Hindu Nurses' Lived Experiences of Caring for Patients at the End of Life in Intensive Care Unit in Indonesia

Ni Komang Sukraandini

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Nursing Science (International Program)

Prince of Songkla University

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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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Abstract

A Husserlian descriptive phenomenology study was conducted to describe Hindu nurses' lived experience in caring for patients at the End of Life (EOL) in an Intensive Care Unit (ICU) in Indonesia. Ten participants were interviewed individually using face to face semi structured interview guideline. Data analysis was done using Colaizzi's process of data generation. Trustworthiness was established following Lincoln and Guba.

The findings demonstrated the four main themes of the Hindu nurse's lived experience in caring for patients at the EOL in the ICU: delivering basic care to patients at the end of life, assisting the family to accept patient's condition, providing spiritual approach based on religious background, and providing compassionate caring. The findings described three themes in delivering basic care to patients at the EOL: fulfilling the basic needs, relieving suffering and following the standard guidelines in providing care. For the family to accept patient's conditions, participants provided information and psychological support to the family. In addition, participants approached the spiritually of the patients based upon religion background, for Hindu patients by chanting gayatri mantra, allowing the family to receive 'Tirtha' (holy water), bring 'Banten' (offerings),

and give ‘Bija’ (Vija), and giving authority the family to bring preacher. As well as for other religion background; praying by nurse and allowing the family to follow their belief. Furthermore, participants provided compassionate caring for the patients as their own family with the feelings of sympathy and empathy.

The findings can be used to promote caring for patients at the EOL concerning on cultural aspect. In addition, the findings can add up the knowledge of caring at the EOL in ICU.

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Ni Komang Sukraandini

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Chapter 1

Introduction

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

Background and Significance of the Problem

The Intensive care unit (ICU) is a unit for saving the patient's life at the critical stage. However, the death rate of hospitalized patients in ICUs was higher than in other wards in the hospital (Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2013). Evidence shows that the death rate in ICUs in the United States of America (USA) was 11.3% from 2010 to 2012 (Zimmerman, Kramer, & Knaus, 2013). In Asian countries, the death rate in an ICU was higher such as in Thailand, on average, was 31.5% from 2005 to 2010 (Luangasanatip et al., 2013), and in Indonesia, the death rate in an ICU was 14.95% in 2014 (Sanglah Hospital Statistic, 2015).

ICU patients at the end of life (EOL) are usually suffering from illness and treatments and are commonly receiving invasive devices or technologies for human care, such as mechanical ventilator and hemodialysis machines as the way to sustain and prolong their lives (Haggstrom, Asplund, & Kristiansen, 2013; Kongsuwan & Locsin, 2011). By using invasive devices, the patients often endure much suffering, such as pain, breathing discomfort, anxiety, fear, and denial (Locsin & Kongsuwan, 2013). They may

die in the unfamiliar environment of the ICU and without being accompanied by their families and loved ones (Bloomer et al., 2013).

Caring for patients during the EOL focuses on promoting comfort and holistic care in order to improve the quality of life and death (Wright, Bourbonnais, Tucker, & Silvar, 2011). The ICU nurses have an important role in caring at the EOL (Efstathiou & Clifford, 2011). The roles of the ICU nurses include providing accurate and current information, assisting in the decision making process, facilitating the wishes of the patients, and promoting a peaceful death (Browning, 2010).

There are some barriers in caring for the EOL patient in the ICU. Previous study shows that the nurses identified a lack of shared understanding in relation to the goals of care for terminally ill patients to care, found the hectic acute setting, identified lack of private rooms reflecting cultural barrier in health care setting, and inadequacies in the approach to communication in the palliative care context (McCourt, Power, & Glackin, 2013). According to Friedenberg, Levy, Ross, and Evans, (2012) nurses' barriers in caring for the EOL patients were significantly different by levels of training, discipline and institution. In addition, the nurses' barriers in EOL care are related to interdisciplinary collaboration with the medical profession about the transition from cure to comfort care (Fridh, 2014).

The ICU nurses demand some needs in caring for the EOL patient to enhance the quality of care. Previous study in Western countries provides some relevant information about the needs of the ICU nurse in caring for patients at the EOL. Nurses need standard guidance for EOL care (Holms, Milligan, & Kydd, 2014), appropriate formal training on EOL care (Harris, Gaude & Reardon, 2014; Holms, Milligan, & Kydd, 2014), support

and good communication between staff (Harris,Gaude & Reardon, 2014; Holms, Milligan, & Kydd, 2014), measures to reduce distress among staff (Holms, Milligan, & Kydd, 2014), and a focus on practicing to the patient satisfaction with creativity and autonomy (Donnelly & Psirides, 2015).

Several studies in Eastern countries revealed additional needs of nurses when caring for the EOL patients in the ICUs. For instance, firstly, nurses need to upgrade their comprehension in preparing for EOL care to support and facilitate better care for the nursing practice (Seo, Kim, Kim, & Lee, 2013; Yang, & Mcilfatrick, 2001). Secondly, they have to manage their time to give priority to care for dying patients (Kongsuwan, 2011). Lastly , they also need discussion about respecting the wishes of patients undergoing intensive care (Kinoshita, 2007).

Indonesia is a country in South-East Asia (Ministry of Home Affairs in Indonesia, 2015). From the literature review, it was found that only two studies focused on EOL care in Indonesian ICUs. One study in Bandung, West Java province by Enggune, Ibrahim, and Agustina (2014) described the perceptions of eight neurosurgical critical care-nurses toward EOL care. All participants were Muslim nurses. These nurses perceived that spiritual care knowledge at the EOL was crucial in order to meet the spiritual needs of the dying patients and their families. Spiritual care knowledge was also significant for promoting a peaceful death. The other study was a descriptive quantitative study which was conducted in the Jogjakarta province by Rahmadani (2014). This study examined the empathetic behaviors in EOL care among 28 ICU nurses. The results showed that 71.4% of these nurses had empathetic behavior at a good level.

Bali is an island in the southern part of Indonesia Nearly 90% of the population in Bali are Hindu while the majority of the population in the other provinces of Indonesia is Muslim (State Government of Indonesia, 2006). The Hindu belief towards EOL is important in that a good or bad death is related to a good rebirth or bad rebirth according to the causal law of karma (Bullow et al., 2008). One of the most important beliefs of Hindus is that a dying individual's thoughts and words should be focused on God because it is a strong belief that the nature of one's thoughts at the time of death determines the destination of the departing soul (Deshpande, Reid, & Rao, 2005). Religious belief can influence care during the EOL (Puchalski & O'Donnell, 2005). Each religion has its own way or ritual of practicing EOL care. Therefore, religious beliefs and practice at the EOL may influence nurses' perspective and caring.

From the literature review, two studies related to EOL care in the ICUs in Indonesia have been conducted (Enggune et al., 2014; Rahmadani, 2014). However, these two studies explore only Muslim nurses. In addition, the findings of qualitative studies are affected by nationality, culture, and lived experience (Ellis, 2013). Every religion has different beliefs, and plays a role in people's views of everyday life (Garrod & Jones, 2009). Human experience of everyday life is valued as knowledge (Russell, 2013). Hindu nurses' thoughts and feelings when providing care for patients at the EOL in an ICU in Bali have not been described and understood.

The experience of the nurses caring for the patients at the EOL can be a source of knowledge. The meaning of the individual's experience and their whole being in their activities is defined as phenomenology (Gina, 2012). Phenomenology is interested in the activities of consciousness and the objects that present themselves to consciousness.

Husserlian descriptive phenomenology emphasizes the consciousness between a person and the world (Giorgi, 2012). In order to have an understanding of the meaning of individual perception or thoughts of nurses, this study aims to describe Hindu nurses' lived experience in caring for patients at the EOL using Husserlian phenomenology.

Objective of the Study

The objective of this study was to describe Hindu nurses' lived experience of caring for patients at the EOL in an ICU in Bali.

Research Questions

What is the lived experience of Hindu nurses in caring for patients at the EOL in an ICU in Bali?

Conceptual Framework of the Study

Husserlian descriptive phenomenology was used in this study as a framework to study the nurses' lived experience. Husserl proposed descriptive phenomenology or transcendental phenomenology as a philosophy during the year 1962. Husserl views that truth or knowledge is in the human consciousness and in the experience which is inter-subjective or shared by all persons (Dowling, 2007; Polifroni & Welch, 1999). Husserl purported that mind and object both occur within experience. In addition, Husserl believes that consciousness is a co-constituted dialogue between a person and the world. Conscious awareness is the starting point in building one's knowledge of reality (Kriegel, 2011). Husserl presented an ideal of transcendental subjectivity (neutrality and openness

to the reality of the others) which is a condition of consciousness wherein the researcher is able to successfully abandon his or her reality and describes the phenomenon in its pure and universal sense (Wojnar & Swanson, 2007).

Based on Huserlian descriptive phenomenology, the two concepts of intentional consciousness and transcendental subjectivity were used in this study.

Intentional consciousness.

Intentional consciousness or intentionality is one's directed awareness of an object or event (Polifroni & Welch, 1999). In this study, the researcher used intentional consciousness while interviewing the participants. There is an interaction between the researcher and the participants in the interview process. The researcher believes that everyone has a subjective feeling to share his/her perspective of caring for the EOL patients in the ICU.

Transcendental subjectivity.

Transcendental subjectivity is back to thinking about themselves to recover the original awareness. This begins with suspensions beliefs, assumptions and biases about the phenomenon under investigations (Polifroni & Welch, 1999). In this study transcendental subjectivity involves employing bracketing. Bracketing is a method used in qualitative research to moderate the potentially destructive effects of preconceptions that may defect the research process (Tufford & Newman, 2012). The researcher identified any preconceived ideas about the EOL care in the ICU before conducting the interviews. The aim was to separate the knowledge between the researcher and Hindu nurses.

Definition of Term

Lived experience of caring for patients at the EOL is the thoughts and feelings of Hindu nurses, according to their own experience of caring for patients at the EOL in an ICU.

Scope of the Study

This study was focused on describing the lived experiences of caring for patients at the EOL in an ICU among Hindu nurses in Bali. The Hindu nurses who were working in an ICU in Sanglah Hospital and had experience of caring for patients at the EOL were recruited as the prospective participants. The participants were interviewed from January 2016 to February 2016.

Significance of the Study

The results of this study could enhance the EOL nursing care in ICU. It also provides information for nurse educators to develop training program regarding the EOL care in the ICU. Furthermore, it could be used as the foundation for future research in improving quality of EOL care in the ICU among Hindu nurses.

Chapter 2

Literature Review

This chapter presents the literature relevant to EOL in ICUs and descriptive phenomenology as described in the following topics:

1. Needs of EOL Care in ICU
    1.1. Definition of EOL
    1.2. Needs of patients at the EOL
    1.3. Needs of families of patients at the EOL
2. Caring for Patients at the EOL in ICU
    2.1. Goal of caring at the EOL
    2.2. Nurses' role in caring at the EOL
    2.3. Problems and barriers in caring at the EOL
3. Nurses' Experience of Caring for Patients at the End of Life in ICU
    3.1. Existing knowledge in other countries
    3.2. Existing knowledge in Indonesia
        3.2.1. System of EOL care in Indonesia
        3.2.2. Research studies
4. Hindu Belief at the EOL in Bali, Indonesia
5. Descriptive Phenomenology
6. Summary of the Literature Review

Needs of EOL Care in ICU

This section presents the definition of EOL, the needs of patients at the EOL and the needs of families during the EOL phase.

Definition of EOL.

EOL is defined as a state of an advanced disability that threatens one's life (Cruz-Jentoft, Boland, & Rexach, 2012). According to the General Medical Council in the United Kingdom (2010), patients are said to be "approaching the EOL" when they are likely to die within the next twelve months.

EOL in ICU is a life threatening condition of the patient who needs special care and expertise in the ICU demanding the highest level of knowledge and competence (Truog et al., 2008). According to Servillo and Vargas (2011) EOL is the patient's last phase of life which needs special care to sustain the patient's life with technical, advanced treatments and procedure that are used to improve the quality and comfort of death.

Therefore, the EOL in ICU can be understood as a state when the patient is expected to die from life-threatening conditions due to acute crisis or from sudden catastrophic events within a few hours or days. These kinds of patients are supported by advanced technology and treatment in the ICU setting.

Needs of patients at the EOL.

The needs of the patients in EOL can be categorized and viewed based upon three categories, namely 1) psychological and emotional need, 2) physical need, and 3) spiritual need.

In regard to the first need i.e: psychological and emotional need (Lewis, 2013) is to be fulfilled because they feel difficulty in decision making about their care (Truog et al., 2008). Furthermore, patients need their psychological distress to be controlled as the situation is distressing and difficult, (O'Grady, Dempsey, & Fabby, 2012). Involvement of family member in providing bedside care helps the patient to feel much comfortable (Kisorio & Langley, 2016). However, psychological need during the EOL is based upon the various human rights, human dignity, solidarity and the freedom of choice (Tsaloukidis, 2010).

Likewise, physical need of EOL patients includes relieve from physical suffering, comfort measures and free of pain (Kisorio & Langley, 2016; Lee et al., 2009; Troug et al., 2008). Until nature takes it course (Kisorio & Langley, 2016). Physical suffering can be minimized and comfort measures can be provided by the administration of intravenous drugs, withdrawal of supporting measures such as vasopressors, hemodialysis (Beckstrand, Callister, & Kirchhoff, 2006).

Spiritual need, patients on the EOL phase needed to satisfy their peacefully, therefore they have a willingness for a dignified and peaceful death (Curtis & Vincent, 2010). Fulfillment of the spiritual needs of the patients at the EOL to improve the well-being of dying patients (Balboni et al., 2012). Spiritual need can be performed by calling a spiritual leader in the hospital to provide spiritual care at the EOL (Kisorio & Langley, 2016).

Needs of families of patients at the EOL.

The needs of family members of EOL patient admitted in ICU can be categorized into informational support, participation in decision making and psychological support.

Lack of information is the most common complaint by the families of patients at the EOL, therefore educational support regarding appropriate information is needed (Holms et al., 2014). As the patient's family is not prepared regarding the patient's prognosis, therefore the healthcare providers need to provide information gradually (Kisorio & Langley, 2016). Information is needed to be shared timely, readily, straight, free of jargon and without any hurry. (Billings, 2011). For making EOL decision making, patient families need clear, direct, and consistent information (Crump, Schaffer, & Schulte, 2010). Therefore, nurses play an important role in fostering communication, which will contribute to ease the environment of both families and patient at the EOL.

The family participation in decision making is also one of the important components and needs of families of patients at the EOL (Luce, 2010). In participation, of making decisions, family members need to understand the condition of the patient with an available option which include necessitates regarding receiving detail and truthful information (Adams, Bailey, Anderson, & Docherty, 2011; Lind, Lorem, Nortvedt, & Hevrøy, 2011). Participation in decision making held by a prompt family meeting is useful when the patient condition changes significantly (Billings, 2011). Fulfilling the need of family decision making can help the patient to access appropriate services on time (Wallace, 2015).

In addition, the family also needs psychological support (Tsaloukidis, 2010), because of the high level of stress communication of the patient and family may be

impaired therefore the family is needed to be communicated with respect, sensitivity and with compassion (Clabots, 2012; Gutierrez, 2012). Family member of the patient at EOL may find difficult to accept the situation and may feel comfort with being emotional and crying (Kaplow & Hardin, 2007). The family of the patient at EOL is needed to feel secure that the patient is receiving the best possible care (Billings, 2011). Family members are very sensitive and seeks for caring, kindness, and respect for the patient's and themselves.

Therefore, understanding the family need during the EOL improves patients and family experience thus improving quality of care of the patient (Rabow, Hauser, & Adams, 2004).

Caring for Patients at the End of Life in ICU

This section describes the goal of EOL care in ICU, the role of nurses in EOL care, and the problems and barriers of caring at the EOL.

Goal of caring at the EOL.

Several studies have defined the goal of the EOL care in ICUs. Hodo and Buller (cited in Lewis, 2013) described that the goal of EOL care is to achieve a peaceful death by reducing symptom distress and by using comfort care. A study by Izumi et al. (2012) defined the goal of the EOL care as to provide palliative care for anyone who is nearing death. In addition, another study by Fridh, Forsberg and Bergbom (2009) reported that the goal of EOL care in the ICU is strongly associated with the quality of care provided by nurses. Quality care at the EOL will support the patient to survive and minimize

suffering, as well as compassionately support the dying process (Bloomer, Tiruvoipati, Tsiripillis, & Botha, 2010).

Nurses' role in caring for patients at the EOL.

Based on previous studies, the roles of nurses in caring for patients at the EOL in ICU are an educator, advocator, collaborator, care-provider and care for the family as explained in the following.

Educator.

The nurse, as an educator, is commonly associated with the educational process. This role focuses on how the nurses change the family's knowledge about the patient's condition. Education during EOL care is a requirement (Fridh, 2014). According to Lewis (2013), nurses are responsible for educating patients about options available at the EOL, as well as about specific care needs for their conditions. In addition, Brown, Johnston and Ostlund (2011) reported that nurses educate patients about symptom management, medication regimens and how to seek help out of hours.

Advocator.

Advocator is an essential aspect of a nursing professional. Advocator is considered to have fundamental value for the professional nurse (Hanks, 2010). According to Lewis (2013) said that nurses can empower patients to advocate for themselves by encouraging them to express their wishes to the healthcare team. A study by Hebert et al. (2011) reported that nurses as advocates have an important role to communicate the information and feelings of patients to the doctors.

Collaborator.

The role of nurses as a collaborator is how nurses work in a team. Based on Petri (2010) collaboration is the condition of the nurses and physicians working together with cooperation and making decisions to fulfill plans for patient care. In addition, Kryworuchko, Hill, Murray, Stacey, and Fergusson (2013) wrote that collaboration among health professionals, patients, and families will be essential to critically ill patients in guiding them when choosing health treatment. Orchard (2010) has explored current understanding about inter-professional collaborative client-centered practice and the nursing role in this form of care delivery and concluded that nurses were one of the professionals in a hospital who should collaborate in patient-centered care.

Care-provider.

Nurses are a vital component in providing care in regards to comfort care. Providing basic care at the EOL in the ICU can begin with comfort and frequent communication when possible with patients and families (Vanderspank et al., 2011). In providing care for patients at the EOL, nurses can do the basic nursing care such as bathing, hair care, mouth care, pressure area care, spiritual care, and the administration of analgesics, sedatives and mucolytic drugs (Lewis, 2013).

Supporter.

The nurses' support is focused on the family. The family is the center of decision making on the condition of patients in EOL. Bloomer, Tiruvoipati, Tsiripillis, and Botha (2010) said that building relationships of trust and mutual respect with the family is an important part of the key success of care for patients in the EOL phase. Nurses are expected to have a meeting with the family right from the beginning of a

patient's admission into the ICU. The nurse's role in supportive family care is expected to create comfortable feelings for the patient's family. Nurses help the families of patients to understand the critical condition of the patient, and they are able to provide information about the patient's progress. Nurses are expected to understand the expectations of the patient's family (Tsaloukidis, 2010).

Problems and barriers in caring for patients at the EOL.

Problems and barriers in caring at the EOL include communication, nurses' knowledge and experience, environment, religious beliefs, cultural beliefs, and hospital/ organizational policy.

Communication.

Communication is becoming a major problem in caring for the EOL patient. Lack of communication can become miscommunication among nurses, doctors, patients or families. The issues of communication include, unclear and inconsistencies communication regarding prognosis of the disease (Aslakson et al., 2012), the way of nurses interpreting the physician communication, ensuring the short and long term implication to the patient and the family (Gutierrez, 2012), and communication regarding wishes and options for care (Garland, Bruce, & Stajduhar, 2012).

According to Hodo and Buller (2012), communication skills are the basis to support the EOL experience. Effective communication is a strong factor of the quality of care at the EOL, and that patient's value non-verbal communication such as sensitivity, presence, and warmth (Cavaye & Watts, 2010). Good communication by nurses can help to promote coordination between health care teams and help to

coordinate the treatment plan (Lewis, 2013). A lack of communication skills means missing the chance to facilitate interaction with patients and family (Efstathiou & Clifford, 2011). Good communication skills enable nurses to establish comfortable communication with the patient and his/her family, thus enhancing the quality of life for the patient in the hospital setting (Moir, Roberts, Martz, Perry, & Tivis, 2015).

Nurses' knowledge and experience.

Knowledge is the basis for the advancement in professionalism. Holms et al. (2014) found that ICU nurses do not feel adequately prepared to give proficient EOL care. Efstathiou and Clifford (2011) revealed that critical care nurses have an essential role in providing effective EOL care. It is noted that educational opportunities need to be provided for critical care nurses to increase their knowledge of planning and delivering EOL care (Efstathiou & Clifford, 2011). Having no experience in dealing with patients at the EOL will influence nurses lack of emotional control (Espinosa, Young, Symes, Haile, & Walsh, 2010). A lack of experience would be a barrier, so nurses who do not have adequate training would not feel confident in dealing with patients at the EOL (Raphael et al., 2014).

Environment.

The busy environment of the ICU has been described as "not the ideal place" for dying patients and their families (Holms et al., 2014). Fridh (2014) mentioned that there is a lack of private rooms for providing EOL care because the ICU environment has not been designed for family-oriented care. This type of environment causes dying patients to be apart from their families thus creating further anxiety (Efstathiou &

Clifford, 2011). It can be anticipated that the ICU environment would be a barrier in caring for patients at the EOL.

Religious belief.

The nurses lacking of religious belief will affect the perspective in caring for the EOL patient. Every religion has a belief in deciding the treatment in the EOL decision (Setta & Shemie, 2015). A lack of religious belief can cause people difficulty in understanding about the process of the EOL, and in some it may cause them to be in denial. Religious belief affects the experiences and creates peace in which patient's perceive and experience illness, including the EOL (Holloway, Adamson, McSherry, & Swinton, 2011).

Cultural beliefs.

Different in cultural belief would be a barrier in EOL care of many aspects (Bullock, 2011; Crump, Schaffer, & Schulte, 2010). Firstly, cultural beliefs can significantly influence patients' reactions to their illness and their decisions making (Lopez, 2007). Secondly, nurses can feel they lack of skill to explore patient cultural belief in practice (Speck, 2016). Thirdly, care providers and families felt uncomfortable for discussing about EOL care, perception of prognosis of patients being uncertain or patient death being seen as a defeat, hospice care. Finally, EOL situations are particularly difficult when the patient is younger, disagreements about whether the patient should be involved in the discussion can lead to difficulty in handling situation for nurses. It is also unclear as to what is a ‘‘natural death’’ or what are ‘‘extreme measures’’ or ‘‘futile measures,’’ particularly when a patient is already on life support in an ICU. Those might

lead to misunderstanding and make patient uncomfortable with EOL care due to the contrast of culture belief between patient and care provider (Aslakson et al., 2012).

Hospital/ organizational policy.

Lack of understanding the hospital/ organizational policy can become a potential barrier in providing care for patients at the EOL (Detering, Hancock, Reade, & Silvester, 2010). Having an understanding of the hospital/ organizational policy will influence nurses in taking action and making the right decisions (Tilden & Thompson, 2009).

Nurses' Experience of Caring for Patients at the End of Life in ICU

Existing knowledge in other countries.

There are some existing studies about nurses' experiences of caring for patients at the EOL in ICU. The studies were conducted in Western countries such as in Scotland (UK), Texas, and New Zealand, and in Eastern countries such as Korea, Taiwan, Japan, and Thailand. The findings from these studies gained some relevant evidence about the experiences of caring for patients at the EOL in ICU.

A phenomenological study was done by Holms et al. (2014), in Scotland (UK) to explore the experiences of ICU nurses who had provided EOL care to patients and their families. The finding of this study describes five themes. First, the integrated care systems. Second, communication in which good communication was vital in teamwork. Third, the intensive care environment where the ICU environment affected the EOL cares. Fourth, the education and training wherein EOL care skills principally learnt

through good and bad experiences and watching other members of staff. Fifth, distressed staff members who have had personal distressing experiences when providing EOL care. These five themes reflected how to improve the EOL care in the practice of the ICU nurses' work environment.

A review study was done by Harris et al. (2014) to assess the quality of nurses' care for patients at the EOL in ICU. This study found three main themes in the review of the relevant literature. First, health care provider barriers which were lack of training and experience which influence the nurses' skills and attitude in dealing with patients at the EOL. Second, the patient and family related barriers where the readiness of a patient to die and the unrealistic expectation of the family for health care providers to save the patient's life. Third, institutional barriers wherein the lack of leadership support and procedure to care can contribute to poor quality EOL care in ICU. These three themes reflected the barriers in enhancing the quality of care for the EOL patient in ICU in Texas.

A grounded theory by Donnelly and Psirides (2015) explored the experience of relatives and staff of patients dying in ICU in New Zealand. This study discussed three interview processes from 'family, nurses' and doctor interviews. In regards to the family interviews, there are five themes. First, the personal and professional attributes of nurses and doctor where the family is willing to have frequent contact with the nurses and doctor. Second, the ICU environment in which the family needs a private room separate for other patients. Third, the limitation of access wherein the family has limited time and number of people who are allowed to accompany the patient. Fourth, the style of communication where accurate communication from nurses and doctors is valued to give

the right decision. Fifth, access to pastoral care wherein it is important to support the family and a patient preparing for dying and a peaceful death. From the nurses' interviews there are five main themes. First, empathy in which nurses have respect for the patient and family. Second, the impact on the nurses where personal and professional experience influences their practice. Third, the continuity of care in which nurses take an interest in holistic care rather than treating the family and the situation as another routine task. Fourth, care for the body wherein the nurses still care for and are responsible for the patient until they leave the ICU. The fifth main theme is handover in which the issue of handover on shift change and at breaks is of concern to nurses with some nurses refusing to leave dying patients. From the patient and family interview reflect their need with dying patient in ICU.

A quantitative correlational study was undertaken to explore nurses' attitudes towards death, coping with death, understanding and performances regarding EOL. In Korea by Seo et al. (2013) this study found that nurses showed significantly different attitudes toward death by age, religion, work unit and EOL care education. Younger nurses tended to score low on the understanding of EOL care, and ED nurses' scores were lower than their peers in the oncology department and ICU. Secondly, EOL care performance positively correlated with attitudes toward death ($p<.001$), coping with death ($p=.003$) and understanding EOL care ($p<.001$). Thirdly, nurses' EOL care performance was affected by the work unit ($p<.001$) and understanding of EOL care ($p<.001$).

In Taiwan, a phenomenological study conducted by Yang and Mcilfatrick (2001) explored the experiences of intensive care nurses caring for patients who were dying. This study found core themes of considering nurses' attitudes to caring for the dying, and

stressors associated with this care and coping strategies that ICU nurses adopt. The study concluded that education for ICU nurses must address these issues to facilitate better care for dying patients in the ICU.

A qualitative study by Kinoshita (2007) examined the ICU nurses experience of difficulties in respecting the wishes of patients in EOL care in Japan. This study reflected the body of knowledge regarding improving caring for the dying patient. There are four main themes found in this study. Firstly, the wishes of the patient are unknown where the patient's wishes cannot be established because of diminished consciousness and lack of information, and there is no-one present who knows what the patient's wishes are. Secondly, decisions made by others in which the family will have priority in the decision making. Thirdly, the function of the ICU is unsuitable for EOL care wherein the ICU environment is inappropriate for dying and gives priority to lifesaving. In this environment the patients are surrounded by machines, and there is no feeling of freedom. Fourthly, the characteristics of ICU EOL care which is the patients have strong expectations of recovery and are not mentally prepared to die. This study reflected that nurses play a crucial role in the decision-making process for patients and family members. In terms of respecting the patients' wishes, it will be important to investigate not only how these wishes are handled but also how nurses interact with patients and family members and become involved in the therapeutic decision-making process.

A phenomenological study by Kongsuwan (2011) describes Thai nurses' experiences of caring for persons who had a peaceful death in the ICU. This study found the essential themes which are reflected in the four lived worlds of corporeality, relationally, spatiality, and temporality. There are four sub-themes reflected under

corporeality. First, mindful readiness to care means that nurses should prepare to deal with a patient in dying and death. Second, offering self authentically to other means the nurses have to be empathetic and have an understanding of what the patient and family feel. Third, communicating caring through touch in which is touch is non-therapeutic communication that is able to provide comfort to the patient and builds trust among nurses, patients and their family.

Relationally have five subthemes. First, understanding relationships vital for dying persons and family members means that the cultural beliefs of family members have an important role in influencing a peaceful death for the dying patient. Second, the family members also need psychological support from the nurses regarding their loss and psychological reactions. Third, valuing the person who has died as a person which still carrying on providing care for other patients when a patient has died. Fourth, enhancing nurses' relationships. Fifth, valuing ending the relationship at the moment of death they believe will get same think by other, referred to 'karma' by other. Spatiality has two subthemes. First, enabling peace of mind (solace) despite space constraints which is fostering an environment around the dying persons' beds as peaceful and private at the moment of death. Second, contentment in the creation of the caring environment or the death in which nurses provide a temporary space around the dying person's bed.

The study reflected five sub-themes for temporality. First, time is short and is a priority; therefore, nurses should have priority in caring for the dying patient and his/her family. Second, open opportunity to care for another means that nurses provide an opportunity for family members to accompany the patient especially in the time nearing death. Third, valuing going on, regardless of time means that nurses continue their care

until the patient actually dies. Fourth, valuing a proper time to care in which nurses consider the best fit of EOL care and the preparedness of the family. And fifth, accepting death as unpredictable and natural in which the nurses cannot predict the time of death and that death happens naturally.

Existing knowledge in Indonesia.

System of the EOL care in Indonesia.

The Ministry of Health Republic Indonesia, Number 812 (2007) stated that health care centers are the places that provide medical health services for the society. The Indonesian system of end-of life care is included in palliative care. The palliative care in Indonesia is still limited in five of the provincial capitals, of Jakarta, Yogyakarta, Surabaya, Denpasar, and Makassar. System of palliative care in Indonesia is judged from the limited number of health care teams who are able to assess the needs of the patients (The Ministry of Health Republic Indonesia, Number 812, 2007).

In Indonesia, the aims of palliative care are to provide palliative care on a legal basis, implement palliative care according to prevailing standards, draft guidelines for palliative care, provide adequate medical personal, non-medically trained personal, facilities and the infrastructure needed for palliative care. The activities of palliative care in Indonesia are the management of pain, physical complaints management, nursing care, psychological support, social support, cultural spiritual support, and support for the preparation of death as well as during the grieving period. Indonesian hospitals follow the

guidelines from the Ministry of Health in order to provide palliative care in ICUs (The Ministry of Health Republic Indonesia, Number 812, 2007).

Nurses' experience of caring at the EOL in Indonesia.

Two studies were found regarding caring for patients at the EOL in the ICU in Indonesia. A study in Bandung, West Java province was conducted by Enggune et al. (2014) to describe the perceptions of neurological critical care nurses (NCCN) toward EOL care. This study found that there are four themes. First, the nurses' understanding about caring for dying patients in which the nurse helps the patients to die peacefully and provided support for the family focused on spiritual guidance. Second, the way of handling the frequency of deaths that occur where the adaptation of nurses to the conditions of dying and the difficulty in determining the critical phase of the dying patient. Third, the role of nurses in preparing for the dying patient which sees the nurses as spiritual guides for the patients, communicators, facilitators, and providers of family emotional support. Fourth, to improve upon EOL care wherein palliative care training is required for nurses who work with critically ill patients, in regards to providing exclusive spiritual guidance, and standard operating procedures of care for the dying patients.

Another descriptive quantitative study conducted by Rahmadani (2014) described the empathy of ICU nurses caring for critical patients in Yogyakarta. This study found that the behavior of nurses in regards to empathy towards EOL care showed a good outcome with the percentage of 71.4%. Good levels of empathy focus on the three aspects of compassionate care, emotional detachment, and perspective taking. The compassionate aspect focuses on building a trusting relationship between the nurse and

the patient's family, from this aspect is the ability of nurses to understand what the patient feels. The emotional detachment aspects focus on empathy to understand the emotional state of the patient and family, good outcome seen in this aspect where the nurse is able to establish a therapeutic relationship. The perspective taking aspects focus on the ability to increase the effectiveness of the provision of empathy for patients.

Hindu Beliefs at the End-of-Life in Bali, Indonesia

The basic belief of Hindu people in Bali is that there are five Sradha (Oka, 1976). The five Sradha are (1) a belief in Brahman, (2) a belief in Atman, (3) a belief in Karmaphala, (4) a belief in Punarbhawa, and (5) a belief in Moksha. Brahman is as the source of existing and the end of all created. Atman is the holy light or the smallest part of Brahman, the life of all beings (humans, animals, and plants). Karmaphala is the result of an action that we did, and is the law of cause and effect. Punarbhawa is the rebirth or reincarnation. Moksha is from all the bonds of karma, earthly bonds (ups and downs), and it is a living bond, and a bond of charity (Rai, 2012).

The people who followed Hindu religion universally are familiar with mantra. Mantra is not just singing the words, but as a means of focusing the mind towards happiness spiritual nature of God / Sang Hyang Widhi and as a means of communication that has a value very religious. That way to be able to feel the spiritual happiness leads to God/ Sang Hyang Widhi. The most important spell and is the principal or the mother of all mantras and the Vedas is Gayatri mantram. Gayatri mantra is a universal prayer in Veda, and quintessence teaching of Veda because four basic statements contained in Four Vedas (Catur Veda) are embodied in Gayatri Mantra. It is believed that this Mantra can

cure body, soul and enlighten our intellectuality. It is believed that anyone who chants Gayatri Mantra will be freed from all of their sins (Atarwa Weda XIX, 71, 1).

'Hindu believes that '*Tirtha*' (holy water), give '*Bija*' (vija), and brings '*Banten*' (offerings) and are the form of offerings to the God. As stated "If one offers Me with love and devotion a leaf, a flower, fruit or water, I will accept it" (Bhagavadgita Sloka IX.22). '*Tirtha'* (holy water) functions to clean the body from any dirt or impurity mind in which it is used by sprinkling it to head, drunk, and washed on the face. It is a symbol to purify body, soul and mind (Wiana, 2000). '*Bija*'(vija) is called gandaksata , derived from the double and aksata , meaning grain intact and smells fragrant . Therefore, it should use the rice is still intact , washed, mixed with perfumes . Eg water mixed with sandalwood and fragrant flowers . '*Bija*'(vija) is considered a symbol as holy seed gift from God in the form Ardhanaresvari . Its use is similar in using '*Tirtha'* (holy water) is spread on a building used in a ceremony as a symbol of the holy sowing which will give sanctity (Sudarma, 2009). After finishing the prayer, so they will have '*Bija*' (vija) and placed on the forehead as the symbol of '*Manahcika Parisudha'* (positive thinking). It is also placed on the chest as a symbol of '*Kayika Parisudha'* (consciousness action) and the '*Bija*' (vija) is eaten as a symbol of speaking of truth and goodness (Wacika Parisudha). Therefore, the concept of using '*Bija*' (vija) in the prayer correlates to the spirit of 'Tri Kaya Parisudha'(three holy deeds); '*Manahcika Parisudha'* (holy thinking), '*Kayika Parisudha'* (good attitude) and '*Wacika Parisudha'* (good speak) (Suhardana, 2005: 165). Banten is offering and means for Hindus closer to Ida Sang Hyang Widhi Wasa or the Almighty God . '*Banten'* (offerings) is also an expression of gratitude , love and

devotion to God because it has been overwhelmed. Fundamentally in the Hindu religion, '*banten*' (offerings) can also be regarded as the language of religion (Input bali, 2015).

Hindus in Bali embrace Siwaisme which teaches five principals of thought (Subagiasta, 2006). One of the Shiva principal is Ganapati Tatwa, discussing the concept of Bhuana (cosmos), the God, yoga, human, and yadnya. In the Ganapati Tatwa, Sloka 50 explains about the deliverance that Hindus believe when the time of death comes, and do not feel the loss of the soul from the body (Sura et al., 1994). Based on Pradnya (personal communication, May 19, 2016) who was explaining the process of praying based on Balinese Hindu, upon EOL family member. The process is started by offering 'banten pejati' (offerings) in family shrine; it is a symbol of self to surrender totally to the God, in order to achieve the wishes including for the cure of the sick person. After that the family pray by the medium of the banten pejati and finally they can be sincere to whatever can happen to the patient, because the family believes that everything happened is based on His willing. After the prayer in family shrine, it is continued by praying for tirta from the shrine by placing a glass of water in the middle of the shrine, it is called as tirta wangsupada, which means the God has blessed the water. Besides that, usually the 'banten pejati' (offerings) is followed by 'white-yellow segehan'; segehan is a special offering intended to 'butha kala' (destructive energy), so it is expected that the 'butha kala' will not disturb the patient. Arrived at home, the 'tirta wangsupada' (holy water) is sprinkled to the patient and hopefully can be drunk so it is expected there will be a miracle from the God of family shrine or the patient will die peacefully without any sufferings. Therefore, it is the determination, if the patient is healthy so he/she will be healthier and if the patient is going to die, he/she will die peacefully.

Descriptive Phenomenology

Phenomenology is commonly understood in either of two ways as a disciplinary field in philosophy, or as a movement in the history of philosophy (Smith, 2013). Phenomenology has been applied in human science, such as psychology, sociology, and nursing (Taylor, 1993) and is a learning of the essence of experience, focused on practicing reflection (Munhall, 2007). Its philosophy and research methods are designed to explore and understand people's everyday lived experiences (Shosha, 2012). As a philosophy, phenomenology is a way for philosophical inquiry into human experience (Husserl, 2012). As a research method phenomenology is a hard, critical, and methodological investigation of phenomena. Phenomenology is one way of describing nursing practice (Taylor, 1993). Since professional nursing practice involves the lived experiences of people, this phenomenological inquiry is well suited for the investigation of the phenomena of this study. Using this phenomenology inquiry, the researcher's aim is to understand and describe the lived experience of Hindu nurses caring for the end-of-life patient.

Descriptive phenomenology is one of the research methods that guide the phenomenological investigations because it is concerned with understanding phenomena fundamental to nursing science (Wojnar & Swanson, 2007). Descriptive phenomenology is based on the phenomenological philosophy by Edmund Husserl (1859-1938). Phenomenological philosophy is stands to achieve the state of pure consciousness. The following discussion of Husserl's ideas is organized by using intentional consciousness

or intentionality and transcendental subjectivity (Polifroni & Welch, 1999; Wojnar & Swanson, 2007).

The notion of intentionality or intentional consciousness is crucial to understanding. The first ideas of Husserl stated that intentionality is the main or central theme of phenomenology (Polifroni & Welch, 1999). Intentionality is being directed towards something, as it is an experience of an object or event. An experience is directed towards an object by quality of its content or meaning together with appropriate enabling conditions (Dowling, 2007; Smith, 2013). According to Polifroni and Welch (1999), intentionality is the active relationship in which participants experience the things and events of the life world as able with meaning.

The notion of transcendental subjectivity refers to a condition of consciousness wherein the researcher is able to successfully leave his or her own lived reality and describe the phenomenon in its natural state. Transcendental subjectivity applied by using the bracketing (Wojnar& Swanson, 2007). Bracketing is defined as a method of phenomenological investigation that requires the thoughtful putting aside of one's own beliefs about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation (Chan, Fung, & Chien, 2013). Bracketing affects the researcher to not influence the participants in understanding the phenomenon, so the participant can present the researcher with new knowledge and new understanding in the search for the essence of things through the identification of essential themes (Hamill & Sinclair, 2010).

Summary of Literature Review

A patient at the EOL in ICU is the state of a patient in the last phase of patient life or terminal disease and is supported by technology as provided in the ICU. In caring for patients at the EOL nurses have to know the needs of the patients and their families especially in regards to physiological and emotional support. The goal of caring for patients at the EOL is to achieve a peaceful death with enhanced quality of care. Nurses have many important roles, such as, educator, advocator, collaborator, care-provider and supporter. Nurses can facilitate families in making good decisions and avoid miscommunication. The problems or barriers in treating patients at the EOL care have been reported from several studies as: lack of communication; lack of knowledge and experience; environment; religious beliefs, cultural beliefs, and hospital/ organizational policy.

From the relevant studies, it can be summarized that study about the needs and barriers of nurses in caring for patients at the EOL in ICU is important. The findings of these studies gleaned different information, and namely, that nationality, culture, and religion have an influence. Hindus have a belief toward the EOL, and this belief can be the basis for the Hindu. Particularly for Hindu nurses, since there are no studies on EOL care in Hindu nurses in Indonesia. Further studies are needed to gain a greater understanding of life experience among Hindu nurses. Huserlian descriptive phenomenology was used in this study. In order to get the essence of the meaning of the lived experiences from the Hindu nurses in ICU towards the EOL care and also, the findings of this study are useful to provide basic knowledge to improve the quality of care for patients in EOL in the context of Hindu nurses in Bali.

Chapter 3

Research Methodology

This chapter presents the methodology for this study, which consists of the design of the study, the setting of the study, participants, ethical considerations, bracketing, data collection, data analysis, translation process and trustworthiness.

Design of the Study

The descriptive phenomenological approach was used as a study design because the research questions of the study focus on describing the Hindu nurses' lived experiences of caring for patients at the EOL in an ICU.

Setting of the Study

This study was conducted at an ICU in Sanglah Hospital, Bali, Indonesia. Sanglah Hospital is under the responsibility of the Directorate General of Medical Services, Ministry of Health, and Indonesia. This hospital is a tertiary hospital, which specially provides service for the province of Bali and Nusa Tenggara. Sanglah Hospital is one of the internationally accredited hospitals and is a center for education and research.

The Sanglah Hospital has the standard care or guideline for the care of patients at the EOL. The standard care or guidelines were used when the patient first enter in the ICU diagnosed as EOL condition. The guideline focuses on three main topics. They are, firstly, a definition of EOL care services, secondly, the scope of caring at the EOL and

thirdly, the administration of caring for a patient in the EOL phase. The definition of EOL care services emphasizes on understanding the EOL with an approach which aims to improve the quality of life of patients and families associated with life-threatening illnesses in this phase. In addition, the scope of caring at the EOL includes palliative care patients and critically ill patients and intensive care patients. Furthermore, the administration of caring for patients in the EOL phase includes the flow of patient care, medico legal aspects of caring for patients at the EOL phase of such approvals, medical interventions for palliative patients, resuscitation in palliative care patients in the ICU, the problem of medico legal aspects on palliative care, the procedure of brain stem death, and the flow of spiritual care.

The ICU of Sanglah Hospital consists of 20 electrically equipped beds with monitors which are separated from each other by curtains. The occupancy rate of these beds per day is 100%. There are facilities, such as syringe pump, infusion pump, central suction, defibrillator, ventilator, and so forth. However, the ICU does not have a special room for patients at the end-of –life. The top five diseases of the patients who were admitted to the ICU in 2014 were sepsis, multiple organ failure, tetanus, post-operative trepanation caused by a subdural hematoma, and post-operative peritonitis. The workload is equally divided among the nurses according to the existing number of beds on a certain day.

The total number of nurses in the ICU at Sanglah Hospital is 47. Out of the 47 nurses, 45 (95%) nurses are Hindu and 80% of the patients are Hindu. In other words, the majority of nurses and patients in the ICU are Hindu. The ratio of nurses to patients shows that one ICU nurse cares for two patients. The nurses are fostered to work three

shifts with 8 hours for every shift. The nurses' daily activities will be according to their shift and according to the patient's needs. There are rules for family visits: twice a day at 12.00 AM to 13.00 PM and at 18.00 PM to 19.00 PM. Only one of the patient's family members is allowed to visit the ICU patient. Before entering and leaving the ICU, family members who visit the patient must wash their hands in the provided space and when the patient's family visits, they are not allowed to carry any goods except what is permitted or recommended by the hospital. However, for patients at the EOL, the time for family visits is flexible according to the situation, but still; only one visitor is allowed at a time.

Participants

The participants of this study were selected by using purposive sampling method. Commonly in phenomenology, this sampling method selects individuals based on their particular knowledge of a phenomenon for the purpose of sharing their knowledge (Streubert & Carpenter, 2011). The prospective participants were recruited by using the following inclusion criteria:

1. Being a Hindu nurse.
2. Having worked in the ICU for at least one year in Sanglah Hospital.
3. Having the experience of caring for at least 3 patients at the end stage of life and dying in the ICU.
4. Willing to share his/her experience to the researcher.

Based upon the inclusion criteria, all of the nurses (45 Hindu nurses) in the ICU were eligible as the participants in this study. The researcher accessed the prospective participants through the head nurse. The head nurse was responsible in managing the

overall activities in the ICU including the nurses. Therefore, the researcher believes that the head nurse would inform the nurses who met criteria to participate in this study based on the inclusion criteria and the nurses' ability to communicate their experiences. Following the selection of the appropriate participants, the head nurse informed the researcher who to contact. The researcher used 10 participants from 45 total numbers of participants. The number of participants was justified by researcher based on the saturation of the data or the information was found redundancy from previous participants.

According to LoBiondo-Wood and Haber (2014), the number of participants depends on data saturation. Data saturation is the term applied when the point at which no new data can be found is reached (O'Reilly & Parker, 2012). However, it was also found that most phenomenological studies had a small number of participants to reach that point of saturation, around six to eight participants (Holloway & Wheeler, 2013).

Ethical Considerations

This study was conducted after getting approval from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkhla University and with agreement from Sanglah Hospital, Bali, Indonesia. The head nurse in the ICU introduced the researcher to the prospective participants. The researcher clarified the purpose of the study, the process and the potential benefits and risks of the study to the participants. The participants were assured that they have the right to choose whether to participate in the program or not and they may withdraw at any time during the study without any negative consequences. The participants' agreement to participate in the program was taken both

verbally and by written informed consent in appendix A. The researcher asked permission to record the conversation before the participants began and if they felt uncomfortable at any time during the meeting, they could ask freely to stop. During the interview process, if the participant began crying or felt sad, the researcher acknowledged the participant's sadness and her/his difficulty during the situation. The decision to interrupt or to discontinue the interview depended on the participant's willingness.

The participants were informed that they were free to not answer or withhold any information, their participation is voluntary and this study had no effect on their job or position. All participants' information was kept confidential, and no identifying information was given anywhere. The real names of the participants were strictly protected by coding each informant, and only the information gained from the participants was used in this study. All data documents and the tape recordings were kept in a locker and a personal computer and only the researcher could open the locker and use the computer. The data will be destroyed by the researcher in five years after finishing the study.

Bracketing

The researcher undertakes a specific role in transforming the information from lived experiences and becomes the description of the particular phenomenon (Speziale, Streubert, & Carpenter, 2011). The researcher acts as the primary data collection instrument (Houser, 2013, p. 401). The researcher also knows the head nurse because the researcher usually accompanies nursing students when they practice in the ICU. The head nurse and some of the nursing staff also teach the students in the private School of

Nursing Institute and are a part of team teaching with the researcher in critical nursing. The researcher has frequent communication and interaction with the head nurse and staff in the ICU. This indicates that the communication and the relationship between the nurses and the researcher are already well established. Therefore, the researcher is already familiar with the ICU in Sanglah Hospital.

The researcher in this study is currently working as a lecturer in the private School of Nursing Institute in Bali. The researcher is a registered nurse and has previously worked at one of the private hospitals in Bali as an ICU nurse for a year. During the year of working in the ICU, the researcher had experience in caring for patients in the ICU. The researcher was familiar with patients at the EOL stage in the ICU. In addition, the researcher noted that the environment of the ICU is predominantly Hindu, as most of the patients and nurses were of the Hindu religion.

The researcher's perception towards EOL care is the caring for the patient in a state of terminal illness, towards the end of his or her life. In such conditions, the researcher believes that emotional and spiritual support is very important through which the patient can experience a peaceful death, and the family can accept the situation without protest and anger. As a Hindu nurse, the researcher considers that the perspective of the researcher's behavior when caring for patients in this state is heavily influenced by Hindu belief. For example, the researcher believes that spiritual support for patients at the EOL can be given by their closest attending family members by whispering a mantra in the patient's ear; this special procedure is believed to help the patient die peacefully. Certainly, based on the views of the researcher, many challenges are faced by nurses in the ICU in the EOL phase.

The researcher assumes that experience as an ICU nurse and caring for patients at the EOL is crucial and this condition is the point of interest. From the experience of the researcher, phenomenological study is needed in order to understand and capture the essence of Hindu nurses' lived experiences in providing the EOL care. Before data collection, the researcher wrote her previous experience and understanding, thereby expected that the participants would described their experiences as a whole without any influence from the researcher.

Data Collection

The interview method and phases of data collection are presented in the following.

Interview method.

A face to face, individual interview with semi-structured interview questions was used as a method of data collection in this study. The semi-structured interview questions guidelines were developed by the researcher based on the research objective and questions. The demographic data form and the interview questions are included in appendix B. The researcher used three experts in EOL care and qualitative studies to validate the interview questions. In addition, the researcher was probing to encourage participants to continue talking deeply about their experiences based on the results of the participants' answers as well as to get the full meaning out of the interviews conducted. The interview was conducted when the nurses finished their shift work and were free from other activities. The place for the interview was held in a special room that is

commonly used as a consultation room. The rooms are conducive and well furnished with chairs and tables as well as having a closed door to maintain confidentiality and the comfort of the participants during the interview process.

Phases of data collection.

There are two phases of data collection; the preparation phase and implementation phase.

Preparation phase.

In this phase, the researcher performed the following steps: Firstly, permission was obtained from the Research Approval Committee from the Faculty of Nursing, Prince of Songkla University. Then the researcher submitted a letter from the Faculty of Nursing Prince of Songkla University to the Director of Sanglah Hospital Bali, requesting permission for data collection at the hospital. Prior to this, the researcher met the Director of the Nursing Department and the Head of ICU Sanglah Hospital to explain the details about the objective and the process of the research and to ask for permission to conduct the study. The researcher asked the head nurses to inform the potential staff nurses who were available and willing to be the participants of this study. Then the nurses who met the inclusion criteria were identified and asked if they would participate in this study. After getting the permission and eligible participants, the researcher prepared an informed consent form, demographic data form, and semi structured interview questions.

Before beginning the actual data collection, the researcher conducted a face to face, individual interview with two ICU nurses from the Sanglah hospital. The

interview was conducted as training for the researcher in data collection. There were four important aspects learned during the training process. These were (1) learning about probing a participant during the individual interview, (2) taking field notes by recording all the events acquired in the field during the interview process, including any nonverbal responses of the participants, (3) recording in a reflective journal by reflecting what is obtained after the interview process was conducted, and also (4) the researcher practices analyze the data by using Colaizzi process.

Data collection phase.

Data was collected using face to face individual interview. The researcher determined the priority of the participants to be interviewed from their seniority as a Hindu nurses in caring the EOL patient in the ICU. The researcher was expected that the longer the participants work as a nurse in ICU, the more experience they had in caring the EOL patient in ICU, and would provide more wide ranging information.

In addition, the researcher also established good relationships with the participants. A good relationship between researchers and participants can be seen from the sociability aspect, the ability to adapt to the environment of the participants, the ability to speak with participants and getting feedback during the communication process.

Data were collected using semi-structured interview guide. Participants were encouraged to talk freely and share the stories using their own words. Each interview lasted from 45 minutes to 60 minutes and all of the interviews were conducted by the researcher. At the end of each interview, the researcher reminded the participants about her need for a second contact with them via telephone calls to meet in face to face

to discuss the study findings and to make sure that the study findings reflect what the participants shared.

Translation Process

To analyze the data, audio tapes were translated into transcripts verbatim. After finishing the transcription process, the interview transcription was analyzed in Indonesian language confirmed by the expert. The result of analyzing the data was translated from Indonesian to English language by the researcher and was checked by the advisor of the researcher.

Data Analysis

The strategy of descriptive phenomenological data analysis is represented by the following steps by using Colaizzi's process of data generation (Holloway & Wheeler, 2013).

1. Describing the phenomenon under study.

2. Gathering descriptions of the phenomenon through the opinion of the participants by conducting interviews and writing in verbatim to be able to describe the experience of a Hindu nurse in caring for a patient at the end-of- life.

3. Reading the entire description of the phenomena that have been submitted by the participants related to EOL care in the ICU.

4. Rereading the transcript of the interview and quoting meaningful keywords by giving a line marker.

5. Coding the sense that there is a significant statement or keywords and trying to find the meaning of keywords to form formulated meaning.

6. Organizing group meaning formulated into a cluster group theme. In this stage, the researcher reads the entire theme of the meaning of existing formulated meaning compares and looks for similarities between the formulated meanings and eventually classifies them. After that, aggregated formulated meanings can be developed by analyzing the previously obtained formulated meanings. Finally, formulated aggregations that have similar meaning are combined to create theme cluster.

7. Writing a complete description where the researcher strings themes found during the analysis of the data and writing it into a deep description related to Hindu nurses experience in EOL care.

8. Validating by meeting the participants again. Validation is performed to ensure the description that has been developed by the researcher is according to the participants' experience.

9. Combining data validation results into the description analysis results. The researcher analyzes the data that has been obtained during validation with the participants and adds to the end of an in-depth description of the research report so that readers are able to understand the experience of Hindu nurses in EOL care.

Trustworthiness

The trustworthiness of the study was examined through four key areas: Credibility, Transferability, Dependability, and Confirmability (Lincoln & Guba, 1985).

Credibility.

Credibility refers to the process of making assurance or correctness of finding answers from the participants' descriptions of the phenomenon (Lincoln & Guba, 1985). It addresses the issue of whether there is consistency between the participants' views and the researcher's representation of them. In other words, it refers to the extent to which the descriptions from the participants are accurate. Credibility was conducted by participants' validation, returning the description that has been made by the researcher to the participants.

Transferability.

Transferability or applicability refers to the chance that the findings of the study have the same meaning or are applicable in a similar situation (Lincoln & Guba, 1985). The way to ensure transferability in this study was to use the "thick description" technique, in which the researcher explains in detail the meaning of Hindu nurses' lived experiences based on the real situation. To meet this element, the researcher described in detail the background of the participants, the study context and setting, as well as writing the report describing in detail the data of the Hindu nurses' lived experiences in caring for patients at the EOL. Therefore, other parties are expected to be able to understand the findings obtained from this study.

Dependability.

Dependability or auditability refers to ensuring the consistency of the study findings, and the collected data (Lincoln & Guba, 1985). According to Savin-Baden and Major (2013), this concept requires the researcher to document the study context, making clear the change that occurs while the study is ongoing. Dependability in this study was

conducted by the process of audit and was conducted with the help of an external reviewer for checking the accuracy of the data and documents that supported the research process. The external reviewers of this study were the expert in qualitative study as well as expert in both Indonesian and English language and the thesis advisor and co-advisors who examined the methods and the study results that had been obtained for use during the data analysis process.

Confirmability.

Confirmability implies that something can be declared as objective if it gets approval from the other part after analyzing the views and opinion of the original person (Lincoln & Guba, 1985). Confirmability in this study was performed by systematically collecting materials and documenting the study results. In this case, the verbatim transcripts, field notes and reflective journal were used, and the thesis advisor and co-advisor was consulted as an external reviewer for performing comparative analysis to ensure the objectivity of the research.

Chapter 4

Findings and Discussion

A Husserlian descriptive phenomenology was conducted to describe Hindu nurses' lived experiences of caring for patients at the EOL in the ICU in Bali, Indonesia. Ten Hindu nurses in ICU were involved as participants in this study. The findings presented in this section are as follows; (1) characteristics of the participants, (2) lived experiences of Hindu nurses in caring for patients at the EOL in the ICU, and (3) discussion of the findings.

Characteristics of the Participants

Demographic data obtained from the participants were age, gender, marital status, education level, experience of EOL training, years of working in ICU, ethnicity, level of belief in Hindu religious principles, and level of strictness in Hindu religious activities. This data are presented in Table 1.

Table 1.

Characteristics of Hindu Nurses (n=10)

Characteristics	*n*	%
Age in years		
30-40	4	40
41-50	5	50
51-60	1	10
Mean (SD) = 42.40 (7.97)		

Table 1

Characteristics of Hindu Nurses (continued)

Characteristics	*n*	%
Gender		
Female	7	70
Male	3	30
Marital status		
Married	10	100
Education level		
Diploma Degree	8	80
Bachelor Degree	2	20
Experience of training EOL		
No training	10	100
Experience		
Years of working experience in ICU		
1-10	4	40
11-20	4	40
21-30	2	20
Mean (SD) = 15.20 (7.65)		
Ethnicity		
Balinese	10	100
Level of belief in Hindu religious principles		
Medium	2	20
Strong	7	70
Very strong	1	10
Level of strictness in Hindu religious activities		
Medium		
Strong	2	20
Very strong	7	70
	1	10

As depicted in Table 1, out of the 10 participants, 7 were female and 3 were male. Their ages ranged between 30-52 years, with a mean age of 42.40 years. All of the participants were married (100%). All the participants were of Balinese ethnicity and belongs to the Hindu religion. The majority of the participants had strong religious principles and strictly believes in religious activities (70%). The majority of the participants graduated from with a Diploma Degree (80%) with 15 years mean of work experience. Though the majority of them had been involved in caring for the ICU patients and EOL care for a long time, they did not have any chance to attend training courses regarding EOL care.

Their background and end- of- life care history are described briefly in the following.

Participant 1

Participant 1 was a female ICU nurse. She is 30 years old, married. She graduated with a Nursing Bachelor in 2011 and started her career as a nurse in 2011. The ICU is the first place where she took her role as a nurse before she finally became a primary nurse and clinical instructor. Throughout this time she has experienced a significant change in her feelings in caring for the dying patients, which in the beginning it was easy for her to get involved with the feelings of the patient and the family, however over time she has become strong in resisting his feelings so did not show the sadness and dissolved in situations. Her purpose in caring for patients is to improve the life quality of the patients at the end of their life. She wishes that her care is able to help the patients to enjoy their life, have more quality and meaning for their families.

She practices Hindu beliefs in daily life. She believes that as a creation of God, she should pray every day as a gratitude for any given pleasure. Besides that, she also believes that as a human she should be sincere and compassionate to others. This is always done by her every day as a nurse, who always starts and ends a nursing activity by chanting "Gayatri Mantra" (Mother of Hindu mantra) to the Hindu patients, and prays by using common language with other patients who have a different religion who are in the EOL phase. She feels that a service of the nurse is a part of "*yadnya"* (yajna) that is a service to others. She gives authority to a Hindu patient's family by giving an opportunity to them to bring "*Tirta*" (Holy water) and "*Banten*" (offerings) ."*Tirta*" is a holy water sprinkled on the patient with the purpose of giving blessings to the patient and "*Banten (offerings)* is a ceremonial offering that is placed close to the patient's bed.

Participant 2

Participant 2 was a female ICU nurse. She is 42-years old, and married. She graduated with a Nursing Diploma in 1993. She started her career as a Nurse in 1993. At first, she was placed in the Emergency Unit for 3 years. After that she was moved to working in the ICU. She is a primary nurse and clinical instructor. She considered the patients as her own family. So, she feels her own care is sincere and not haphazard. She feels enormous happiness in helping the patients and their families, especially poor families. She thinks that family support and solid teamwork support her to care for EOL patients in the ICU. By family support she means in which the family trusts her to take care of the patient, thus she feels comfortable and confident in conducting EOL care for the patient in ICU.

She believes that as a Hindu, religious beliefs are a foundation in doing an activity. Therefore, praying regularly is a must do for her. She believes that as a human we should be kind to others. She gives authority to the Hindu patient's family by instructing them to pray to the ancestor in "*kemulan"* (family shrine), and then giving "tirta" (holy water) to the patient.

Participant 3

Participant 3 was a male ICU nurse. He is 49-years old, and married. He graduated from Senior High School of Nursing in 1989 and he continued his education to Nursing Diploma and graduated in 1995. He started his career as a nurse in1989. When he started his career he was placed in the Emergency Unit for 2 years. After that, he moved to the ICU. He is a primary nurse and clinical instructor. For him, caring for the EOL patient is a nurse's responsibility which means that he has to meet his obligation based on the nursing standards for the patient. He was aware that the patients have their needs. He always considers the patient as his own family. So, preparing the family to face the worst scenario is a part of his obligations in caring for the patients. By giving support, he wishes the family would not get surprised or shocked by the situation. He thought that communication is very important in caring for patients in the ICU. Good communication in giving information can improve the knowledge of the patient and the family toward the condition of the patient.

As a Hindu, he prays regularly. Before and after conducting care for the patient, he always prays based on his belief. He believes that by thinking, doing and speaking well as a creation of God, there will be goodness upon him. For him, this present life is a result of a previous life, so he believes that when looking after a Hindu patient as a

terminal patient, he tries to give instruction or authority to the family to ask the "*orang pintar"*(shaman) who is related to the ancestor spirit and others as to whether the condition is purely caused by the disease or there is a relationship to his/her birth. Usually, the family would do this search for their mental – emotional comfort so they would not feel guilty of not doing anything, based on patient and the family's beliefs.

Participant 4

Participant 4 was a male ICU nurse. He is 40 years old, and married. He graduated with a Nursing Diploma in 2001. He is studying for Bachelor of Nursing in Bali. He started his nursing career in 2001. 5 years later, he was moved to the ICU. Now he is an associate nurse. In caring for ICU patients, he is always creating comfortable conditions for the patients and their families to help the family to accept the patient's condition. The loss theory principle is the most important that he uses in creating comfortable feelings for the patient and the family. He knows the exact time to give information based on the steps of the loss theory. For him, maintaining an interpersonal relationship especially for the closest person of the patient is very important to form a trusting relationship and to know any needed information about the patient. He always tries to understand the feeling of the patient and the family, but he always tries to be strong so he can care for the patient and support the family.

He believes that as a creation of God, we should pray every day as a gratitude for any given pleasures. Besides, he believes that all humans are the same before the God. He does this everyday as a nurse, caring for patients without differentiating a patient's social status. He gives authority to the Hindu patient's family by providing an opportunity for them to bring "*pemangku*" (priest) for praying for the patient with the family. With other

religious patients, he always does the same practice by praying in "*Bahasa Indonesia*" (common language) and facilitating the family for spiritual services based on the available nursing standards in the ICU.

Participant 5

Participant 5 was a female ICU nurse. She is 50 years old, and married. She graduated with a Nursing Diploma. She started her career as a nurse in 1989. She has been placed in ICU for 25 years. At the present time she is a primary nurse and clinical instructor. She always cares for the patient well, even though the patient maybe in an unconscious condition. His /her need is always fulfilled. As a mother with two children, her instinct leads her to be easily touched when caring for a child patient in the EOL phase. She really understands the feelings of the parents. She thinks that family accompaniment is important for the patient to provide comfort to the patient. In caring for the patient, she always considers the nursing standards in the ICU.

She believes that everything should be maintained with gratitude. Praying and providing service to other people is the way to be grateful upon God's gift. As a Hindu she always prays before and after conducting care for the patient. She gives authority to the Hindu patient's family by giving an opportunity to them to bring "*Tirta"* (holy water) and *Banten* (offerings). To other patients with different religions she gives authority based on nursing standards, such as giving authority to the family if they want to prepare a visit from a spiritual leader.

Participant 6

Participant 6 was a female ICU nurse. She is 50 years old, and married. She graduated with a Nursing Diploma. She started her career as a nurse in 1990. The ICU is

the first place that she started her role as a nurse. She was placed in the ICU 14 years ago until now. At the present time she is a primary nurse. She considers the patient as a part of herself. Therefore, the fulfillment of the patient's needs is the main objective. She always does the best for the patient, while praying for the best for the patient. For her, although the patient has been diagnosed with no more life opportunity, she must conduct maximum care based on the available standard.

She believes that everything is based on God's Will and it also applies to patient care. She always prays based on her beliefs. In caring for Hindu patients, she believes in using *"mantra"* (Chanting). Besides that, she also gives authority to the family such as instructing the family to pray in the temple and have "*Tirta"* (holy water) or the family is asked to pray in the family temple and have "*Banten"* (offerings) close to the patient's bed. To other patients with different religions she gives the same care by always praying and giving instruction as well as facilitating the family in terms of spiritual services.

Participant 7

Participant 7 was a female ICU nurse. She is 52 years old, and married. She graduated with a Nursing Diploma. She started her career as a nurse in 1990. She has been placed in the ICU for 9 years. At the present time she is an associate nurse. She always tries to fulfill patients' rights. Even though the patient is in the end-of- life condition, the fulfillment of patients' needs is an obligation of a nurse. Monitoring patient progress is also the main objective, as an evaluation of a patient's condition progresses as well as a basis in giving information about the patient to the family.

She believes that as a creation of God, we should pray everyday as gratitude for any given pleasures. As a nurse she always prays to the patient by whispering the "*Gayatri mantra"* (Mother of Hindu mantra) and sprinkling "*Tirtha*" (holy water) on the patient. She does the same thing with patients of different religions by praying and facilitating the family to prepare a spiritual leader based on patient nursing standards especially in regards to spiritual services.

Participant 8

Participant 8 was a female ICU nurse. She is 40 years old, and married. She graduated with a Nursing Diploma. She started her work in 1997. At the present time she is an associate nurse. In ICU her care for the patient is focused on creating comfortable feelings, and she hopes that the patient does not feel pain. Therefore, a patient's complaint is a priority that she takes care of for the patient. She feels sad if there is a young patient in the EOL condition. When she finds the family is hysterically shocked about a patient's condition, at that moment she feels deep sorrow. She finds it hard to hide her feelings. She always tries to maintain communication with the family.

As a Hindu, she believes that every single human is the same before the Almighty God. Therefore, for her there is no significant difference in caring for patients. She always prays before and after conducting care for the patient based on her belief. She gives authority to Hindu patients to pray by reciting "Gayatri Mantra" (Mother of Hindu mantra). For other patients with different religions, she facilitates them based on their beliefs.

Participant 9

Participant 9 was female ICU nurse. She is 41 years old, and married. She graduated with a Nursing Diploma. She started her career in 1996 in the ICU. At the present time she is a primary nurse. The standard of nursing for an end- of -life patient is guidance for her to care for the patient. Supporting the family is the main objective besides giving care to the patient. She always tries to prepare the family mentally, which means the family would not be shocked and would accept the worst possible condition of the patient. The supporting approach that she utilizes for the patient and the family is a spiritual approach.

She believes that empathy is a form of care to others. Therefore, it triggers her to pray for the best for the patient. She considers the same both for Hindu and non-Hindu patients. Sometimes, she gives instruction to the Hindu patient's family to pray to the ancestor spirit and to bring "*Tirta"*(holy water) to be given to the patient.

Participant 10

Participant 10 was a male ICU nurse. He is 41 years old, and married. He has had a Bachelor of Nursing since 2011 and started his career as a nurse in 2011l. The services that he conducts for the end-of- life patient in ICU is supporting the patient in terms of the disease, for example, supporting a cardiovascular patient with medicines and supporting the family by giving information about the patient's progress and treatment that will be given to the patient. As a father, he can feel the sorrow of loss when the patient is the backbone of the family. He does really understand how the family is feeling. The process of caring for the EOL patient in ICU is a cycle of family response that is felt by him as a nurse. He feels that the first time the patient comes into the ICU,

the family tends to have difficulty in accepting that. Therefore, there should be therapeutic communication so the family can accept this.

As a Hindu nurse as well as the backbone of his family, health is the most precious gift given by God. He tries to care for the patient sincerely and believes in "*Karma",* so his goodness will be granted by goodness as well. He gives authority to the Hindu patient's family by giving an opportunity for them to bring "*Tirta"* (holy water) and "*Banten"*(offerings).

Lived Experience of Caring for Patients at the EOL in the ICU

The lived experiences of Hindu nurses in caring for the EOL patients in the ICU were described by the participants. There were four themes: (1) delivering basic care to patients at the EOL, (2) assisting the family to accept patients' conditions, (3) providing spiritual approach based on religious background, and (4) providing compassionate caring. These themes are presented with related sub-themes.

Delivering basic care to patients at the EOL.

The activities that were performed the same as those that were given to other patients and not specific or special treatment for the EOL patient. The activity in the ICU that the participants had done same like as routine care. There are three sub themes: (1) caring focused on fulfilling the basic needs, (2) caring focused on relieving suffering and promoting comfort, and (3) caring focused on following the standard guideline in ICU. The three sub-themes were described by the participants in the following:

Fulfilling the basic needs. Participants caring for the EOL patient focused on fulfilling the basic needs. The fulfillment of basic needs is like the daily needs activity that patients usually did. Such as, taking a bath, toileting, and dressing. Excerpts of two participants:

> *"To the patient, I was fulfilling the basic needs of the patient from A-Z such as taking a bath, brushing teeth, cutting nails, cleanliness and giving medicines. Meanwhile to the family I give motivation and prepare them mentally as well as the patient about his/her condition….."*.
>
> (P2.L41-47)

> *"Activity as usual daily activities such as bathing help with eating and drinking, if in an unconscious condition this will be via NGT, and do suctioning. If there were drugs in accordance to time I also administer these. I did fluid balancing every 3 hours. To the family when it's visiting time I informed the family of the condition progress of the patient."*
>
> (P2.L146-152)

Relieving suffering and promoting comfort. The participants focused on their caring to decrease any suffering from pain, shortness of breath/dyspnea, hydration, nausea, vomiting, fever, and delirium. For example, for the patient with a painful condition, the nurse tried to focus on reducing the patient's pain score level and promoting comfort. This was evident by:

> "*The service that we do for the terminal patient in ICU is unconscious patient to the patient we give treatment by creating feelings of being comfortable also maybe because the level of consciousness is worsening because the pain is increasing if it happens we give analgesic maybe to maintain".*
>
> (P8.L20-30)

> "*To give comfort to the patient in his/her last time for instance in cancer patients the pain is the priority because it can cause the patient to feel nausea and puke thus we may be able to decrease the patient's suffering*".
>
> (P8.L48-52)

Following the standard guideline in ICU. Participants' cares were based on standard guidelines of caring which were applicable in the ICU. This standard guideline contained the reference for the EOL care in the form of the scope of caring and the management of caring for patients with EOL in the ICU. As two participants described

> *"Keep giving treatment to human means even though the human had no more opportunity to live because of such as brain stem death I must still treated him/her following the standard guideline*".
>
> (P3.L60-65).

> "*The caring that we did appropriate to the standard care to the terminal patient in term of still maximal. Maximally based on what was needed and what were the rights of the patient in ICU*".
>
> (P9.L25-32)

Assisting the family to accept patients' conditions.

The participants in the study described their supports toward the patients' family members to accept the conditions of the patients into three sub-themes: (1) Giving information to the family, and (2) Providing psychological support to the family.

Giving information to the family. The emerging sub-themes regarding giving the information were concern on informing patient' conditions and care activities continuously to the family; confronting different level of understanding of the family; and giving significance of effective communication to the family.

Concerning on informing patient' conditions and care activities continuously to the family. Participants strived to provide accurate information about the patient's progress and activities that were done upon the patient; The participants always gave adequate information to the patient's family about the caring that would be given. Therefore, the families knew and understood. In addition, the families are expected to accept the possibility of the worst possible condition that will happen to the patient. The participants understood what the family felt and could support the family by giving information to the family. This was revealed in the following excerpts:

> "*Regular treatment that we need to do is informing the patient's family is the most important because the patient is unconscious which may be no more treatment needed so the family should be informed more frequently and anytime the patient can be passed away*".
>
> (P1.L36-44)

> "*… Before we do the care activity for the patient we strive to provide giving the information. the readiness of the participants is maintained to give information to the family about the activity that would be done upon the patients*".
>
> (P7.L54-59)

> "*Always support family and give information about the progress of patient's condition. The information is always informed to the family continually so it can create comfortable feeling for the family as well as improving family trust to the medical team".*
>
> (P9.L64-74)

Confronting different level of understanding of the family. The participants had difficulty to communicate about the EOL conditions with the family. The

EOL condition was a sensitive issue because the family members might have a different education level and experience about the EOL. The participants felt that he/she had to inform to the family members about the patient's conditions clearly because the family members had difficulty in understanding the information. Different understanding and knowledge could be a miscommunication and was really influenced the family comprehension. The participants described this in the following:

> "*Family's understanding was not comprehensible even though they had got information and it made miscommunication; they insisted that their family should be cured*".
>
> (P3.L134-137)

> *"Just level of understanding, so it really influenced the comprehension, I think so. It can be because of the educational background and experiences of the family or the patient*".
>
> (P3.L143-147)

Giving significance of effective communication to the family. The participants realized that giving significance of effective communication was the importance to provide information to the family. However the participants still had the problem with the way to communicate. The participants described this in the following:

> "*Yeaahh, I think the main obstacle is communication. Because sometimes from less-satisfaction of which was caused by lacking of knowledge made the patient complain. We as participants strive to provide effective communication in terms of providing accurate information about the patient's progress*".
>
> (P2.L182-192)

> "*Yeaah, I think the barrier is the way how we communicate to the family. There is clumsy feeling, sometimes I feel uncomfortable because the family always asking many times, although I already informe*d" .
>
> (P5.L90-93)

Providing psychological support to the family. In giving information to the family, the participant felt that the family should be supported by nurses through creating feelings of comfort and helping to prepare the family for the worsening conditions of the patient. It is expected that to have family become acceptable in a worsening condition of a patient if psychologically prepared. The participants described this in the following:

> "*Try to create comfortable condition so the family can accept the condition. making the patient and family accepting sincerely so if indeed the patient dies he/she will die in peace and at the last minute be with the family*".
>
> (P4.L88-91).

> "*Firstly giving comfort to the family, because the patient has no more life opportunity. So, here we support and serve the family and it is expected the family will find comfort or be able to accept the patient's condition, that is what I feel*".
>
> (P9.L58-62)

Providing spiritual approach based on religious background.

The participants' activity in providing spiritual approach was performed to prepare the patient and the family in facing the death peacefully. They described their activity in two main sub-themes: (1) Spiritual approach for Hindu patients, and (2) Spiritual approach for other religions.

Spiritual approach for Hindu patients. The participants' activity in the spiritual approach for EOL patients who followed the Hindu religion was described in several issues such as: (1) Chanting Gayatri mantra, (2) Allowing the family to receive 'Tirtha' (holy water), bring 'Banten' (offerings), and give 'Bija' (Vija), (3) Giving authority the family to brings preacher**.**

Chanting Gayatri mantra. Chanting a mantra was one of the participants' activities in spiritual approaches for Hindu patient. The chanting of a mantra was done by chanting Gayatri mantra appropriate to Hindu belief. The patients could still hear, so that the words of prayer expected the patients could participate to chant. The participants described that by doing these activities; they could provide serenity and help the patient to relax. Two participants' excerpts illustrate this in the following:

> "*As a Hindus participant I believe Gayatri Mantra was able to bring strength and miracle to the patient. I usually ask them to pray. Who knows there will be the miracle of the healing if he/she is healed if he/she is going to die let him/her die peacefully and not too long suffering. More about the way to pray because I am Hindu so I am able to spell mantra. Sometimes I ask the family to set Walkman for the patient to listen Gayatri mantra that was usually I did*".
>
> (P6.L11-123)

> "*I usually support the patient chant mantra while instruct the patient to chant as well I believe even though the patient was unconscious he/she can listen and follow and for the rest I give it to the patient's family .....*''.
>
> (P10.L146-154)

Allowing the family to receive 'Tirtha' (holy water), bring 'Banten' (offerings), and give 'Bija' (vija). The participants in the spiritual approach believed that

faith in the Hindu religion can be practiced in the activities of the spiritual approach. According to the Hindu belief, Tirtha' (holy water), 'Banten' (offerings), and 'Bija' (vija) were a part of worship of the Hindu in Bali. The participants provided more flexibility for the patient's family to worship activities such as carrying "banten" (offerings), spreading "tirta" (holy water) on the patient and giving "bija" (vija). These were brought by the families after performing prayers at home, by praying to the ancestors in "Kemulan" (Family shrine) and wishing the best for the patient. The religious activities were allowed to be conducted with the patient, but thereafter the families were required to take out any offerings or items they brought in. The following excerpts reflected this point:

> "*Sometimes based on the family's belief by taking holy water and bring offerings I am in medical care usually let holy water be spread on the patient but the patient was not allowed to drink it. I was careful to let offerings get left inside even though offerings cannot be separated in Bali and indeed it is a faith for all Balinese Hindus I was let offerings in but after the ceremony I suggested families to take them outside*".
>
> (P1.L203-210)

> "*If it is Hindu there was holy water and vija, offerings for Hindu patients if the patient had deterioration in a terminal condition or post-accident. If the belief was Balinese Hindus as my belief I instruct the family to conduct Ngulapin ceremony. It is a religious ceremony in Bali in which there was Urip shrine to be touched to the patient with holy water. I was indeed had a policy in the terminal phase to bring offerings and holy water. But after the ceremony, I instructed them to take the offerings and other things out*".
>
> (P5.L119-129)

Giving authority the family to brings preacher. The participants in caring for EOL patients explained the patient's condition, such as informing the family that the condition cannot be helped anymore. So, the participants gave authority to the

family to bring a preacher. In addition, the family usually asked the "shaman" based on their belief. The following excerpt reflected this point:

> "*Usually, I just informed the family that the patient's condition was already terminal or there was no more opportunity for his/her cure so the family may pray at home, in a temple or conduct a non-medical cure. Usually some of them ask from the "shaman" (orang pintar) whether the disease was related to the spirit ancestor or what. It was a medical disease or related to the birth. Usually, the family did this to find comparison for the sake of mental tranquility in order not to feel guilty because of not doing anything. Finally, they did everything they can*".
>
> (P3.L159-165)

Spiritual approach to other religion background. The participants' activities for patients with other religious backgrounds were described in two issues: (1) praying by nurse, and (2) Allowing the family to follow their belief.

Praying by nurse. The participants' activities in a spiritual approach to a patient who had a different religious background were done by praying for the patient. They were not using their religious beliefs in other religions. They used "Bahasa" (common language) in their praying, and did not chant mantras. It was essentially expected to be the best for the patient. As two participants described:

> "*Just maybe I pray using Bahasa (common language), the point is that I pray for the best for the patient while instructing the family to bring a priest and accompany the family while praying for the best for the patient. The point was that if the patient dies, he/she would at peace*".
>
> (P1.L216-221)

> "*If a different religion, I believed that every religion had the same purpose to the God. Just different in the way. I personally still have no difference in my feelings towards a patient just that in a patient with a different religion I prefer to use Bahasa in praying. I do not use my conviction in this case because of religious differences. But it still helps to pray in a common language*".
>
> (P2.L186-192)

Allowing the family to follow their belief. The participants provided more flexibility for the family to practice their beliefs based on the patient and family religion. They instructed the family to be close to the patient and to pray for the best. The participant lets the family to provide a preacher by themselves. The participants tried to facilitate the preacher if the family did not provide one by themselves. The following excerpts illustrated this:

> "….. *I just let the family did whatever based on their beliefs or let them prepare a spiritual figure to accompany the patient besides that the hospital had a spiritual guide prepared if needed by the family. Because sometimes the family provided their own spiritual guide to lead the prayer*".
>
> (P6.L131-139)

> "*I tend to instruct the family to accompany the patient and did spiritual approaches based on his/her religion. For Hindu and non-Hindu families who were willing to have a spiritual guide the hospital would provide that, I usually help to facilitate the spiritual service*".
>
> (P7.L123-128)

Providing compassionate caring.

The participants provided the compassionate care for the EOL patients by positioning the patients as their own family and sharing their feelings of sympathy and

empathy in caring for the EOL patients. The participants' expressions were described in the following:

Positioning the patients as their own family. The participants thought of the patients at the EOL as a part of their own family. They did their best sincerely and compassionately for the patients. The following excerpts illustrate this:

> "*I care for the patient as if he/she is a part of my life and I even position the patient as one of my family. So, I take care of the patient with love and prayer in my heart hopefully it will not happen to me so it think I should be sincere to fulfill the patient's needs rather than I become the patient"*. (P2.L64-73)

> "*My feeling in the beginning because of my experience in caring for critical or terminal patients but morally I felt compassion and consider the patient as my own family*".(P3.L39-43)

Sharing the feelings of sympathy and empathy. The participants felt that they were able to share their feelings of sympathy and empathy in caring for the EOL patients and patients' family members in the ICU. Sharing their feelings of sympathy meant the participants could feel what the patients and the families felt. The participants felt sad when seeing the patients and the families sad. The participants always felt sympathetic when the patients were the breadwinners and the ages of the patients were children or the young. Participants felt as a mother losing a child, and participants also felt how it feels to lose the backbone of the family. In addition, there was a feeling that the maximum support from the medicines that would only prolong the suffering of the patients. This condition made them difficult to resist feelings of sadness. Moreover the participants also shared their feeling of empathy. They were able to understand the

feelings of the EOL patients and their families in the ICU. However, the participants did not express their feelings directly to their patients and their families. As described by participants in the following:

> "*Sometimes I feel sad, I feel pity for the terminal patient because I think the condition is terminal just like suffering because maximum support from the medicine will only make the suffering longer. If the patient is young and the family backbone at that moment I am sad to see this I can't see that. I feel just like what the family feels. I feel sympathy to see an enthusiastic family upon the cure of the patient while the condition is impossible; yes personally there is a feeling of sadness*". (P10.L42-56)

> "*I can understand what the family feels but I am as a nurse trying to be stronger than the family, so I am not crying or sad. One thing that makes it difficult is to hold back the tears is if the patient is a child*". (P9.L38-42)

Summary of the experience of caring patient at the EOL in the ICU.

The experience of caring for patients at the EOL in the ICU was described based upon the four themes. Firstly, delivering basic care to patients at the EOL in fulfilling the basic needs, relieving suffering and following the standard guidelines in providing care. Secondly, assisting the family to accept patients' conditions by giving information to the family and providing psychological support to the family. Thirdly, approaching the patients spiritually based upon the belief of Hindu and other religion background. Finally, providing compassionate caring in positioning the patients as their own family, sharing the feelings of sympathy and empathy.

Hindu Nurses' Lived Experiences of Caring for Patients at the End of Life in the ICU

Major-theme	Sub-themes
1. Delivering basic care to patients at the EOL	1.1. Fulfilling basic needs 1.2. Relieving sufferings and promoting comfort 1.3.Following standard guideline in ICU
2. Assisting the family to accept patients' conditions	2.1. Giving information to the family 2.1.1. Concerning on informing patient' conditions and care activities continuously to the family 2.1.2. Confronting different perceptions of the family 2.1.3. Giving significance of effective communication to the family 2.2. Providing psychological support to the family
3. Providing spiritual approach based on religious background	3.1. Spiritual approach for Hindu patients 3.1.1. Chanting Gayatri mantra 3.1.2. Allowing the family to receive 'Tirtha' (holy water), bring 'Banten' (offerings), and give 'Bija' (Vija) 3.1.3. Giving authority the family to brings preacher 3.2. Spiritual approach to other religious background 3.2.1. Praying by nurse 3.2.2. Allowing the family to follow their belief
4. Providing compassionate caring	4.1. Positioning the patients as their own family 4.2. Sharing the feelings of sympathy and empathy

Figure 1: Hindu Nurses' Lived Experiences of Caring for Patients at the EOL in the ICU in Indonesia

Discussion

This section presents an overview of the findings generated from this study. The research results in conjunction with current literature are also discussed.

The participants described their lived experiences while caring for the EOL patients in the ICU. This study found four themes which describe these lived experiences: (1) delivering care to patients at the EOL, (2) assisting the family to accept patients' conditions, (3) providing spiritual approach based on religious background, (4) providing compassionate caring.

The participants' activities in delivering care to the EOL patient in the ICU were described in the following three sub-themes; fulfilling the basic needs, relieving sufferings and promoting comfort, and following standard guideline in ICU.

The participants performed the activities as with any other patient, which is similar to routine care. The nurses caring for the 'fulfilling the basic needs' focuses on meeting the patient's daily needs such as taking a bath, toileting, and dressing. Patients at the EOL are categorized in total care in which the nurse should meet the patient's needs especially in regards to the basic needs. One participant described that focusing on the needs of patients is considered as the basic human needs as mentioned in Maslow's theory. This current study is supported by Kinzbrunner, Weinreb, and Policzer (2012) who said that the caring in assessing the activities of daily living is the most common method to assess the functional status of patients. In a related way, a study done by Mylén, Nilsson, and Bertero (2016) revealed that paying attention to patients' daily needs such as achieving personal hygiene can make a patient feel caring as a human being and become more confident. In another study by Cypress (2010) about the intensive care unit:

experiences of patients, families, and their nurses; this study perceived that nurses' activities to fulfill daily living by bathing the patient and rendering oral care is the physical care which is a priority in the needs of critically ill individuals in the ICU.

In the delivering care focused on 'relieving suffering', the participants care was focused on creating feelings of comfort and fulfilling any patient burden. This finding was similar to a study done by Gallagher et al. (2015) which explored the nurses' EOL decision-making in the ICU. They said that patient suffering was associated with comfort and pain. The patient at the EOL stage usually feels suffer from his/her illness which also induces stress on the family. The nurses focused on relieving suffering by creating comfortable feelings and reducing patient burden. Nurses believe that providing comfort to the patient can also avoid distress for the family. Another study by Mylén, Nilsson, and Bertero (2016) described patients' lived experiences to feel strong in an unfamiliar situation in neurosurgical intensive care. They said that the ICU nurses had an important role to provide comfort care to the patient to avoid patient suffering from the negative effects from their experience of their ICU stay. Relieving the suffering of patients at the EOL stages in ICU also helps the family to have good memories during the last moments with their dying family member. In addition, based on the study by Kongsuwan et al. (2010) which described Thai Buddhist intensive care unit nurses' about their perspective of a peaceful death, they perceived that the dying person would have a peaceful death when the dying person was not suffering. Therefore, to relieve suffering for the dying patient can also help to create a peaceful death for the EOL patient.

'Following standard guideline in ICU'. The participants in caring for patients at the EOL fulfill the needs of the patients based following the standard guidelines which

are applicable in the ICU. These standard guidelines are a set of directions and limitations of the EOL care patients in the ICU. This current study was similar to a study done by Espinosa, Young, Symes, Haile, and Walsh (2010) which described ICU nurses' experiences in providing terminal care. They said that standard guidelines were one of the nurses' needs as a protocol and directions to provide care to terminal patients in ICU. Nurses also focus on standard guidelines during resuscitation and in using advanced technologies. The nurses were very strict in following the guidelines as an attempt to prolong a patient's life and to keep away death (Kongsuwan et al., 2016).

The participants' activity in 'assisting the family to accept patients' conditions' focus on giving information to the family and providing psychological support to the family. Giving information to the family was one of the responsibility of the nurses. The information should include patient' conditions and care activities continuously to confronting different perceptions of the family, and also giving significance of effective communication to the family.

'Concerning on informing patient' conditions and care activities continuously to the family'. The participants' expected that would help families understood and accept the worst possible fate that occurs in the patients. This finding was similar to a study by Adams et al. (2014) about nursing strategies to support family members of ICU patients at high risk of dying. The study revealed that nurses have an important role in providing information on the environment, the treatment and the patient's condition in the ICU. The nurse's role in providing information can help patients and families to improve their understanding, prepare families about any possibility that occurs in the future and improve family coping. Giving accurate and concise information about the prognosis of a

patient's disease can also help to achieve a clear understanding of the severity of the situation and help in making important decisions regarding the rest of their lives (Lee, 2012). Another study done by Noome, Dijkstra, van Leeuwen, and Vloet (2016) explored family experiences of nursing aspects of EOL care in the ICU. They described the nurses' activity in giving accurate information about a patient's progress to the family who were present during the visit, which can help the family to feel appreciated and amazed to see the nurses, they feel they can ask questions and express their emotions.

A study done by Crump, Schaffer, and Schulte (2010) about critical care nurses' perceptions of obstacles, support, and knowledge needed in providing quality EOL care found that nurses have an important role in fostering good communication; they provide accurate information about the caring process administered to the patient. This could had an effect on the creation of an environment more humane for patients at the EOL care in the critical care unit. Another study by Mylén, Nilsson, and Bertero (2016) also had the same perception regarding giving information about the care administered to the patient. They looked at ways of creating interaction and determined ways of informing. It is important to raise the awareness of the nurses about physical and psychological reactions of patients.

'Confronting different level of understanding of the family' was influenced the knowledge and family understanding about the EOL condition of the patient. Participants felt the difficulty of communicating with families to provide an understanding of the patient's condition. The EOL is a sensitive issue; different communication skills may result in different perceptions about what the nurses have informed to the patients. Nurses felt it was explained clearly, but the family still did not fully understand. The results of

this study have highlighted the different perspectives in some research studies. A study by Billings (2011) about the EOL family meetings in intensive care showed the nurses perceived that the family often did not know what information to focus upon, and that they might receive different impressions from different staff members. The nurse who works in the morning shift will provide different information to the nurses who work in the afternoon or night shift to the family based on the current conditions. Another study done by Holms, Milligan, and Kydd (2014) described that the family did not understand and felt confused about the information, where they got mixed information from the doctor, nurses, and patient. This condition also caused inconsistencies in the EOL practice, especially the decisions to withhold/ withdraw treatment or the practicalities of dying in the ICU. In addition, the lack of knowledge and education regarding EOL also become barriers in delivering information. The families do not feel comfortable. (Aslakson et al., 2012; Borhani, Hosseini, & Abbaszadeh, 2014).

'Giving significance of effective communication to the family' participants provide effective communication in terms of providing accurate information about the progress of the patient conditions. However, the participants feel that the way how to communicate to the family is an obstacle in conveying the information. Information about EOL choices should be shared with significant others. The patient and family have the right to receive truthful information. Effective communication requires clear and specific explanations (Kaplow & Hardin, 2007). Through good communication, all people involved in the patient care have better understanding about how to care patient and family (Morton, Fontaine, Hudak, & Gallo, 2005). Communication seems to be the

most common source of complaint in families across studies and should be the center of efforts to improve end of life care (Urden, Stacy, & Lough, 2013).

The nursing activity ‘Providing psychological support to the family’. The participant in providing support to the family focused on providing a sense of comfort as well as preparing the family’s psychological readiness in anticipating the worst that could happen to the patient. Providing supportive care to the family who have family members in the EOL stages was one of the essence cares in palliative care (Ferrel, 2016). Another study by Kisorio and Langley (2016) described the nurses who want to always support the family by frequently having contact with the family. However, nurses tend not to have much time.

The nurses’ activity in providing spiritual approach based on religious background was done to prepare the patient in facing death peacefully and the families having a better way of coping with the situation of their dying family member. Nurses can play a significant role in the assessment of patients’ spiritual needs and the provision of spiritual care in overall nursing profession (O’Brien, 2013). In this study, the spiritual approaches were done following two main themes; spiritual approach for Hindu patients and other religions background.

The nurses providing their caring activity in the spiritual approaches of Hindu patients. They described their activities in three main issues; chanting a mantra, allowing the family to spread holy water, bringing offerings and giving Vija, and giving authority for the family to bring a preacher. The nurses’ activity in the spiritual approach for Hindu patients is done by ‘chanting a mantra’ based on Hindu beliefs, the nurses’ chanted Gayatri Mantra when praying in order to help the patient to feel peaceful and calm.

Universally, all Hindu followers know how to chant mantras. A mantra is not only a song of words, but a medium to concentrate on divine spiritual happiness and a communication medium to high religious values. The most divine and the main mantra which is sometimes called the mother mantra or 'Veda' is Gayatri Mantra (RegWeda III.62:10).

Hindu nurses also performed the spiritual approach by 'encouraging the family to spread 'Tirtha' (holy water), bring 'Banten' (offerings) and give 'Bija' (vija). The word 'Tirtha' (holy water) is derived from Sanskrit language which means holiness or a drop of water, holy water, purified by water. Based on Pradnya (Personal Communication, May 19, 2016) said that the function of 'Tirtha' (holy water) depends on the mantra given by the holy priest, especially to the sick person who prays for a cure. 'Banten' (offerings) is a holy offering to God. Here,'Banten' (offerings) is a symbol of surrender to His Almightiness. In other words, 'Banten' (offerings) is a medium to express devotion and sincerity to God (Erawati, 2016). In this study, the nurses expressed their experiences by instructing the family to pray for a cure in 'kemulan' (family shrine) at home and the'Banten' (offerings) is taken to the ICU to be placed close to the patient in order to have the best result. 'Bija' (vija) in Sanskrit is called 'gandaksata' which comes from the word 'ganda' and 'aksata' has meaning grain intact and smelling (Sudarma, 2009). The material of 'Bija' is rice, as a symbol of prosperity. 'Bija' (vija) is derived from Bahasa biji which means a seed, in this context 'Bija' (vija) as a basic material of ceremony or as a form of gratitude to God, so every time Hindu worshippers finish their prayer they will use 'Bija' (vija) in three ways based on the concept of Tri Kaya Parisudha.

Moreover, the nurses' activity in the spiritual approach for Hindu patients by 'giving authority for the family to bring a preacher', the nurse tried to maintain a good

relationship with the family, when the nurse provides information about the poor condition of the patient, for example, of the conditions that cannot be helped anymore. Nurses tried to give authority if the families want to bring their own preacher. The families usually ask the shaman to determine whether the patient's illness comes purely from a medical stance or if there is another factor. The disease is always associated with symptoms of disharmonious relationships with sesame and the supernatural that causes a disease.

The participants as Hindu nurses also had to care for patients of another religion. The participants described the spiritual approach to other religions background in two issues; pray for the patient by the nurses, and allowing the family to follow their beliefs.

The nurses' activities, pray for the patient was established by using common language in their praying. The prayer principally wishes the miracles and the best for the patient. This finding is similar with a study done by Slater et al. (2012) which described the communication by nurses in the intensive care unit. They revealed that silently praying for the patients by the nurses in ICU is one part of nonverbal communication. Another study by Schaefer, Stonecipher and Kane (2012) described the spiritual mindfulness quality in medical cardiovascular ICU. They revealed praying for others is also one of the oldest and most common interventions used to decrease suffering.

The nurses 'allowing the family to follow their beliefs'. The nurse activity in the spiritual approach was giving authority to the family to provide a preacher. The nurse provided an opportunity for the families to be close to the patient and pray based on their beliefs. The nurses also gave the families an opportunity to bring in a preacher according to their beliefs. However, the nurses also provided a preacher based on the families

beliefs if the family did not prepare one themselves. This current study is similar to the study by Kisorio and Langley (2016) about intensive care nurses' experiences of EOL care. This study revealed that the nurses tried to provide an opportunity for the patient and his/her family to follow their own beliefs, as a manifestation of respect for the differences in beliefs between the nurses, patients and their families. It also supported the family in following their beliefs as long as there was no negative impact on the patient and it did not affect other patients. This activity also makes the family feel more appreciated. They have the possibility to perform their own rituals during the dying process of the patient (Noome, Dijkstra, Leeuwen & Vloet, 2016). In addition, based on Baliza et al. (2015) about factors influencing intensive care unit nurses in EOL decisions, it was found that allowing preachers to visit based on the patient's beliefs is one performance factor to enhance the peacefulness of patients and their families during the EOL process.

The participants provide compassionate caring by positioning the patient as their own family and sharing the feelings of sympathy and empathy for the EOL patients.

The participants positioning the patient as their own family; they would feel close and more responsible to do their best like when one of their family members felt sick. They felt more sincere and compassion. The finding of this is in contrast with a study done by Boroujeni, Mohammadi, Oskouie, and Sandberg (2009) who described the nurses keeping a professional distance between themselves and the patients and not to assume they are like a family member in preparation for loss as in the loss of the patient This is to avoid the sense of closeness and connection that tends to worsen nurses 'grief and sense of bereavement.

Most participants felt there was a change in the feelings of sympathy to empathy. The nurses' feeling of empathy, of which they did not express their feelings directly, like sadness or crying with the patient and his/her family. They understood what the patient and family felt. These feelings show that nurses can be stoic and stronger than the patient and his/her family. This finding is similar with a study done by Billings (2011) who explored the EOL family meeting in intensive care. They described the empathy feeling as the nurse's key opportunities in dealing with a patient's family regarding the condition of the patient in the ICU. Whereas, the patient's family would express their emotions in the EOL phase. In a related way, a review study by Adams, Bailey, Anderson, and Docherty (2011) states that the empathy feeling during the EOL period is the one of nurses' strategies for supporting and building trust with the family. The empathy feeling also allows nurses to develop a personal bond or meaningful commitment (Shorter & Stayt, 2010).

Although most nurses had experiences in EOL care, they sometimes felt sympathy for the patient. There was a difficult situation to cover up their feelings. They were positioning themselves as the patients or their families. They felt the same in the situation, when the nurses were a mother who had a child they felt how it would be to lose a child and the nurses who were a father and the family backbone also could understand what the patient's family felt when they loss a father or the backbone of their family. This condition tends to feelings of sadness. The finding of this current study confirms the finding of another study. The study by Valiee, Negarandeh, and Nayeri (2012) explored the intensive care nurses' experience of end-of-life care in Iran. They described the nurses' feelings of sympathy and compassion when caring for EOL

patients. Nurses found it difficult to cover up their feelings when providing care to most of the patients who were treated in a state of EOL phase and there was no hope of survival. The high workload made it difficult to control their emotions. Likewise, a study by Espinosa, Young, Symes, Haile, and Walsh (2010) also described the nurses' feelings of sympathy by crying with a family when a patient was dying. Nurses found it difficult to hide their feelings. This feeling, as the nurse mechanism to coupe the conditions.

Most of the participants in the study describe their lived experience in caring for the EOL in positive ways. It can be discussed that their thoughts, feelings and practices in caring for the EOL with a regular worship would be shaped by their strong belief in Hindu religious principle. Based on Steinberg (2011) described that religious belief can influence the person perspective in caring the patient at the EOL. In Hindu belief, there is an underlying concept of how someone behaves in everyday life or the way of life in Hindu is called to the concept of *'Tri Kaya Parisudha'.* There are three basic behaviors of Hindus in everyday life to be purified. Namely, '*Manacika*' (to think in a good way), '*Wacika'* (to speak in a good way), and '*Kayika Parisudha'* (to do in a good way) (Suhardana, 2007). Firstly, *Manacika*' (to think in a good way) is an action that should be a priority because basically all things start from thinking. Therefore, always to think positively in order to be positive in speaking and attitude. Secondly, *Wacika'* (to speak in a good way) means to speak in the truth, not hurting others. Lastly, '*Kayika Parisudha'* (to do in a good way) is doing the right thing which means doing beneficial thing to the world (Jaya, 2015).

This philosophy could give direction for the Hindus in daily lives. Therefore, the participants who stricted in religious belief often described their believe of goodness.

This belief would enable them to bring positive feelings in caring for the EOL patients. Caring genuinely is a form of gratitude for the blessings given by God. The participants applied it by caring for the patients at the EOL and their family members with a sincere and compassionate care in every aspect of their care activities and expressed most positive caring behaviors at the EOL.

Chapter 5

Conclusion and Recommendation

A Husserlian descriptive phenomenology was used to describe the Hindu nurses' lived experiences of caring for patients at the EOL in the ICU in Bali, Indonesia. The study was conducted from January 2016 to February 2016. The researcher as the instrument in this study used face to face individual interviews with unstructured interview questions as a method of data collection. The unstructured interview questions were developed by the researcher based on the research objective and questions. The strategy of data analysis is represented by using Colaizzi's process of data generation. The summary of the findings, strengths of the study, limitations of the study, and recommendations based on the findings are discussed in this chapter.

Summary of the Findings

In this particular study there were more female Hindu nurses (70%) than male nurses (30%). The average age was 30-52 years, most were married and (80%) had graduated with a Nursing Diploma. Their work experience in the ICU ranged from between 1-10 years (40%) and 11-20 years (40%) with both groups having similar percentages. All of the nurses (100%) who participated in this study did not have experience in training for EOL care. Most of the nurses (70%) had strong religious principles and strictness in religious activities.

The lived experiences of the Hindu nurses regarding EOL care in the ICU was drawn and described. The nurses' experience of caring for the EOL patient in the ICU consisted of four major themes: delivering care to patients at the EOL, assisting the family to accept patients' conditions, providing spiritual approach based on religious background, and providing compassionate caring. The participants delivering care to patients at the EOL by fulfilling basic needs, relieving sufferings and promoting comfort, and also following standard guideline in ICU. In regards to 'assisting the family to accept patients' conditions' the participants described in the following two sub-themes: Giving information to the family and providing psychological support to the family.

The participants' activity for providing spiritual approach to Hindu patients was using their beliefs while caring for the patient. These were described as: chanting a mantra, allowing the family to spread holy water, bringing offerings and giving Vija, and giving authority to the family to bring a preacher. The spiritual approach for other religions background was described as praying for the patients by the nurses and encouraging the family to follow their beliefs. 'Supporting the family', the nurses' activity in providing support to the family was preparing the readiness of the family. By doing this was expected that the family would not be shocked and would be able to accept the conditions. The participants also positioning the patient as their own family and sharing the feelings of sympathy and empathy in 'providing compassionate care'.

Strength of the Study

This study used EOL care based on Hindu perspectives. It could be useful to provide cultural care based on religious background in EOL care for patients in the ICU.

Thus, the study can provide the basic knowledge of the understanding of Hindu nurses to guide the EOL care practice in the hospital.

Limitation

The study had done in one setting and the method of the study was phenomenological approach. Due to the limit of this approach to small number of participants and describe the phenomena of caring at the EOL in one ICU in Bali, the findings of the study would not be generalized.

Recommendation

Based on the findings and discussions of this study, the following recommendations for nursing practices, nursing education, and nursing research are offered for the following aspects:

Nursing practices. The results of this study could be used as guideline practices for the nurses in caring for the EOL patient. For example, (1) most of the negative responses of the patients' families were coming from unclear information given by the nurses so it affected a family's understanding about a patient's condition as well as the reaction of the family. Therefore, it is suggested that in the future there should be training about the strategy of information delivery to patients' families and protocol guidelines about information flow to the family when the information should be delivered and when compulsory information should be given to the family. (2) This study also emphasizes spiritual approach in regards to the activities undertaken by the nurses, about how the nurses encourage the family based on their spiritual and religious backgrounds. It is

suggested that in the future, there should be training for nurses to provide care focused on spiritual care.

Nursing education. The findings of this study can be used to suggest recommendations for educators in nursing to emphasize the role of ICU nurses at the EOL care, provide better care and provide a bigger picture of the lived experience of EOL care in the ICU. Besides this, there should be education about the influence of religious beliefs on caring for patients, so a religious approach can be additional material in nursing education especially in caring for the EOL patients.

Nursing research. This study had provided basic information on the experiences of nurses caring for the EOL patients in the ICU. For further nursing research the results of this study can be used as support evidence or guidelines for establishing some educational programs to enhance and promote caring and to provide references for a study on the experiences of nurses in caring for the EOL patients based on the Hindu nurses' perspective in the ICU.

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Appendix A

Informed Consent

Dear Participants,

My name is Ni Komang Sukraandini, I am a Master's student of the Faculty of Nursing, Prince of Songkla University, Thailand. I am also a lecturer at the Nursing College STIKes Wira Medika PPNI, Bali, Indonesia. I am conducting research regarding "Hindu Nurses' Lived Experience of Caring for Patients at the End-of-Life in the ICU in Bali, Indonesia". The purpose of this study is to explain and describe the experience of caring for patients at the end-of-life in the ICU.

Your participation is voluntary. After an explanation of the study if you decide to participate, the investigator 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 of caring for patients at the end-of-life in the ICU. The interviewer may request a follow-up interview at a later date. The follow-up interview may last between 45 minutes and 60 minutes. This data and audio recorded tapes will be stored in a locked file cabinet that only the researchers working on the study can open. Your personal identity and all information will be kept confidential and will only be used for the purpose of this research project. If you disagree or feel uncomfortable, you can withdraw from this study at any time without any negative consequences. You also have the 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 that 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 of the dying patients, 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 cares for

patients at the end-of-life in the ICU. You may have the satisfaction of knowing that your experience may contribute to improving and developing the quality of end of life nursing care in the 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.

……. ……..
Participant Researcher

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Appendix B

Demographic Data Form and Interview Questions

Demographic Data Form
Code: _____ * Date: _____
Instruction: Please fill the blank and give a mark (√) in the bracket appropriate to your Answer where indicated.
1. Age : ……..years
2. Gender : ( ) Female ( ) Male
3. Marital status ( ) Single ( ) Divorce ( ) Married ( ) Widow or widower
4. Level of education ( ) Diploma ( ) Bachelor ( ) Master
5. Experience of training about end-of-life care ( ) Yes ( ) No Topic……... Duration……..
6. Year of working experience in ICU……. years
7. Ethnicity …….
8. Level of belief in religious principle () ( ) very weak ( ) medium ( ) strong ( ) very strong
9. Level of religious practice OR strictness in religious activities ( ) very weak ( ) medium ( ) strong ( ) very strong

Very Weak : Practice in religious principle worship only if feeling down

Medium : Practice in religious principle prying if there is a religious ceremony

Strong : Practice in religious principle with regular worship

Very Strong : Practice in religious principle with regular worship and practice in daily life

Semi-Structure Interview Questions

1. Please tell me about your understanding of "end-of-life care in ICU", what is it like?
2. Please tell me your caring for the patient at the end stage of life in the ICU. (And the patient's family)
3. How did you feel when you are caring for the patient at the end-of- life in ICU? And please explain to me about that feeling and what made you feel that. (And the patient's family)
4. Based on your point of view, how did the end of life patients and their families react/respond to you and the care you provided them
5. What were the care activities that you provided to the patient at the end-of- life in the ICU? (And the patient's family) And what were the reasons to do those activities? Or what were your thoughts?
6. Did you have any barriers during caring for the patient at the end stage of life in ICU? What were the barriers? And what did you think about that barrier?
7. How about the supportive things to promote your caring for the patient at the end-of- life in ICU and their family? Why did you think it could promote your caring?
8. Do you want to improve your caring for the patient at the end-of- life in ICU and the patient's family? What things do you want to improve? Please tell me what are the reasons?
9. How did you feel when you provide care for end of life Hindu patients (the same religion with you)?
10. How did you feel when you provide care for end of life patients with different religion from you? Do you have any problem? Please share me your story

Appendix C

List of Experts

1. Assist. Prof. Dr. Luppana Kitrungrote
   Surgical Department
   Faculty of Nursing, Prince of Songkla University Thailand
   Email: luppana.k@psu.ac.th

2. Assist. Prof. Dr. Tippamas Chinnawong
   Medical Department
   Faculty of Nursing, Prince of Songkla University Thailand
   Email: tippamas.c@psu.ac.th

3. Assist. Prof. Dr. Yaowarat Matchim
   Medical Departement
   Faculty of Nursing, Thammasat University Thailand
   Email: yaowarat.m@gmail.com

4. Dr I Gede Putu Darma Suyasa, SKp, MNg, PhD
   Lecturer Stikes Bali
   Head of the Center of Research and Community Services Stikes Bali
   Jalan Tukad Balian No. 180 Denpasar, Bali, Indonesia
   Email: putudarma.stikesbali@gmail.com

Appendix D

Letters

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 0521.1.05/3458

Ethics Committee Approval

December 14, 2015

To whom it may concern:

This letter is to confirm that the Nursing Faculty Ethics Committee approved the research study of Mrs.Ni Komang Sukraandini ID. 5710420010 entitled "Hindu Nurses' Lived Experience of Caring for Patients at the End of Life in Intensive Care Unit in Bali, Indonesia" on November 11, 2015. The study is a major part of Mrs.Ni Komang Sukraandini' 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 harmful to the participants in the future.

Sincerely,

Waraporn.

(Assistant Professor Dr. Waraporn Kongsuwan)
Assistant Dean for Research and Graduate Studies
Faculty of Nursing,
Prince of Songkla University
THAILAND

2. Approval letter from Sanglah hospital research ethics committee Denpasar, Bali

UNIT PENELITIAN DAN PENGEMBANGAN
(LITBANG) FAKULTAS KEDOKTERAN
UNIVERTAS UDAYANA/RUMAH SAKIT UMUM
PUSAT SANGLAH DENPASAR
Jalan P. Serangan Denpasar Bali (80114) Email : Litbang.unud.rsup@gmail.com Telp. (0361) 244534, (0361)227911-15(p.227)

ETHICAL CLEARANCE

NO. 1944/UN.14.2/Litbang/2015

This is to certify that following study project entitled :

"HINDU NURSES'. LIVED EXPERIENCE OF CARING FOR PATIENTS AT THE END OF LIFE IN INTENSIVE CARE UNIT IN BALI, INDONESIA."

Principal Investigator : Ni Komang Sukraandini, S.Kep.,Ns

Research Development: ICU RSUP Sanglah Denpasar

Protocol Number : 918.02.2.2015

Has been evaluated in accordance with the ethical aspects in using human being as a study subject and considered proper to be executed.

1. Progress report every..... month
2. Final report

Denpasar, December 31, 2015

Research and Development Unit,
Medical Faculty University of Udayana/
Sanglah Hospital Denpasar

dr.Ni Nengah Dwi Fatmawati, SpMK, Ph.D
NIP. 19780114 200212 2 003

Research Ethic Committee,
Medical Faculty University of Udayana /
Sanglah Hospital Denpasar

Prof. Dr. dr. Sri Maliawan, SpBS (K)
NIP. 19560114 198303 1 005

3. Permission letter to research ethics committee of Sanglah hospital Denpasar

KEMENTERIAN KESEHATAN RI
DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT UMUM PUSAT SANGLAH DENPASAR
Jalan Diponegoro Denpasar Bali (80114)
Telepon. (0361) 227911-15, 225482, 223869, Faximile. (0361) 224206
Email : info@sanglahhospitalbali.com, Website : www.sanglahhospitalbali.com

SURAT IJIN

No: LB..02.01./II.C5.D11/1004 /2016

Sesuai dengan Surat Keterangan Laik Etik (Ethical Clearance) No. 1994/UN.14.2/Litbang/2015 yang dikeluarkan oleh Komisi Etika Penelitian Fakultas Kedokteran Universitas Udayana/Rumah Sakit Umum Pusat Sanglah Denpasar. dengan ini diberikan Ijin Penelitian kepada:

Principal Investigator	:	Ni Komang Sukraandini, S.Kep., Ns
Judul Penelitian	:	***"HINDU NURSES'. LIVED EXPERIENCE OF CARING FOR PATIENTS AT THE END OF LIFE IN INTENSIVE CARE UNIT IN BALI, INDONESIA"***
Program Study	:	Faculty of Nursing, Prince of Songkla University THAILAND.
Unit/Tempat Penelitian	:	ICU RSUP Sanglah Denpasar
Waktu Penelitian	:	dari tanggal 31 Desember 2015 s/d 30 Desember 2016 (Sesuai dengan masa berlaku Ethical Clearance)

Peneliti diwajibkan untuk memenuhi persyaratan sebagai berikut:

1. Menyerahkan laporan perkembangan penelitian yang disyaratkan oleh komisi Etik/Bagian Diklit RSUP Sanglah Denpasar, disertai daftar Rekam Medik dari sample penelitian (formulir laporan dapat diambil di Bagian Diklit)
2. Mengumpulkan hasil penelitian (soft copy) ke Bag Diklit RSUP Sanglah Denpasar.

Demikian surat ijin ini kami buat untuk dapat dipergunakan sebagaimana mestinya.

15 Januari 2016
Direktur SDM & Pendidikan

Drg. Triniti Nugroho, M.Kes
NIP 195801191984101002

Tembusan:
1. Ka. Ruang Rawat Inap ICU RSUP Sanglah Denpasar
2. Yang bersangkutan.

4. Approval letter from ICU Sanglah hospital about validation of participants

KEMENTERIAN KESEHATAN RI
DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT UMUM PUSAT SANGLAH DENPASAR
INSTALASI ANASTESI DAN TERAPI INTENSIF
(IATI)
Jalan Diponegoro Denpasar Bali (80114)
Telepon. (0361) 227911-15, 225482, 223869, Faximile: (0361)224206
Email : info@sanglahhospitalbali.com Website : www.sanglahhospitalbali.com

Denpasar, 7 June 2016

To whom it may concern

This letter is to confirm that Mrs. Ni Komang Sukra Andini had collected the data regarding Hindu nurses lived experiences in caring for the end of life patient in the ICU for her study. She did the data collection since January to February 2016. This is to certify that after analysis data, the result is also sent to participants for validations of findings.

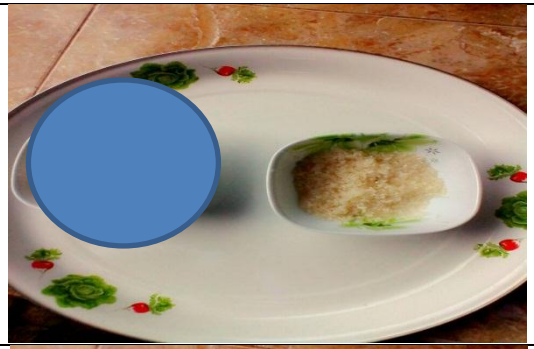
Sincerely

(I Made Oka Adnyana, S.Kep.,Ners)
NIP 197309161996031001

Appendix E

Description of The Term

The Term	Picture	Description
'Bija' (Vija)		It is ritual medium used in daily life by Hindu, especially in Bali. *Bija* is derived from Bahasa *biji* which means a seed, in this context *bija* as a basic material of ceremony or as a form of gratitude to God, so every time Hindu finishes their prayer, they will use *bija* in three ways based on the concept of *Tri Kaya Parisudha*. Etymologically, *Tri Kaya Parisudha* is derived from word *Tri* which means three; *Kaya* which means deed; *Parisudha* which means holy. So *Tri Kaya Parisduha* is three holy deeds consisting of *Manahcika Parisudha* (holy thinking), *Kayika Parisudha* (good attitude) and *Wacika Parisudha* (good speak) (Suhardana, 2008: 24-25). After finishing the prayer, so they will have *bija* and placed on the forehead as the symbol of positive thinking (*Manahcika Parisudha*). It is also placed on the chest as a symbol of consciousness action (*Kayika Parisudha*) and the *bija* is eaten as a symbol of speaking of truth and goodness (*Wacika Parisudha*). Therefore, the concept of using *bija* in the prayer correlates to the spirit of *Tri Kaya Parisudha* (three holy deeds) *Manahcika Parisudha* (holy thinking), *Kayika Parisudha* (good attitude) and *Wacika Parisudha*

		(good speak). Mantra used to purify the *bija* is: *Om Kung Kumara Bija Ya Namah Svaha*
'Tirtha' (holy water)		It is the most basic ritual media for Hindu; it makes sense Balinese Hindu is known as Religion of *Tirta* because all of rituals use water taken from water spring or from the Hindu priest. If they come to a temple and they do not have *Tirta*, the prayer will be considered unfinished, because water is considered as a source of life. *Tirta* is purified water, so the plain water can be considered as a holy water used for many things such as *Tirta Pengentas* for the death ritual, *Tirta Penglukatan* for salvation, *Tirta Wangsupada* for praying, *Tirta Caru*, etc. It depends on the Mantra chanted by the priest or the ceremony intended for the holy water.

‘Kemulan’		*Kemulan* is derived from Balinese word *mula* which means the beginning, so *Kemulan* is the beginning of human, which is the God himself and his manifestation as *Hyang Guru* or the worshipping of the ancestor. *Kemulan* is also called as *Gedong Rong Tiga* because it has three holes and the position is usually in the east of *Sanggah Merajan* (family temple). In the holy script of Purwa Bumi Kamulan, it is mentioned that the right hole is intended for male ancestor, right hole is intended for female ancestor and the middle hole is intended for *Hyang Guru* or God. Hindu believes that their life is ruled in *Kemulan* shrine, so any kinds of activity should be started form *Kemulan* in order to have blessing and success from the Almighty God.

'Banten' (Offering) used when there is a sick family member		Firstly, they offer *Banten Pejati* in *Kamulan*, *Banten Pejati* is a symbol of self-truth to offer themselves totally or *atmanastuti* to the God, so everything wished will be granted including praying for safety for those who are sick. After that, the family can sincerely accept the condition because they believe everything is depending on the Almighty God. After that they will plead *tirta* by placing a glass of water in the middle hole of the *Kamulan* shrine. Then it is named as *tirta wangsupada*, which means God has blessed the water. Besides that, the order of *Banten Pejati* is *segehan putih kuning*. *Segehan* is a special ceremony medium devoted to *butha kala* (destructive energy), so it is hoped that *butha kala* would not disturb the sick person. In the hospital, the *tirta wangsuhpada* from the *Kamulan* is sprinkled to the patient and it is hoped that there would be a miracle from *Hyang Guru* or die by escaping the spirit from its body, so he/she will unite again with the *Hyang Guru.* Therefore, it is the determination, if the patient is healthy, he/she will be healthier, if it is the time to die, his/her spirit would be purified and unite with the God.

'Gayatri Mantra'		Gayatri Mantra is the mother of mantra and taken from first mantra of *Tri Sandya* (three holy pray) However, Gayatri Mantra is chanted (repeatedly) by the patient family, so it is hope there would be miracle from the mantra, for those who are sincerely chanting the mantra is actually the same with those who are pleading *Tirta* in *Kemulan.* If the patient is healthy, he/she will be healthier, if it is the time to die, his/her spirit would be purified and unite with the God.

VITAE

Name **Sukraandini Ni Komang**

Student ID **5710420010**

Educational Attainment

Degree	Name of Institution	Year of Graduation
Bachelor of Nursing	Institute of Health Science Nursing, Surya Global, Yogjakarta Indonesia	2008
Nursing Internship program	Institute of Health Science Nursing, Surya Global, Yogjakarta Indonesia	2009

Scholarship Award during Enrollment

Thailand's Education Hub for Southern Region of ASEAN Countries (TEH-AC) Partial Scholarship, funded by the graduate school, Prince of Songkla University, Thailand

Partial Scholarship, funded by Institute of Health Science Nursing, Wira Medika PPNI Denpasar, Bali, Indonesia.