Intensive care unit nurses' perceptions of obstacles to the provision of end-of-life care in the Kingdom of Saudi Arabia: A mixed methods study

Submitted by

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Abstract

Background

Many patients die in intensive care units within an intense medical treatment environment, and this situation can affect the quality of end-of-life care. Studies have reported that nurses may feel a sense of failure when their patient is dying, and can find the provision of end-of-life care emotionally difficult. Very little is known about this phenomenon in the Kingdom of Saudi Arabia, where multiple cultural influences may further influence end-of-life care provision.

Aim

The aim of this study was to explore nurses' perceptions of obstacles to the provision of end-of-life care in intensive care units in Saudi Arabia.

Method

A sequential explanatory mixed method design was used. This method included two phases: questionnaires and interviews. For Phase One a questionnaire developed by Beckstrand and Kirchhoff (2005) was modified and only data about obstacles were collected. For Phase One 87 questionnaires were returned from 140 potential respondents, representing a 62% response rate. In Phase Two, face-to-face interviews were conducted with four ICU charge nurses. The two phases were conducted in a major specialist hospital in Saudi Arabia.

Results

The Phase One findings highlighted concerns with patient's family, physicians who differed in opinions, cultural differences, and how language barriers affect communication. The nurses also suggested avoiding unnecessary care, the need for end-of-life care awareness, education and preparation were also issues. The Phase Two findings indicated concerns when family members did not understand the

patients' situations, lack of family support, cultural differences and language barriers. The nurses suggested the need for both end-of-life care awareness for nurses and increased involvement of nurses in decision-making. Education and preparation for dying patients and their family were also recommended by nurses.

Conclusion

The findings of this study show a number of obstacles to the provision of end-of-life care in intensive care units, which may affect nurses' ability to maintain quality end-of-life care. Therefore, the further development of both end-of-life care guidelines and nursing education about end-of-life care in intensive care units is recommended.

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List of Abbreviations

EoLC	End-of-life care
EoL	End of life
QoL	Quality of life
ICU	Intensive care unit / Intensive Care
CCU	Coronary care unit
KSA	Kingdom of Saudi Arabia
MoH	Ministry of Health
PICo	Population, Phenomena of Interest and Context
MeSH	Medical Subject Headings
UN	United Nations
PBUH	Peace Be Upon Him
JCI	Joint Commission International
DNR	Do Not Resuscitate

DECLARATION

This project/thesis/portfolio does not contain any material which has been accepted for the award of any other degree or diploma in any university and that, to the best of the candidate's knowledge and belief, the project/thesis contains no material previously published or written by another person except when due reference is made in the text of the project/thesis/portfolio.

Signed:

Date: 01/03/2016

Ethical approval for this research was granted by both the Standing Committee on Ethics in Research Involving Humans (SCERH) at Monash University on March 23 2015 (Project CF15/518 – 2015000245) and the hospital's Office of Research Affairs on April 19 2015 (Project ORA/0508/36).

Chapter One: Background

1.1 Introduction

Research suggests that large numbers of people die in hospital (Miller, Forbes, & Boyle, 2001), with as many as one in five Intensive Care Unit (ICU) patients amongst those dying (Angus et al., 2004). Nurses consider the ICU environment as a place of aggressive medical treatment where a large number of patients die (Calvin, Lindy, & Clingon, 2009; McCallum & McConigley, 2013). The ICU environment may affect nurses' abilities to maintain quality end-of-life care (EoLC) (Ranse, Yates, & Coyer, 2012; Valiee, Negarandeh, & Dehghan Nayeri, 2012). Aggressive medical treatment may also affect dying patients' quality of life (QoL) (Calvin et al., 2009). These issues may influence ICU nurses' experiences and how they meet the needs of dying patients. Since this phenomenon is very little discussed in the Kingdom of Saudi Arabia (KSA), this study was conducted to explore EoLC in ICU in the Kingdom of Saudi Arabia and consider areas where improvements may be made.

1.2 The Kingdom of Saudi Arabia

The Kingdom of Saudi Arabia (KSA), often referred to as Saudi Arabia, is known as an Islamic homeland (Mufti, 2000). King Abdul-Aziz Al Saud instituted the KSA in 1932 (Mufti, 2000). The King, the Committee of Ministers, and the Majlis Al Shura (Consultative Committee) have been substituted for the legislative and executive section of government (Mufti, 2000). The constitution is established in accordance with Shari'ah Law. All laws and rules are developed and then projected to a community of religious scholars to ensure that Islamic Shari'ah is considered accordingly (Majlis Al-Shura, 2015). Majlis Al Shura was established by King Abdul Aziz to develop the government's policy and solve population issues in accordance

with the Shari'ah, which is based on the Qur'an and Sunnah (Hadith) (Majlis Al-Shura, 2015).

The KSA has developed rapidly, particularly after oil was discovered in 1983 (Mufti, 2000). Due to the development of the oil industry, the socio-economic conditions have improved significantly (Mufti, 2000). As social and economic circumstances have improved, the population's birth rate has increased (Gallagher & Searle, 1985). Based on United Nations (UN) projections, the population of the KSA is expected to be 44.8 million by 2025 (Mufti, 2000). The total population of the KSA is 29,195,895, the annual population growth rate was 3.19 per cent between 2004 and 2010, and average life expectancy is 73.8 years (Ministry of Health, 2012).

The KSA is considered the most influential state in the Middle East because of its oil resources and, as such, it is the main force in the Arab countries (Walston, Al-Harbi, & Al-Omar, 2008). It occupies around 80% of the Arabian Peninsula, with a total area of approximately 2.24 million square kilometers (Mufti, 2000). It shares borders with Iraq, Kuwait, and Jordan to the north, the United Arab Emirates, Qatar, and Bahrain and the gulf to the east, Yemen and Oman to the south; and the Red sea to the western frontier (Mufti, 2000).

1.3 Health care system in the Kingdom of Saudi Arabia

The health care system in the KSA includes public, private, and military health care services. The Ministry of Health (MoH) has the responsibility for health care services in the KSA and is the largest provider of publication funded health care services (Al Mutair, Plummer, O'Brien, & Clerehan, 2014). Health care is provided by an incorporated system that is managed at national and regional levels and there is also private sector healthcare (Al Mutair et al., 2014). The MoH is also responsible for

health planning and policy (Ministry of Health, 2012). The Minister of the MoH is responsible for the administration of 19 health regions in the KSA (Ministry of Health, 2012). Every health region has a general directorate, responsible for all hospitals, health care centres, technical equipment and staff (Al-Yousuf, Akerele, & Al-Mazrou, 2002).

The MoH is a government agency and the primary health care provider, offering 63% of the total hospital beds and 60% of health services in the country (Al-Yousuf et al., 2002). There are 259 MoH hospitals and 2,259 primary health care centres, and a total of 35,828 hospital beds (Ministry of Health, 2012). The MoH hospitals have 82,948 nurses, 45,875 of whom are Saudi nationals, which represents 55.3% of the total nursing workforce (Ministry of Health, 2012). Primary health care centres serve the community and hospitals serve as referral centres (Ministry of Health, 2012). The MoH workforce includes Saudi staff and many non-Saudi staff who are recruited from Arab and Muslim countries or from other countries such as India, the Philippines, and many Western countries (Al Mutair et al., 2014).

The health care system in the KSA includes both government agencies and private agencies (Almalki, Fitzgerald, & Clark, 2011). The main government agency is the MoH and other governmental health provider agencies include the King Faisal Specialist Hospital and Research Centre, the National Guard Hospital, and the Ministry of Higher Education Hospital (a teaching hospital) and other referral hospitals (Almalki et al., 2011). These other government agencies have 11,043 hospital beds and employ 28,380 nurses, 3,820 (13.5%) of them being citizens of the KSA. In the private sector, there are 137 hospitals with a total of 14,165 beds, 2,168 private sector dispensaries, and 198 private clinics. The total number of nurses

employed in the private sector is 28,373, of whom 3074 are Saudis (Ministry of Health, 2012).

1.4 Intensive care units in the Kingdom of Saudi Arabia

An intensive care unit (ICU) is defined as an area in the hospital where patients need frequent attention, monitoring, and intervention (Arabi & Al Shimemeri, 2006). Intensive care units (ICUs) are an essential part of the health care system, but statistics about ICU capacity and services in the KSA are scarce. The demand for ICU services is increasing due to the ageing community, the treatment of previously incurable diseases, and surgeries or therapies that require intensive care (Al-Omari, Abdelwahed, & Alansari, 2015). The ICU mission includes maintaining human values and the wellbeing of patients with acute illness or injury, utilising rehabilitative care when the patient begins to recover, and providing empathetic care to dying patients and their families (Arabi & Al Shimemeri, 2006). However, the function and structure of ICUs differ considerably among hospitals (Arabi & Al Shimemeri, 2006).

The ICU structure in the KSA hospitals can be considered on three different levels (Arabi & Al Shimemeri, 2006). Primary care hospitals have small ICUs with little equipment. The nursing and medical staff have some ICU knowledge and training, but they usually have not had ICU education (Arabi & Al Shimemeri, 2006). Secondary care hospitals have larger ICUs, which are better equipped than primary care hospital ICUs and include general and neonatal ICUs. Usually, these ICUs are managed by ICU physicians, but the patients' treatment is provided by non-ICU-trained medical staff (Arabi & Al Shimemeri, 2006). Tertiary care hospitals usually have different speciality and well-structured ICUs. These include medical-surgical, neonatal, paediatric, burns, coronary care, and cardiovascular units. These ICUs are usually run

by physicians who are certified by a North American or European Critical Care Board. ICU nurses are well trained, with North American or European qualifications (Arabi & Al Shimemeri, 2006). The performance of tertiary hospital ICUs in the KSA are well functioning and potentially similar to industrialized countries units function (Al-Omari et al., 2015). Commonly, ICU nurses in the KSA come from different countries and multicultural backgrounds due to a shortage of nurses (Arabi & Al Shimemeri, 2006).

Nurses play a significant role in ICUs, but their responsibilities differ among hospitals and health care systems (Bersten & Soni, 2009). The American Association of Critical Care Nurses [AACN] (2015) defines the critical care nurse as a "licensed professional nurse who is responsible for ensuring that acutely and critically ill patients and their families receive optimal care" (para. 1). The responsibilities of ICU nurses include obtaining a patient history, physical examination, treatment, advocacy and education of patients to improve their health (Camelo, 2012). ICU nurses need to assess and evaluate patients' needs by applying a holistic approach to care, which incorporates the physical, psychological, spiritual and emotional aspects of care (Dawson, 2008).

1.5 Religion and Culture in the Kingdom of Saudi Arabia

The religion and culture in the KSA is based on the Qur'an and Sunnah (Hadith), which is the narrative of the prophet Mohamed (Peace Be Upon Him; PBUH). The main religion in the KSA is Islam. The basic duty of Muslims is to submit and be obedient to Allah (God) and His law (Omar & Allen, 1996). The Qur'an is the last issued word of Allah that was brought in Arabic by the Archangel Gabriel to the Prophet Mohammed (PBUH) (Omar & Allen, 1996). Allah said, "Verily, we have

sent it down as an Arabic Qur'an in order that you may understand" (Qur'an 12/3).[2]

The primary foundation for all Muslim knowledge is the Qur'an (Omar & Allen, 1996) and secondary in significance is the Sunnah (Hadith). This second source is retrieved from the prophet Mohammed's sayings, or Hadith, that represent the collection of the prophet's traditions, action, sayings, and his tacit approval of what was done or said during his life (Kamali, 1991).

The prophet Mohammad (PBUH) brought the message of the Allah, providing his people the best guidance and advice. This message supports Muslim scholars, as they inherited the light of knowledge of the Prophet after he died. The knowledge is passed from one generation to the next by Islamic scholars by teaching and leading the people to the righteousness of the Islamic religion (The General Presidency of Scholarly Research and Ifta, 2015a).

Some senior Muslim scholars in the KSA set up the Board of the Permanent Committee for Scholarly Research and Ifta. This committee includes senior scholar members from the KSA. The senior Muslim scholars give Ifta (Fatwa is the singular word of Ifta) based on the Qur'an and Sunnah (The General Presidency of Scholarly Research and Ifta, 2015a). The Fatwa is defined as an authorised opinion provided by Islamic law specialists for a particular issue. Many Fatwas have been set by these senior Muslim scholars to solve their peoples' issues (Black, Esmaeili, & Hosen, 2013).

It is estimated that 100% of Saudi citizens identify as Muslims, but there are different religious cultural groups, such as most of them Sunnah and the rest is Shia. Although

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[2] The Qur'an, (1989). Surah Yousuf, (12/3). (Arabic version, Translated by Yusuf Ali) Saudi Arabia: The Holy Qur'an Complex in Madinah.

the Islamic culture may differ between groups, they share commonalities as well as differences in practices, beliefs, and norms. Furthermore, they may become conservatives, traditionalists or liberals (Peachy, 1999). In the KSA the Qur'an is the highest authority resource for Islamic information, followed by the Sunnah (Peachy, 1999).

The purpose of Islam focuses on the entire human being's life, including principles, knowledge, worship, transactions and law. Islam gives strategies and guidance for society, human behaviour, and an equitable economic system (Searle & Gallagher, 1983). In Islam, it is believed that life is a journey to a particular location, either safe (Heaven) or unsafe (Hell). Islam provides guidelines that are present in Muslims' minds during their life. The ultimate goal of Muslims is to be in Heaven (Searle & Gallagher, 1983). Thus, faithful Muslims consider the guidance of the Qur'an and Sunnah for their life habits and actions to reach the ultimate goal, which is to be in Heaven, because they are always conscious that they can die at any time and they should be well prepared for the hereafter (Searle & Gallagher, 1983).

In Islam, practices, values, and morals are an inseparable aspect of Saudi culture. The teaching and practice of Islam for Saudi people can help inform their social behaviour of how to be a Muslim (Al-Shahri, 2002). Islam incorporates the spiritual, intellectual, and material, and also covers all knowledge, scientific, moral, and value obligations in Saudi people's lives. Education level, environmental factors and financial status can affect the culture of individual Saudis (Al-Shahri, 2002; Searle & Gallagher, 1983).

1.6 Muslims Dying in Hospitals

Nurses help Saudi patients to meet their spiritual needs by allowing them to pray. They pray five times a day and sometimes ask nurses to wake them up for prayer

(Halligan, 2006). Due to their deep faith, they believe everything will happen according to the will of God (Halligan, 2006). This means that Muslims believe that all things, good or bad, must be accepted with thanks by saying *Alhamdulillah* 'All praise be to God'. However, this situation may frustrate non-Muslim nurses, particularly when they feel that patients do not fully depend on nurses' care (Halligan, 2006).

When a Muslim dies, there are certain customs that should be observed if at all possible. It is ideal to position the person who has died in a way that allows them to face toward Makkah (Al-Alaiyan & Al-Hazzani, 2009). Makkah (Mecca) is a sacred place for Muslims and it is the place Muslims face during prayers (Netton, 2013). However, it is sufficient to turn the patient's face to the right side in hospital. Further, the person's mouth and eyes should be closed, their arms and legs straightened, and a sheet should cover their body (Al-Alaiyan & Al-Hazzani, 2009; Contro, Larson, Scofield, Sourkes, & Cohen, 2004).

A study has identified aspects considered to contribute to the quality of a Muslim death (Tayeb, Al-Zamel, Fareed & Abouellail, 2010). Three domains were identified, including faith and beliefs, a patient's self-esteem, and thinking of the family's financial status (Tayeb et al., 2010). In the Muslim faith, beliefs and preferences in the dying process include being sure there is someone to prompt the patient with (Shahadah) "bearing witness that there is no true God but Allah and Muhammad is verily His Servant and His Messenger" (Tayeb et al., 2010, p. 7), as the last statement of faith. The presence of somebody to recite chapters of the Holy Qur'an at the bedside and to place the dying person in a position facing Meccah is important (Tayeb et al., 2010).

A patient's self-esteem domain includes avoiding distortion after death, such as through septic wounds, deformities, and bad smells. Keeping the clothes and body free of stool, urine, and vomit, and ensuring that the body appears normal after death, are therefore important (Tayeb et al., 2010). This domain considers the patient's self-esteem and their image in front of their relatives and their friends (Tayeb et al., 2010).

Thinking of the family's financial status involves the patients' family income and their situation. To reduce patient concern they need to feel that their family will be safe and have no issues after he or she has died. This primarily concerns the economic and social aspects of life (Tayeb et al., 2010).

Saudi families are committed to supporting their family members, and Saudi Muslim families have strong ties with their neighbours and friends. This means that families, neighbours and friends will visit the sick and dying as a way of supporting them (Khan, 1994). Visiting those who are sick is highly regarded in the Islamic culture in the KSA (Khan, 1994). Therefore, a hospitalized person can expect a large number of visitors (Al-Shahri, 2002).

1.7 End-of-life care

Critical care polices do not clearly promote EoLC or palliative care approaches, leaving ICU nurses without a clear approach to caring at this stage of illness (Efstathiou & Clifford, 2011; Pattison, 2006). ICU nurses frequently encounter issues with providing EoLC and meeting the patients' needs. Therefore, the role of ICU nurses in providing EoLC should be improved (Aldawood et al., 2012).

The availability of facilities and the approach to care in the KSA is determined by policies and regulations. The General Presidency of Scholarly Research and Ifta set a

group of Fatwa that concern medical issues and regulations regarding the care of sick patients (The General Presidency of Scholarly Research and Ifta, 2015a). Some Fatwas identify medical rules regarding dying and withholding technical life support in the KSA, which can be used by Muslims (The General Presidency of Scholarly Research and Ifta, 2015b). For instance, one Fatwa states that if the specialist physician considers that giving medication to a patient is more beneficial than harmful to their condition, it is legal to continue the treatment, even if there is only a temporary impact (The General Presidency of Scholarly Research and Ifta, 2015b). Another Fatwa clarifies that if three specialist physicians or more agree to withhold technical life support in cases where patients are incapacitated and their condition incurable, their decision is permissible, even though they may live longer (The General Presidency of Scholarly Research and Ifta, 2015b). However, it is not permissible to consider a patient is dying unless the signs of dying are clearly present (The General Presidency of Scholarly Research and Ifta, 2015b). Therefore, these policies and regulations need to be considered by physicians when providing decision-making for critically- ill patients in the KSA.

An observation study conducted in a medical-surgical ICU of a teaching hospital in the KSA during one year estimated that of every1000 patient admissions, 176 died, 135 after EoLC decisions were made and 41 when they were on life support (Aldawood et al., 2012). Patients receiving EoLC stayed in the ICU longer than those receiving aggressive treatment (six versus three days). Therefore, the quality of life (QoL) for patients who have EoLC concerns in ICUs needs to be considered (Aldawood et al., 2012). However, another study found that it is not easy to measure QoL, because patients' experiences of their life are different and individualised (Randall & Downie, 2006).

It is suggested that enhancement of QoL can be viewed as optimising health, including psychological, physical and emotional well-being (Randall & Downie, 2006). QoL is a fundamental aim of the palliative care approach to care (Randall & Downie, 2006). Therefore, palliative care is focussed on "the relief of pain and other symptoms; the maximisation of physical functioning; and the provision to patients of the information they seek about their illness, in order to take part in decisions and lessen emotional distress" (Randall & Downie, 2006, p. 48).

The difference of intent between the terms palliative care and EoLC is that EoLC is an approach provided for patient's final days or hours and palliative care is the care provided for patients who have an illness no longer amenable to cure, but may not be in the final days of life. EoLC is the last phase of palliative care. (Lewis, 2013). Therefore, identifying the shift in the goal of care at the end of life (EoL) can guide nurses in providing appropriate care for dying patients and their families (Reinke et al., 2010).

A study defined EoLC as ''to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages'' (Izumi, Nagae, Sakurai, & Imamura, 2012, p. 616). EoLC is focused on the physical, psychological, and spiritual needs of dying patients and their families (Lewis, Heitkemper, & Dirksen, 2007). Meeting the dying patient's needs and improving their quality of life are important in EoLC (Lewis et al., 2007).

1.8 Significance

Ifta in the KSA supports policies and regulations, based on the Qur'an and Sunnah, relating to patients' concerns about decision-making at the end of life in the ICU. Studies in other countries indicated that many patients are dying in an ICU, within an aggressive medical treatment environment, the situation can cause stress for the ICU nurses and affect the quality of EoLC. Nurses can feel a sense of failure when their patient is dying, and can find providing EoLC emotionally difficult. Very little is known about this phenomenon in the KSA, where multiple cultural influences may further influence EoLC provision. This study can help to identify nurses' perceptions of obstacles in providing EoLC in the KSA, thus contributing to improved EoLC nursing care in the ICU, increased nursing and research knowledge and the development of organisational policies to support ICU nursing practice.

Chapter Two: Literature Review

2.1 Introduction

This chapter outlines the literature related to this study. Studies that focus on nurses who provide end-of-life care (EoLC) in intensive care units (ICUs) were reviewed. The Population, phenomena of Interest and Context (PICo) (Schneider, Whitehead, LoBiondo-Wood, & Haber, 2013) was used to determine the research question, by identifying that the population includes nurses from ICUs, the phenomenon of interest is nurses' perceptions of providing EoLC, and the context is adult ICUs (refer to Table 1).

Table 1.

Population, phenomena of Interest and Context development in this study

Population	phenomena of Interest	Context
ICU nurses	Perceptions of providing EoLC	Adult ICU

Medical Literature On-Line (Medline) and The Cumulative Index to Nursing & Allied Health (CINAHL) are reputable databases for nursing researchers to access, as most of the source material is peer-reviewed (Polit & Beck, 2012). These two databases were used for reviewing the published studies that were congruent with the research question.

Medical Subject Headings (MeSH) terms and key terms associated with the study PICo were used. The selected MeSH terms that were used for the search included "nurses", "terminal care", "intensive care unit" and also the selected key terms "nurses perception" and "end of life care". All these terms were used to search in both MedLine and CINAHL.

2.2 Inclusion and exclusion criteria

The database search inclusion criteria included primary resources, peer-reviewed journals, nursing field and adult ICU. Other articles out of those criteria were excluded. Searches in databases were processed, titles and relevant abstracts were read and then the full texts of a total of 42 studies were thoroughly read. Further, the reference lists of the selected articles were screened and the full texts of relevant abstracts were examined. The articles related to the study's PICo were labelled in a Word file, and the selected articles were examined in accordance with the inclusion criteria. Eleven articles met the inclusion criteria (Figure 1) and their findings are summarised in the following sections.

MedLine and CINAHL databases

Full texts of 42 articles were examined

Thirty-one articles did not meet
the inclusion criteria

Eleven articles met
the inclusion criteria
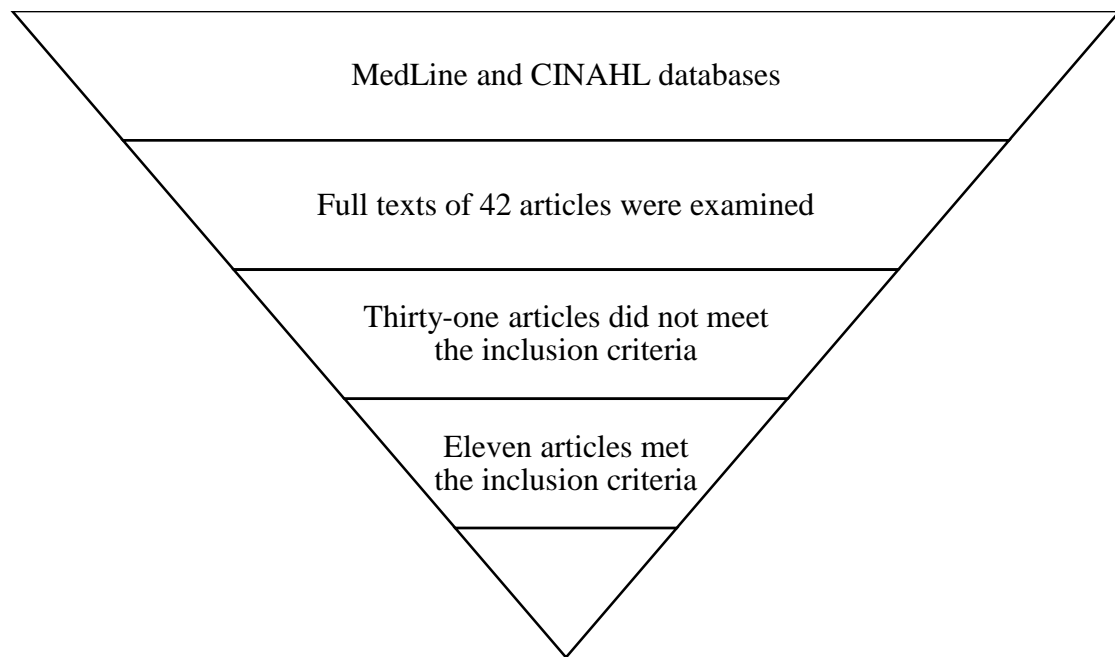
Figure 1. *Literature review flow diagram.*

2.3 Emotional stress

ICU nurses may become emotionally stressed by feelings of helplessness, frustration, anger, and sadness when providing EoLC (Holms, Milligan, & Kydd, 2014; Valiee et al., 2012). Daily exposure to critical illness and traumatic injuries in the ICU can cause nurses emotional stress compared to other workplaces (Ranse et al., 2012). Nurses further described concerns when they were unable to administer opioid medications to keep critically-ill patients comfortable because it led to respiratory depression (Espinosa, Young, Symes, Haile, & Walsh, 2010).

Sometimes the EoLC of patients is steeped in uncertainty due to the unpredictability of the course of dying, and this can create feelings of helplessness, confusion, and emotional stress for nurses and families (Calvin, Kite-Powell, & Hickey, 2007). Nurses expressed different feelings about the realisation of EoLC (Calvin et al ., 2007). For instance, more medical intervention is used for survival purposes in the ICU, but from the other perspective, death with dignity considers alleviating pain and

suffering rather than extending life (Calvin et al., 2007). Some nurses felt the difficulty of providing psychological, emotional, and physical care when moving from curative to comfort care (Calvin et al., 2007). They expressed feelings of sadness and thoughts about their own life and death experiences (Calvin et al., 2007). However, it was found that ICU nurses do not express the same feelings regarding EoLC (Calvin et al., 2007). Some nurses are better at EoLC, but sometimes experience emotional distress or situations in their personal lives that may influence their provision of EoLC (Espinosa et al., 2010). Nurses may turn off or become hardened and it is preferable that these nurses do not provide EoLC (Espinosa et al., 2010).

Nurses witnessing patients' and their families' suffering and pain at the end of life (EoL) may become emotionally stressed. Further, watching families grieving and making EoLC decisions may become emotionally painful. The powerlessness that patients' families and health care providers feel in the face of a patient's impending death may be similar (Calvin et al., 2007). Providing EoLC may impact on nurses' own perceptions of the hereafter and life after death (Valiee et al., 2012). This stress may be related to lack of experience and training in EoLC, poor communication, and inconsistency in practice in the ICU environment (Holms et al., 2014).Therefore, it seems that caring for critically ill patients and EoLC are difficult and need advanced practice skills (Ranse et al., 2012).

2.4 Lack of nurses' involvement

Nurses frequently express a desire to be involved in patients' plans of care. Physicians often do not involve nurses in decision-making regarding patient care when nurses believe that they knew the patient best (Espinosa et al., 2010). The most common areas causing stress are different EoLC decision-making among physicians, and

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nurses' lack of involvement in EoLC decision-making (Holms et al., 2014).

Therefore, nurses' limited role in decision-making, particularly regarding withdrawal or withholding of medical life support, may cause frustration (Espinosa et al., 2010).

Nurses appear to prefer a holistic model of providing EoLC in ICUs, whereas physicians appear to focus on illness and treatment (Espinosa et al., 2010). These two different models of care may cause conflict or miscommunication and have an impact on the provision of EoLC (Espinosa et al., 2010). Patients in ICUs are often managed by several specialist physicians, each potentially focused on a particular organ system or symptoms (Espinosa et al., 2010). Sometimes these specialists disagree regarding the patient's prognosis (Espinosa et al., 2010). Therefore, EoLC decision-making surrounding patients' prognosis involves uncertainty and ambiguity (Ranse et al., 2012). Nurses may view this ambiguity as a barrier to delivering optimal EoLC (Espinosa et al., 2010).

2.5 Providing unnecessary care

Patients with poor prognoses may receive unnecessary care without any progress, rather than comfort care (Calvin et al., 2007). Nurses may become stressed because they are expected to provide non-beneficial or unnecessary care (Meltzer & Huckabay, 2004). ICU nurses experience emotional stress when providing unnecessary care and may feel as if this care is torturing patients (Badger, 2005). The nurses who were interviewed perceived that unnecessary care was misery prolonging instead of comfort care (Badger, 2005). Nurses indicated concern when continuing medical interventions for dying patients were implemented to prevent natural death (Badger, 2005). Nurses also found that although technology can keep patients alive longer, QoL rather than length of life can become an issue (Badger, 2005).

2.6 Communication

Communication is a common theme in the research literature in relation to EoLC. Research shows that nurses can facilitate communication between the patient's family and physicians. Good communication helps to clarify the plan of care to make it more understandable and acceptable to all (Calvin et al., 2007). Furthermore, conversation between nurses and the patient's family can help to clarify and verify patient wishes for EoLC (Calvin et al., 2007).

When communication breaks down between health care providers, patients and families, it can influence the information received and EoLC practice, particularly the decision to withdraw or withhold treatment (Holms et al., 2014). For instance, Badger (2005) found that facilitating communication between medical staff and families can become difficult in clinical situations, particularly when the medical staff talk honestly about the outcome of the patient's condition. In this situation, it can be most challenging for nurses trying to reconcile the patient's advance directive or patient and family wishes (Calvin et al., 2007).

2.7 End-of-life Care Education

Education is a common theme in the research in relation to EoLC. A study indicated that no policy or protocol for EoLC was identified in the study site and noted that organisational support for EoLC was needed (Ranse et al., 2012). Nurses interviewed in a 2010 study identified a desire for clear protocols or guidelines for EoLC (Espinosa et al., 2010). ICU nurses stated that they have very little education and training on EoLC, particularly in the ICU. EoLC skills are learned through good and bad experiences and also from watching their colleagues (Holms et al., 2014). In their research, Calvin et al. (2009) found that experienced nurses supported novice nurses

in providing EoLC. Novice nurses experienced discomfort or fear of dealing with dying and death or talking with family members (Ranse et al., 2012). Nurses claimed that education and training in how to communicate with the patient's family were desirable (Ranse et al., 2012). Although experienced ICU nurses provide guidance for junior nurses, it sometimes does not adequately address the complexity of EoLC (Ranse et al., 2012). Nurses desire to relieve patients' suffering and create good memories for the family during the end of the patient's life (Espinosa et al., 2010).

2.8 The ICU Environment

The ICU environment may be inconsistent with EoLC, because it is noisy and not the ideal place for dying patients and their families. When the ICU is crowded and noisy, nurses need to be aware of the dying patients in the unit (Holms et al., 2014). Such a physical environment is considered a major challenge to providing EoLC for dying patients and their families. For instance, when a patient has died in the ICU and there are other patients waiting for the bed, it becomes a stressful situation for nurses because they are under pressure to free up the bed. Therefore, the structure, capacity and purpose of ICUs needs to be considered (Fridh, Forsberg, & Bergbom, 2009).

The ICU environment is considered as a curative care area rather than a comfort care area. There are also issues in ICUs, identified by nurses, which are challenging and painful to deal with, such as distressed families' reactions (Valiee et al., 2012). In addition, the provision of EoLC in ICU may be impacted by nurses' own perceptions of life after death (Valiee et al., 2012). Lack of time to attend to consideration of these important issues can affects nurses' attention to how they are able to cope with their own experiences (Calvin et al., 2007).

Lack of private rooms may be considered an obstacle, because it is difficult to create privacy for patients' families in ICUs. This restricts both the presence of family members at the bedside and limits the family's chance to fully express their sorrow (Fridh et al., 2009). Therefore, private rooms allow relatives and friends to sit with the patient and create a calm and peaceful environment (Fridh et al., 2009; Ranse et al., 2012). This also relieves other patients and families from being inadvertently exposed to dying patients and their families (Ranse et al., 2012).

Modifying the bedside environment and creating a peaceful setting for dying patients and their families in the ICU should be considered (Ranse et al., 2012). Some minor changes can create a peaceful and dignified bedside scene. For example, reducing the noise level in the unit when the grieving family is present can make a difference (McClement & Degner, 1995). Sometimes the lack of a private room leaves patients' families waiting in the corridor or other crowded areas (Fridh et al., 2009).

2.9 Caring for the Dying Patient

Ranse et al. (2012) found that comfort care should be considered for dying patients. Comfort care focuses on emotional, psychological, and physical comfort for dying patients and their families. Comfort care includes such things as hair care, bathing, mouth care, spiritual care, pressure area care, and administering pain relief (Ranse et al., 2012). Despite the difficulties and challenges of EoLC, nurses feel the privilege and worthwhile nature of providing this care (Calvin et al., 2007). Some nurses find it gratifying to help patients die with dignity and free of pain and other symptoms (Calvin et al., 2007).

As previously stated, nurses consider providing holistic care and being supportive as important (Calvin et al., 2007; Valiee et al., 2012). This includes acting as advocates

for their patients and meeting their needs (Calvin et al., 2007; Valiee et al., 2012).

However, when the patient's prognosis is poor, a nurse's own spirituality may lead

them to extend their care and sometimes they pray for their patients (Calvin et al.,

2007).

Calvin et al. (2007) found that nurses can facilitate the transition from cure to

palliation by clarifying with family members that aggressive treatment is not working

to cure the patient or is not having the desired outcome. This includes being honest

without dashing all hope, respecting and showing empathy for patients and family

members who express anger; understanding the reasons for the anger and not taking it

personally (Calvin et al., 2007). Thus, nurses who are unable to manage anger

reactions need to learn how to find solutions in order to avoid frustration and manage

their interaction with patients and families (McClement & Degner, 1995).

Some coping strategies mentioned by ICU nurses include conversations between

nurses about their experiences as a significant source of assurance and support.

Several nurses also found that they often cried with the family while delivering EoLC

(Espinosa et al., 2010). The nurses felt that it helped the family and other staff

members to cope with loss of the patient. A study has also indicated that sometimes

using humour in specific patient conditions is useful (Espinosa et al., 2010).

Developing strategies to manage EoLC situations should be considered for ICU

nurses (Calvin et al., 2007)

For the sake of the patient, ICU nurses appreciate the presence of the family. The

presence of family members can support nurses to prepare the family to accept the

patient's deteriorating condition (Calvin et al., 2007). Responding to the family's need

for information is important, because sometimes family members can be frustrated

when health professionals do not meet their need for information, particularly when the patient's condition becomes unstable (Calvin et al., 2007). Moreover, supporting the family to accept the reality of death is important. This can be achieved by giving information about funeral arrangements, allowing family members to remain with the body, showing respect for the deceased by being unhurried, and handling the body gently (McClement & Degner, 1995) and according to cultural requirements.

Nurses describe the tragic situation that occurs when an unaccompanied patient dies and sometimes nurses act as professionals and fellow human beings at the same time (Fridh et al., 2009). The nurses in this study felt that an unaccompanied patient should be cared for with warm and compassionate care in a similar way that other patients, whose family members are present, would receive (Fridh et al., 2009).

2.10 Perceptions of Obstacles in Providing End-of-life Care

Three key obstacles to providing EoLC, different physicians with various opinions and plans of care; friends or family members who frequently ask nurses for updates about the patient's status rather than the designated contact person; and physicians who are evasive with the patient's family were identified by Beckstrand and Kirchhoff (2005). Other highlighted obstacles include patients' families who do not understand the meaning of lifesaving measures, anxious family members, denying the patient's poor prognosis, and families wanting continuing life-sustaining measures even though the patient is dying (Beckstrand & Kirchhoff, 2005). Another study that used the Beckstrand and Kirchhoff (2005) questionnaire found similar family concerns in EoLC (Crump, Schaffer, & Schulte, 2010). The highest obstacles include family and friends who continually ask for updates, family members not understanding what lifesaving measures mean, poor ICU design, dealing with angry

family members and family members not accepting the patient's situation (Crump et al., 2010). Other highlighted obstacles include family members requesting different care plans, nurses who do not know the unconscious patient's wishes, dealing with distraught family, continuing painful treatments for dying patients, and disagreements between family members regarding treatment plans (Crump et al., 2010).

2.11 Conclusion

Many patients are dying in an ICU within an aggressive medical treatment environment and this situation may be similar in KSA. This can affect the quality of EoLC and cause stress for the ICU nurses. Nurses can experience emotional distress when their patient is dying and can find providing EoLC emotionally difficult. This focus means that accepting a person may be dying and providing EoLC can be challenging for nurses. The EoLC phenomenon in ICU in the KSA is not well researched, but there is some research about nurses' concerns about obstacles that can hinder the quality of EoLC in the ICU generally. Therefore, a study of ICU nurses' perceptions of obstacles in providing EoLC in ICUs specific to the KSA can contribute to knowledge of the phenomenon in that region. It is hoped that this study may support and improve EoLC policy in the KSA.

Chapter Three: Method

3.1 Introduction

The literature review chapter examined what is known about end of life care (EoLC) in ICUs and highlighted the lack of research available about EoLC in Saudi Arabian ICUs. This chapter outlines the methodological approach taken to study the phenomenon in this research. Mixed method and how it was used in this study were described in the following details.

3.2 Aim

The aim of this study is to explore ICU nurses' perceptions of obstacles to the provision of end of life care in the KSA.

3.3 Mixed method development

The study uses a mixed methods approach to explore the phenomenon in the KSA. Mixed methods is an appropriate approach for this study because it includes the collection and analysis of data from both qualitative and quantitative approaches, from either one or multiple studies (Creswell & Plano Clark, 2011). This method has been used for the past 50 years (Creswell & Plano Clark, 2011) and the use of mixed methods designs has increased in recent years (Andrew & Halcomb, 2009). Some researchers consider the mixed-method approach the third major research method (Burke Johnson, Onwuegbuzie, & Turner, 2007; Creswell & Plano Clark, 2011). A mixed-method design uses a combination of both quantitative and qualitative approaches to investigate the study's phenomena in depth (Creswell & Plano Clark, 2011).

Designs of a mixed-method approach can be used sequentially or simultaneously (Creswell, 2009). There are three possible sequences used in mixed methods designs: collecting data in the qualitative phase first, collecting data in the quantitative phase first, or collecting data in both phases simultaneously (Polit & Beck, 2012). The most common mixed methods designs include convergent parallel design, sequential explanatory design, exploratory sequential design, embedded design, transformative design and multiphase design. Every design has own procedures and guidelines (Creswell & Plano Clark, 2011). Different mixed methods design strategies can give researchers many options to find the appropriate design for their study (Creswell & Plano Clark, 2011).

3.3.1 Philosophical paradigm

A paradigm is identified as the sum of shared views and practices that direct the scope of inquiry (Morgan, 2007). There are competing opinions expressed in the literature about paradigms of mixed methods research. One view is that constructivist qualitative and positivist quantitative paradigms have different ontological views and it can be difficult to combine them (Sandelowski, 2000). Another view argues that mixed methods might become the third paradigm because it combines quantitative and qualitative approaches (Burke Johnson et al., 2007). However, using multiple paradigms can help researchers to gain further knowledge from different perspectives. This knowledge, from multiple paradigms, can expand nursing knowledge for practice (Leddy, 2000; Weaver & Olson, 2006).

The pragmatic paradigm focuses on advantages of the research outcome rather than the research method process (Creswell & Plano Clark, 2011). Pragmatism argues that outcomes are more essential than the method, indicating that using quantitative and

qualitative approaches can strengthen the outcome from two perspectives and more fully answer the research question (Burke Johnson & Onwuegbuzie, 2004). The pragmatic paradigm depends on abductive reasoning that seeks data from both induction through qualitative methods, and deduction using quantitative approaches as needed (Morgan, 2007). Therefore, abductive reasoning in the pragmatic paradigm is commonly utilised by researchers who conduct a sequential mixed method study (Morgan, 2007).

3.4 Mixed methods strengths and weaknesses

Mixed method studies have weaknesses and strengths. The most common weakness in mixed methods is that it is time-consuming (Hesse-Biber, 2010) and researchers need to learn more about simultaneous mixed methods to apply it effectively (Greene, 2007). However, using mixed methods sequentially is useful, because phase one results may influence the design of phase two (Hesse-Biber, 2010). As quantitative and qualitative approaches each have their own weaknesses and strengths, combining them can help to overcome the weaknesses of each (Creswell & Plano Clark, 2011). The use of a mixed methods design, to explore nurses' perceptions of obstacles of providing EoLC in ICU in KSA, helps to give a deeper understanding of the study phenomena (Creswell & Plano Clark, 2011). Using a mixed methods approach was thought most suitable to facilitate a richer understanding of the study phenomena, as opposed to using only one approach (Creswell, 2009). Johnson and Onwuegbuzie (2004) explore some of the strengths and weaknesses of mixed methods. A summary of these strengths and weaknesses is presented in Table 2.

Table 2

Mixed methods strengths and weaknesses

Strengths	Weaknesses
Words can give meaning to numbers and number can raise the accuracy of the words.	It can be difficult for one researcher to conduct mixed methods simultaneously.
It gives robust evidence by convergence and corroboration of results.	Researchers should know more about mixed methods and how to use them appropriately.
It raises understandings that are perhaps missed if only one method is utilised.	Expensive and time-consuming.
It can enhance the generalizability of the findings	
It provides comprehensive knowledge that supports theory and practice	

Adapted from Johnson and Onwuegbuzie (2004).

3.5 Study design

In this study, a sequential explanatory design (refer to Figure 2) was used, in which the first phase of data collection was quantitative in nature, followed by qualitative data collection (Creswell & Plano Clark, 2011). The analysis of quantitative results can enhance understanding of important issues and further qualitative research can explain those important quantitative components in more depth (Ivankova, Creswell, & Stick, 2006). The qualitative phase complements the quantitative phase by exploring the study phenomena from another perspective (Creswell & Plano Clark, 2011). Creswell and Plano Clark (2011) suggest that this design is straightforward because it implements two procedures in separate phases, that is sequentially, and only gathers one kind of data at a time.

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          │     collection      │
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          ┌─────────────────────┐
          │   Qualitative data  │
          │      analysis       │
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          │ Integration of results│
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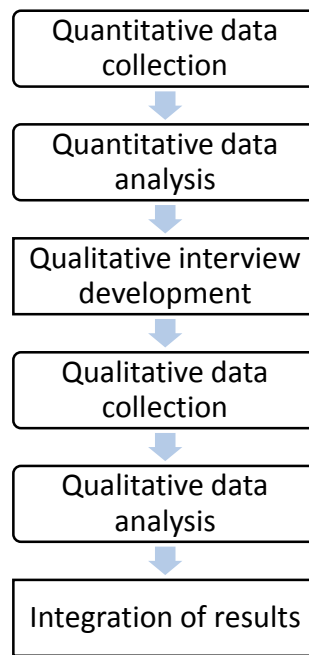
Figure 2. *Sequential explanatory design adapted from Creswell and Plano Clark (2011)*

A sequential explanatory design was used in this study. The first step of this design was the collection of quantitative data, followed by the analysis of the data. The important components of the analysed quantitative data were used to develop qualitative interview questions. The interview data were then collected and analysed. Finally, the results of both quantitative and qualitative data were integrated (Creswell & Plano Clark, 2011).

3.6 Setting

The study was conducted in the major specialist hospital in the KSA. The hospital is a government organisation that aims to provide high quality specialised healthcare services for the people of SA, with a secondary focus on education and research (XXXXXXXXX, 2015). The major hospital is a 936-bed hospital and is considered to be one of the leading hospitals in SA (XXXXXXXXX, 2015). The Joint Commission International (JCI) and the American Nurse Credentialing Centre Magnet designation

also accredit the hospital (XXXXXXXXX, 2015). The total number of adult ICU beds in the hospital is 129 (Ibrahim, personal communication, May 14, 2015). There are six separate ICUs, one for medical patients, two with a specific focus on chronic medical, haematological and oncological conditions, a surgical ICU, a cardiothoracic surgical ICU and a cardiac medical ICU (Ibrahim, personal communication, May 14, 2015).

3.7 Phase One: Quantitative questionnaire

There are disadvantages associated with the use of questionnaires, including the reliance on people being honest in the data they provide and ensuring the security of the data (Jirojwong, Johnson, & Welch, 2011). Despite their disadvantages, a major advantage of a questionnaire over other methods of data collection is that questionnaires are an effective and efficient way of collecting self-reported information from participants (Jirojwong et al., 2011). Moreover, questionnaires are appropriate for gathering certain forms of accurate and descriptive data (De Vaus, 2014).

3.7.1 Questionnaire Development

The Beckstrand and Kirchhoff (2005) questionnaire was created to evaluate nurses' perceptions of the intensity and frequency of obstacles and helpful behaviours in providing EoLC to patients and their families in ICU. This questionnaire is well known and a number of studies have been conducted around the world utilising it (Attia, Abd-Elaziz, & Kandeel, 2013; Beckstrand, Collette, Callister, & Luthy, 2012; Beckstrand & Kirchhoff, 2005; Beckstrand, Moore, Callister, & Bond, 2009; Losa Iglesias, Pascual, & Becerro de Bengoa Vallejo, 2013). The questionnaire contains 72 items, of which 29 relate to obstacles to EoLC, 24 relate to supports for EoLC, fifteen are demographic questions designed to elicit participant demographic information and

four are open-ended questions (Beckstrand & Kirchhoff, 2005). Two open-ended questions enable participants to provide additional information on obstacles and supports for EoLC in the ICU, another asks participants about aspects of EoLC they would change and the last question enabled participants to provide further comment (Beckstrand & Kirchhoff, 2005).

Reliability

The internal consistency of the questionnaire was measured with a Cronbach α of .89 for the 29 items that related to 'obstacle intensity and frequency' and Beckstrand and Kirchhoff (2005) suggest that these items are internally consistent. Internal consistency estimates of reliability were also computed for the 24 supportive behaviour intensity items, showing a Cronbach α of .86 and the 24 supportive behaviour frequency items, with a Cronbach α of .81 (Beckstrand & Kirchhoff, 2005).

3.7.2 Paper-based questionnaire

Research comparing the differences in response rates between paper-based questionnaires and online questionnaires indicates that paper questionnaires achieve a higher response rate than online questionnaires (Nulty, 2008). Given this evidence and the fact that paper-based questionnaires are preferred at the major specialist hospital, we chose to use a paper-based questionnaire.

After obtaining permission from the original authors by email for the use of their questionnaire in the KSA (see Appendix 1), minor modifications were made. These included organising the items in tables and demographics questions. This revision was conducted to make the questionnaire clearer for participants. The questionnaire was conducted in the English language because English is the language used by health

care professionals in hospital medical records in the KSA, and because most nurses are expatriates who speak English (MoH, 2012).

Pilot test

A pilot test was conducted in the KSA with ICU nurses to ensure the questionnaire wording was appropriate. The test included completing the questionnaire and answering some questions relating the clarity of the questionnaire and adding any comments if noted. Four ICU nurses conducted the pilot test and also went on to complete the questionnaire. These nurses reported that they found the instructions, items and open-ended questions clear and understandable. They also noted that the study might be useful to improve EoLC in ICU in the KSA.

3.7.3 Questionnaire modifications

The original intention of this study was to utilise the Beckstrand and Kirchhoff (2005) questionnaire with minor modifications for the Saudi Arabian setting, particularly given that it had already been tested. Unfortunately, when the questionnaires were photocopied prior to dissemination, an error was made. The error was not noticed until the completed questionnaires were collected. The error related to the instructions for the 'support' items. A decision was taken to not use any data relating to the 24 'support' items and data analysis instead focused solely on the 'obstacles' items and other relevant data.

The remaining parts of the questionnaire consisted of 29 items focusing on the intensity and frequency of obstacles to the provision of EoLC in ICU and demographic questions, totalling 42 items. The 29 'obstacle' items were in the form of Likert scales ranging from zero to five, where zero means 'no value' and five

means 'extreme' or 'significant value'. An open-ended question enabled participants to provide additional information related to obstacles to EoLC in the ICU. One question asked participants about aspects of EoLC they would change, with another encouraging participants to make further comments. The final ten questions were designed to collect participants' demographic information.

3.7.4 Ethical Approval

Approval to conduct the research was granted by the Monash University Human Research Ethics Committee (Human Ethics Certificate of Approval CF15/518 – 2015000245) (see Appendix 3). The Office of Research Affairs of the major specialist hospital in which the research was conducted required both the student researcher and the primary supervisor to complete an online course entitled 'Protecting Human Subject Research Participants' by the National Institute of Health (NIH) and to sign a collaborative agreement between the hospital and Monash University before the research could be conducted. At the request of the hospital, a liaison staff member was appointed to approach hospital staff, post flyers (see Appendix 4), distribute explanatory statements (refer to Appendix 5) and questionnaires and then collect the completed questionnaires on behalf of the student researcher. No conflict of interest was identified for any of the researchers. Ethical approval was granted from the hospital once all conditions had been met (Number 2151 074) (see Appendix 6).

The questionnaires were distributed as paper questionnaires for the reasons discussed earlier and participation in the research and completion of the questionnaire was voluntary. Participants were asked to seal the completed questionnaires in the envelopes provided and then deposit these in a collection box left in the ICU for the duration of the research. No identifiable data were collected and participants had the

opportunity to skip answering questions they did not feel comfortable answering.

Potential participants were encouraged to complete the questionnaire only if they felt

comfortable doing so and to cease participation if they experienced any discomfort or

distress. The risk and benefit of participating of this study were discussed in the

explanatory statement.

Participants were informed that all data would be reported as aggregate findings,

further protecting the anonymity and confidentiality of participants. Furthermore, data

related to the study were stored in the locked office of the student researcher and only

accessible to the student researcher. All electronic data are password-protected and

hard copy questionnaires will be shredded when no longer needed.

Consent

Participants were encouraged to read the Explanatory Statement before deciding to

participate in this study. The Explanatory Statement clarified that returning a

completed questionnaire would be considered as implied consent.

3.7.5 Participants

More than 367 registered nurses are employed in the adult ICUs at the specialist

hospital (Kardesh, personal communication, Jan 05, 2015). Approximately 88% of the

nurses are expatriate nurses from other countries and cultures, indicating an ethnically

and culturally diverse nurse population (Ministry of Health, 2012).

3.7.6 Sample

Convenience sampling was used to recruit participants for this study. This sampling

approach is appropriate for small exploratory quantitative studies (Schneider et al.,

2013). A limitation of this approach is that it tends to produce less accurate and less

representative samples, which limits the ability to generalise to a population level (Schneider et al., 2013). Bias may also exist in convenience samples, as participants are self-selecting and the information obtained comes only from those who participated (Schneider et al., 2013). However, given the specific population that was the focus of the questionnaire, convenience sampling was considered the most appropriate sampling method.

Inclusion and Exclusion Criteria

The inclusion criteria of this study included nurses who work in intensive care at the hospital and who have provided care for dying patients on at least one occasion in an ICU. ICU nurses from the six ICUs who met the inclusion criteria were eligible to participate. Other nurses who did not met those criteria were excluded.

3.7.7 Participant Recruitment

As stipulated by the management at the hospital and detailed in the ethical approval, an independent staff member of the hospital was appointed as the liaison and 'data collector' person. The hospital routinely assigns a staff member who has completed an online course for Protecting Human Subject Research Participants by the National Institutes of Health (NIH) to act in a liaison role between researchers and hospital personnel (National Institutes of Health, 2015). The investigators of the study were not involved in participant recruitment or the distribution or collection of questionnaires.

The data collector initially met with each ICU Nurse Manager to discuss the study and what it would involve. The data collector also approached potential participants in their workplace, informing them of the study, its purpose and procedure. All potential participants were provided with a copy of the Explanatory Statement and

questionnaire. The questionnaires were distributed with an open envelope and participants were asked to complete the questionnaire, place it in the envelope, seal it and place it in the questionnaire collection box. The data collector also returned regularly to each of the six study ICUs to collect completed questionnaires. An email was sent to all potential participants two weeks after the questionnaires were originally disseminated, prompting nursing staff to complete the questionnaire if they wished.

3.7.8 Data Collection

At the end of the data collection period approximately four weeks, the questionnaires were collected. The participants' answers, excluding the open-ended responses, were entered initially into Microsoft Excel 2010 and then transferred into SPSS Version 20 for analysis (Pallant, 2013).

3.7.9 Data Quality

Questionnaires were checked for completeness and legibility. Incomplete questionnaires, defined as those with more than 25% of the questions left unanswered, were excluded from the analysis. All questionnaire data, except for the open-ended responses, were converted to numeric codes according to a pre-defined coding sheet (see Appendix 2), to enable data entry into Microsoft Excel and SPSS Version 20 for analysis (Pallant, 2013). Data entry is considered an error-prone process (Polit & Beck, 2012); therefore the student researcher initially undertook the process of data entry and then 10% were checked at random by supervisor to ensure accuracy in data entry.

A unique identifier in the form of an identity (ID) number was assigned to each questionnaire and this identifier was utilised to indicate authentic citations. The use of authentic citations increases the reliability of the data and demonstrates how the themes were developed (Elo & Kyngas, 2008). However, participant anonymity was ensured, as no data that might enable the identification of any questionnaire participant was collected.

3.7.10 Data Analysis

Descriptive statistics were used to examine the demographic data, including age, sex, years of nursing experience and employment status. Demographic data were summarised using numbers and percentages. Data analysis for the rest of the questionnaire content in this study was modelled on the analysis undertaken by Beckstrand and Kirchhoff (2005). Measures of central tendency and reliability statistics were calculated for all obstacle items. Obstacle items were then ranked on the basis of their mean scores to determine the intensity and occurrence of each obstacle item. The obstacle scores were then ranked from highest to lowest.

The qualitative manifest content analysis method was used to analyse the questionnaire comments (Graneheim & Lundman, 2004). The content analysis process consisted of developing meaning units, interpreting meaning units, developing sub-themes and then themes. The process of analysis involved using questionnaire quotations in the meaning units' field, interpreting the meaning unit and developing sub-themes and then themes. Each theme was developed in accordance to the row data that included sub-theme, interpretation and meaning unit. The consistency between each meaning unit and its theme was reviewed. This process was developed by Graneheim and Lundman (2004) and is presented in Appendix 10.

3.8 Phase two: Qualitative Interviews

Using qualitative semi-structured interviews assists the further exploration of the outcomes of the quantitative phase (Creswell & Plano Clark, 2011). The advantage of semi-structured interviews is that they are useful for increasing understanding of other findings (Andrew & Halcomb, 2009). When a researcher knows the research questions well but does not know the exact answers, using semi-structured interviews is useful (Morse, 2012). Interviews assist the researcher to further investigate particular issues in great detail and also allow participants to express their thoughts (Minichiello, Sullivan, Greenwood, & Axford, 2004). The purpose of conducting the interviews was to gain deeper understanding of the major obstacles raised in the quantitative results, and probe any other obstacles that interviewees identified.

ICU managers or charge nurses who did not participate in the questionnaire in the major specialist hospital were considered for the interview. It was anticipated that the different participants might add different perspectives to the study's findings. Therefore, the interviews might identify further obstacles to the study and also complement Phase One questionnaire data in depth.

3.8.1 Interview Questions

In an iterative process, interview questions were developed from a preliminary analysis of Phase One questionnaire responses (see Appendix 7). Questions or prompts for the semi-structured interviews focussed on good EoLC and the perceived obstacles to providing this good EoLC. Questions also focused on any perceived impact of language, cultural, religious and nursing workforce issues related to providing EoLC. In addition, participants were encouraged to add anything else they considered relevant to the study.

3.8.2 Sample

In a sequential explanatory design, purposive sampling is recommended in the second qualitative phase (Creswell & Plano Clark, 2011). This sampling method supports the selection of eligible participants who have experience and knowledge of a particular field (Patton, 1990; Schneider et al., 2013) to provide details of the study's topic in depth (Schneider et al., 2013). Therefore, purposive sampling was used in recruiting ICU charge nurses and managers as potential interviewees for this study.

Inclusion Criteria

For the interviews, ICU managers and charge nurses who did not participate in the quantitative study were eligible. These participants were suggested because it was assumed that mangers or charge nurses had more responsibility and experience of EoLC in ICUs. Secondly, it was also anticipated that experienced nurses, not involved in the quantitative study content, would add another dimension to the topic under consideration. Therefore, ICU charge nurses who had experience in EoLC and who did not participate in the previous quantitative study were eligible to be interviewed.

3.8.3 Ethical Approval

An explanatory statement and consent form were developed for conducting the interviews. An amendment of the original ethical approval was requested from Monash University and the major specialist hospital. The amendment was approved by both Monash University Human Research Ethics (number CF15/518 – 2015000245), and the site hospital Office of Research Affairs (number 2151 074).

Allocating each interviewee a unique identifier helped protect their anonymity. Unique identifiers were used to demonstrate authentic citations in reporting data. No information that may have revealed the identity of any participant was collected.

Participants were informed that if they feel discomfort of answering any question, they can avoid the question. Potential participants were encouraged to complete the interview only if they felt comfortable doing so and cease the interview if they experienced any distress or discomfort. The risk and benefit of participating of this study were discussed in the explanatory statement.

3.8.4 Participant Recruitment

The liaison person from the major specialist hospital identified suitably qualified ICU charge nurses and provided them with an Explanatory Statement and a brief outline of the research (see Appendix 8). If they expressed an interest in being interviewed, they were then introduced to the researcher. The researcher met with eligible participants who were interested in being interviewed. Four ICU charge nurses met the inclusion criteria and agreed to participate in this study.

3.8.5 Data Collection

After obtaining consent (refer to Appendix 9) from potential participants, the interviews were conducted in the ICU meeting room of their units. The rooms were convenient for the interviewees to access, and there were no interruptions to the interviews. This may have contributed to participants feeling free to discuss the key issues. Each interview was scheduled to take up to 45 minutes. All interviews were recorded using the student researcher's mobile telephone device.

3.8.6 Data Analysis

The interviews were all recorded by the researcher on a mobile telephone device and then sent to the second and third researchers for review, via a secure file-sharing website. Interview durations was up to 21 minutes. The audio recordings of the

interviews were listened to many times and then transcribed into Microsoft Word files
and saved as a separate document by the researcher. Participants were assigned a
numeric code to protect their identity. The time of each transcribed quote, retrieved
from the recorded interview, was noted. The congruence between interviews and
transcriptions was checked by the researcher and then checked again by the second
and third researchers to maintain the accuracy of the data.

The manifest qualitative content analysis method (refer to Figure 3) was used to
analyse the transcribed data. The process of manifest analysis keeps the main meaning
of the text without any change and clarifies what the text says (Graneheim &
Lundman, 2004). The process of this content analysis involves identifying meaning
units, condensing the meaning units, interpreting the condensation and developing
sub-themes and then themes (Graneheim & Lundman, 2004).

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│ Interpretation  │
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│     Theme       │
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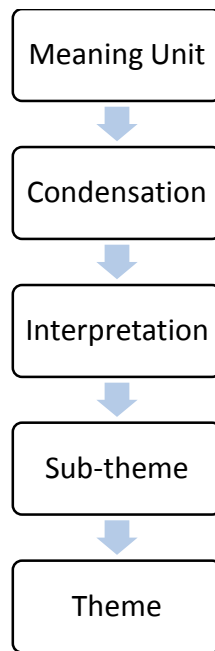
Figure 3. *Content analysis process developed by Graneheim and Lundman (2004)*

All transcriptions were read several times. The importance of the transcribed data that answering the study's aim was highlighted. The common highlighted quotes were divided into meaning units. Each quote in a meaning unit was condensed and then interpreted. Each interpretation was made in accordance with the condensed meaning unit. The interpreted text was categorized into sub-themes. Similar sub-themes were further categorized into themes. Each theme was developed in accordance with the row data that included sub-theme, interpretation, condensation and meaning unit (see Appendix 11). The consistency between each meaning unit and its theme was reviewed. This process was managed in a table format developed by Graneheim and Lundman (2004). All these processes were used to ensure that the interpretations and understanding of the results were consistent.

Consent

All participants received verbal information regarding the study before the interview commencement. Participation in this study was voluntary and participants were informed that they could withdraw at any time during the interview. Participants were also encouraged to read the explanatory statement before deciding to participate in this study and then their consent were obtained. Each participant involved in the study was asked to sign the consent form before the interview commenced.

3.9 Conclusion

This chapter has outlined the processes used in conducting this study, including the study design, data collection, analysis and ethical considerations of each phase. The processes and reliability of methods to be used in this study were also discussed. A mixed method approach was considered the most effective way to address the aims of this study because it facilitates exploration of the topic through the collection of quantitative and qualitative data. This method facilitates in-depth exploration of the study phenomena from different perspectives. Ethical approval from Monash University and the study site hospital was obtained and other organisational requirements were met. The results of the data analysis are reported in detail in the following chapter.

Chapter Four: Results

4.1 Introduction

This chapter reports the results of both quantitative and qualitative data drawn from a questionnaire adapted from Beckstrand and Kirchhoff (2005) obstacle items about nurses' perceptions of obstacles to providing end-of-life care (EoLC), and the analysis of interviews conducted with senior Intensive Care Unit (ICU) charge nurses. The results are reported in two phases, with Phase One of the research relating to the questionnaires and Phase Two relating to the semi-structured interviews.

4.2 Phase One: Questionnaire results

From 140 potential participants 87 questionnaires were returned, representing a 62% response rate. Of the returned questionnaires, ten were not included in the analysis because the participants had only completed the first page of the questionnaire. Therefore, 77 questionnaires were included in the analysis. Data analysis for the questionnaire content in this study was modelled on the analysis undertaken by Beckstrand and Kirchhoff in their original 2005 study. Measures of central tendency and reliability statistics were calculated for all obstacle items. Obstacle items were then ranked on the basis of their mean scores to determine the intensity and occurrence of each obstacle item. The obstacle scores were ranked from highest to lowest scores. The results reported include participant's demographic information and items listed as obstacles.

4.3 Participants' demographic information

Descriptive statistics were used to examine the demographic data of participants including age, sex, years nursing and employment status. Demographic data were summarised using numbers and percentages. The demographic characteristics for the

participants are reported in Tables 3 and 4. The majority of participants were female (82.9%) and the mean age was 34 years. Participants had an average of 10.8 years experience as a registered nurse and 8.6 years experience of working in ICUs. Postgraduate qualifications were reported by 32.4%, although only 29.7% of the participants specified that their postgraduate qualifications were in critical care, including intensive care.

Many of the participants were experienced in providing EoLC and many participants had themselves given immediate EoLC to more than 30 patients (42.3%), between 21 and 30 patients (21.1%), and between 11 and 20 patients (21.1%). Participants reported working between12 and 84 (mean 48.6) hours per week. The number of beds in each of the ICUs ranged from 7 to 30 (mean 18.2).

Table 3.

Questionnaire participants' age and years of experience

Characteristic	Range	Mean	Std. Deviation
Age	25 - 63 yrs.	34.39	8.21
Years of experience as a RN	3 - 30 yrs.	10.8	5.77
Years of experience in ICU	1 - 20 yrs.	8.6	4.51

Table 4.

Questionnaire participant demographics

Characteristics	N	%
Gender		
Male	13	17.1
Female	63	82.9
Total	76	100
Qualifications		
Undergraduate nursing qualification	26	35.1
Postgraduate critical care nursing qualification	22	29.7
Postgraduate nursing qualification (other than critical care)	24	32.4
Other	2	2.7
Total	74	100
No of times EoLC has been provided		
More than 30 patients	30	42.3
Between 21 and 30 patients	15	21.1
Between 11 and 20 patients	15	21.1
Between 5 and 10 patients	7	9.9
Less than 5	4	5.6
Total	71	100
Participant's Role		
Direct care / Bedside / Staff nurse	40	57.1
Charge nurse/ Staff nurse	28	40
Other	2	2.9
Total	70	100
Type of ICU		
Intensive Care Unit	54	74
Combined ICU/CCU	8	11
Other	6	8.2
Coronary Care Unit	5	6.8
Total	73	100

4.4 Results of obstacle items

The results of obstacle items include measures of both intensity and frequency of occurrence. Obstacle intensity indicates how intense or large, each obstacle was considered. Frequency reflects how frequently each of the obstacles occurred. The obstacle items drawn from Beckstrand and Kirchhoff's (2005) questionnaire focus on ICU nurses' perceptions of obstacles to providing EoLC. These obstacle items offered a range of choices covering personal, inter-professional, environmental, patient and family-related obstacles. All the obstacle items are shown in Table 5.

4.4.1 Obstacle intensity items

The obstacle intensity items were scored from zero, where a zero implies the 'item' was not an obstacle, to five which implies the item was an extremely large obstacle. The means of all obstacle intensity items ranged from 1.27 to 4.26. The top ten obstacle intensities, based on the highest means, were determined by their means in descending order. The four obstacle intensity items ranked as having the highest intensity, were related to concerns with patients' families (means ranged from 3.95 to 4.26). The other six obstacles of high intensity included when multiple physicians differed in opinion (mean = 3.91), dealing with distraught family members (mean = 3.81), liberal visiting hours (mean = 3.71), continuing intensive care for a patient with a poor prognosis (mean = 3.56), physicians who were evasive (mean = 3.54), and continuing treatment for a dying patient (mean = 3.42). On the other hand, the lowest obstacle was restrictive visiting hours (mean = 1.27) (Table 5).

4.4.2 Obstacle frequency items

The obstacle frequency items were scored zero, which implied that the item never occurred, to five, for always occurred. The means of all obstacle frequency items ranged from 4.08 to 1.50. The top ten obstacle frequencies rated with the highest frequencies were determined by their means in descending order. The highest rated frequencies were family and friends who continually called the nurse wanting an update of a patient's condition (mean = 4.08), families not accepting their patient's poor prognosis (mean = 3.90), liberal visiting hours (mean = 3.84), dealing with distraught family members (mean = 3.81), dealing with angry family members (mean = 3.73), family members not understanding what 'life-saving measures' really meant (mean = 3.72), the nurse knowing about the patient's poor prognosis before the family was told the prognosis (mean = 3.63), multiple physicians involved who differed in opinion (mean = 3.55), continuing intensive care for a patient with a poor prognosis (mean = 3.45), and continuing treatment for a dying patient even though it increased suffering (mean = 3.26). On the other hand, the lowest obstacle frequency was restrictive visiting hours (mean = 150). All items of intensity and frequency are presented in Table 5.

Table 5.

Obstacle items including both intensity and frequency

Obstacle Items	Intensity			Frequency		
	Mean	SD	Rank	Mean	SD	Rank
1. Families not accepting what the physician is telling them about the patient's poor prognosis.	4.26	0.90	1	3.90	1.05	2
2. The nurse having to deal with angry family members.	4.13	1.08	2	3.73	1.11	5
3. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	4.06	1.11	3	4.08	1.07	1
4. Family members not understanding what 'life-saving measures really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compression.	3.95	1.18	4	3.72	1.26	6
5. Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	3.91	1.26	5	3.55	1.27	8
6. The nurse having to deal with distraught family members while still providing care for the patient.	3.81	1.22	6	3.81	1.17	4
7. Unit visiting hours that are too liberal.	3.71	1.53	7	3.84	1.56	3
8. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.56	1.40	8	3.45	1.30	9
9. Physicians who are evasive and avoid having conversations with family members.	3.54	1.31	9	3.00	1.40	15
10. Continuing treatment for a dying patient even though the treatment causes the patient pain or discomfort.	3.42	1.63	10	3.26	1.47	10
11. The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	3.42	1.49	11	3.18	1.48	13
12. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	3.38	1.50	12	3.26	1.44	11
13. When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.30	1.26	13	2.89	1.26	16
14. Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	3.29	1.48	14	2.82	1.60	18
15. Intra-family fighting about whether to continue or stop life support.	3.25	1.60	15	2.86	1.41	17

Obstacle Items	Intensity			Frequency		
	Mean	SD	Rank	Mean	SD	Rank
16. Physicians who are overly optimistic to the family about the patient surviving.	3.20	1.35	16	3.19	1.09	12
17. Physicians who will not allow the patient to die from the disease process.	3.08	1.35	17	2.78	1.34	19
18. The family, for whatever reason, is not with the patient when he or she is dying.	3.06	1.43	18	2.70	1.27	21
19. Dealing with the cultural differences that families employ in grieving for their dying family member.	3.05	1.46	19	3.13	1.42	14
20. The unavailability of an ethics board or committee to review difficult patient cases.	3.03	1.46	20	2.59	1.55	22
21. Being called away from the patient and family because of the need to help with a new admission or to help another nurse care for his/her patients.	2.94	1.38	21	2.75	1.33	20
22. The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	2.79	1,90	22	3.63	1.56	7
23. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	2.69	1.94	23	2.20	1.86	27
24. Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.66	1.48	24	2.33	1.36	25
25. The patient having pain that is difficult to control or alleviate.	2.65	1.63	25	2.57	1.38	23
26. Poor design of units which do not allow for privacy of dying patients or grieving family members.	2.61	1.75	26	2.55	1.61	24
27. No available support person for the family such as a social worker or religious leader.	2.35	1.64	27	2.26	1.59	26
28. Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	2.31	1.76	28	2.00	1.62	28
29. Unit visiting hours that are too restrictive.	1.27	1.61	29	1.50	1.66	29

4.5 Questionnaire open-ended response question regarding further obstacles in EoLC

The questionnaire included one open-ended question regarding any further obstacles that were not mentioned in the questionnaire items. The open-ended question offered participants the opportunity to comment on any missing obstacles. The open-ended

responses were analysed using the approach to content analysis developed by Graneheim and Lundman (2004).

4.5.1 The need for EoLC awareness

One participant commented that EoLC was not available in the ICU:

"End of life care in ICU is almost non-existent" (Participant 50).

One participant noted that there was limited knowledge about the dying process in the ICU:

"Lack of knowledge of the dying processes of the patients" (Participant 20).

Participant stated that most of the time, painkillers and sedation for dying patients were not considered. This may indicate the need for EoLC awareness:

"Lack of analgesia and sedation for dying patients 99% of the time"

(Participant 39).

One participant reported that patients' culture could become barriers to dying comfortably, particularly when they refused pain relief medications:

"Overcoming cultural barriers to allow patients to die with dignity (patients are subjected to measures that do not provide relief)" (Participant 38).

When asked about obstacles to EoLC, one participant noted the difficulty in providing EoLC for brain-dead patients who were considered potential organ donors. This case may need EoLC attention:

"Brain death in a potential organ donor" (Participant 68).

4.5.2 Language barrier

Many participants noted that language issues could influence the EoLC and found that even the Arabic translators were considered a large barrier to providing EoLC. These barriers could hinder nurses' ability to meet patient and family needs because

speaking Arabic would facilitate the communication and conversation regarding EoLC:

> *"Not being able to speak Arabic prohibits real conversations about EoL wishes"* (Participant 38).

> *"Language obstacles are very frequent"* (Participant 56).

> *"Arabic translator is the primary barrier to perform end of life care, all the time"* (Participant 47).

4.5.3 Physician behaviour

Some comments indicated that physicians did not involve or inform family regarding the decision about the patient's resuscitation status, leaving them without explanation or preparation for Do Not Resuscitate (DNR) orders. Thus, when death occurred, the family were confused and blamed the nurses. Family suffering and nurses' care were potentially affected:

> *"The physician did not discuss with the family members when they decided to put on DNR status"* (Participant 76).

> *"DNR not explained by physicians to family and when deaths occur, patients' families blame nurses for the death so huge confusion faced by the patient's family"* (Participant 77).

Participants suggested that physicians might ignore palliative care needs, and they considered more aggressive interventions or futile care instead. Participants also stated that sometimes physicians appeared to delay a patient's death by passing the patient to another physician's shift:

> *"Many doctors are arrogant and ignorant about palliative care. Super aggressive treatments or futile care used in our ICU"* (Participant 50).

> *"Doctors try to avoid the death and pass it the next shift"* (Participant 50).

One comment suggested that physicians often did not educate the patients' families regarding the patient's situation because of their beliefs, particularly when a patient has a poor prognosis. Because of this, the suffering of patient and family could be prolonged:

> *"Nobody to talk to the family, prolonging the misery of poor prognosis in patients because of religious beliefs"* (Participant 21).

One participant comment indicated the nurse perceived that physicians and the community did not acknowledge nurses as knowledgeable independent professionals. Some nurses felt that they were seen in a support role and not appreciated for their specialist skills and knowledge:

> *"In Saudi, nurses are treated as helpers only, not as professionally qualified nurses"* (Participant 29).

4.6 Questionnaire open-ended response question regarding an aspect that would change EoLC

The questionnaire included one open-ended question regarding an aspect participants would like to change in EoLC.

4.6.1 Avoiding unnecessary care

Participants implied that intensive care and painful interventions could increase a dying patient's suffering and prolong their death, and therefore the care should be avoided:

> *"Avoid intensive care and painful activities"* (Participant 19).

> *"Avoid unnecessary line insertion like chest tube or urostomy, which is extremely painful for the patient who is dying"* (Participant 9).

Participants noted that unnecessary care was provided for patients who were brain dead, stating that this should be changed because it did not benefit such cases:

"I would like to change the idea of keeping the brain death patients on

ventilators and active management" (Participant 11).

"Treating everybody fairly and ending care for those who are not going to

benefit. E.g. brain death" (Participant 27).

Participants commented that unnecessary care should be withheld from dying patients

to maintain dignity and comfort. Instead, EoLC should be provided for all dying

patients, to facilitate patient dignity and peaceful death, as well as enhancing the

acceptance of the patient's family:

"Stop the dysthanasia" (Participant 56).

"Give end-of- life care irrespective of the status of family" (Participant 12).

"Accept that everyone dies when the time comes and they should let their

patients die comfortably and in a dignified way" (Participant 29).

4.6.2 Education and preparation

Participants stated that organising a meeting with the family for education and to

discuss the ICU team's expectations about the patient's situation, the health care plan

and family understanding of their patient situation, might prepare family members and

improve EoLC:

"To have a meeting with the family to set the expectations of the health care

team" (Participant 26).

"Explain to the family about procedures and the exact situation. Explain the

management and how to help the patient die peacefully rather than multiple

procedures" (Participant 33).

Participants suggested that education of and communication with families about

patients' prognoses and diagnoses was an area of practice that needed improvement.

Participants recommended clear communication between health professionals and families about a patient's situation:

> *"Better communication and education about the patient's diagnosis and*
> *prognosis"* (Participant 10).

> *"Tell the truth, give detail about patient's prognosis"* (Participant 20).

Good communication between physicians, patients and their families was not only recommended by participants but also identified as lacking in ICUs particularly for sensitive death related discussion. Further, involving or informing family members about any decisions about the care of their patient, like DNR status, should be considered:

> *"Good communication by clinicians with patients and their families"*
> (Participant 3).

> *"Physicians should discuss sensitively"* (Participant 40).

> *"Putting the patient in DNR* [Do Not Resuscitate] *with the involvement of the*
> *family"*
> (Participant 37).

Participants suggested that telling the truth, allowing family members to be present, giving realistic details about the patient's condition, including the situation of impending death and how treatment might prolong suffering, should considered:

> *"Tell the family truthfully what is happening and allow them to be with their*
> *family members as they make the transition to death"* (Participant 38).

> *"Informing the patients and families of the actual condition, including the*
> *likelihood of death, the fact that treatment would not cure them – just prolong*
> *the dying process"* (Participant 39).

Many comments indicated that family acceptance of the fact that their family member was dying would support good quality EoLC. The grieving process should be well facilitated, including allowing family members enough time to come to terms with the impending death of their loved one. Therefore, the process of how to enhance acceptance by the family needs to be considered:

> *"Allow enough time to the dying patient and family to accept the situation and grieving process"* (Participant 76).

> *"Patient family member accepting of end of life"* (Participant 32).

> *"Easy acceptance from family"* (Participant 1).

Participants noted that the dying patient needs to be more involved in decision-making and provided with opportunities to develop advance directives for their care:

> *"Giving them the choice about their end of life according to their will"* (Participant 8).

> *"Asking patients to sign advance directives for their care"* (Participant 21).

Some participants' comments indicated that preparation of the ICU environment needed to be improved by maintaining a calm environment, and lowering the volume of monitors and alarms:

> *"Environment should be calm and silent. Monitors and alarms must be at the minimum sound and, if possible, turn off the alarms"* (Participant 68).

4.7 Phase Two: Semi-structured interviews

The student researcher interviewed four ICU charge nurses for this study. Interviews were scheduled at times suitable for the participants. Interviews ranged in duration from 12 to 21 minutes.

4.8 Participants' Demographic Information

Two charge nurses were from the Surgical ICU and two charge nurses were from the Medical ICU. All participants were female and had a Bachelor degree in nursing. The participants had worked in the ICU for between 5 and 15 years. The participants spoke English but it was not their first language and none spoke Arabic well.

The findings from interviews included themes about obstacles to providing EoLC in ICUs. The themes were when the family does not understand the patient's situation, the need for EoLC awareness, language barriers and education and preparation.

4.9 When the family does not understand the patient's situation

The participant considered that families have difficulty accepting their relative's declining health status because physicians often do not indicate that the patient is dying, due to relatives religious and cultural beliefs. This combination of belief and close family ties has an impact on EoLC for the participants:

> "*Mostly physicians do not say a patient is dying due to cultural beliefs. The culture has very close family ties. The combination of belief and culture makes the situation very difficult*" (Interview 2).

According to the participants, nursing care could be affected by culture and beliefs. An example offered was using honey and holy oil for dying patients when there are signs of infection. They suggested that sometimes nurses educate family members on the consequences of such actions related their culture or belief, but the physicians allow family use these practices. However, the participants believe some religious and cultural practices potentially hinder nursing care. When nurses are responsible for maintaining patient health and respecting patient and family beliefs, the situation

reflects an ethical dilemma between the nursing care of the patient and the family's belief:

> *"Sometimes, families use a treatment of honey and holy oil for their dying patient when there are already signs of infection... We inform them it can cause infection... [However] Physicians allow them because of their culture and beliefs. This mostly hinders nursing care"* (Interview 3).

It was noted that families often request a different care plan, and that family wishes may hinder the goal of care and interfere the nursing care plan, increasing patient suffering:

> *"Families interfere with nursing care and they don't know their patients are suffering"* (Interview 1).

> *"Sometimes, every family member asks for another care plan and this increases patients' suffering"* (Interview 3).

> *"Decisions regarding treatment plans between medical professionals and family sometimes becomes a problem"* (Interview 3).

A suggestion was made that EoLC may be affected when a family has an authority that may change the plan of care for the dying patient:

> *"Sometimes family have authority that can change medical decision of their dying patient"* (Interview 1).

When family members search the internet for treatment options, they may change the treatment plan request. Physicians sometimes accept the request to satisfy the family:

> *"Sometimes families request another treatment seen in Internet resources and sometimes the physician allows this to satisfy the family"* (Interview 3).

Participant reported that medical care might be disregarded because of certain beliefs. Families may deny their loved one's situation and believe that their loved one will survive through the will of God:

> *"Our role as medical professionals is overridden because of religious beliefs; for example, a patient was very sick with multi-organ failure and the family still believed the patient would survive and that God would help"* (Interview 2).

According to the participants, families may believe that there is still hope for their relative to survive, even when no treatment can help. Sometimes, the families of patients with very bad prognoses want more medical interventions. It seemed to participants that families prefer aggressive resuscitation and life-saving intervention rather than palliative care:

> *"Families refuse Do Not Resuscitate status because they believe the patient still has hope, but in medical terms, nothing can be done"* (Interview 1).
> *"Sometimes families want to do everything that can be done for the patient, even if they have very bad prognosis"* (Interview 3).
> *"Families refuse to transfer their patient to palliative care or another hospital, even if there is another patient waiting in the ER* [Emergency Room] *with the right to be treated"* (Interview 1).

Participants perceived that family acceptance was a big obstacle to providing EoLC, and acceptance was dependent on their understanding of the patient's situation. The most difficult phase of acceptance was the denial phase:

> *"Family acceptance at end of life is a big hindrance. It is different from person to person and it depends on their understanding of the situation"* (Interview 3).

"The denial stage of acceptance is the most difficult" (Interview 3).

It was suggested that the emotions of patients with chronic disease might be influenced when their family is not available. In this case, a patient might experience loneliness and lack of emotional support:

"Sometimes for chronic patients, the absence of family members may impact patients thinking and emotions" (Interview 4).

4.9.1 The need for EoLC awareness

The participant interviewed suggested that a lack of guidelines and protocols for providing EoLC may be an obstacle to giving care to a dying patient. The situation may affect the nurses' ability to improve care:

"We do not have any protocols or guidelines for dealing with dying patients, but we try to do our best" (Interview 4).

The participants reported that families may put holy oil or water on the patient and this could interfere with patient hygiene. This example reflects the fact that cultures are not always well understood by nurses but family's beliefs are respected. This may mean that patients' cultures and beliefs are not well addressed in EoLC in the ICU:

"Sometimes they bring holy oil or water. Sometimes I clean the patient and they put on the oil. We do nothing because of their beliefs, but we clean the patient later" (Interview 4).

"Not all cultures are understood, but we allow them to do whatever they believe" (Interview 4).

In the interviews the participants reported that when many family members come to visit the patients in ICU, limits needed to be set because of the ICU environment. The participants also said they sometimes need support to control family reactions or

aggression when they realise that the patient is dying. Furthermore, the ICU environment needs to be a calm area and when family members cry loudly, it may upset other patients. These comments may indicate a need for further arrangements in EoLC:

> *"Sometimes when a patient is dying, family members overcrowd the bedside or become very aggressive and then we need help to control the situation"* (Interview 4).

> *"So many family members come to patient bedside and we need to keep a limit because this is ICU"* (Interview 4).

> *"Sometimes they cry loudly and it can affect other patients"* (Interview 4).

The participants said that they become emotionally stressed when caring for dying patients for long periods of time. Providing nursing care to a patient for a prolonged period of time creates a relationship, making it difficult for the nurses when the patient dies. This may indicate that nurses need to develop strategies to manage their reactions when they are providing EoLC:

> *"When patient stay longer we feel a little attached and we cry if they passed away"* (Interview 1).

> *"We are with the patients more than the physician is, and our emotional stress can affect the quality end of life care. We need emotional stability"* (Interview 2).

4.9.2 Language barriers

One particpant suggested that families who do not speak English well or who have interpreters who are not medical professionals may experience difficulties with their understanding. Sometimes, the patients with different cultures affect the interpreters'

understanding, or the interpreter does not clarify the patient's condition. Therefore, language barriers can present challenges in providing EoLC:

> *"Sometimes, they speak good English but don't know medical terms. Sometimes an interpreter who is not a medical practitioner does not describe the actual condition or give full details. Sometimes the interpreter does not understand the patient and their family due to different cultures. This is really the big hindrance"* (Interview 3).

In contrast to this view, other partipants noted that communication with patients is manageable, and different languages are not a problem. In difficult situations, medical practitioners can be called on for translation:

> *"We do not speak Arabic but communication can be solved, for instance, with a translator"* (Interview 2).
>
> *"I do not speak Arabic, but I know how to communicate with patient. If there is difficulty, we can find a medical practitioner. So language is not a problem"* (Interview 4).

4.9.3 Education and preparation

The participants stated that families need to receive more educations about the patient's condition and prepared for the dying process. The importance of educating the patient and their family about the situation was noted, as was meeting the needs and wishes of both patient and family and involving them in decisions regarding care, potentially leading to increased acceptance:

> *"Importantly we need to focus on how to educate the family and the patient... Considering patients and their families' wishes and involving them in the care"* (Interview 3).

> *"Sometimes the family does not know about their patient's condition, so*
>
> *educating and preparing them to approach end of life is important and it can*
>
> *enhance the acceptance"* (Interview 2).

One participant noted that some physicians worsen the family situation by saying *Inshallah* [God willing], which may give false hope and increase family denial. The participant said that they want to support the families emotionally, but the language barrier restricts their ability:

> *"Some physicians give the family false hope by saying* Inshallah *when their*
>
> *patient has a bad prognosis. Our burden is to try to support them emotionally,*
>
> *but the language barrier restricts us"* (Interview 3).

Participants suggested that saying *Inshallah* alone was not enough, and that physicians need to be honest about the patient's situation and considered that facilitating a peaceful death could help prepare the family to accept the situation. Therefore, the doctors should provide the explanation of patients' condition, as the role of the nurses is limited:

> *"Strong doctors should explain the reality of the patient's condition, not just*
>
> *say safest word,* Inshallah. *We need to give the patients human dignity, a*
>
> *peaceful death and not prolong the agony"* (Interview 2).
>
> *"The physician is supposed to provide education because we as nurses are*
>
> *restricted from telling the full details, even though we know the patient's*
>
> *condition well"* (Interview 3).

Culturally sensitive care needs to be considered for Muslim patients. For instance, families need to be allowed to come, to pray and fulfil their religious duties:

> *"End of life care should be culturally sensitive and should allow the family to*
>
> *come and pray and fulfil their religious"* (Interview 4).

The participant supported the presence of family members because they believe it helps dying patients. If the family is not available, the nurses enhance patient spirituality by supporting them to read or listen to the Quran and invite religious leaders as needed:

> *"Mostly we allow the family to be present with their patient"* (Interview 3).
>
> *"When family is not present, we put on Quran TV or bring a religious leader beside the patient to pray and read the Quran... We try to contact the family to come"* (Interview 4).

The participants stated that freedom from pain, family presence and meeting patient needs were significant in EoLC. Nurses want to work as advocates, alleviating the patient's and their family's suffering and facilitating a peaceful death:

> *"Managing pain, enhancing relatives' presence and maintaining their needs"* (Interview 1).
>
> *"We want peaceful deaths, no grief or struggle for the patient and their family, so we are advocates"* (Interview 2).

The participants recommended preserving the respect and dignity of the patient and their family, as well as maintaining comfort and relaxation, to support a peaceful death:

> *"Keeping the dignity and respect for patient and their family"* (Interview 3).
>
> *"Comfortable, pain free and relaxed"* (Interview 4).
>
> *"Comfort, dignity and a peaceful death"* (Interview 2).

4.10 Conclusion

The results have been reported as two phases. The Phase One questionnaire results included both obstacle items and open-ended responses. These elicited many concerns about providing EoLC related to health professionals and family members in ICUs. The Phase Two interview results largely complemented the concerns highlighted in Phase One and contributed a further perspective to the study. The obstacles to providing EoLC in ICU and the potential implications of these are discussed in more detail in the following chapter.

Chapter Five: Discussion

5.1 Introduction

The findings of an analysis of Intensive Care Unit (ICU) nurses' perceptions of providing End of Life Care (EoLC) in the Kingdom of Saudi Arabia (KSA) are discussed in this chapter. The study was conducted using a sequential explanatory mixed method design and was conducted in two phases. The nurses highlighted many obstacles that may influence EoLC provision in ICUs. The four most commonly cited obstacles in the questionnaire were issues related to patients' families. The fifth-ranked obstacle related to multiple physicians being involved in the care of one patient, but differing in opinions about the goals of care. The open-ended responses identified further obstacles, including the need for EoLC guidelines, language barriers and physician behaviour. Another open-ended question invited participants to suggest ideas that would change EoLC. Participants noted that avoiding unnecessary care, education and preparation for the dying patient and their family for EoLC would improve the standard of care. The major concerns of the findings were explored more fully in the interviews than was possible in the questionnaires.

The major findings of this study are discussed with reference to what is already known about the topic and the outcomes of similar research. The two phases are discussed in tandem because the Phase Two findings of the study complement the Phase One findings. The outcomes of the study have the potential to influence the quality of EoLC in ICUs in the KSA. Broadly, the main obstacles to EoLC in the KSA include family concerns, cultural differences, language barriers, physicians' behaviour, the need for both EoLC guidelines and more nurses being involved in EoLC. These key obstacles and how they influence EoLC in ICUs, identified by participants, are represented in Figure 4.
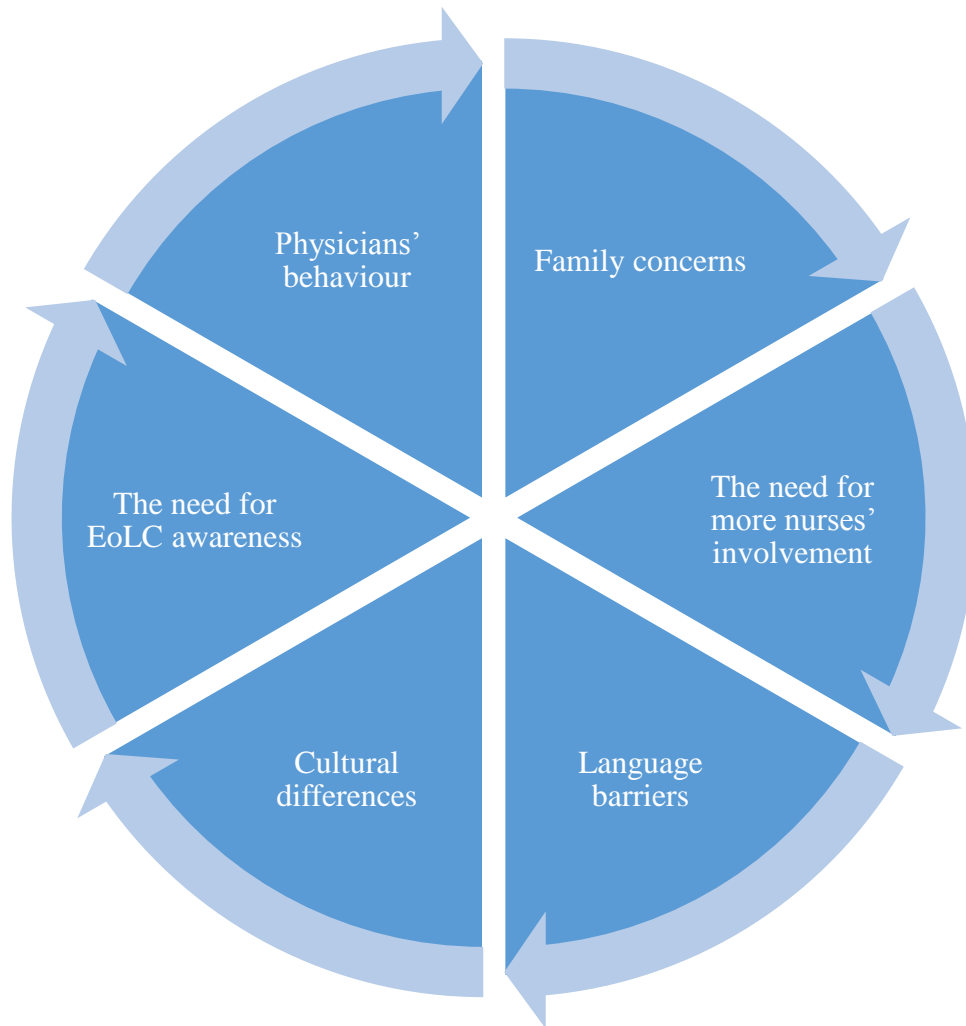
Figure 4. Perceived obstacles to EoLC in Saudi Arabia

5.2 Family concerns

Family issues were the highest-ranking concerns for nurses in providing quality EoLC in the study. This finding is similar to previous studies on the topic (Beckstrand & Kirchhoff, 2005; Crump et al., 2010). Major family issues identified by participants in providing EoLC include the family not accepting the patient's poor prognosis, dealing with difficult family reactions, continual requests for updates on the patient's condition from family members, and the family not understanding what constitutes life-saving measures. Moreover, the findings also show many examples of when

families do not understand the patient's situation or do not understand issues related to EoLC.

The nurses who participated in this study perceived that families want everything to be done for their patient and they refuse palliation care only. Although family acceptance was considered an obstacle to providing EoLC, the nurses found in current study that families need to know that additional interventions might increase the pain and suffering of their patients. Families may not really know what palliative care is. On the other hand, most families in the KSA are Muslim and they believe that all things, good or bad, must be accepted with thanks by saying *Alhamdulillah* (Halligan, 2006). Therefore, more explanations about the patient's situation and a clear plan of care by physicians and other health professionals may enhance family acceptance.

5.3 Physician behaviour

The nurses highlighted some issues related to physicians' roles in EoLC during the study. This concern has also been noted in other research about EoLC in ICUs (Beckstrand & Kirchhoff, 2005; Crump et al., 2010). The issues referred to physicians who differ in opinions from each other, do not communicate a poor prognosis to family members, and intensive care being continued due to fear of the future threat of legal action. The nurses also suggested that families do not understand their patient's condition because no one fully explains it to them. It was also perceived by nurses that physicians do not say someone is dying due to the patients' culture and beliefs. In Islam, it is not permissible to say a patient is dying unless the signs of dying are clearly present (The General Presidency of Scholarly Research and Ifta, 2015b), and perhaps because of this regulation, physicians hesitate to say a patient is dying.

There are Fatwas clarifying the medical position in relation to the end of life and these Fatwas may guide physicians' decisions in EoLC. There are also Fatwas that guide whether the specialist physician considers giving medications to patients more beneficial than harmful to their condition, and whether it is legal to continue the treatment even if there is only a temporary impact (The General Presidency of Scholarly Research and Ifta, 2015b). Another Fatwa clarifies that if three specialist physicians or more agree to withhold technical life support in cases where patients are incapacitated and their condition incurable, their decision is permissible, even though the patients may live longer. The current study showed that sometimes when a patient is dying the physicians did not fully consider the implications of the Fatwas, and may not have educated families sufficiently about their patients' conditions. Sometimes, physicians change the treatment plan to satisfy the family need and this may increase the patients suffering. It seems that in some cases physicians may breach both the Fatwas that clarified the medical position related to EoL and Socratic basic principle of medical ethic of do no harm. The development of clear EoLC guidelines and education that addresses Fatwas, ethical principles, patients' cultures and beliefs may be of benefit for physicians in ICUs in the KSA.

5.4 Cultural differences

The findings revealed that not all families' cultures are understood by nurses. For instance, it was noted that families might put holy oil or water on the patient and this could interfere with patient hygiene. Participants perceived that the practices potentially interfered with nursing care. The example reflects the fact that cultural differences may not be well understood by nurses. However, nurses should acknowledge cultural differences and undergo cultural sensitivity training annually to

enhance their awareness (Hebert, Moore, & Rooney, 2011). This may help nurses to deal with and appreciate patient cultures and beliefs appropriately.

The current study showed contrasting findings in relation to visiting hours. While the obstacles created by liberal visiting hours scored highly in this study, other research scored this item as less of an obstacle to care (Beckstrand & Kirchhoff, 2005; Crump et al., 2010). It is a cultural expectation of Islam in the KSA that people visit those who are sick. Saudi families are committed to supporting their family members and they also have strong ties with their neighbours and friends. This means that families, neighbours and friends tend to visit the sick and dying as a way of supporting them. Visiting those who are sick is highly regarded in the Islamic culture of the KSA (Khan, 1994). A hospitalised person can expect a large number of visitors (Al-Shahri, 2002). However, family members sometimes cry loudly and this can upset other patients. This situation indicates that further arrangements and processes for the environment of dying patients in ICUs need to be considered.

The hospital could have one assigned family member to be a representative for other family members in requesting and relaying information. However, the findings demonstrated that having a designated family member might be less effective because other family members continue to ask for updates and there can be a lack of consensus between family members. This issue has also been noted in two other studies (Beckstrand & Kirchhoff, 2005; Crump et al., 2010). A further study indicated that communication with families in EoL crisis situations is difficult because they may not grasp the reality of the situation (Schaffer & Norlander, 2009).

5.5 Language barriers

Although some nurses considered that language barriers could be managed somehow, some nurses experienced difficulties regarding their communication with dying patients and families because of language barriers. Some nurses also found that Arabic interpreters were found by some nurses to be a barrier to providing EoLC. Therefore, it appears that language barriers may affect nurses' ability to maintain quality of EoLC in ICUs in the KSA.

5.6 The need for more nurses' involvement

This study has revealed concerns about nurses' involvement in the EoLC process. This is evidenced by the findings that nurses have a limited role because they are not treated as knowledgeable independent professionals and it is challenging for nurses to provide unnecessary care. The concern about the lack of nurses' involvement has also been highlighted in other studies, which have found that nurses have a limited role in EoLC decision-making in ICUs (Espinosa et al., 2010). Nurses know the patients best but physicians often do not involve nurses in decision-making regarding the care (Espinosa et al., 2010). The current study showed that nurses stay for a prolonged period of time with patients and this creates a relationship. Therefore, nurses frequently express a desire to be involved in patients' plans of care (Espinosa et al., 2010).

The current study also found that nurses are challenged trying to maintain quality EoLC in ICUs. This study and other research show that nurses' opinions are not valued and there is not enough time to give EoLC (Beckstrand & Kirchhoff, 2005; Crump et al., 2010). These situations may reflect that the nurses' position in providing EoLC in ICUs is weak and their involvement in the decision-making process is

limited. Therefore, the development of EoLC protocols, guidelines, education for nurses about EoLC/palliative care programs in ICU may be benefit to empower nurses' roles and improve EoLC. Furthermore, physicians should be well educated about the significance of nurses' role in providing EoLC in ICU and how it is important to involve nurses in the decision-making.

5.7 The need for EoLC awareness

The findings suggest many issues around EoLC awareness. These concerns relate to the lack of EoLC guidelines, insufficient knowledge among nurses about the dying process, physicians' reluctance to prescribe analgesia and sedation for dying patients, and families not being well supported by health professionals. Some research has suggested that nurses have very little education and training about EoLC in an ICU setting (Holms et al., 2014) and find it is challenging to deal with distressed families reacting to their dying family member (Valiee et al., 2012). In addition, no policies on or protocols for EoLC are in place and therefore organisational support for EoLC is needed (Ranse et al., 2012). Nurses in the current study agreed with this. This situation potentially indicates that there is a need for EoLC guidelines, protocols and education. Therefore, the development of EoLC guidelines, protocols and education programs are perceived by participants as an important strategy to guide the improvement of EoLC in ICUs in the KSA.

Clear EoLC guidelines focused on improving quality of care and meeting the patients' and their families' needs would be a significant improvement. Patients and their families need to be well educated and informed about their condition to meet their needs. This may reflect that quality EoLC is not only the nurses' responsibility but also that of physicians, social workers and other professionals. Therefore, it seems

that EoLC should be enabled by an ICU team approach and decision-making should be coordinated between ICU team members. Many studies encourage teamwork and its outcomes. Combining team members' experiences and knowledge can enhance the kind of creativity that is useful in complex situations (Lonsdale, Webb, & Briggs, 1980). Another view suggests that synthesising team members' assessments and outcomes may enhance a more holistic approach to care (Porter-Williamson, Parker, Babbott, Steffen, & Stites, 2009). Moreover, another study indicates that discussing the dying patient and their families' conditions in a team can also enhance a holistic view of their needs (Klarare, Hagelin, Furst, & Fossum, 2013).

5.8 Summary

The mixed method study explored nurses' perceptions of obstacles to providing EoLC in ICUs . Many obstacles are identified and highlighted in this study. The obstacles to providing EoLC can influence nurses' ability to meet the patients' and their families' needs. The need for communication with the family about their patient's condition is highlighted. Clear EoLC education, training and guidelines are recommended by the participating nurses. In addition, enabling EoLC by ICU teams could enhance a holistic view of patients' and their families' needs. The conclusion of this study is reported in detail in the following chapter.

Chapter Six: Conclusion

6.1 Introduction

This final chapter outlines the conclusions and includes the methodological strengths and limitations of this study. This chapter concludes with the implications for clinical practice, education and research.

6.2 Conclusion

Many issues for providing end of life care (EoLC) in intensive care units (ICUs) in the Kingdom of Saudi Arabia (KSA) were indicated in the findings. Dying patients continue to receive aggressive medical treatments even when this may be futile. It is hoped that the study can inform practice that more education about how cultural differences and language barriers may affect the quality of EoLC may be of benefit for ICU nurses in the KSA. The results of this study also suggest that physicians' behaviours and their roles in EoLC need to be researched because it may affect the quality of EoLC for dying patients and their family members. Participants suggested that avoiding unnecessary care, education and preparation for the dying patient and their families should be included as recommendations from the study. The current study also noted the need of both EoLC awareness and greater involvement of nurses in EoLC decision-making. The findings of this study and the literature review reveal many issues in providing EoLC in ICUs. This may reflect nurses are concerned that dying patients and their families may suffer in the ICUs. Dying patients and their families need to be well educated and prepared about their situation. In addition, effective EoLC protocols and guidelines should be developed and implemented by ICU teams. Therefore, further development of both EoLC guidelines and nursing education about EoLC should be considered in ICUs.

6.3 Methodological strengths and limitations

6.3.1 Methodological strengths

The research used a mixed method sequential explanatory design to explore the study topic in greater breadth than might be possible by using only a quantitative or qualitative method alone.

When the findings of questionnaires showed a variety of EoLC obstacles in providing EoLC, a decision was made to interview experienced ICU charge nurses or managers to gain deeper understanding of these obstacles. Phase Two in this study was developed based on the findings of Phase One. Therefore, Phase Two is complementary and helps to explore the study phenomena in depth (Creswell & Plano Clark, 2011).

Creswell and Plano Clark (2011) consider that the mixed method is a straightforward process because it has two phases and each phase is conducted at different times. This give the researcher an opportunity to conduct each phase of the study separately.

The questionnaire developed by Beckstrand and Kirchhoff (2005) is well known and a number of studies have been conducted around the world utilising their questionnaire (Attia et al., 2013; Beckstrand et al., 2012; Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2009; Losa Iglesias et al., 2013). The internal consistency of this questionnaire was measured by Beckstrand and Kirchhoff (2005). Furthermore, a pilot test was conducted by the researcher to enahnce the reliability of the quetionnaire.

A liaison staff member at the hospital was appointed to negotiate with the staff, distribute explanatory statements and questionnaires and then collect the completed questionnaires on behalf of the researcher. Participation in the research and completion of the questionnaire was voluntary. Furthermore, this liaison person also

negotiated with potential participants in interviews and the researcher then interviewed the eligible participants. All these processes reduced the potential for coercion or bias in the study.

Participants who provided EoLC at least one time in ICU were eligible to participate in Phase One of the study. Managers or charge nurses of ICUs who had experience in providing EoLC in ICUs but did not participate in Phase One were eligible to participate in Phase Two of the study. Managers or charge nurse participants were considered because it was assumed that they would have had more responsibility and experience of EoLC in ICUs. Secondly, it was also anticipated that experienced nurses, who do not participated in the questionnaire phase of this study, would add another dimension to the topic under consideration. Moreover, inclusion criteria ensured that nurses who participated in this study were aware of the topic and could explore obstacles to providing EoLC in an ICU in depth.

6.3.2 Methodological limitations

Seventy-seven participants responded to the questionnaire, which is small, and could therefore not provide statistically significant outcomes. Participation rates in future studies may be improved by recruiting from a range of ICU nurses representative of ICUs throughout the geographic location in which the research is conducted.

The study was conducted in only one large governmental specialist hospital in only one region of KSA and only one Islamic country. Therefore, future research focus on different hospitals type from many regions in KSA may enhance the generalizability of the findings in the KSA.

The intention of this study was to utilise the questionnaire developed by Beckstrand and Kirchhoff (2005), given that it had already been tested, but when the completed questionnaires were collected, an error was found in the 'support' item instructions. Due to this error, the focus of the study by default had to consider the obstacles items only and the support items were ignored. However, a future study including supportive behaviours in providing EoLC in ICU in the KSA would be advised.

6.4 Implications

The current study results have implications for three areas: practice, education and research.

Implications for practice

The findings of this study have revealed new knowledge about obstacles related to providing EoLC in clinical practice in the KSA. The findings indicate that cultural differences and language barriers are an obstacle to maintaining quality EoLC in ICUs in the KSA. Another implication is that phyician behaviours and their different roles regarding EoLC compared to nurses were perceived to affect nurses' ability to maintain quality of EoLC in ICUs. For instance, when physicians do not educate a patient's family about the patient's situation, this may affect family acceptance of the imminent end of life and increase their suffering.

Nurses with a limited role in EoLC could affect the quality of care. Including the nurses in EoLC decision-making may improve the quality of EoLC because they knew the dying patients and their families best. Nurses have more frequent and close contact with dying patients and their family members.

This study suggests that EoLC could be improved by ICU team members who working together to facilitate holistic care and meet the needs of dying patients and their families.

Implications for education

The nurses who participated identified a need for ongoing education and training about the dying process and EoLC, including consideration of patients' cultures and beliefs.

Language barriers and translators who have no training in medical interpreting, particularly about EoLC issues are considered as obstacle to maintaining quality EoLC in ICUs. EoLC is likely to be improved if the nurses who provide EoLC can speak the language of the people they care for. It would therefore be an advantage if expatriate nurses studied the national language of the country in which they practise and train interpreters for the medical conditions.

Physicians should be well educated about the significance of nurses role in providing EoLC in ICU and how it is important to involve nurses in the decision-making. Furthermore, physician need more education about both Fatwas in KSA and patients and their families should be well educated of the right situations.

Education for dying patient and their family about EoLC and clear information about the situation may enhance their acceptance of impending death. This education process could be enabled by ICU team to enhance the shared decision- making between family members and health professionals in ICUs.

Implications for research

Further research focusing on the dying patient's family and physician perspectives of EoLC obstacles are important to explore the phenomenon more widely. Articulating obstacles from family and physician perspectives involved in EoL may significantly help to overcome EoLC obstacles. When obstacles to the provision of EoLC in ICUs are widely articulated, it may support the planning and development of clear EoLC protocols and guidelines or pathways that can be implemented by ICU teams to improve EoLC. This process may improve EoLC and more fully meet the needs of dying patients and their families in ICUs in the KSA.

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XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

Appendices

Appendix 1. Communication with Renea Beckstrand

Renea Beckstrand <Renea_Beckstrand@byu.edu>

16/09/2014

to me

Here is the questionnaire. The margins are wrong due to it being created in a different program. If you complete any translation you must sent me a copy of the translated questionnaire. If you publish your research, I need a copy of the publication or at least a link. You have permission to complete this study in Australia only. Best wishes, Renea

Renea L. Beckstrand, PhD, RN, CCRN, CNE

Professor

Brigham Young University, College of Nursing

Provo, UT 84602

renea@byu.edu

From: Zakaria Ahmed Mani [mailto:zaman2@student.monash.edu]
Sent: September 10, 2014 7:09 AM
To: renea@byu.edu
Subject: Inquiry of supportive and obstacle of providing EoLc questionnaire.

Zakaria Ahmed Mani <zaman2@student.monash.edu>

16/09/2014

to Renea

Hello Dr Renea,

Actually, I would like to conduct this study in my country Saudi Arabia, So could I do it in my country instead of Australia?

Thank you a lot for your cooperation.

Regards,

Zakaria Mani.

Renea Beckstrand <Renea_Beckstrand@byu.edu>   16/09/2
                                                               014

to me

Yes, you can complete it in your home country as long as it is not the U.S.A. Renea

From: Zakaria Ahmed Mani [mailto:zaman2@student.monash.edu]
Sent: September 16, 2014 11:47 AM
To: Renea Beckstrand
Subject: Re: Inquiry of supportive and obstacle of providing EoLc questionnaire.

Zakaria Ahmed Mani <zaman2@student.monash.edu>   16/09/2
                                                               014

to Renea

Thank you a lot, and I will follow your considerations as well.

My warm regards,

Zakaria Mani.

Appendix 2 Questionnaire used in this study

Intensive Care Unit (ICU) Nurses' Perceptions of Providing End-of-Life Care in Saudi Arabia

The end of life is currently recognised as an important life phase. Critical care nurses are frequently responsible for care of patients who are at the end of life and dying. Care dilemmas arise for nurses as dying patients are placed in an environment created to support and sustain life.

The following items pertain to your perceptions of possible **obstacles** in providing end-of-life care to dying patients and their families. As you read each item, please **circle** the numeric response that most closely characterises how **much of an obstacle** you have found each item and then **circle** the other numeric response for how **frequently** you have experienced the obstacle as you have cared for dying patients.	**0** = Not an Obstacle **1** = Extremely Small **2** = Small Obstacle **3** = Medium Obstacle **4** = Large Obstacle **5** = Extremely Large	**0** = Never Occurs **1** = Almost Never Occurs **2** = Sometimes Occurs **3** = Fairly Often Occurs **4** = Very Often Occurs **5** = Always Occurs
1. Physicians who are overly optimistic to the family about the patient surviving.	0 1 2 3 4 5	0 1 2 3 4 5
2. Families not accepting what the physician is telling them about the patients poor prognosis.	0 1 2 3 4 5	0 1 2 3 4 5
3. The nurse having to deal with distraught family members while still providing care for the patient.	0 1 2 3 4 5	0 1 2 3 4 5
4. Intra-family fighting about whether to continue or stop life support.	0 1 2 3 4 5	0 1 2 3 4 5
5. The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	0 1 2 3 4 5	0 1 2 3 4 5
6. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patients' life.	0 1 2 3 4 5	0 1 2 3 4 5
7. Poor design of units which do not allow for privacy of dying patients or grieving family members.	0 1 2 3 4 5	0 1 2 3 4 5
8. Unit visiting hours that are too restrictive.	0 1 2 3 4 5	0 1 2 3 4 5
9. The patient having pain that is difficult to control or alleviate.	0 1 2 3 4 5	0 1 2 3 4 5
10. Dealing with the cultural differences that families employ in grieving for their family member.	0 1 2 3 4 5	0 1 2 3 4 5
11. No available support person for the family such as a social worker or religious leader.	0 1 2 3 4 5	0 1 2 3 4 5
12. Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	0 1 2 3 4 5	0 1 2 3 4 5

The following items pertain to your perceptions of possible **obstacles** in providing end-of-life care to dying patients and their families. As you read each item, please **circle** the numeric response that most closely characterises how **much of an obstacle** you have found each item and then **circle** the other numeric response for how **frequently** you have experienced the obstacle as you have cared for dying patients.	0 = Not an Obstacle 1 = Extremely Small 2 = Small Obstacle 3 = Medium Obstacle 4 = Large Obstacle 5 = Extremely Large	0 = Never Occurs 1 = Almost Never Occurs 2 = Sometimes Occurs 3 = Fairly Often Occurs 4 = Very Often Occurs 5 = Always Occurs
13. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	0 1 2 3 4 5	0 1 2 3 4 5
14. Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	0 1 2 3 4 5	0 1 2 3 4 5
15. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	0 1 2 3 4 5	0 1 2 3 4 5
16. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designed family member for information.	0 1 2 3 4 5	0 1 2 3 4 5
17. Lack of nursing education and training regarding family grieving and quality end-of-life care.	0 1 2 3 4 5	0 1 2 3 4 5
18. Physicians who won't allow the patient to die from the disease process.	0 1 2 3 4 5	0 1 2 3 4 5
19. The unavailability of an ethics board or committee to review difficult patient cases.	0 1 2 3 4 5	0 1 2 3 4 5
20. Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	0 1 2 3 4 5	0 1 2 3 4 5
21. Unit visiting hours that are too liberal.	0 1 2 3 4 5	0 1 2 3 4 5
22. Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	0 1 2 3 4 5	0 1 2 3 4 5
23. The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	0 1 2 3 4 5	0 1 2 3 4 5
24. The nurse having to deal with angry family members	0 1 2 3 4 5	0 1 2 3 4 5
25. The family, for whatever reason, is not with the patient he or she is dying.	0 1 2 3 4 5	0 1 2 3 4 5
26. Physicians who are evasive and avoid having conversations with family members.	0 1 2 3 4 5	0 1 2 3 4 5
27. Multiple physicians, involved with one patient, who differ in opinion about the direction of care that should go.	0 1 2 3 4 5	0 1 2 3 4 5

The following items pertain to your perceptions of possible **obstacles** in providing end-of-life care to dying patients and their families. As you read each item, please **circle** the numeric response that most closely characterises how **much of an obstacle** you have found each item and then **circle** the other numeric response for how **frequently** you have experienced the obstacle as you have cared for dying patients.	0 = Not an Obstacle 1 = Extremely Small 2 = Small Obstacle 3 = Medium Obstacle 4 = Large Obstacle 5 = Extremely Large	0 = Never Occurs 1 = Almost Never Occurs 2 = Sometimes Occurs 3 = Fairly Often Occurs 4 = Very Often Occurs 5 = Always Occurs
28. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	0 1 2 3 4 5	0 1 2 3 4 5
29. When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	0 1 2 3 4 5	0 1 2 3 4 5

30.   Please describe any missing obstacles in detail. Indicate how <u>large</u> each obstacle is and how <u>frequently</u> it occurs.

_____

31.   If you had the ability to change just one aspect of the end-of-life care given to dying ICU patients, what would it be?

_____

Now please tell a little about yourself by circling and filling the appropriate answers.

32.   How many years of experience do you have as a **RN**? _____

33.   How many years of **ICU** experience do you have? _____

34.   What is your gender?

Male☐

Female☐

35.   What year were you born? 19_____

36.   What is your **highest completed** level of education?

☐ Undergraduate nursing qualification

☐ Postgraduate nursing qualification

☐Postgraduate nursing qualification (Critical Care or Intensive Care)

☐Other_____

37.   Over your nursing career, how many ICU patients have you, yourself given immediate end-of-life care to?

☐ Less than 5   ☐ Between 11 and 20   ☐ More than 30

☐ Between 5 and 10   ☐ Between 21 and 30   ☐ Other_____

38.   In which **type of ICU** are you primarily employed?

☐ Intensive Care Unit   ☐ Coronary Care Unit

☐ Combined ICU/CCU   ☐ Other (Please specify)

39.   The **position** you hold at the facility is?

☐ Direct care/Bedside/Staff Nurse   ☐ Clinical Nurse Specialist

☐ Charge Nurse/Staff Nurse   ☐ Other (Please specify)_____

40.   What is the number of beds in your unit? _____

41.   How many **hours per week** do you usually work in ICU?

42.   Do you have any comments about this study?

_____

_____

_____

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY.

PLEASE RETURN THE QUESTIONNAIRE

IN THE ENCLOSED ENVELOPE

Appendix 3. Monash Human Ethics Certificate of Approval

MONASH University
Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

> **Project Number:** CF15/518 - 2015000245
>
> **Project Title:** Intensive Care Unit Nurses' Perceptions of Providing End of Life Care in Saudi Arabia
>
> **Chief Investigator:** Ms Katrina Recoche
>
> **Approved:** **From:** 23 March 2015   **To:** 23 March 2020

Terms of approval - *Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.*

1. The Chief investigator is responsible for ensuring that permission letters are obtained, <u>if relevant</u>, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must include your project number.
6. **Amendments to the approved project (including changes in personnel):** Require the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.

8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.

9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.

10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.

11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Nip Thomson
Chair, MUHREC

cc: Dr Melissa Bloomer, Mr Zakaria Mani

Monash University, Room 111, Chancellery Building E
24 Sports Walk, Clayton Campus, Wellington Rd
Clayton VIC 3800, Australia
Telephone: +61 3 9905 5490 Facsimile: +61 3 9905 3831
Email: muhrec@monash.edu
http://intranet.monash.edu.au/researchadmin/human/index.php
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix 4. Flyer

MONASH University

A research project is being conducted in this ICU

Intensive Care Unit (ICU) Nurses' Perceptions of Providing
End-of-Life Care in Saudi Arabia

This research project is being conducted by a student from Monash University, and has ethics approval from KFSH & RC and the Monash University Human Research and Ethics Committees.

The aim of this project is to explore ICU nurses' perceptions of providing end-of-life care in ICUs in Saudi Arabia. If you work in the ICU and have experience in providing end-of-life care to at least one patient, then we would appreciate your participation. Explanatory Statements, questionnaires and envelopes for return of completed surveys will be provided in your work area. Please read the Explanatory Statement carefully before deciding to complete the questionnaire. Completing this questionnaire may take up to 40 minutes.

Should you have any concerns or require more information about the research project, we would welcome your enquiries.

Who can I contact?

For further information concerning this project, please contact the liaison person

Name: Mahmoud Ibrahim.

Email: mibrahim@kfshrc.edu.sa

Mobile: +966502740902

For complaints about any aspect of this research, such as how it is being conducted or any enquiries about participating in this research project in general, you may contact:

Name: Sofia Macedo, Nursing Research Senior Specialist.

Email: mmacedo96@kfshrc.edu.sa.

Telephone:+966114647272

Appendix 5. Questionnaire Explanatory Statement

EXPLANATORY STATEMENT

(Questionnaire)

Project title: Intensive Care Unit (ICU) Nurses' Perceptions of Providing End-of-Life Care in Saudi Arabia

Chief Investigator's name	**Student Investigator's name**
Katrina Récoché	Zakaria Mani
School of Nursing and Midwifery	Phone : +966508585585
Phone: +61 3 9904 4655	email: Zaman2@student.monash.edu
email: Katrina.Recoche@monash.edu	

You are invited to take part in this study because you work in an Intensive Care Unit. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

This research is being conducted using an anonymous questionnaire. Completing this survey may take up to 40 minutes.

Who can be involved in this research?

You have received this information because you are an ICU nurse of the KFSH & RC. This research is open to Registered Nurses working in ICUs in KFSH & RC in Riyadh, Saudi Arabia, with experience in care of dying patients. If this is you, then we would appreciate your participation.

Source of funding

This project is funded by Ministry of Higher Education, Cultural Mission of Royal Embassy of Saudi Arabia in Australia. There are no perceived conflicts of interest.

Consenting to participate in the project and withdrawing from the research

Please read this Explanatory Statement before deciding to participate in this study. Your consent will be implied by you taking and/or completing the survey. Participants have the right to withdraw from completing this survey at any time.

Possible benefits and risks to participants

Participation in this anonymous questionnaire may take up to 40 minutes. It is not expected that participation in this questionnaire will have any risk to participants other than the inconvenience of time to complete it.

There is no direct benefit to participants for taking part in this study other than the opportunity to share your perspectives on the topic. The results of this study may contribute to improving end-of-life care in ICUs in Saudi Arabia. The results also may influence practices in countries with similar cultures and beliefs.

If you become uncomfortable at any point, please cease completing the questionnaire.

Confidentiality

No identifiable data will be collected. That is, no data will be collected that will enable another person to identify you. All data will be reported as aggregate findings, further protecting your anonymity and confidentiality. When the findings of the survey are published, only the aggregate findings will be used.

Storage of data

Data related to this study will be stored in the locked office of the student researcher and only be accessible to the student researcher. All electronic data will be password-protected.

Results

At the completion of the study, we aim to publish the results in an academic journal and/or conference presentation. The results will also be shared with KFSH & RC in the form of a final report.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the **liaison person:**

Mahmoud Ibrahim

Email: mibrahim@kfshrc.edu.sa

Mobile: +966502740902

Thank you,

Signature

Katrina Récoché

Appendix 6. Hospital Office of Research Affair Approval

OF Ś CH

MBC 03, Fax 27894, Ext ☎32907

INTERNAL MEMO

TO: Zakaria Mani, Master Candidate, RN   DATE: 30 Jumad Al Thani 1436
Mani_Zakaria@yahoo.com   19 April 2015

Mahmoud Ibrahim, RN
Clinical Instructor, Critical Care Nursing
Nursing Affairs

FROM: Ammar Al Kawi, MD   REF: ORA 0508 36
Acting Chairman, Research Ethics Committee
Office of Research Affairs

SUBJECT: Project # 2151 074
Intensive Care Unit Nurses Perceptions of Providing End of Life Care in Saudi Arabia

The above-referenced proposal was reviewed expediently by the Research Ethics Committee (REC on 16 April 2015. It is my pleasure to inform you that the REC has recommended the proposal for approval as submitted; and I would like to take this opportunity to congratulate you on behalf of the Research Advisory Council.

Please be informed that in conducting this proposal, the Investigators are required to abide by the rules and regulations of the Government of Saudi Arabia, ... Further, you are required to submit a Progress/ Final Report by 16 March 2016; so it can be reviewed by the REC without lapse of approval. The approval of this proposal will automatically be suspended 16 April 2016, pending the acceptance of the Report. You also need to notify the ORA as soon as possible in the case of any amendments to the project, termination of the study, any event or new information that may affect the benefit/risk ratio of the proposal. Further, the Committee would like to remind you that the process of obtaining the Verbal Consent should be documented in the Medical Record/Investigator file of enrolled subjects. This should clearly specify:

1. The research subject' acceptance to participate in the study;
2. The project's RAC number;
3. The date the verbal consent was obtained;
4. The name and signature of the principal investigator delegate.

Please observe the following:

1. Personally identifying data should only be collected when necessary for research.
2. The data collected should only be used for this proposal.
3. Data should be stored securely so that only a few authorised users are permitted access to the database.
4. Secondary disclosures of personally identifiable data are not allowed.
5. Should there be a need to contact the research subjects for follow-up information, you will need to seek the authorisation of the RAC prior to such contact.

We wish you every success in your research endeavours.

AK GH   cc Ms. Marinha Ma   nt & Saudization Depar nt
ORA   RAC File
A   Ir karia Mani RE pproval   E Mail ·
r

101

Appendix 7. Interview Questions

Interview questions/prompts

CF15/518-2015000245

Intensive Care Unit (ICU) Nurses' Perceptions of Providing End-of-Life Care in Saudi Arabia

Question 1 - What is good end-of-life care?
Question 2 - Are there obstacles to good end-of-life care in the ICU?

With each of the obstacles the participant identifies in Question 2, ask the following:-
    a) Can you tell me a little more about how that impacts on good end-of-life care?
    b) Can you give an example?
    c) What strategies do nurses use to minimise the obstacle?

(If not already identified in Question 2 above):

Question 3 – Does culture or religion impact on your ability to provide good end- of-life care in the ICU? If so, how?

Question 4 – Does language have an effect on providing good end-of-life care?

Question 5 – As a nurse, how do you feel about the quality of end-of-life care you provide?

Question 6 – Does providing end-of-life care in ICUs have an impact on the nursing workforce?

Question 7 – Is there anything else you would like to add?

Appendix 8. Explanatory statement for the interview

<div align="center">

EXPLANATORY STATEMENT (Interview)

</div>

Project title: Intensive Care Unit (ICU) Nurses' Perceptions of Providing End-of-Life Care in Saudi Arabia

Chief Investigator's name	**Student Investigator's name**
Katrina Récoché	Zakaria Mani
School of Nursing and Midwifery	Phone : +966508585585
Phone: +61 3 9904 4655	email: Zaman2@student.monash.edu
email: Katrina.Recoche@monash.edu	

This research has been approved by the Monash University Human Research Ethics Committee (CF15/518-2015000245). In the first phase of the research ICU nurses completed questionnaires about end-of-life care in ICUs. You are invited to take part in the second phase of this study because you work in a senior nursing role in an Intensive Care Unit. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the telephone numbers or email addresses listed above.

What does the research involve?
This phase of the research is being conducted using interviews. An interview will be conducted at a time and location suitable to you. The interview will be conducted by Zakaria Mani who can be contacted by email (zaman2@student.monash.edu) or telephone as listed above to make an appointment. It is anticipated that the interview will take no more than 45 minutes of your time.

Who can be involved in this research?
You have received this information because you are a senior ICU nurse at the KFSH & RC. This research is open to senior Registered Nurses working in ICUs in KFSH & RC in Riyadh, Saudi Arabia, with experience in care of dying patients. If this is you, then we would appreciate your participation.

Source of funding
This project is funded by Ministry of Higher Education, Cultural Mission of Royal Embassy of Saudi Arabia in Australia. There are no perceived conflicts of interest.

Consenting to participate in the project and withdrawing from the research:

Please read this Explanatory Statement before deciding to participate in this study. If you agree to being interviewed you will be asked to sign a consent form.

Possible benefits and risks to participants
Participation in the interview may take up to 45 minutes of your time. It is not expected that participation in an interview will have any risk to you, other than the

inconvenience of time to complete it. There is no direct benefit to participants for taking part in this study other than the opportunity to share their perspectives on the topic. It is hoped that the results of this study will contribute to improving end-of-life care in ICUs in Saudi Arabia. The results also may influence practices in countries with similar cultures and beliefs. That is why your thoughts on the topic will be so valued. If you become uncomfortable at any point, please indicate this to the interviewer and the interview will be terminated immediately.
Confidentiality

No identifiable data will be collected. That is, no data will be collected that will enable another person to identify you. All data will be reported as aggregate findings, further protecting your anonymity and confidentiality. When the findings are published, only the aggregate findings will be used.
Storage of data

Data related to this study will be stored in the locked office of the student researcher and only be accessible to the student researcher. All electronic data will be password-protected. After five (5) years all data will be destroyed in accordance with Monash University Human Research Ethics Committee guidelines.

Results

At the completion of the study, we aim to publish the results in an academic journal and/or conference presentation. The results will also be shared with KFSH & RC in the form of a final report, copies of which will be made available in the ICUs from which study participants were drawn.

Complaints
Should you have any concerns or complaints about the conduct of the project, you are welcome to contact either:

The Liaison person at KFSH & RC**:** Mahmoud Ibrahim **Email**: mibrahim@kfshrc.edu.sa **Mobile**: +966502740902	The Executive Officer Monash University Human Research Ethics Committee (MUHREC) Room 111, Building 3e Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Email: muhrec@monash.edu Fax: +61 3 9905 3831

 Thank you,

Katrina Récoché

Appendix 9. Consent

CONSENT FORM

Interview

Project: Intensive Care Unit (ICU) Nurses' Perceptions of Providing End- of-Life Care in Saudi Arabia.

Chief Investigator: Katrina Recoche

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following:	Yes	No
Participating in an interview either face-to-face or by telephone or Skype	☐	☐
Audio recording during the interview	☐	☐

Name _____ of
Participant _____

_____

Participant's
Signature _____ Date _____

Appendix 10. Example of manifest content analysis of Questionnaire comments

Meaning Unit	Interpretation	Sub-theme	Theme
Comment on obstacle in EoLC. "Lack of knowledge of the dying processes of the patients." (Participant 20)	One comment in the survey proposed that lack of EoLC guidelines and education could influence nurses' ability to provide EoLC, highlighting that lack of nurse's knowledge about the dying process in the ICU was a challenging issue.	Lack of knowledge of the dying process	Lack of EoLC protocols or guidelines
Comment on obstacle in EoLC. "In Saudi, nurses are treated as helpers only, not as professionally qualified nurses." (Participant 29)	This comment suggests that nurses are not treated as knowledgeable independent professionals in the perception of physicians and the community. Some nurses felt that they were seen in a support role and not appreciated for their specialist skills and knowledge.	Nurses are not well treated as an independent profession	Nurse' burden
Comment on aspect would change EoLC "Avoid intensive care and painful activities." (Participant 19) "Avoid unnecessary line insertion like chest tube or urostomy, which is extremely painful for the patient who is dying." (Participant 9)	Comments imply that intensive care and painful interventions could increase a dying patient's suffering and prolong their death and therefore this care should be avoided.	Avoid intensive care and painful interventions	Avoiding unnecessary care

Appendix 11. Example of manifest content analysis of interview results

Manifest content analysis of interview results

Meaning Unit	Condensation	Interpretation	Sub-theme	Theme
Sometimes family use treatment of honey and holy oil for their dying patient when there is already signs of infections. This is not good for patient but we respect their culture and believe and we inform them it can cause infection. Even if we prevent this, they will inform physicians and physician will allow them because they have the same culture and believe. So this is most of the time is hindrance of our care.	"Sometimes, families use a treatment of honey and holy oil for their dying patient when there are already signs of infection... We inform them it can cause infection... [However] Physicians allow them because of their culture and beliefs. This mostly hinders nursing care." (Interview 3)	According to the nurses, nursing care can be affected by culture and beliefs. For instance, using honey and holy oil for dying patients when there are signs of infections. Sometimes, nurses educate family on the consequences of such actions, but physicians allow such cultural beliefs, which may hinder nursing care. When nurses are responsible to maintain patient health and respect patients and their family's beliefs, this situation reflects an ethical dilemma between nursing care and patient and their family's beliefs.	Physician does not educate family due to the culture	Family does not understand the patient's situation

Meaning Unit	Condensation	Interpretation	Sub-theme	Theme
Sometimes we cry when patient passed away, we feel what the relative feel particularly when patient stay longer time we feel a little attached with them.	"When patients stay longer we feel a little attached and we cry if they pass away." (Interview 1) "We are with the patients more than the physician is and our emotional stress can affect the quality EoLC. We need emotional stability." (Interview 2)	The nurses said that they became emotionally stressed when caring for dying patients longer. Providing nursing care to a patient for a prolonged period of time creates a relationship, making it difficult for the nurses when the patient passes away. This could impact the provision of EoLC and therefore, nurses' emotional stability should be considered.	Nurses emotionally distressed	Lack of EoLC protocols or guidelines
The education supposedly given by physician because we as a nurse we cannot tell the full detail. We always have a restriction of given information even though we know the patient condition and what will happen then.	"Sometimes, they speak good English but don't know medical terms. Sometimes an interpreter who is not a medical practitioner does not describe the actual condition or does not understand the patient and their family due to different cultures. This is really the big hindrance." (Interview 3)	One nurse suggested that families who do not speak English well or who have interpreters who are not medical professionals could have difficulties in their understanding. Sometimes, different cultural backgrounds affect interpreters' understanding, or the interpreter does not clarify the patient's condition well. Therefore, a language barrier can be a big challenge in providing EoLC.	Lack of Arabic language	Language obstacles