space we share with them (Van Manen, 1990).

Summary of Literature Review

EOL decision making is a process which conducted to consider patient's treatment during their end of life stage. There are several type of EOL decision making such as advance directives, withholding and withdrawing therapy, and euthanasia. Nurses in ICU together with physicians and allied healthcare such as

spiritual advisors should be able to deliver care during end of life decision making and carry out their role for the patient and the patient's family as well. EOL decision making in ICU consist of assessment, disclosure, discussion and consensus building by documentation. This process could spent time from hours until weeks or month. Nurses have very important roles during end of life decision making, such as, educator, advocator, collaborator, and supporter. Nurses can facilitate the patient's families during end of life decision making to get clear information and prevent miscommunication. There are some factors that can influenced the process of EOL decision making such as knowledge and experience of healthcare provider, patient's condition, religion and belief, communication, and culture.

Previous studies provide information that nurses in ICU perceive that the patient's family is a crucial part of EOL decision making in ICU. The literature review showed that ICU nurses in western countries tend to want to get involved in EOL decision making compare with the nurses in other countries. Previous evidence showed that nurses' cultural background and religion have relation with their willingness and perception regarding their involvement in EOL decision making in ICU. The nurses in ICU also facing dilemma and moral distress during their involvement in EOL decision making in ICU due to their lack of knowledge and contradiction between their role and their moral belief. However, particularly for Muslim nurses there is no reported published study regarding end of life decision making for Indonesian Muslim nurses. Thereby, it is necessary to conduct a study regarding Muslim nurses' lived experience in involvement at the EOL decision making in ICU.

Chapter 3

Research and Methodology

This chapter presents the methodology for this study, which consists of the design of the study, participants, ethical consideration, data collection, data analysis, and trustworthiness.

Design of Study

The hermeneutic phenomenological approach was used as the study design to explore the lived experience and being of Indonesian Muslim nurses in end of life (EOL) decision making in the intensive care unit (ICU). The hermeneutic phenomenological approach was used because this method focuses on the interpretation process which aims to seek a deeper understanding of the phenomena by rediscovering the phenomena by using the researcher's pre-understandings.

Setting of the Study

This study was conducted in the ICU at Margono Soekarjo Hospital, Central Java, Indonesia. Margono Soekarjo Hospital is under the auspices of the government of Central Java. This hospital is the biggest hospital in the southern part of central Java and is also designated as a referral hospital. This hospital has one general ICU. The total number of beds in the ICU is 11 beds. The total number of nurses in this unit is 26 nurses. All of nurses in this unit are Muslim.

During the delivery of care to the patient, Margono Soekarjo Hospital is equipped with a ventilator machine, defibrillator, bedside monitor, and other

technological support. Almost all life support equipment in the ICU is the latest version of its kind. Calibration and routine maintenance for this equipment is also conducted to guarantee the highest quality of care in the ICU.

The ICU in the Margono Soekarjo Hospital provides a specific room which can be used by family and the healthcare team for discussions regarding the patient's condition. This specific room is equipped with comfortable chairs and an air conditioner to make sure that the patient's family can feel comfortable during their discussions.

Only one person is allowed to enter the ICU room during the family visiting time. Normally this hospital provides family visiting time only twice a day. But when the patient falls into the end of life (EOL) stage, the family visiting times can be more flexible. The patient's family can give spiritual care to the patient based on their culture or religion as long it does not disrupt the caring process of the healthcare team. The patient's family can also be involved in the EOL decision making as decision makers on behalf of the patient when the patient is unconscious.

Margono Soekarjo Hospital categorizes nurses who work less than two years as junior nurses. Junior nurses are responsible only for routine care and are rarely involved in EOL decision making. They may be involved in this process but under the supervision of a senior nurse. Nurses in the ICU work the morning shift from 07.00 am to 02.00 pm, nurses who work the afternoon shift work from 02.00 pm to 09.00 pm, and the nurses who work the night shift start work from 09.00 pm to 07.00 am.

During the EOL decision making process, the healthcare team in the ICU of Margono Soekarjo Hospital always attempts to respect the authority of the patient and the patient's family during the EOL decision making process. In this hospital the

medical doctor has the responsibility to assess the patient's condition before making a decision to start discussions regarding EOL decision making. The doctor also has the role to explain the patient's condition to the family and lead the discussion during EOL decision making. During EOL decision making, the nurses have the role to contact the patient's family based on the doctor's order and support the doctor's role by providing evidence regarding the patient's condition. The nurses also have the role of clarifying the family's confusion regarding EOL decision making and give psychological support to the family during EOL decision making. When the medical doctor is busy, the nurses will take over the role as the healthcare team representatives to have discussions with the patient's family. The EOL decision making option such as withholding or withdrawing a patient's treatment is considered only when the patient's prognosis is poor and the treatment is useless.

A summary of the decision, which consists of the patient's prognosis, persons involved in the decision making process, and details of the treatments, is documented. Informed consent is also requested from the family on behalf of the patient. All discussions are conducted in a consultation room to make sure the patient's family feels comfortable during this process.

Participants

The participants in this study were selected using the purposive sampling method. The prospective participants were recruited using these inclusion criteria:

1. Muslim nurse
2. Work experience of at least three years in the ICU.
3. Willing and able to share his/her experience with the researcher

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. Data saturation is achieved when the researcher finds data redundancy from the participants. Creswell (1998) suggested that phenomenological studies need five to 25 participants and Morse (1994) suggested at least six persons. From those suggestions, the number of participants in this study was 14 which provided the saturated data.

In this study the researcher accessed the participants through the head nurse in the ICU. The head nurse provided the researcher with a list of names of nurses who fulfilled the inclusion criteria and were able to communicate their lived experience.

Ethical Considerations

This study was conducted after the researcher received approval from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand and with agreement from Margono Soekarjo Hospital, Central Java, Indonesia. The head nurse of the ICU introduced the researcher to the eligible participants. The researcher explained the purpose of the study, the process of the study, and the risk and benefits of the study to the participants. The researcher also made it clear to the participants that they have the right to choose whether they will participate in this study or not, and they also have the right to withdraw from the study without any consequences. Agreement from the participants was taken both verbally and by written informed consent (Appendix A).

This study did not have any direct risks to the participant physically and plans were prepared in case a participant felt emotional distress such as sadness or anger.

The researcher would stop the interview at that moment and be attentive to the participant's responses and try to understand what the participant was feeling. The researcher then decided to interrupt or discontinue the interview process depending on the preference of the participant.

The participants were informed that the researcher would use a tape recorder to record the conversation and if they felt uncomfortable at any time during the interview process, they could ask to stop the conversation even after they signed the informed consent to participate in this study.

The participants were informed that this interview would have no effect on their job or position. All information from the participants in this study was kept confidential and protected with anonymity. All results from the interview were kept in a place that only the researcher could access. The data would be destroyed by the researcher within five years after finishing this study.

Translation Process

In the first step, the recordings of the interviews were transcribed verbatim. From the transcripts the researcher conducted the first analysis with the help from an expert who graduated from the Doctorate Program in the Faculty of Nursing and had experience conducting qualitative studies. The results from the first analysis were translated from the Indonesian language into English by the researcher and the translation was confirmed by an expert who also graduated from the Doctoral Program in the Faculty of Nursing and had experience conducting qualitative studies. All experts were fluent bilingual speakers in both the English and Indonesian languages.

Researcher's Background

I am a devout Muslim and I have lived in Central Java Province for about 27 years. My experience as a nurse is about two years in a hospital working in the ward and operating theatre. I also had experience as an assistant lecturer in a university for about two years lecturing on topics related to medical and surgical nursing. I have had experience in withholding and withdrawing treatment, which is one form of EOL decision making, during the time in the hospital not only as a nurse but also as part of a patient's family when the researcher was involved in EOL decision making in the ICU for my grandmother. From that experience, I noticed that nurses often experience difficulty dealing with their religion when they were involved in EOL decision making in the ICU. Furthermore, sometimes the nurses also felt dissatisfied with their role during EOL decision making because they perceived that the medical doctor should be engaged more in this process instead of only giving directions and orders to the nurses. I believe that EOL decision making is allowed from the perspective of a Muslim and the decision to withdraw a patient's treatment is also allowed when the patient is in a critical condition and the prognosis is bad. Withdrawing treatment should be considered only when the treatment only prolongs the patient's life and cannot heal the patient because this kind of treatment only prolongs the suffering of the patient.

Data Collection Methods

The method of interview and the data collection phase are presented in this part.

Interview method. This study used an in-depth interview with semi-structured questions as the data collection method. The semi-structured questions were developed based on the research objective. The demographic data of the participants were assessed using a form (Appendix B) which consisted of information regarding age, gender, marital status, level of education, experience of training regarding EOL decision making, working experience, and ethnicity. The interviews in this study were conducted in the consultation room which was appropriate and comfortable for the interview process.

The interview questions in this study were:

1. What you understand about EOL decision making?
2. Your experience during involvement in EOL decision making, what is it like?
3. What are your roles in EOL decision making?
4. What exactly you do during EOL decision making?
5. What do you feel when taking part in EOL decision making?
6. Is there anything else that you would like to share with me?

The researcher used probing questions to encourage the participants to elaborate on their answers when participant's answer was brief or unclear. Examples of probing questions used in this study were:

1. How did you decide….?
2. How did you conclude….?

3. What sort of impact did you think….?

The researcher was also careful to end the interview by asking the participant whether there was anything else the participant would like to discuss with the researcher. The researcher also asked each participant whether they could like to be contacted later to discuss the findings of the study to make sure the findings reflected the intended meaning of the participant.

Phases of data collection. There were two data collection phases in this study: the preparation phase and the interview phase.

Preparation phase. In the preparation phase, the researcher obtained permission from the research approval committee from the Faculty of Nursing, Prince of Songkla University. The researcher also asked for permission from the Director of Margono Soekarjo Hospital. After getting permission, the researcher prepared an informed consent form, demographic data form, and the semi-structured interview questions.

The researcher was trained to interview participants and how to conduct the data analysis by the thesis advisor who is an expert in qualitative studies. The researcher also received knowledge on philosophy by attending lectures and gathering information from a literature review.

Before starting the actual data collection, the researcher conducted a face-to-face interview with two ICU nurses from Margono Soekarjo Hospital as practice for the researcher to gather the data. There were three important aspects that the researcher learned from the training process: how to probe a participant during the individual interview, how to write a reflective journal by reflecting on the information

obtained after conducting the interview, and how to analyze the data using Van Manen's perspectives.

Data collection phase. Data was collected using an in-depth interview with the participants. The interview was based on semi-structured interview questions which had already been prepared by the researcher. The researcher established rapport with the participants before conducting the interview by clearly explaining the research context to the participants and ensuring their safety and anonymity in this study.

The researcher contacted the participant three times. The first contact was conducting the interview regarding the phenomenon of this study. The second contact was conducting by the researcher to clarify the participant's explanations. The third contact was conducted to provide an opportunity for the participants to check the data to prevent any misinterpretation.

The interview process was conducted in 45 minutes to one hour. During the interview the researcher recorded the interview. Field notes also provided rich data to help the researcher triangulate the data. The reflective journal was another method used to gain a deep understanding of the phenomena. The interviews were conducted in a consultation room equipped with chairs, a door, a good lightning system, and an air conditioner to make the participant feel comfortable during the interview process.

Data Analysis

Van Manen's (1990) thematic analysis approach was adopted to understand the structure of the lived experiences of Muslim nurses who were involved in the EOL decision making in the ICU. Van Manen explains the structure to approach the

interpretation of hermeneutic phenomenology and looks into the structure of the human lifeworld by using four lifeworld existentials as a guide for reflection in the research process. These four lifeworld existentials consist of lived space, lived body, lived time, and lived relation to others. This lifeworld can be different between one person and another person. Even one person can have different lifeworld existentials at different times. Lifeworld existentials consist of (1) lived space (spatiality) which is a felt space, (2) lived body (corporeality) which refers to the phenomenological facts that every person has a body in the world, (3) lived time (temporality) which refers to subjective time, and (4) lived human relation to others (relationality) which refers to the relationships that every person maintains with others.

Lifeworld existential was adopted to describe and interpret the phenomena. Lived space is a category to describe human spatial dimensions of their daily experience. Lived body is a phenomenological fact that a human being always lives as a body in the world. Lived time is the temporality of subjective time that can vary between persons as opposed to objective time. Lived human relation refers to the relationships that are maintained with other persons in the personal space we share with them (Van Manen, 1990).

The strategy of analysis in this hermeneutic phenomenological study, which is based on Van Manen's (1990) methodical structure of human science research, is designed to uncover recurrent themes that, in this situation, represent the lived experience of Muslim nurses in the involvement of EOF decision making in the ICU.

1. Turning to a phenomenon which seriously interests us and commits us to the world (Van Manen, 1990, *p* 30). Lived experience is the starting point and ending point of phenomenological research. Lived experience should be unique for

the participants, which allows them to recall it upon reflection. A commitment to be concerned with all phenomena is needed and should be understood as a practice of thoughtfulness. This understanding is crucial in formulating a research question in a study. Therefore, to understand the phenomenon of the lived experience of Muslim nurses in the involvement of EOL decision making in the ICU, it started with the formulation of a research question related to this phenomenon.

2. **Investigating experience as we live it rather than as we conceptualize it (Van Manen, 1990, *p* 30).** Phenomenological studies aim to understand specific experiences from the participants and try to take a new look at that specific world by turning our concern to that experience. This step is concerned with the methods that will be used to investigate the lived experience regarding a specific topic.

While conducting phenomenological studies, the researcher should be concerned about choosing the methods to investigate the lived experience in question, for example, using in-depth interviews for data collection. In this study, the lived experience of the participants was gathered using in-depth interviews. The results of the interviews were kept in audio format and transcribed verbatim, and then translated to understand the meaning of the lived experience.

3. **Reflecting on the essential themes which characterize the phenomenon (Van Manen, 1990, *p* 30).** A theme is an element which occurs frequently in the text from data collection. Themes were identified from the results of the interviews. The researcher aimed to capture the essential meaning of the lived experiences. Phenomenological themes may be understood as the structure of experience in several situations which were treated as concrete occasions to examine the nature and role of meaningful themes in human science research and writing. The process of

approaching data to isolate the theme of a phenomenon can be conducted using three steps.

The holistic or sententious approach. The researcher can read text holistically and try to capture a phrase which is substantial and consists of the main significance of the text as a whole.

The selective or highlighting approach. The researcher can highlight the statements that seem particularly important and revealing about the phenomenon.

The detailed or line-by-line approach. The researcher should concentrate on every single sentence or sentence cluster to check whether or not that sentence or sentence cluster reveals anything about the phenomenon or the experience. When the themes are identified, the researcher can gather the most common themes that can be captured into single statements which can hold the main meaning of the themes.

The structure of the meanings of lived experience in Muslim nurses who were involved in the EOL decision making in the ICU was described and interpreted using four lifeworld existential themes. These themes consisted of (1) lived space (spatiality) as a felt space which refers to the ICU setting where the nurse is involved in EOL decision making, (2) lived body (corporeality) refers to the phenomenological fact that every person has a body in the world which in this study represents the participants who share their lived experience, (3) lived time (temporality) refers to subjective time which is the period of time when the nurses are involved in EOL decision making in the ICU, and (4) lived human relation (relationality) refers to the relationships that every person maintains with others which represents the relationships the nurses have with other healthcare providers in the ICU setting, the patient, and the patient's family.

4. **Describing the phenomenon through the art of writing and rewriting (Van Manen, 1990, *p* 30).** This part is very important especially in the analytical process of this study. Through writing, the researcher can articulate a clear view about the feelings, attitudes, and thoughts of the participants.

During this study, constant revising and refining of ideas during the data collection and transcription were conducted which were further clarified during the writing, rewriting, and reading.

5. **Maintaining a strong and oriented pedagogical relation to the phenomenon (Van Manen, 1990, *p* 31).** The researcher should focus on the research question which is already prepared for the interview. The researcher should take interest in the phenomenon with full consciousness to establish a strong connection with the phenomenon and the questions as well. The researcher should use the research question as a guideline during the analysis and consultation with the advisor and co-advisor to assure that the researcher was working in the right way.

6. **Balancing the research context by considering parts and whole (Van Manen, 1990, *p* 31).** The researcher is asked to constantly measure the overall design of the study against the significance that the parts play in the total textual structure. When the researcher gets confused in some parts, the researcher can look back to the contextual texts to consider how these parts contribute to the whole.

Trustworthiness

Trustworthiness represents reliability and validity of a qualitative study. The trustworthiness in this study used four criteria based on Lincoln & Guba (1985). The

four criteria for developing trustworthiness are credibility, dependability, confirmability, and transferability.

Credibility. Credibility is about the assurance of data and the interpretations of them (Lincoln & Guba, 1985). The credibility of a qualitative study represents the consistency between data from the participants and the researcher's interpretation. The researcher chose the participants based on the inclusion criteria to make sure the participants have the information that is necessary for this study. The researcher maintained rapport with the participants before conducting the interview to ensure the participants could explain their lived experience in a meaningful conversation. The researcher maintained credibility by validating the results with descriptions of the experiences of the participants. The researcher allowed the participants to check the data and the findings after the themes were identified, and the participants could also request a correction when they disagreed with the findings.

Dependability. Dependability is used to confirm the stability and reliability of the data over time and any condition (Lincoln & Guba, 1985). Dependability should be considered to maintain the credibility of the study. Dependability in this study was obtained by describing the research design and its implementation at a strategic level. Details of the data collection process and a reflective appraisal of the project were also addressed to explain the process in the field and evaluate the effectiveness of the inquiry process.

Confirmability. Confirmability represents the objectivity of the study results. The accuracy of the results should be based on the perspectives of the participants and not be affected by the researcher's bias or perspectives. Confirmability in this study

was maintained by systematically collecting the materials and documenting the results of this study. In this regard, the verbatim transcripts, field notes, and reflective journal were used. Consultation with the advisor and co-advisor was also conducted to perform a comparative analysis to ensure objectivity of the research.

Transferability. Transferability refers to the applicability of the study results in other settings or groups. The researcher explains the context of the study and gives a description of the participants in this study to enable someone interested in this study to conclude whether transfer is possible or not. The researcher explained the context of the study, setting, and report writing which described the data in detail so other parties would be able to understand the findings obtained from the study. The researcher also used thick description techniques, which means the researcher explained detailed descriptions of the lived experience of the Muslim nurses during their involvement in EOL decision making in the ICU because it is important to convey the phenomenon and the extent of the context.

Chapter 4

Findings and Discussion

The hermeneutic phenomenological study was conducted to describe the lived experience of Muslim nurses during their involvement in EOL decision making in the ICU. There were 14 ICU Muslim nurse participants in this study. The findings and discussion presented in this section are: (1) characteristics of the participants, (2) lived experiences of the Muslim nurses during their involvement in EOL decision making in the ICU, and (3) a discussion of the findings.

Findings

This section includes characteristics of participants and lived experience of Muslim nurses in involvement at the EOL decision making in ICU.

Characteristics of the participants. Demographic data obtained from the participants were age, gender, marital status, level of education, experience of EOL training, working experience in the ICU, and ethnicity.

Table 1.

Characteristics of Participants (n = 14)

Characteristics	n	%
Age (years)		
20-30	3	21
31-40	8	57
41-50	3	21
Mean = 35, Min = 25 Max = 42		

Table 1 (continued)

Characteristics	n	%
Gender		
Female	8	57
Male	6	43
Marital Status		
Single	4	29
Married	10	71
Level of education		
Diploma	10	71
Bachelor	4	29
Experience of EOL training		
No	14	100
Yes	0	0
Working Experience in ICU (years)		
4-10	10	71
11-18	4	29
Mean = 9, Min = 4 Max = 18		
Ethnicity		
Javanese	13	93
Sundanese	1	7

Eight participants in this study were female and 6 were male and their ages ranged from 25 to 42 years old with a mean age of 35 years old (Table 1). Ten participants were married and four participants were single. The majority of participants (71%) graduated from a diploma degree program which is three years of formal instruction in nursing. The working experience of the participants ranged from 4 to 18 years with a mean of 9 years. Almost all participants were Javanese (93%). Although the majority of them had a long experience in the ICU, especially regarding

involvement in EOL decision making in the ICU, they had not attended a training course in EOL decision making.

Each participant provided their personal backgrounds and histories in EOL decision making.

Participant no. 1. Participant no. 1 was a male nurse in the ICU. He was 31 years old and married. He graduated as a bachelor in nursing. He started his career as a nurse in the ICU in 2008. The ICU is the place where he took the role as a primary nurse. He believed if he works as a nurse while paying attention to Islamic rules, he will receive a reward from Allah. At all times he understands that Islamic values cannot be separated from his work as a nurse, especially when he is dealing with dying patients. He believes that every patient has their own destiny, and a nurse as a human doesn't have the right to interfere in that process. He disagrees with stopping treatment during the EOL decision making process but still agrees with giving minimal therapy to a dying patient. He believes that the patient's family has the right to get enough information before they make the decision and he would respect their decision. He often feels sad when involved in EOL decision making and often imagines the patient as a member of his family. He realizes that the patient's family has a difficult time when they are involved in this process. As a Muslim, he believes that every person must achieve a good death in the end of life, and to stop a life support machine is an example of an inhuman act that can disrupt a patient in achieving a good death.

Participant no. 2. Participant no. 2 was a male nurse in the ICU. He was 28 years old and single. He graduated with a nursing diploma. He started his career in a regular ward before working in the ICU for the last 4 years. He believes that EOL

decision making is a serious process and should be done only by senior nurses to prevent miscommunication and ensure the patient's family feels satisfied. As a Muslim he should try his best while delivering care to the patient and surrender the results to God. He often feels sad when a patient's family decides to stop treatment because it's like preceding God's decision. On the other hand, he understands that the patient doesn't have a chance to survive. He believes that conducting good communication and delivering spiritual support to the patient's family is important to help the family during this process.

Participant no. 3. Participant no. 3 was a female nurse in the ICU. She was 40 years old and married. She has a diploma degree in nursing. She started her career as a nurse in a regular ward and then moved to the ICCU for 3 years. Now she has been working in the ICU for 9 years. She believes that a patient's death is a prerogative of God and she should not interfere in that process. She believes that stopping a patient's life support machine is forbidden by her religion. She often feels sad when involved in the EOL decision making and the patient is still young, but she can accept the situation when the patient is elderly or has a chronic disease. She believes that her role is to help every patient to achieve a good death when the patient is dying. As a Muslim she believes a good death or khusnul khatimah by declaring syahadah is crucial because it can help the patient to enter heaven in the hereafter.

Participant no. 4. Participant no. 4 was a male nurse in the ICU. He was 41 years old and married. He has a diploma degree in nursing. He started his nursing career in a regular ward before spending his last 12 years as a nurse in the ICU. He believes that his involvement in EOL decision making is a form of intervention and he can be punished by God for his sin. He does not like to involve himself in EOL

decision making because this is a part of euthanasia. He respects the privilege of the patient's family to make the decision, but he would try to make suggestions to them based on his beliefs. Even though he doesn't like to be involved in this process, he would try to give support to the family mentally and spiritually because he believes that this is a difficult time for the patient's family.

Participant no. 5. Participant no. 5 was a male nurse in the ICU. He was 41 years old and married. He has a bachelor degree in nursing. He started his career in the emergency room and then he moved to the ICU 16 years ago. He believes that religion is the most important part in his life. Therefore, he would use his religion as a basis for all of his actions including when he delivers care to a patient. He believes that both the patient's family and the nurse are experiencing difficulty and often feels of being in a dilemma during the EOL decision making. He believes that healthcare providers who are involved in this process should understand their roles and do it responsibly. He had an experience years ago when a patient's family asked him to stop the life support machine. He felt that he was in a dilemma at that time because he felt scared that he would be committing a sin just because of his involvement even though he didn't stop the machine. Whenever he felt guilty doing something that is contrary to his beliefs he would do taubah prayer (specific prayer to ask forgiveness from Allah). Even though he feels uncomfortable during this process, he always tries to deliver continued support to ensure that the patient achieves a good death based on his beliefs.

Participant no. 6. Participant no. 6 was a female nurse in the ICU. She was 36 years old and married. She has a diploma degree in nursing. She spent her early career as a pediatric nurse before she started working in the ICU 6 years ago. During her

involvement in EOL decision making, she felt that the doctor needs to give clearer explanations to the family to prevent misinterpretations. As a Muslim she would try to be a devout Muslim by following all of God's orders and avoid His restrictions. She always tries to deliver the best care for her patients, and often feels like the patient is her own family. She had an experience taking care of a patient with a family who decided to withhold the machine even though the patient had already died biologically due to brainstem death. At that time she noticed that the patient's body had become swollen and smelled bad just like a corpse. She felt sorry for the patient but she could not do anything. Although she also believes that spiritual support for the family is crucial, unfortunately, nurses in the ICU cannot do that due to the workload of delivering care to other patients.

Participant no. 7. Participant no. 7 was a female nurse in the ICU. She was 36 years old and married. She has a diploma degree in nursing and has been working in the ICU for 12 years. She is a devout Muslim and always starts her duty everyday with prayer. She believes that patients who have no chance to survive should not be disrupted by a life support machine. She feels sorry for a patient like that. She believes that a nurse, as part of a healthcare team in the ICU, has a role that must be conducted with responsibility during EOL decision making. She values a nurse's ability to adapt to many kinds of families during EOL decision making and mentioned it as an art of being a nurse. During her involvement in EOL decision making, she believes that she would not be committing a sin because this process uses scientific knowledge as supporting data.

Participant no. 8. Participant no. 8 was a male nurse in the ICU. He was 31 years old and single. He has a diploma degree in nursing. He started his career in a

general ward and worked there for several months before spending his last 8 years working in the ICU. He believes that EOL decision making is a team work process which requires him to help each other. He always respects the family's authority to make decisions and always tries to deliver high quality care to the family during those difficult moments. He said that support for the family should be conducted continually from the very first time they meet to make sure the patient's family can feel satisfied since they feel involved during the patient's care.

Participant no. 9. Participant no. 9 was a female nurse in the ICU. She was 36 years old and married. She has a diploma degree in nursing. She had experience in a general ward before spending the last 7 years working in the ICU. She believes that a patient's family often experiences difficulty making a decision as to whether they would stop or continue the life support machine, because they feel afraid they would be blamed for the patient's death but, on the other hand, they know that the patient has almost no chance of being healed. She explained that involving herself in this process would not be a sin because she always uses scientific data concerning the patient's progress, and this process would be conducted only when the patient doesn't have any chance of getting better. She believes that a patient who is undergoing EOL has already died biologically and every vital sign that we can assess is just a result of using the life support machine. She has felt confused in the past whether her involvement in this process is a sin or not. She asked a Muslim scholar regarding this issue and the answer he gave was that involvement in this process is not a sin, and to stop the machine is not a sin either as long as we are sure that the patient doesn't have any chance of surviving.

Participant no. 10. Participant no. 10 was a female nurse in the ICU. She was 30 years old and married. She has a bachelor degree in nursing. She has been working in the ICU for six years. She believes that religion is very important and must be used as the first consideration before she does anything. She said that during her involvement in EOL decision making, she always tries to respect the family's privilege to make the decision. She believes that she can reduce the FiO2 of a patient's machine but she cannot stop the machine because it would be classified as euthanasia, which is very dangerous and can cause her legal problems. She also believes that collaboration with a Muslim scholar or ustadz is needed to deliver spiritual support to the family during EOL decision making.

Participant no. 11. Participant no. 11 was a male nurse in the ICU. He was 25 years old and single. He has a diploma degree in nursing and has been working in the ICU for 4 years. He said that EOL decision making is not a simple process and needs good teamwork from all of the healthcare providers to deliver high quality care. He often feels difficulty when he has discussions alone with the family without any support from the doctor. He believes that God has already decided the patient's destiny so he doesn't want to be involved in EOL decision making because it is like killing the patient. He believes that maybe the patient is still able to hear while they are dying, and to stop the machine would be like choking the patient while sleeping. He always tries to make all of his patients achieve a good death, and interfering in a patient's death by stopping the machine can make them die unnaturally and from his point of view that is not a good death.

Participant no. 12. Participant no. 12 was a female nurse. She was 33 years old and single. She has a bachelor degree in nursing and has been working in the ICU

for seven years. She always believes that high quality care for a patient and the family is a priority, so she always values teamwork as an important part during her work in the ICU. She feels that involvement in EOL decision making is a part of her job as a nurse, and as long as this process is based on the right procedures she feels fine. She always respects the family for any decision that they would take in EOL decision making.

Participant no. 13. Participant no. 13 was a male nurse in the ICU. He was 40 years old and married. He has a diploma degree in nursing and has been working in the ICU for eight years. He believes that EOL decision making can be started only when the patient really doesn't have any chance to survive. He believes that a patient's life support machine should not be stopped, otherwise that would be called a sin by God. He wants to make sure that if the family still decides to stop the machine, the family should do it themselves. He has come to realize that actually the patient's family has difficulty if they have to stop the machine, so he would try to suggest giving the patient minimal therapy instead of stopping the machine support. He wants to try as best as he can to avoid withdrawing the machine from a patient because he believes that it is like he is preempting God's decision and could be accused of killing the patient. He always values communication with the patient's family as an important part because he can imagine that the family must be feeling anxious when they are with the patient because they cannot stay continuously inside the ICU.

Participant no. 14. Participant no. 14 was a male nurse. He was 41 years old and married. He has a bachelor degree in nursing and has been working in the ICU for 17 years. He said that EOL decision making is an inseparable process when a nurse is working in the ICU. He is often involved in this process but he still feels sad when he

meets with the patient and the family during EOL decision making. He believes that EOL decision making is a difficult process and it can be a dilemma not only for the family but for the nurses as well. He always tries to deliver high quality care to the patient's family by making sure that the patient's family understands the entire situation and makes them feel that they are not abandoned. He understands that this process needs good teamwork which involves everyone in the healthcare team. He believes that spiritual support is crucial during EOL decision making and he said that collaboration with a Muslim scholar is needed to give spiritual support to the family who is facing a difficult time during their involvement in the EOL decision making.

Lived experience of Muslim nurses involved in end of life decision making in the ICU. The participants in this study illustrated their lived experience during involvement in the EOL decision making in the ICU. The findings from the analyzed and interpreted data were reflected by using the fundamental thematic structure of lifeworld (Van manen, 1990) which consists of lived body, lived time, lived relation, and lived space.

Lived body. Lived body refers to the physical presence which conceals some aspects of a person. Lived body can hide or reveal some truth which can explain phenomenological facts that happen on the inside (Van Manen, 1990). When the Muslim nurses in the ICU were involved in the situation of EOL decision making, they use their body in being in that situation. How the nurses lived bodily and felt in relation to their body were revealed in the lived experience of the nurses which included three thematic categories: (1) Feeling of dilemma (2) Feeling spiritual distress, and (3) Feeling powerless as presented in the following categories.

Thematic category: Feeling of dilemma. A dilemma is a feeling that occurs in a situation when the participants had difficulty deciding during their involvement in EOL decision making because the participants felt that the family's decision consisted of undesirable consequences. This dilemmatic condition often occurred when the participants had a different opinion than the members of the patient's family regarding the patient's directions of care during EOL decision making even though the participants and the family members had the same religion. The participants mentioned that they were in a dilemma between following their beliefs as a Muslim to not stop the patient's treatment or to follow their role as a nurse to stop the patient's treatment based on the family's decision. This dilemmatic situation could trigger discontent for the nurse during their involvement in EOL decision making. The participants had these explanations.

> 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 faced in the ICU, between the patient's condition and our faith or beliefs. [P 6, L 106-109]
>
> Honestly, there is a dilemma in my heart…deep inside my heart, in my faith as a Muslim, I believe that life and death is Allah's prerogative, the one and only. And I believe that I have no right to discuss something that affects someone's death. [P 5, L 54-58]
>
> I feel I'm in a dilemma when I should 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, L 72-75]

On the other hand, the participants understood that the machine could not heal the patient but only forced them to keep breathing. This condition put the participants

in a perplexing situation because they did not want to prolong the patient's suffering but at the same time they did not want to stop the machine. The other consequence of not withholding the machine was the huge daily increase in the economic cost the families of the patients must bear. The participants knew that consequence but they still had difficulty when the family decided to stop the machine in this conflicting situation. They experienced difficulty between following their beliefs and conducting their role as advocator for the patient's family.

> It's a dilemma, because we know that the machine actually cannot heal the patient, we only prolong the patient's suffering. [P 12, L 44-45]
>
> I also feel another dilemma, for example, patients who are without any insurance. I don't want to withdraw anything, but on the other hand I think of the patient's family who should bear the treatment costs in the ICU when the patient's prognosis is bad and the cost of treatment in the ICU is not cheap. [P 5, L 65-69]

Thematic category: Feeling spiritual distress. Spiritual distress is unpleasant feelings caused by a disturbance in the participant's religious beliefs or faith while being involved in the EOL decision making. The spiritual distress of the participants included feeling sad, guilty, and frustrated. The EOL decision making often causes the participants involved in the process to stop or continue the patient's life support on a machine. This can contradict a nurse's Islamic beliefs especially regarding Allah's prerogative as God to decide the patient's death. The participants also explained that their role during EOL decision making often made them infringe on God's rules that made them feel guilty.

> I think, it violates Islamic law, regardless whether the process is correct or not…we should tawakkal (give our maximum effort and surrender to Allah for the result) to Allah. When we decide to withdraw the treatment, it shows that we violate God's order to tawakkal and maybe I have sinned for that. [P 4, L 125-127]
>
> They asked me to remove the ventilator, but I refused to do it…I will not withdraw that ventilator machine. Finally, the patient's family agreed to remove the machine themselves. After this situation, I felt very worried, so I went to do taubah pray (specific praying to ask forgiveness from Allah), and prayed to God to forgive me and my sins. [P 5, 96-101]

During EOL decision making the participants often felt guilty and had a moral burden when the family finally decided to stop the life support machine because it was against God's command. They felt that they had the responsibility for the patient's condition and would be asked by God in the hereafter.

> I feel burdened when we should remove a patient's life support machine because I should bear a very big responsibility in the presence of God... I feel anger inside my heart and maybe a little frustration because maybe I have sinned. [P 6, L 121-123]
>
> Instinctively, when we stop the machine and then we see the patient die after a couple of minutes, it's like we preceded the patient's destiny which is the same as we killed the patient…moreover in the ICU we provide total care, which makes me think that a nurse has the full responsibility for the patient's condition… I feel that I have sinned for that and it becomes a 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 have this job because I feel guilty and I will be sinning because I am involved in the patient's dying process. [P4, L 128 - 133]

Thematic category: Feeling Powerless. Powerless is a participant's feeling of disability to explain their argument and express their dissatisfaction during EOL decision making when they have a disagreement with the final decision made by the family. The participants explained that they felt weak when they had a disagreement with the patient's family regarding the decision. The participants explained that they felt uncomfortable in that unavoidable situation but they could not do anything to change the decision because they did not have the authority to change the decision. The participants understood that they have the role to be involved during EOL decision making and they must do the intervention based on the final decision even though they disagree with the decision. This condition would cause the participant to feel disabled and could trigger dissatisfaction for the participant. The participants explained the conditions in these excerpts.

> ….when the doctor decides on a patient's condition and they are sure that the patient has no chance to survive, they will write a DNR in the patient's medical record…after that we start to reduce the FiO2 in patient's ventilator, which I think can also be included as euthanasia. That makes me feel uncomfortable but I cannot do anything to refuse or avoid it because I should do the intervention. [P4, L 72-77]

> I had a baby patient a couple weeks ago. The baby's condition was very poor… In the end of the day, the parents told us that they wanted to take the baby back home and they refused all treatment and just wanted to take the

> baby home. At that moment, I felt very weak because I could not refuse their decision even though I did not agree with them. [P 6, L 75-80]
>
> I had the experience of facing a patient's family who refused to withdraw the supporting machine… finally the patient started to swell and became swollen like a corpse, even the patient smelled like a corpse. But we could still see the vital signs because of the machine. I could not do anything because all of the decisions were made by the family and we should respect their decisions but I felt sorry for the patient. [P 6, L 91-97]

Lived time. Lived time refers to the temporal being in the world which is determined by feelings and psychological conditions and consists of the dimensions of present, past, and future (Van Manen, 1990). When the participants were involved in the EOL decision making, their subjective perceptions and experiences can affect their perspective of their temporal way of being during this decision making process. The participants temporal lives were revealed in two thematic categories: (1) Being in uncertain time and (2) Continuous time of caring.

Thematic category: Being in uncertain time. Being in uncertain time is the participant's perception of time while being involved in the EOL decision making because the time cannot be expected and indicated exactly when the decisions can be done by the patient's family members. The participants explained that they always lived in an uncertain time when the patient's family members could not make a decision whether they wanted to stop or continue the treatment due to many factors such as waiting for other family members who stayed in another city or the family's fear of being accused of murder when they decided to stop the treatment. This uncertainty is caused mainly by the unclear direction of care while waiting for the

family's decision until the time of decision. This uncertainty reveals that EOL decision making is a dynamic process which can go back and forth to adjust to the family's needs. The family can change their decision when they consider another option that is better. The participants did not know how long they should wait until finally they would get the final decision. Some examples on this theme were given by the participants.

> Some families may say that they cannot decide because they still have to wait for their family from another city. This condition puts me as a nurse in a state of uncertainty because I should wait several days…I don't really know how long I should wait and what I should do during the waiting time. [P4, L 60-63]
>
> …sometimes the patient's family told me that they have difficulty deciding whether they want to continue or stop, even though the patient doesn't 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, L 61-64]
>
> The patient's family often feels confused when deciding 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. This process may take a long time until finally the family gives their decision. [P 9, L 12-19]

Disagreement between the family members can make the participants feel exhausted because they had to wait until the family came to an agreement regarding the direction of care for the patient during this uncertain time. The participants

mentioned that they did not want to violate the family's privilege to decide on the patient's care. One participant stated that

> the families often have disagreements among themselves; one person may ask to stop the treatment, while another family member refuses to stop the treatment. I can only wait until they can have an agreement. [P 10, L 60 - 62]

Another participant mentioned that

> when we meet a family who cannot decide whether they will stop or continue the treatment and just pass the decision to the healthcare team to decide, it puts us in a difficult condition because the decision is the right and responsibility of the family members. 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, L 106-110]

Thematic category: Continuous time of caring. Continuous caring during EOL decision making refers to delivering care from the first moment EOL decision making is initiated until the patient's family makes their decision and the care continues until the patient achieves a good death. This continuous support was delivered comprehensively to the family which consisted of physical, psychological, and spiritual support. The participants could comprehend that EOL decision making was a dynamic process which enabled the family to consider and shift their decision along this process. The participants understood that EOL decision making was a difficult process and they believed that providing continuous caring was important to help the family to make a decision. Two participants in this study give these explanations.

> We have the specific role to accompany the patient's family from the very beginning of this process (EOL decision making) such as giving psychological

> support to the family and we should be ready if the patient's family has some issues to be clarified during this time… [P 6, L 63-65]
>
> We have the role to accompany the family from the beginning (EOL decision making) to clarify all information which is confusing to them, and support them psychologically and spiritually until they want to make a decision. [P 9. L 68-70]

Continuous time of caring usually centered on continuous communication with family members to update the patient's signs and symptoms. One participant said that

> communication with the patient's family should be maintained continually to ensure they know and understand the patient's progress in the ICU (while waiting for the family's decision), because in the ICU there are restrictions on the family on when they can meet the patient. [P 8, L 73-76]

Lived Relation. Lived relation refers to the connections individuals maintain with other persons who live in the same interpersonal space (van Manen, 1990). Every individual can have an impression regarding other persons which can be affirmed in interactions with them. When the participants are involved in EOL decision making, they should deal with other healthcare providers, patients, and the families of the patients. How the participants lived their relationships during their involvement in EOL decision making were revealed in four thematic categories: (1) Receiving overwhelming role (2) Valuing competency in communication with the family (3) Understanding the family's feeling, and (4) Being a supporter for the family.

Thematic category: Receiving overwhelming role. An overwhelming role was an unpleasant circumstance when the participants were obliged to act in the role of another healthcare provider. During EOL decision making the participants worked together with other healthcare providers which unfortunately made the participants feel like they were being forced because they felt they were doing another person's responsibility, such as leading the discussion with the family during EOL decision making and turning off the life support machine when the family decided to stop the treatment. This could make the participants feel uncomfortable during their involvement in EOL decision making. In these excerpts, the participants had these explanations.

> …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 you can imagine I don't feel comfortable during this process. [P 4, L 88-91]

Another participant also mentioned that

> honestly, I feel uncomfortable to do something like this (discuss the situation alone with the family) which is actually part of the doctor's duty... [P 11, L 16-17]

The participants explained that they tried to negotiate with other healthcare members to be responsible in performing their own roles during EOL decision making and not just delegate it to the nurses.

> When a doctor asks me to discuss the situation alone with the family, I feel that it is a problem, so when I face that condition (asked by the doctor to talk

> alone with the family), I try to talk politely to the doctor so the doctor will agree to talk with the patient's family. [P5, L44-46]

The participants explained that the guideline for EOL decision making needs to be revised and then published for all healthcare providers so they can understand the right steps during EOL decision making and all persons can conduct their own roles with full responsibility. The participants mentioned in excerpts that

> …we need to clarify our guideline. We need clearer steps and what kind of information we should explain, and who is a responsible for this process. [P 4, L 132-134]

> …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, L 130-132]

The participants explained that even when they were asked to conduct an overwhelming role during their involvement in EOL decision making, they often felt like an invisible person for the family. Being invisible meant that the participant felt they were overlooked by the family during EOL decision making. The participants explained that they felt that the family preferred to talk with the doctor instead of them during EOL decision making. When the participant had to conduct the doctor's role to discuss the situation with the family, they often did not get enough appreciation from the family. This situation made the participant feel uncomfortable because they thought the family did not want to talk with them even though the participant tried to deliver high quality care as mentioned in these excerpts.

> When I discussed the situation alone with the family, some of them told me that they felt unsatisfied because they wanted to talk with the doctor instead of me. [P 9, L 55-57]
>
> …I hope the doctor can explain directly to the family so the family can feel satisfied during the discussion process, because some families said they only wanted to talk with the doctor. This kind of family tends to have greater demands and I feel uncomfortable talking alone with them.
> [P 13, L 47-49]

Thematic category: Valuing competency in communication with the family. Valuing competency in communication with the family represents the participant's appreciation of the nurse's ability to explain and discuss the situation with the family at the time of EOL decision making. During EOL decision making, the participants always valued the discussion with the family as a substantial part. The discussion process during EOL decision making, especially between healthcare providers and the family, was important to help the family in dealing with a difficult situation. The participants mentioned that conducting high quality communication could make the family feel comfortable; on the other hand, failure of communication could trigger a family's dissatisfaction. Participants had these comments.

> ...in my opinion this process (discussion with the family) should be done by senior nurses, because it's an important communication with the family which can decide on the patient's care. We need persons with a lot of experience to prevent an incorrect explanation; it's very dangerous if we explain something incorrectly. [P 2, L 4-7]

> I notice that junior and senior nurses have a very wide gap regarding their ability to communicate with the patients, especially during the EOL decision making process. Junior nurses should learn more about it to understand the situation and understand what kinds of information we should give to the patient's family. [P 5, L 115-119]
>
> …a senior nurse should be able to learn more about listening ability, because I think we are busy talking and do not give enough attention listening to the patient's family perceptions, feelings, and expectations. [P 5, L 120-122]

Competency in communication with the family during the EOL decision making was also crucial for the nurses because it could increase the confidence of the nurses when they talk with the family and at the same time can decrease a nurse's stress. The participants also mentioned that they often felt afraid to talk alone with the family because some families often demanded more explanations from the nurses. The participants worried that the family could not accept the patient's condition although they were already given information that was supported with data. The participants gave these comments.

> Some difficulty often occurs when we face the patient's family with good knowledge, it increases the pressure during the EOL decision making. We have to carefully explain all the information to the family. [P 1, L 61-63]
>
> …when I have to talk alone with the family, I am afraid the family cannot accept the patient's condition, even though we explain the patient's progress and even though we use data to support our explanation. [P 9, 60-62]

Thematic category: Understanding the family's feeling. Understanding the family's feeling is the participant's feeling of compassion for the family which occurs

when they are witnessing a family's difficulty and confusion while making a decision on the patient's life and death. The participants explained that they understood that the family often experienced the feeling of being a killer when they made the decision to stop the patient's life support. The participants gave these explanations.

> ..some family members refuse to make a decision to withdraw the supporting machine because they are afraid they will be accused of being 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 has the responsibility to stop the machine, not the doctor and not the nurse. After they receive the explanation, many of them change their decision to give the patient minimal therapy instead of withdrawing the life support machine. I know this is not easy for them. [P 13, L 14-17]
>
> The family was afraid that they will be blamed if they decide to stop the machine, it sounds like they are killing the patient…they must be confused because they just want to make the best decision for the patient. [P 13, L 19-21]

Thematic category: Being a supporter for the family. Being a supporter for the family refers to the participant's role during EOL decision making to ensure that the family can understand the situation and can show positive coping while dealing with this difficult situation. The participants explained that EOL decision making was a difficult process for the families because they were asked to make a decision which would affect the patient's life. The families often felt confused when they had to make a decision regarding the patient's direction of care because they did not have enough

knowledge regarding the patient's condition. The family's confusion can get worst when the family members are unprepared mentally and psychologically. The participants valued psychological and spiritual support for the families as an essential part during their involvement in EOL decision making. These excerpts provide some comments by the participants.

> We have a duty to support the family mentally and spiritually during this difficult process. I believe that this is not easy for them because this decision concerns the life of a family member. [P4, L40-42]
>
> …this process is never an easy process for the patient's family, so we should support them to make the best decision, not only for the patient but for the patient's family as well. [P 5, L 125-127]
>
> We have the specific role to accompany the patient's family from the very beginning of this process, such as giving psychological support for the family, and we should be ready if the patient's family has some issues to be clarified… [P 6, L 63-65]

The participants also mentioned that another way to support the family was by translating unfamiliar terms to the family. The participants said that when they explained the patient's condition to the family, the unfamiliar terms often used by the healthcare team could make the family feel confused. The participant would try to translate those unfamiliar terms into everyday language and clarify the issues that were important to the family. The participants had these comments concerning communication.

> Nurses also give information to the patient's family regarding decision making, I mean we facilitate giving them the information they need and we

> can explain by using simple language which can be easily understood by the patient's family compared with when they discuss the patient's condition with the doctor. [P 1, L 33-36]
>
> …a nurse has the role to conduct re-counseling…we can clarify some terms and make sure the family understands the information they get by using language that is easy to understand by the patient's family. [P 7, L 32-35]

Lived space. Lived space refers to the dimension of world or landscape where the people have experiences and try to find themselves during day-to-day experiences (van Manen, 1990). The space can affect the way people feel and it can be influenced by a person's background, childhood memories, interests, and profession. When the participants are involved in the EOL decision making process, their perception of space can influence their being in that situation. How the participants reflected their lived spatiality in relation to their perceptions was revealed in two thematic categories: (1) Respecting privacy and (2) Evading the process.

Thematic category: Respecting privacy. Privacy is a privilege for the patient's family members during their time to make a decision regarding the patient's treatments when the patient's condition has deteriorated. The participants understood that preparing a private space for the family by closing a curtain and allowing the family to stay for a while next to patient's bed was important to help them make a decision and accept the decision. Allowing the family to spend time with the patient was also important to help the family face the reality when the patient's condition is getting worst. The participants had these comments.

> When we tell the family that the patient's condition is getting worst we also close the curtain around them… we understand the family's need for privacy during this difficult time before they finally make a decision. [P 5, L 85-86]
>
> …a family which refuses to accept the patient's condition can start crying and hug the patient without allowing us to do anything. At this moment we understand that they need space to be alone and it is impossible for us to start a discussion. So we just close the curtain to partition off their space. [P 7, L 45-49]

Another participant explained that respecting the family's privacy was useful to enhance spiritual support for the patient as stated in this excerpt.

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

Thematic category: Evading the process. Evading the process refers to the participant's feeling that the EOL decision making process be avoided as their response to the EOL decision making. The participant believes that EOL decision making is a process which is prohibited by God and their involvement during EOL decision making would cause them to sin because they have violated a prohibition of God. The participants thought that their involvement would affect the patient's life or death which was actually God's prerogative. The participants gave these comments concerning evasion of EOL decision making.

> Personally, I do not want to be involved in the decision making process or a discussion with the family on how to decide whether we stop or continue the

> machine. I think that it is Allah's prerogative and honestly I do not want to be involved. [P 11, L 33-35]
>
> … 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 support for the patient with a ventilator machine instead of stopping the treatment. [P 3, L 21-27]
>
> I believe that Allah has a plan for everything including a patient's life. If the patient's destiny is to die today, we don't need to do anything and the patient will still die because of God's decision. We don't need to be involved in this process. [P5, L 62-65]

The participants explained that they did not want to be involved in EOL decision making because they felt worried that they have sinned and will be punished by God. The participants thought that they did not have the right to be involved in this process because they believed that making a decision which affects someone's life or death is a right that belongs only to God. A participant gave this explanation.

> Actually, I think that when I am involved in this process and the patient's family decides to withdraw treatment, I feel I have sinned because I took a role in the patient's dying process. [P 4, L98-100]

The participant explained that when the family decided to stop the life support machine, the participant felt guilty because the participant believed that stopping the patient's life support machine was similar to killing the patient intentionally which could be classified as a major sin in Islam. The participant believes that God has decided the best destiny for the patient and they thought that stopping a patient's life

support machine could be considered as an intervention process which would cause the patient to die unnaturally. The participants gave these comments.

> …. I am afraid I have sinned and I feel guilty when I am involved in the family's decision making process and then the family decides to stop the machine. [P 10, L 54-56]
>
> …when the family decides to stop the machine that is supporting the patient and if they ask me to stop the machine on behalf of them, of course I will refuse because it is like I am killing the patient. [P 11, L 42-44]

Table 2

Muslim Nurses' Lived Experience in Involvement at the End of Life Decision Making in Intensive Care Unit

Four lifewords	Thematic categories
1. Lived body	1.1.Feeling of dilemma 1.2.Feeling spiritual distress 1.3.Feeling powerless
2. Lived time	2.1.Being in uncertain time 2.2.Continuous time of caring
3. Lived relation	3.1.Receiving overwhelming role 3.2.Valuing competency in communication with the family 3.3.Understanding the family's feeling 3.4.Being a supporter for the family
4. Lived space	4.1 Respecting privacy 4.2 Evading the process

Discussion of the Findings

This section presents an overview of the findings gathered from this study. The evidence related to this study is also discussed.

Lived body. In this study the findings of lived body included three thematic categories. They are ‘feeling of dilemma’, ‘feeling spiritual distress, and ‘feeling powerless’. The theme of feeling of dilemma represents the feelings of the participants when they have to be involved in the EOL decision making. Dilemma in this study occurred because the participants in this study had to follow the family’s decision which could be contrary to their beliefs.

Being in a dilemma during a nurse’s involvement in EOL decision making is a common phenomenon. Similar findings from a study by Karnik and Kanekar (2016) explained that healthcare providers may have different beliefs regarding EOL decision making with a patient or patient’s family. This problem could be triggered by the family members who have unrealistic expectations of care (Karnik & Kanekar, 2016) or the nurse’s incompetence (Adams, 2013). The participants in this study were dominated by nurses with a diploma degree and without any EOL training. This lack of knowledge and training in the participants will affect their perceptions during EOL decision making and cause them to be dominated by their beliefs only because of their limited competencies. This lack of knowledge and training will cause the participants to use their own feelings as the only consideration instead of their competencies. This condition could trigger a dilemma when the nurses have a disagreement with the family because they do not have the competencies to deal with this kind of situation. This result was similar to the studies by Adams (2013) and Mani (2016) which explained that nurses who lack training and knowledge regarding EOL decision

making will make the nurses feel unprepared and rely only on their feelings instead of knowledge during their involvement.

The second theme in lived body is feeling spiritual distress, which is represented by the participant's unpleasantness due to spiritual disturbance during their involvement in EOL decision making. The spiritual distress in this study is caused by their role which contradicts the nurses' Islamic beliefs. In this study the participants mentioned that they felt distressed when involved in EOL decision making due to a conflict between their role and beliefs. The participants also explained that they thought they were responsible for the patient's death and often felt that they were killing the patient by being involved in the EOL decision making.

A study by Jordan, Clifford, and Williams (2015) mentioned a similar finding that Christian nurses also perceived themselves as a murderer when they were involved in EOL decision making. The nurses often had difficulty when they had to shift care from curative into comfort care (Calvin, Kite-Powell, & Hickey, 2007). Furthermore, the participants explained that they often felt responsible for a patient's death even though they were not the person who stopped the treatment. This finding was similar to a study by McMillen (2008) which reported that the family often felt guilty when they were involved in EOL decision making even though they did not stop the treatment. Disturbance of a nurse's spirituality could influence a nurse's feeling and care during their involvement in EOL decision making (Baliza et al., 2015). A different perspective was explained by Valiee, Negarandeh, and Nayeri (2012) which stated that ICU Muslim nurses in Iran did not have spiritual distress when they were involved in EOL decision making. This difference could be influenced by a different level of education of the nurses and the lack of a clear

guideline. Sufficient knowledge regarding EOL decision making and a clear guideline would help nurses to understand their role and reduce spiritual distress.

The theme of feeling powerless represents the feelings of the participants when they have disagreements with the family during EOL decision making. Nurses often continued the treatment just because they must follow the family's decision not to stop the treatment even though the patient's prognosis was poor. This condition forces the nurses to prolong the patient's suffering because they do not want to face legal action (MengJie et al., 2015). The participants understand that they did not have the power or authority to influence the family's final decision and this made the participants feel powerless. Similar findings were stated by Haddad (2006) which explained that the powerlessness of the nurses during EOL decision making was affected by the disparity between their roles and their lack of authority which causes the values and views of the nurses to be overlooked. Moreover a nurse's powerlessness can lead to moral distress which reduces professional empowerment (McAndrew & Leske, 2015) and can trigger burn out as a consequence (Zuzelo, 2007).

Lived time. The thematic categories in lived time are 'being in uncertain time' and 'continuous time of caring'. The theme of being in uncertain time represents the participant's perception during their involvement in EOL decision making as they cannot predict the time when the decision would be made by the family and how long they should have to wait. A similar study from Nunez et al (2015) and Ranse (2013) reported that the patient's family often had difficulties when they had to make a decision regarding EOL decision making because they felt that their decision would make them responsible for the patient's death. A nurse in the ICU understands that

EOL decision making is a dynamic process, so they would give enough time for the family during EOL decision making because it is important to ensure they accept the patient's condition and comprehend the situation. This was similar to a study by Nunez et al, (2015) which explained that a family often wanted to reconsider their decision several times before they make the final decision. However, the nurse is also aware that the patient can get prolonged useless treatment and unnecessary suffering while waiting for the family's decision. Efstathiou and Walker (2014) reported that the uncertainty of time for a nurse also occurred after the family made a decision. They mentioned that the nurse questioned how long and how far they should be involved during the EOL decision making. This uncertainty can be caused by unclear guidelines for EOL decision making.

The second theme in lived time is continuous time of caring. This theme represents the participant's preference to continuous care for the family during EOL decision making. When the patient's condition gets worse, the EOL decision making usually will be initiated by the doctor. When the EOL decision making is started, the nurses are expected to be able to provide medical literature as strong evidence to the family and maintain the discussion by using good communication skills at the beginning of the discussion, especially regarding sensitive issues (Adams, 2013; Coombs, Parker, Ranse, Endacott, & Bloomer, 2016).

The participants understood that continuous caring for the family was crucial during this dynamic process. A study by Kisorio and Langley (2016) stated that the nurse's presence to accompany the patient and family for a long period during EOL decision making could also reduce the family's anxiety and increase their confidence. Continuous support by the nurse is crucial to clarify questions and ambiguous

information, or just being present can be important for the family during this difficult time (Ranse, Yates, & Coyer 2012; Pattison, Carr, Turnock, & Dolan, 2013). Continuous care for the family and patient should be maintained even when the final decision is made by the family. The nurse's duty is to help the patient to achieve a good death and maintain emotional support for the family while assisting the family by creating positive memories (Coombs et al., 2016).

Lived relation. The thematic categories in lived relation are 'receiving overwhelming role', 'valuing competency in communication with family', 'understanding the family's feeling', and 'being a supporter for the family'. The theme of receiving overwhelming role represents the participant's condition when being forced to conduct the role of another person. The participants mentioned that they often had to bear the role of another healthcare provider during their involvement in EOL decision making. This finding was similar to a study by Adams (2013) which explained that the role of the nurses and other healthcare providers such as the doctor often overlapped even though they have different duties during EOL decision making. This condition could be caused by the lack of a clear guideline to assign the roles of each healthcare provider in this process and this causes the participant to bear the role of other healthcare providers. This finding is consistent with a previous study by Davatgar (2015) which reported that during EOL decision making the doctor often did not conduct their role to explain clearly regarding EOL decision making to the family and left that difficult responsibility to the nurse. These ambiguous roles in the healthcare providers during EOL decision making can be triggered because the nurse's involvement is often decided on the doctor's preference, level of experience or seniority within the team (Flannery, Ramjan, & Peters, 2016). A study by Tao,

Ellenbecker, Wang, and Li (2016) mentioned that receiving an overwhelming job can decrease job dissatisfaction among nurses in the ICU and was related to burn out. Furthermore, the participants mentioned that they did not get the respect that they deserved from the family even though they bore an overwhelming role during EOL decision making. This finding was similar to a study by Tao et al. which mentioned that even though the nurse tried to deliver their job with full responsibility, they often did not get enough respect from the family because the family thought that the nurse is the doctor's subordinate.

The theme valuing competency in communication with the family represents the participant's appreciation to deliver high quality communication to the family during EOL decision making by using language that is easy to understand. The participants mentioned that communication skills are important during EOL decision making and should be conducted by nurses who have experience to prevent an incorrect explanation. This finding is consistent with a study by Adams (2013) which explains that nurses believed that a discussion with the family during EOL decision making is a difficult process which requires skill that must be learned and cannot be guided by using the nurse's instinct. Similar results from a previous study of Baliza et al. (2015) and Brooks, Manias, and Nicholson (2017) also explained that nurses often perceived communication with the family during EOL decision making as one of the biggest barriers especially for novice nurses. Limited education and training for ICU nurses regarding EOL decision making can become a barrier to conducting high quality communication with the family during EOL decision making (Brooks et al., 2017).

Another theme category in the lived relation is an understanding of the family's feeling of becoming a murderer. This theme represents the participant's feeling of compassion for the family due to the family's difficulty and confusion while making a decision because they are afraid they will be blamed for the death of the patient. A study by Adams (2013) mentioned that the family often felt guilty and regret due to the sense of responsibility for their decision. A study by Schenker et al. (2012) also stated a similar finding which said that the patient's family felt that their decision during EOL decision making can be classified as causing the patient to die, and this role made them endure emotional discomfort due to responsibility for the patient's death. The family's emotional barriers such as anxiety and depression when they are involved in EOL decision making could be problematic due to possible biases that can influence the decision based on the patient's benefit (White, 2011).

The participants in this study understood that EOL decision making was a difficult process for the family. This finding is consistent with the studies by Adams (2013) and Hilden and Honkasalo (2006) which reported that nurses in the ICU understood that a family could experience acute stress, depression, anxiety, post-traumatic stress disorder, and complicated grief during EOL decision making. These conditions require the nurses to be able to support the family by providing clear and unambiguous information during the decision making. The support from the nurses to ensure that the patient's family understands the situation and terms that are used during the discussions is essential to prevent the family from miscalculating the consequences of their decision on the patient's quality of life and functional state (Hilden & Honkasalo 2006; Coombs et al., 2016; Enggune et al., 2016). Delivering support for the family can be started by assessing the needs of the patient's family for

information, and then try to select several issues of concern to be explained to the family by using clear and considerate language (Coombs et al., 2016).

Lived space. Lived space in this study includes two thematic categories. These are ‘respecting privacy’ and ‘evading the process’. The theme of respecting privacy represents the participant’s appreciation to prepare a private space for the family to stay together during their decision making. A study by Noome, Dijkstra, van Leeuwen, and Vloet (2016) mentioned that the family wished to be able to stay with the patient while the patient was in a critical condition to stay next to the patient and without any interest from the nurses and other healthcare providers during that time. Supporting the family’s privacy to stay with the patient during EOL decision making is important to deliver spiritual care to the patient, although the nurses often felt disturbed by the family’s presence when they were delivering care to the patient (Enggune et al., 2016). Preparing a space with privacy for the family during EOL decision making can help the family to deal with the situation and reduce the family’s suffering which is important to assess the family’s preference during EOL decision making (Andrews, 2015).

The second theme in lived space is evading the process which represents the participant’s preference to avoid the EOL decision making process. The participants in this study mentioned that they did not want to be involved in EOL decision making because they thought that their involvement would affect the patient’s death and violate God’s prerogative. A similar finding was reported in a study by Baliza et al, (2015) in Brazil which explained that the nurses in the ICU often felt uncomfortable when they had to be involved in EOL decision making because they believed they would be involved in the process of advancing the patient’s death. Other findings by

Velarde-Garcia, et al. (2016) also mentioned that even nurses in the ICU, who have an opportunity to participate in EOL decision making, will choose not to be involved in that process due to the emotional burden and they would rather leave the decision to the doctor. This finding is consistent with a study by Meng Jie et al. (2015) which mentioned that they chose to maintain a distance from the family when EOL decision making occurred because they wanted to avoid disputes with the family that could lead to a medical lawsuit.

Different results in studies from Belgium (Inghelbrecht, Bilsen, Mortier, & Deliens, 2009) and Turkey (Badir et al., 2015) indicated that almost all nurses in the ICU were clearly willing to be involved in EOL decision making and felt disappointed if the physician made a decision without consulting them. This difference could be caused by different levels of education and the lack of nurse competencies regarding EOL decision making in the ICU. A nurse's lack of knowledge and competency may lead to misperceptions which could decrease their confidence and cause them to avoid EOL decision making.

In this current study, most participants had a diploma degree but did not have any training regarding EOL decision making or EOL care. This meant that the participants did not have sufficient knowledge to conduct their roles during their involvement in EOL decision making. Their limited understanding regarding EOL decision making also made them perceive that their religion was against their involvement in EOL decision making. This was different with other countries which have a well-developed education and guidelines regarding EOL decision making such as Iran and Turkey even though they have a similar religion as the participants in this study. The limited access to knowledge and training in EOL decision making also

caused the participants to have low competency and low self-confidence in conducting their roles.

The context of the hospital in this study also did not support the nurses to conduct their roles during involvement in the EOL decision making process in the ICU. A well-developed guideline is needed to ensure every healthcare provider understands their own role and responsible to conduct it. A clear guideline is also important to prevent overlaps of roles between the healthcare providers. A good policy to deliver training to nurses and develop a clear guideline regarding EOL decision making could prevent the dissatisfaction of the nurses and at the same time could increase the quality of EOL decision making in ICU.

Chapter 5

Conclusions and Recommendations

The hermeneutic phenomenological approach was used to explore the lived experience and being of Muslim nurses during their involvement in EOL decision making in the ICU. This study was conducted from January 2017 to February 2017. The researcher used an in-depth interview with semi-structured questions as the data collection methods. The semi-structured questions were developed by the researcher based on the research objective. The strategy of data analysis is represented by using Van Manen's thematic analysis approach. The summary of the findings, strength of the study, limitation of the study, and recommendations based on the findings are discussed in this chapter.

Summary of the Findings

Fourteen nurses who met the inclusion criteria were the participants; eight of the nurses were female. The average age of the participants was 35 years old. Most of the participants (71%) were married and had a diploma degree in nursing (71%). Their average working experience in the ICU was nine years. None of the participants in this study had any training experience regarding EOL decision making.

Eleven thematic categories were found and reflected within four lifeworlds. Lived body consisted of three thematic categories; 'feeling of dilemma', 'feeling spiritual distress', and 'feeling powerless'. Lived time consisted of the themes 'being in uncertain time' and 'continuous time of caring'. Lived relation included four thematic categories; 'receiving overwhelming role', 'valuing competency in

communication with the family', 'understanding the family's feeling', and 'being a supporter for the family'. Lived space consisted of two thematic categories of 'respecting privacy' and 'evading the process'.

The participants in this study used their beliefs of their religion as a basis for their involvement in EOL decision making in the ICU. They explained that while conducting their role they felt they were in a dilemma which made them bear spiritual distress as a consequence, and made them want to stay away from EOL decision making. They often felt uncomfortable when they had to deal with the family and other healthcare providers which made them feel powerless. Even though they were often overlooked by the family during EOL decision making, the participants mentioned that they will always try to deliver high quality care for the patient and family during EOL decision making by understanding their feeling during this difficult time and support the family's needs during EOL decision making.

Strength of the Study

The strength of this study is that both the researcher and the participants are Muslim with similar backgrounds. Common backgrounds can be very useful during the interpretation of the findings reflected by the participants which helped to gain a deep understanding of the phenomenon of nurse involvement in EOL decision making in the ICU.

Recommendations

Based on the findings and discussions of this study, the following recommendations for nursing practice, nursing education, and nursing research are offered.

Nursing practice. The findings of this study could be used as evidence to establish clear guideline practices for EOL decision making. From this study we learned that nurses often feel uncomfortable when conducting their role during EOL decision making. Therefore, it is suggested that in the future there should be clarifications regarding an EOL decision making guideline which should contain the roles of each healthcare provider during EOL decision making and information that should be explained to the family. Furthermore, this guideline should be shared with all healthcare providers who are involved in the EOL decision making process.

This study also emphasized the nurse's need to obtain specific training regarding EOL decision making. This study revealed a lack of knowledge and training regarding EOL decision making which can precipitate negative responses and feelings among the nurses which can increase the rate of nurse burn out and decrease the quality of EOL decision making in the ICU.

Nursing education. The findings of this study can be used to suggest recommendations for nursing educators to create a short course or training on EOL care in the ICU, particularly regarding EOL decision making.

Nursing research. This study provided information regarding the lived experience of Muslim nurses during their involvement in EOL decision making. The

results of this study can be used as evidence to support further studies to develop a practice guideline for EOL decision making in the ICU.

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APPENDICES

Appendix A

Informed Consent Form

Dear Participants,

My name is Arif Imam Hidayat. I am a graduate student at the Faculty of Nursing Prince of Songkla University. In order to fulfill my study at Master Program I have to conducting a research and at this time I offered you to join in this research. The topic of the research is “Muslim nurses’ lived experience in involvement at the end of life decision making in intensive care unit”. The purpose of the research is to explore the lived experience of Muslim nurses in involvement at the end of life decision making in ICU.

Your participation is voluntary. After an explanation of the study, if you decide to participate, the interviewer will ask you to indicate your permission to participate and to be audio-recorded. The interview process will last approximately one hour. You will be asked to describe your experience during end of life decision making in ICU. The interviewer may request a follow up interview at a later date. Your personal identity and all information will be kept confidential and will be used only for the purpose of this research. If you disagree or feel uncomfortable, you can withdraw from this study at any time without any negative consequences. You also have right to review the transcript and elect not to have it used as data for this study.

While there is always minimal risk associated with research, the level of risk involved in completing this interview is not greater than ordinarily encountered in daily life. If you show signs of anxiety and hesitation or feel sad or are having a

difficult time accepting the situations, the interviewer will provide support and offer to end the interview.

Potential benefits that you may attain from participation in this research study include a greater understanding of your own self of being a person who have role in end of life decision making in ICU. You may have the satisfaction of knowing that your experience may contribute to improving and developing the quality of end of life decision making in ICU, congruent with culture and society.

Lastly, if you need further information or have any questions regarding this study please do not hesitate to contact either the researcher or advisor listed below. Thank you for your willingness and cooperation to participate in this study.

Researcher:
Arif Imam Hidayat, S.Kep, Ners
Master student of Faculty of Nursing Prince of Songkla University Thailand
Email: hidayat.al.fatih@gmail.com (+6285729032696)

Advisor:
Assoc. Prof. Dr. Waraporn Kongsuwan.
Faculty of Nursing Prince of Songkla University Thailand.
Email: waraporn.k@psu.ac.th (+6674286404)

After I read all the statement above, I understand and I will join this research: Muslim nurses' lived experience in involvement at the end of life decision making in intensive care unit without forces from anyone.

Participant

( )

Appendix B

Demographics Data Form and Semi Structured Interview Questions

Demographic Data Form
Code:_____ Date: _____
Instruction: Please fill the blank and give a mark (√) in the bracket appropriate to your answer indicated.
Age :……..years
Gender ( ) Female ( ) Male
Marital status: ( ) Single ( ) Divorce ( ) Married ( ) Widow
Level of education ( ) Diploma ( ) Master ( ) Bachelor ( ) Other (please identify) …….
Experience of training about end-of-life decision making ( ) Yes ( ) No
Year of working experience in ICU ……. Years
Ethnicity ( ) Java ( ) Other (please identify) ……. ( ) Chinese

Semi-structured interview questions

The researcher used semi-structured interview questions and probing in response to the individual's answers to elicit further information.

Please tell me:

1. What you understand about EOL decision making?
2. Your experience during involvement in EOL decision making, what is it like?
3. What are your roles in EOL decision making?
4. What exactly you do during EOL decision making?
5. What do you feel when taking part in EOL decision making?
6. Is there anything else that you would like to share with me?

Appendix C

List of Experts

1. Assist. Prof. Dr. Luppana Kitrungrote

   Adult and Elderly Nursing Department

   Faculty of Nursing, Prince of Songkla University, Thailand

2. Assist. Prof. Dr. Kantaporn Yodchai

   Adult and Elderly Nursing Department

   Faculty of Nursing, Prince of Songkla University, Thailand

3. Suhartini Ismail, Ph.D.

   Emergency and Critical Care Nursing Division

   Nursing school, Faculty of Medicine, Diponegoro University, Indonesia

4. Mekar Dwi Anggraini, Ph.D.

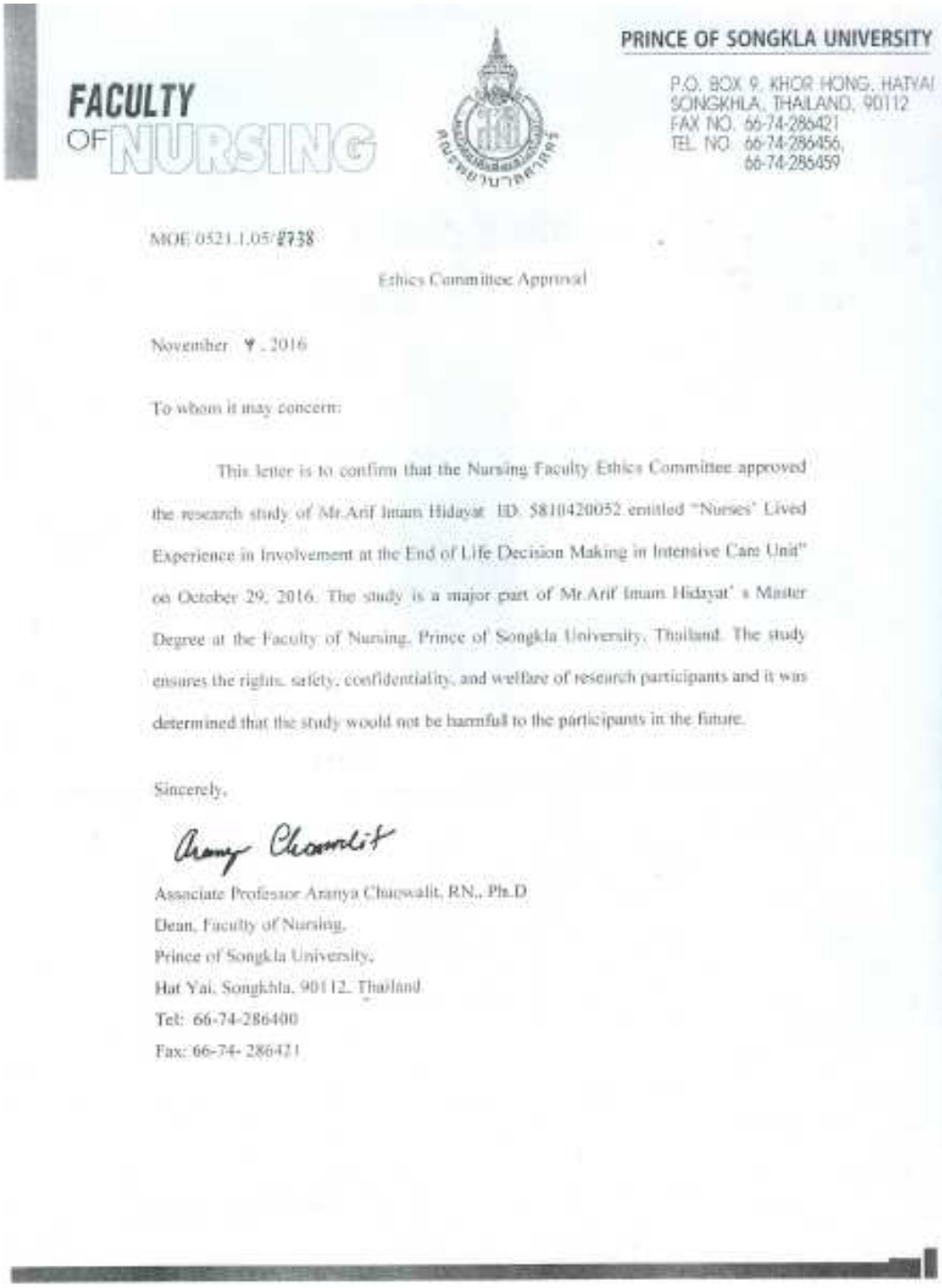
   Maternity and Pediatric Nursing Department

   Faculty of Nursing, Jenderal Soedirman University, Indonesia

Appendix D

Letters of Ethical Consideration and Permission

Letter 1: Ethics committee approval from Prince of Songkla University



FACULTY OF NURSING

PRINCE OF SONGKLA UNIVERSITY

P.O. BOX 9, KHOR HONG, HATYAI
SONGKHLA, THAILAND, 90112
FAX NO. 66-74-286421
TEL. NO. 66-74-286456,
66-74-286459

MOE 0521.1.05/7738

Ethics Committee Approval

November 7, 2016

To whom it may concern:

This letter is to confirm that the Nursing Faculty Ethics Committee approved the research study of Mr.Arif Imam Hidayat ID. 5810420052 entitled "Nurses' Lived Experience in Involvement at the End of Life Decision Making in Intensive Care Unit" on October 29, 2016. The study is a major part of Mr.Arif Imam Hidayat' s Master Degree at the Faculty of Nursing, Prince of Songkla University, Thailand. The study ensures the rights, safety, confidentiality, and welfare of research participants and it was determined that the study would not be harmfull to the participants in the future.

Sincerely,

Aranya Chaowalit

Associate Professor Aranya Chaowalit, RN., Ph.D
Dean, Faculty of Nursing,
Prince of Songkla University,
Hat Yai, Songkhla, 90112, Thailand
Tel: 66-74-286400
Fax: 66-74- 286421

Letter 2: Permission letter from Prof. Dr. Margono Soekarjo Hospital

PEMERINTAH PROPINSI JAWA TENGAH
RUMAH SAKIT UMUM DAERAH (RSUD)
PROF. Dr. MARGONO SOEKARJO PURWOKERTO
Jalan Dr. Gumbreg nomor 1 Telepon 632708 Fax. 631015 Purwokerto
Email : rsmargono@jatengprov.go.id

Purwokerto, 4 Januari 2017

Nomor : 420/0023 a /I/2017
Sifat : Biasa
Lampiran : -
Perihal : **Ijin Penelitian an. Arif Imam Hidayat**

Kepada :
Yth. Dekan Fakultas Keperawatan
Prince of Songkla University
Di -
THAILAND

Menanggapi surat saudara tanggal 17 Nopember 2016 nomor : MOE 0521. 1. 05/2858 perihal : Ijin Penelitian di RSUD Prof. Dr. Margono Soekarjo Purwokerto, pada prinsipnya kami tidak keberatan dan mengijinkan permohonan tersebut dengan ketentuan sebagai berikut :

1. Mematuhi peraturan yang berlaku di RSUD Prof. Dr. Margono Soekarjo Purwokerto;
2. Menanggung semua biaya Penelitian sebesar Rp.450.000,- / mahasiswa/ bulan/ unit (sesuai Peraturan Gubernur Jawa Tengah No. 52 th. 2013 yang berlaku)
3. Penelitian tentang Muslin nurses' lived experience in involvement at the end of life decision making in intensive care unit dilaksanakan pada tanggal 7/-17 s/d 7/2-17
4. Melapor ke Bidang Pendidikan dan Penelitian RSUD Prof. Dr. Margono Soekarjo Purwokerto sebelum pelaksanaan Penelitian pada jam dinas.
5. Menyerahkan hasil penelitian yang telah disahkan.

Demikian atas perhatian dan kerjasamanya kami sampaikan terima kasih.

RSUD Prof. Dr. Margono Soekarjo
Wadir. Penunjang dan Pendidikan

Dr. Lilijani, MMR
Pembina Tingkat I
NIP. 19590413 198602 2 001

Tembusan Kepada Yth. :
1. Ka. Subag. Rekmed;
2. Ka. ICU I;
3. Ka. ICCU I
4. Arsip ----------

Vitae

Name Mr. Arif Imam Hidayat

Student ID 5810420052

Educational Attainment

Degree	Name of Institution	Year of Graduation
Bachelor of Nursing	University Of Jenderal Soedirman, Indonesia	2012

Scholarship Awards During Enrolment

- Thailand Education Hub for Southern Region of ASEAN Countries (TEH-AC) scholarship funded by the Graduate School, Prince of Songkla University, Thailand.

List of Publication and Proceedings

- Hidayat, A. I., Kongsuwan, W., & Nilmanat, K. (2017, July). *Indonesian Muslim Nurses' Lived Experience in Involvement at the End-of-Life Decision Making in an Intensive Care Unit: A Preliminary Study*. Abstract paper presented at the International Nursing Conference on Ethics, Esthetics, and Empirics in Nursing: Driving Force for Better Health, Prince of Songkla University, Songkhla, Thailand.