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OBSTACLES AND SUPPORTIVE BEHAVIOURS TO END-OF -LIFE CARE IN ADULT INTENSIVE CARE UNITS: PERCEPTIONS OF INTENSIVE CARE NURSES

Patricia Dorsaa

A research report submitted to the
Faculty of Health Sciences, University of the Witwatersrand, Johannesburg
in partial fulfilment of the requirements for the degree
of
Master of Science in Nursing

Johannesburg, 2019

DECLARATION

I, Patricia Dorsaa, declare that this research report is my own work. It is being submitted for the degree of Master of Science (in Nursing) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature …….

……day of …… 2019

Protocol Number M180746

DEDICATION

Dr. Paul Ofori Atta for stepping in when I lost my dad

and

Edward Dayirabie Dorsaa, my late dad

ACKNOWLEDGEMENTS

To God Almighty, Father I am grateful for your goodness and mercy.

To Prof. Shelley Schmollgruber, my supervisor and great mentor, my heartfelt gratitude for your time, support and patience.

To the institution where the study was done and to all my study participants. This report could not have been possible without you. Thank you.

To my mom, brothers, Edward, Solomon and Emmanuel, my beloved Freddie, friends, colleagues and loved ones, thank you for your immense support and prayers.

ABSTRACT

Background: Despite the efforts of Intensive Care clinicians to save lives, the Intensive Care Unit is a common place of death. Globally, one out five (20%) Intensive Care admissions die before, or shortly after discharge. Evidence indicates that critically ill patients are at risk of having their end-of-life care needs unmet. Intensive Care nurses are mandated to provide optimal end-of-life care to dying patients and their families, however, these nurses are reported to face challenges providing optimal care and sometimes suffer moral distress. These, and the limited studies on obstacles and supportive behaviours to providing end-of-life in adults ICUs in South Africa, necessitates studies on the phenomenon to help improve care for dying patients and their families.

Purpose: The purpose of this study was to identify and describe the obstacles and supportive behaviours to providing end-of-life care in adult ICUs as perceived by Intensive Care nurses.

Method: A non-experimental quantitative descriptive survey and cross-sectional design was used for this study. The entire population of Intensive Care nurses in adult ICUs in the selected study site were invited to participate in the study. The National Survey of Critical-Care Nurses Regarding End-of-Life Care Questionnaire, developed by Beckstrand and Kirchhoff (2005), was adopted for data collection. Data was collected in one month and analysed with STATISTICA statistical software version 13.2. Descriptive statistical tests, including measures of frequency, central tendency and dispersions, were used to analyse the data. Hsieh and Shannon's (2005) descriptive summative method of content analysis was used to analyse open-ended questions.

Setting: The study was conducted in five adult ICUs namely cardiothoracic, coronary care, multidisciplinary, neurosurgery and trauma ICUs of an academic hospital in Johannesburg.

Results: 91 Intensive Care nurses from the five adult ICUs completed the survey, representing 86.7% response rate. The top three perceived obstacles were, frequent calls from family for update on patient, nurses having to deal with distraught family and dealing with angry family members. The three largest and most frequently occurring supportive behaviours were allowing families adequate time to be alone with the patient after death, providing peaceful and dignified bedside scene for the family after the patient's death and having the physician meet the bereaved family in person after the patient's death to offer support.

Conclusion: The major obstacles and supportive behaviours to optimal end-of-life care in adult ICUs are related to patient family issues. This may be attributed to the uniqueness of each families' needs.

Keywords: end-of-life care, Intensive Care Unit, critically ill patient

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CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

This chapter outlines the presentation of this study. It begins with the background of the study, the problem statement, purpose and objectives, significance of the study, operational definitions, overview of research methodology, validity and reliability, and the ethical considerations observed.

1.1 BACKGROUND OF THE STUDY

Intensive Care is a distinct medical specialty in healthcare. It is made up of a multi-disciplinary and specialised inter-professional team who use advanced technology for close monitoring, and apply various interventions to help patients survive reversible critical or life-threatening illnesses and injuries. Presently, the scope of intensive care practice is beyond the Intensive Care Unit (ICU). It encompasses provision of compassionate care during end-of-life, supporting families, rehabilitation of ICU survivors, and preparing societies for future crises (Marshall et al., 2017).

Despite the efforts of Intensive Care clinicians to save lives, the ICU is a common place for death (Norton, Hobson & Kulm, 2011). Globally, about one in every five (20%) ICU admissions die before or shortly after discharge (Angus et al., 2004). Thus, caring for dying persons forms an essential part of intensive care. Latour, Fulbrook and Albarran (2009) define end-of-life care as the care given to persons whose critical illness cannot be reversed including the support given to their families after the decision to withhold and/or to withdraw life-sustaining treatments has been concluded. It involves interventions aimed at reducing suffering and assisting patients who are confronted with death to have the best life possible before they die (Izumi, 2012). Patients' families are also supported to cope with patient's poor prognosis and transition. Weyant et al. (2017) identified nursing behaviours, such as providing information, reassurance, exhibiting proficiency, being present and providing guidance to patients and families, as supportive.

End-of-life issues in the ICU, and particularly the decision to either withhold or and withdraw life-sustaining treatment, are complex and emotionally charged with ethical issues. When interventions to reverse critical illness do not work, there may be the need to stop all treatments that sustain life. This is done on the basis that continuous treatment is medically inappropriate, “futile,” and the patient will not benefit, but it will somewhat prolong death and suffering. At this point, the quality of the dying process becomes an important outcome measure (Myburgh et al., 2016, Truog et al., 2008). The focus of care needs to be redirected from restorative to comfort care. The transition from cure to comfort care can be stressful and it has been reported to be the most difficult period for clinicians, patients and their significant others (Festic, 2010). Festic reported on how some physicians are unwilling to initiate end-of-life care because to them it means they are giving up on the patient and have failed to rescue them. Coombs, Addington-Hall and Long-Sugehall (2012) also highlight how Intensive Care nurses have challenges transitioning from cure to comforting care. These and many other factors do not only put ICU patients at risk of not having their end-of-life care needs met (Zhang, Nilsson & Prigerson, 2012), but also causes moral distress amongst Intensive Care clinicians (Henrich et al., 2017). Zhang argues that patients who receive timely and adequate end-of-life care are saved from unwanted prolonged procedures and thus have better quality of life prior to dying.

Nurses are uniquely placed to offer compassionate and skilled care when death is inevitable. It is known generally that nurses are the care professionals who work closely and spend the most time with the patients. Therefore, they are often the first to detect a change in patients’ condition. They are also able to develop relationships with patients and their families. Through nurse-patient interpersonal relationships, nurses can elicit patients’ values and preferences and integrate them into care to enhance the provision of comprehensive care. Thus, Intensive Care nurses need to engage in therapeutic interactions via active listening and investing time to understand patients and their families’ perception and understanding of prevailing situation before planning and implementing care plans (Weyant et al., 2017). This may not be possible for the Intensive Care nurse. Aside from the fast-paced and stressful environment these nurses work in, patients admitted into the ICU are in the acute face of illness, and may be sedated and intubated as part of their treatment. This limits communication and the opportunity for Intensive Care nurses to form relationships with their patient (Beckstrand et al., 2008: Truog et al., 2008).

The limitations in the ICU do not exempt Intensive Care nurses from fulfilling their mandate of providing comprehensive care and advocate for patients to enhance quality end-of-life care (Izumi, 2012; Harris, Gaudet & O'Reardon, 2014). In an editorial, Dracup and Bryan-Brown (2005) highlighted the emotional distress nurses go through when end-of-life care is delayed because either the medical team or patient's relatives have not accepted the inevitability of imminent death. According to Beckstrand and Kirchhoff (2005), on the premise of hope, some family members or patient's surrogates reject the poor prognosis of their loved ones and attempt to overturn the advance directives of patients. Henrich et al. (2017) underscores the negative impact of moral distress in the ICU to include compromised patient care and high health professional turnover rates. For Intensive Care nurses to give their best, they need to address their own emotions and concerns regarding working with dying patients and their families daily (Kisorio & Langley, 2016). Ranse and Yates (2015) recommend that healthcare clinicians should be supported by their institutions and be adequately prepared to enable them to render quality end-of-life care.

Literature suggests that Intensive Care nurses want to give optimal end-of-life care. However, these nurses have challenges providing such care to patients in an 'ICU' created to possibly save and support life (Beckstrand & Kirchhoff, 2005). South African Intensive Care nurses are reported to be less involved in decisions preceding withdrawal of life support (Langley et al., 2013). Caring behaviours in the ICU can be undermined by factors such as the working environment, dysfunctional inter professional communication on care goals, inadequate resources, family behaviours (such as over optimism about patient poor prognosis, frequent calls for update) and nurse workload (Beckstrand & Kirchhoff, 2005; Attia, Abd-Elaziz & Kandeel, 2012; Bloomer & O'Connor, 2012).

Although some studies have been done on obstacles and facilitators regarding optimal end-of-life care (Beckstrand & Kirchhoff, 2005; Attia, Abd-Elaziz & Kandeel, 2012; Iglesias, Pascual, & de Bengoa Vallejo, 2013), there is paucity of literature on the phenomenon within the South African context. Differences exist in healthcare practices around the globe, and from setting to setting. Adopting strategies developed in other settings may not be applicable in South Africa. It is therefore imperative to know Intensive Care nurses' perceptions on the extent to which specific obstacles and

supportive behaviours have an impact on their practice in the ICU. This may help provide information to better describe the phenomenon and guide the development of local strategies to enhance nursing care in adult ICUs. Thus, the researcher intends to study obstacles and supportive behaviours to providing end-of-life care to dying patients and their families as perceived by Intensive Care nurses in adult ICUs, in an academic hospital in Johannesburg.

1.2 PROBLEM STATEMENT

Due to advances in medical technology, death has become more painful, especially in the ICU where death may be preceded by the withdrawal of the patient from life-support. Studies show that the transitioning from cure to comfort care is stressful and challenging for physicians, nurses, patients and their significant others. Furthermore, there appears to be a strong indication that balancing between the demanding roles of using technology, addressing patient needs and the dichotomy between saving lives and improving care for dying patients puts pressure on the roles of Intensive Care nurses. These challenges may hinder optimal end-of-life care and reported to cause moral distress among the nurses. Although some studies have been done on barriers and facilitators to end-of-life care, there is little evidence of South African Intensive Care nurses' views on this topic in adult ICUs. Results of this study may provide information to help stakeholders in the development of local strategies to improve end-of-life care.

The research question addressed in this study was:

- What are Intensive Care nurses' perceptions of obstacles and supportive behaviours to end-of-life care in adult CUs?

1.3 PURPOSE OF THE STUDY

The purpose of this research was to identify and describe nurses' perceptions of behaviours that are obstacles to or support the provision of effective end-of-life care in adult ICUs of an academic hospital in Johannesburg.

1.4 RESEARCH OBJECTIVES

The objectives of this study were:

- To identify and describe nurses' perceptions of behaviours that are obstacles to end-of-life care.
- To identify and describe nurses' perceptions of supportive behaviours that facilitate optimal end-of-life care.

1.5 SIGNIFICANCE OF THE STUDY

This study sought to gather information about Intensive Care nurses' perceptions of the obstacles and supportive behaviours to end-of-life care in adult ICUs. Knowing this information may guide stakeholders to adopt local and culturally sensitive reforms to improve ICU nursing practices, such as enhancing the supportive behaviours and reducing or possibly eliminating the obstacles. Improved end-of-life practices will complement patients' family satisfaction and facilitate the achievement of closure after patient death. This may also go a long way in helping to address moral distress among Intensive Care nurses, thereby improving overall health outcome in the ICU, and curb the tendency of high staff turnover rates. For the researcher, the outcome of this study will guide future research.

1.6 OPERATIONAL DEFINITIONS

Definitions for the purpose of this study are as follows:

- **Adult Intensive Care Unit**

A specially staffed designated area within a hospital with complex technologies for close monitoring and management of adult patients with a potentially reversible life-threatening condition or injuries (Marshall et al., 2017). For this study, five Intensive Care Units namely; Cardiothoracic, Coronary care, Multi-disciplinary, Neurosurgery and Trauma ICUs will be involved.

- **Critically ill patient:**

An adult patient admitted to the ICU with life-threatening illness or injury who requires life-sustaining treatment and continuous haemodynamic monitoring.

- **Family:**

Persons biologically or emotionally related to the critically ill, including friends and loved ones.

- **Intensive Care nurse:**

Also known as a Critical Care nurse, this is a registered nurse, with an additional specialisation in Intensive Care, who applies high-level knowledge and decision-making skills and competencies to care for critically ill patients and support patients and their families through the critical illness to discharge or to a peaceful death (De Beer, Brysiewicz & Bhengu, 2011).

- **End-of-life care:**

In the ICU, end-of-life care refers to activities that assist patients confronted with death to have the best life possible by promoting comfort and preventing suffering. Latour, Fulbrook and Albarran (2009) defines it as the care and support dying patients and families receives after the decision to withhold or to withdraw life-sustaining treatments has been made.

- **Perceptions:**

Perception is defined as an idea, belief or image that someone has based on how he/she understands something (Oxford Dictionary, 2007). In this study, perceptions of nurses will be attained by nurses completing the survey on Critical Care Nurses Regarding of End-of-Life Care (Beckstrand & Kirchhoff, 2005).

- **Obstacles:**

Obstacles are factors that interfere with an action or process (Oxford Dictionary, 2007). In this study, obstacles are the challenges, impediments or barriers that interfere with or prevent Intensive Care nurses from providing optimal, effective or evidenced-based end-of-life care.

- **Supportive Behaviours:**

Being supportive is defined as providing encouragement or emotional help (Oxford Dictionary, 2007). Supportive behaviours, in this study, are helpful actions that enhance, assist and facilitate the provision of effective, optimal or evidence-based end-of-life care and pain relief.

1.7 OVERVIEW OF RESEARCH METHODOLOGY

Research methodology refers to the “overall plan that guides a study to have control over the factors that could interfere with desired outcomes” (Burns & Grove, 2009). An overview of the research methodology is provided in the next section, which will be discussed in detail in Chapter Three.

A descriptive and cross-sectional survey design was utilised in this study, using a self-administered questionnaire developed by Beckstrand and Kirchhoff (2005). The study respondents were ICU nurses affiliated to ICUs at a 1,088 public sector hospital in Johannesburg; the ICUs included Multi-disciplinary, Trauma, Cardiothoracic, Neurosurgical and Coronary Care.

Ethical clearance and permission to conduct the study (appendix C) was obtained from the Human Ethics Committee (Medical) of the University of the Witwatersrand, the hospital Chief Executive Officer (CEO) and Director of Nursing Services for the Gauteng Department of Health (appendix D). Permission to use the research instrument (appendix F) was granted by the originators. Participation in this study was voluntary and respondents were free to withdraw at any time.

After permission was obtained from the hospital and relevant ICU nurse managers, the questionnaires were distributed. It was indicated that return of a completed questionnaire was accepted as consent given. Descriptive statistics were employed to analysed results of the study, with STATISTICA (version 13.2) used for analysis of the data. Categorical data (demographic and questionnaire schedule) were analysed using frequencies and percentages. In addition, content analysis was used for the analysis of the open-ended questions, using the descriptive summative method of Hsieh and Shannon (2005).

Reliability of the study was maintained by ensuring the researcher adhered to the guidelines provided by the developers of the questionnaire. The researcher was the sole data collector. The convenience sampling method was utilised to achieve the study sample. Face and contentment validity of the questionnaire was achieved by ensuring the questionnaire, used for data collection, was verified by a small group of local domain experts to confirm applicability of the questionnaire to the South African context. Methods of trustworthiness were followed in the content analysis, and audit trail was conducted. Findings were verified by an experienced nurse researcher.

1.8 OUTLINE OF THE STUDY

The study will be presented as follows;

Chapter One:	Overview of the study
Chapter Two:	Literature review
Chapter Three:	Research methods
Chapter Four:	Results
Chapter Five:	Discussion of findings, limitations and Recommendations

1.9 SUMMARY

This chapter provided an overview of the study. The background of the study was described, followed by the problem statement, the research questions, study objectives and operational definitions. The overview of the study methodology, validity and reliability and ethical considerations have been outlined. The next chapter will discuss the literature review.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

End-of-life care in a setting created to support life can be challenging for caregivers (Combs, Addington-Hall & Long-Sugehall, 2012; Vanderspank-Wright, Efstathiou & Vandyk, 2018). In South Africa, Intensive Care nurses suffer moral distress in addition to other challenges when caring for dying patients and their relatives (Kisorio & Langley, 2016; Langley et al., 2013), a situation that has instigated worldwide concerns amongst clinicians in the Unit. Consequently, research about the phenomenon has been recommended to explore opportunities that may enhance the practice. This study aims to identify and describe behaviours that may obstruct and or help provide effective end-of-life care as perceived by Intensive Care nurses in adult ICUs.

This chapter analyses existing literature to provide the context within which to situate this current study (De Vos et al., 2010). The review will entail the description of critical illness, end-of-life care, withholding and or withdrawal of life-sustaining treatment, collaborative care, practices during end-of-life, role and perception of the family and nurses, obstacles and supports towards end-of-life care.

2.2 CRITICAL ILLNESS AND THE INTENSIVE CARE UNIT

Critical illness is an acute state of a patient with multisystem life-threatening illness or injuries, resulting in physiological deterioration and multisystem processes that may lead to significant morbidity and mortality. The critically ill patient requires prompt attention and admission into the ICU for constant monitoring and comprehensive care, including aggressive life-sustaining therapies such as respiratory and cardiovascular support with mechanical ventilator and vasoactive medications respectively (Drews, 2013; Robertson & Al-Haddad, 2013).

The ICU is a specially staffed and equipped setting within a hospital, created to provide care for patients with life-threatening conditions. The staff is made up of multidisciplinary professionals including physicians, Intensive Care nurses, respiratory therapists, pharmacists, dieticians, physiotherapists, radiology technicians, social

workers, and spiritual carers. The team use rapid decision-making skills and advanced technology to apply various interventions to help patients survive reversible critical illnesses and injuries (Marshall et al., 2017). Central to the activities of the highly technological ICU environment is the Intensive Care nurse who provides care by applying high-level knowledge and decision-making skills for complex patient assessment, continuous patient monitoring, prompt administration of therapies and interventions, documents patient's status and serves as an advocate for the critically ill and their families (De Beer, Brysiewicz and Bhengu, 2011; Drews, 2013). Munro and Savel (2018) describes the medical and nursing approach to critical illness as assertive and intense respectively.

Admission into the ICU is perceived differently by the patients, their families and clinicians. Angus et al. (2004) describes the ICU experience as traumatic and fear provoking, to the patient, it may indicate a threat to life and well-being, whilst families' experiences may cause them to perceive the admission as a sign of impending death. Intensive Care nurses view the Unit as a place where delicate lives are keenly looked after and preserved. Understanding what intensive care means to patients and families is important to guide nursing care (Morton et al., 2005).

2.3 DYING IN THE ICU

Despite the efforts of Intensive Care clinicians to save lives, not all patients survive (Norton, Hobson & Kulm, 2011). The trajectory of critical illness is not always known, and there are times when death occurs suddenly. Sometimes death occurs after aggressive resuscitative efforts have failed, other times it may be anticipated when options to reverse critical illness have been exhausted with no sign of recovery. Thus, there may be conscious movement over time in which treatment goals change from providing aggressive curative therapies to comfort-directed plan of care. Comfort care may involve withholding or withdrawing specific therapies to focus on reducing suffering and alleviating pain of patients and their families (Coombs, Addington-Hall & Long-Sugehall, 2012; Fridh, Fosberg & Bergbom 2007; Gallagher et al., 2015).

Globally, approximately one in 5 (20%) ICU admissions die before or shortly after discharge (Angus et al., 2004). South Africa's ICU mortality rates are higher (31.5%) due to the quadruple disease burden profile, acuity of illnesses and limited resources,

including shortage of specialised Intensive Care nurses (De Beer, Brysiewicz & Bhengu, 2011; Scribante, Schmollgruber & Nel, 2004). The decision to withhold and or to withdraw life-sustaining treatment is common when patients are unresponsive to curative measures (Sprung et al., 2014) and so is end-of life care.

Dying patients may not live to tell us their experiences but literature on ICU survivors suggests that patients admitted to the ICU are at risk of developing psychological symptoms such as anxiety, depression and post-traumatic stress, symptoms that may impair their quality of life (Combe, 2005; Scragg, Jones & Fauvel, 2001).
A South African study on ICU survivors' experiences showed that 58% of the respondents had combined anxiety and depression symptoms, which was described by the authors as severe enough to cause a possible clinical disorder. In the study, 48% of participants had symptoms of anxiety, 28% depression, 32% post-traumatic stress (Hachett, Langley & Schmollgruber, 2010).

Nursing care focused towards averting these symptoms may help to ensure 'good death' in the ICU. Omerov and colleagues (2013) observed that measures undertaken around the time of death could reduce the negative impacts of death on surviving families and healthcare professionals. Buckley et al. (2015) reported that bereavement intensity remained high when surviving families perceive that the death of their loved one was violent, prolonged and when the dead seemed to have suffered. Experiences of patient's deaths in the ICU can be viewed on a continuum. Along this continuum of care is a multitude of complex issues that patients, patient's family and the healthcare team must work through to optimise care of the dying patient. (Morton et al., 2005).

2.4 END-OF-LIFE CARE

The concept end-of-life care may be interchanged with palliative care. While palliative care is recommended for all seriously ill patients in order to improve symptom management, the former is indicated for the period leading to the death of a patient with poor prognosis. Knowing the difference between these two concepts helps caregivers to provide appropriate care to their patients (Munro & Savel, 2018). In the ICU, end-of-life care involves the care and support offered to patients, who have been withdrawn from life support, and their relatives (Latour, Fulbrook & Albarran, 2009). Evidence shows that about 76% of ICU deaths are preceded by withdrawal of life

support (Sprung et al., 2003; Wilkinson & Savulescu, 2012), with 72% dying within six hours (Bloomer et al., 2010). Therefore, nurses have limited time to give adequate care and death may be deemed unnatural.

Beckstrand, Callister and Kirchhoff's (2006) study, involving 861 Intensive Care nurses, sought to collect suggestions that may improve end-of-life care. 'Good death' emerged as the main theme, where nurses ensured that patients died at peace and in a dignified manner. To the respondents, this could be accomplished when the following were done: dying patients are not left alone; patients' pain and discomfort is adequately managed; patients' values and preferences are inculcated in nursing care; timely withdrawal of life support; effective communication between the multidisciplinary team, patient and or family; professional end-of-life training and education; creating public awareness.

In another study, Zomorodi and Lynn (2010) explored what nurses viewed as quality end-of-life care in relation to the personal, relational and the environmental conditions that impact on the care. The researchers identified four themes that nurses engaged in to optimise care, which included, (1) finding the balance between utilising technology and the needs of the patient, (2) trial and error, (3) coaching the physician and (4) taking a step back. Aside adequate pain management and the adoption of patient- and family-centred care, because of the peculiar needs of each family, respondents pointed out that having effective communication skills was paramount to quality care.

Despite the varied end-of-life practices around the world, health professionals have accepted the principle that, dying patients have the right to a dignified death (Sprung et al., 2014). According to Cook and Rocker (2014), dignified death among ICU patients can be ensured when healthcare professionals enhance care by identifying the dying patient's unique perspective on what is meaningful to determine which vital therapies to be withheld or withdrawn. Cook and Rocker considered this as key to providing care that is consistent with the dying patient's values as death approaches. Unfortunately, this is not always done.

Problems with end-of-life care have existed since the invention of ICUs (Coombs, Addington-Hall & Long-Sugehall, 2012: Fridh, 2014). In the early eighties, Intensive Care nurses recognised some dilemmas with end-of-life care, which led to some

studies identifying obstacles to providing the care and the impact end-of-life decisions have on ICU nurses (Dunaway, 1988; Webster, 1985). Dunaway reported on the need for collaboration to facilitate the processes leading to withdrawal of vital interventions, and Webster recommended that nurses required support and coping strategies and clinicians had to be honest about end-of-life communications. Intensive Care practices continue to evolve. Current practices have been associated with their own ethical challenges. For example, it is recommended that ICU patients should have lighter sedation (Barr et al., 2013), which implies patients in the ICU are likely to be conscious of their worsening condition and may be aware of their impending death (Fridh, 2014). The dilemma this may pose may include whether to involve the patient in determining the goal of care.

Even though nurses are mandated to care for dying patients and their relations, collaboration among the multidisciplinary team facilitates the process. Brooks, Manias and Nicholson (2016) recommend collaboration and leadership during transitions of care to improve the end-of-life decisions.

2.5 COLLABORATION IN END-OF-LIFE CARE

Collaboration is the practice where “individual team members assume profession-specific roles, but as a team they identify and analyse problems, define goals and assume joint responsibility for actions and interventions to accomplish the goals” (Counsell et al., 1999: 1145). Effective inter-professional collaboration does not only have positive correlation with improved health outcomes, including patients and patients’ families’ satisfaction, but also foster increased active participation in clinical decision making and respect for each team member’s contribution (Zwarenstein & Reeves, 2006).

Literature indicates that inter-professional collaboration is necessary in end-of-life care (Espinosa et al., 2010, Festic et al., 2012; Montagnini, Smith & Balistrieri, 2012). It is also evident that nursing and medical staff have divergent views and competencies on certain aspects of end-of-life practices (Festic et al., 2012; Flannery, Ramjan & Peters, 2016; Montagnini, Smith & Balistrieri, 2012). For example, physicians are reported to be more confident with end-of-life communication, while nurses are better providers of comfort care, including pain management (Moss et al., 2005).

Even though the ICU healthcare team is made up of several specialties (Marshall et al., 2016), Reeves, Nelson and Zwarenstein (2008) suggest that a successful service delivery is dependent on the effective collaboration between nurses and physicians. Festic et al. (2010) describe Intensive Care nurses and physicians as the principal healthcare providers for the critically ill, thus, their collaboration is crucial to optimal end-of-life care. Disagreements between physicians and nurses about the direction of care are common, reportedly one of the largest obstacles to effective end-of-life care and could cause job strains in the ICU (Azoulay et al., 2009; Beckstrand & Kirchhoff, 2005).

In an explorative study to determine the experiences and perspectives of nurses and physicians regarding communication and shared decision-making, Brooks, Manias and Nicholson (2017) realised the need for improved inter-professional acceptance and application of end-of-life care plans. Nurse and physician-led end-of-life decision-making and communication was recommended to advance outcomes for caregivers, patients and family. When nurses and physicians collaborate and communicate effectively, positive outcomes such as improvement in quality of care and patient safety are achieved (Rose, 2011).

Nurses are more likely to know the preferences and values of patients and the family because they are usually with the patient, yet are hardly consulted (Kisorio & Langley, 2016).

2.6 END-OF-LIFE DECISION-MAKING, WITHHOLDING AND WITHDRAWAL OF LIFE-SUSTAINING THERAPIES.

Thelen (2005) defines end-of-life decision-making as the steps taken by patients and/or families and healthcare providers to determine what treatment is appropriate for the critically ill. Ongoing advances made in medical technology, medicine and pharmacology give hope to many. These, in addition to prognosis uncertainty and not knowing when to start end-of-life discussion with families, make decisions on withholding and withdrawing life-sustaining therapies complex and challenging (Coombs, Addington-Hall & Long-Sugehall, 2012).

The need to withhold or withdraw patients from life-sustaining treatments becomes imperative when medical options to reverse critical illness are exhausted. It is done on the basis that continuous treatment is medically inappropriate, “futile,” and the patient will not benefit, but it will somewhat prolong death and suffering. At this point, the quality of the dying process becomes an important outcome measure (Myburgh et al., 2016; Truog, et al., 2008).

Withholding treatment is a situation where the multidisciplinary team resolve not to initiate a life-sustaining intervention nor augment what has been started. Conversely, withdrawal is actively terminating treatment (Sprung et al., 2014). Deciding on whether to withdraw or withhold an intervention may raise ethical concerns which impacts on Intensive Care practices. The ethical question dominating health discourse is the distinction between the life-saving use of new technologies in the ICU, versus death prolonging and a misuse of limited ICU resources (Kompanje et al., 2013). Thus, ethical issues of patient autonomy, informed consent, inter-professional relationships and resource distribution should be considered in clinical decision-making (McCarthy et al., 2011; Schmollgruber, 2006).

Challenges associated with deciding on which intervention to withdraw or withhold prompted the development of ethical framework of good practice by many countries, including South Africa, to guide ICU clinicians. Some of the points to consider include:

- The framework encourages the multidisciplinary team to communicate effectively, which necessitates the inclusion of patients and or families in discussing the plan of care for a patient with poor prognosis.
- The ultimate decision-maker is the senior physician responsible for the patient. However, he or she must not hasten the process until after consultation with the multidisciplinary team.
- The views and preferences of the patient and patient’s significant others should be integrated in the patient end-of-life care plan. The team leader should have adequate information from the bedside caregivers regarding patients and their families’ understanding of the current situation, their coping mechanisms and their decision-making styles.
- The clinician in-charge should ascertain whether the patient could participate in the decision-making. Patients’ participation or otherwise determines the venue for discussion.

- Team members, including patients and or the family, should agree and be clear about the goal of care and their individual roles.
- After all the consultations, the reasons and procedures in the decision-making process must be well documented, including any misunderstanding and how it was resolved (Crowe, 2017; Flannery, Ramjan & Peters, 2016; Gallagher et al., 2015; Health Professional Council of South Africa (HPCSA); Medina & Puntillo, 2006).

In-spite of the guidelines, evidence shows that the decision process is fraught with numerous challenges. Aside from family members' disagreements among themselves or with ICU healthcare team (Beckstrand et al., 2017; Friedenberg et al., 2012), other factors such as disagreement among the multidisciplinary team on the plan and goal of care (Brooks, Manias & Nicholson, 2017; Espinosa, 2010) and physicians being evasive and focusing on curative measures rather than comfort care (Coombs, Addington-Hall & Long-Sugehall, 2012; Festic, 2010) have been reported. Stacy (2012) argues that for patients to experience peaceful death and for families and healthcare providers to experience closure, the decision-making process warrants continuous planning and management in addition to effective communication among the parties involved.

2.7 END-OF-LIFE CARE PRACTICES IN ADULT ICU

Evidence shows variations in end-of life practices across settings. Recommended withdrawal practices include the discontinuation of all curative and supportive measures such as antibiotics, vasoactive medications, dialysis and mechanical ventilation, routine monitoring, haemodynamic monitoring, pulse oximetry, electrocardiography, serial laboratory tests, parenteral nutrition and blood transfusions; also, all tubes, drains and catheters are removed. The only exception may be an intravenous catheter for the administration of pain medications and a nasogastric tube may be left in-situ if vomiting is anticipated **(**Cox et al., 2005**;** Szalados, 2007**;** Troug et al., 2008),

In 2009, Latour, Fulbrook and Albarran conducted a survey on the views and attitudes of European Intensive Care nurses towards end-of-life; 164 nurses attending an international conference participated in the survey. The researchers reported that the

majority of respondents (91.8%) were directly involved in end-of-life care, with 73.4% reporting they participated in decision-making. Even though findings suggested nurses had similar perceptions and attitudes, variations in views regarding some aspect of end-of-life practices were reported. The majority of respondents agreed on practices such as continuous pain relief for dying patients (98.8%), open visitation (91.3%), commitment to family involvement in decision-making (78.8%) and decreasing the flow of inspired oxygen to room air (65%). However, 78% were against transferring dying patients to a single room, a practice that has been perceived as support for dying patients and their family in other studies. No consensus was reached on whether the dying patients should have deep sedation (44% were for deep sedation) and continuation of nutritional support (41.6 vs 42.3%).

A similar study, conducted in South Africa, by Langley and colleagues (2013) involved 100 Intensive Care nurses within Johannesburg. The researchers modified the VENICE tool by Latour, Fulbrook and Albarran (2009). Results showed that 67% of respondents directly care for patients at the end-of-life, but only 29% of them are engaged in planning the direction of care for dying patients. Eighty six percent indicated commitment to family involvement in decision-making. Results regarding practices on withdrawing and or withholding life sustaining therapy were, 54% of respondents supported decreasing the flow of inspired oxygen to room air, continuous pain relief (84%), open visitation (72%) while 68% felt nursing the dying patient should be continued in the ICU. The majority of the nurses (62%) indicated they were against keeping the patient deeply sedated, and regarding continuation of nutritional support and hydration, the majority of nurses (84% and 85% respectively) were in favour; 93% also supported religious, traditional or cultural rituals for the patient.

On comparing the two studies, the majority (73.4%) of European Intensive Care nurse partake in end-of-life decision-making, while South African nurses are rarely involved (29%). However, South African Intensive Care nurses are more certain about which interventions to provide during care for the patient.

An Australian study identified six core practices undertaken by Intensive Care nurses when caring for patients at the end-of-life. These included, sharing information, setting up patient's surrounding to suit the event, giving emotional support, adopting patient- and family-centred decision-making, management of patients' symptoms and offering

spiritual support. However, the researchers found that the nurses' level of engagement in these practices were of varying degrees. It was reported that, the nurses were less engaged in symptom management and emotional support. (Ranse, Yates and Coyer, 2016).

The literature search thus far has shown varying practices and perceptions on end-of-life care across settings. Ambiguity in care for dying patients is attributable to lack of practical guidelines or standardised approach to care (Coombs et al., 2015; Flannery, Ramjan & Peters, 2014; Noome et al., 2016), which contribute to the challenges nurses face. In a recent review paper, Crowe (2017) developed an *ICU withdrawal of Life-Sustaining Therapies Bedside Nursing Checklist* to help nurses to enhance care for dying patients and their family. The checklist is a 14-item guideline put into three sections: Decision-making, Preparation and Implementation. When implemented, the checklist may promote best practice and provide a standardisation for end-of-life care. Nonetheless, further research may be indicated before widespread adoption across Critical Care settings.

2.8 PERCEPTION AND ROLE OF THE FAMILY

Literature illustrates that patients are rarely admitted with advance directives. Most critically ill patients remain unconscious due to the critical illness or from treatments such as sedation, thus ICU clinicians rely on the patient's families for decision making to direct the goal and plan of care (Kentish-Barnes et al., 2009). Families act as the patient's representative by proxy, family spokesperson and partner in care giving emotional support to patients (Quinn et al., 2012). Even though there is a high tendency to concentrate mainly on the dying person, it is imperative to be concerned about the health and welfare of the bereaved families. Studies show that ICU bereaved survivors are at increased risk for complicated grief, prolonged grief, post-traumatic stress, major depression, anxiety and sleep disorders (Azoulay et al., 2005; Gries et al., 2010; Sundararajan et al., 2014).

A phenomenological study to explore family members experience from admission through to end-of-life care in adult ICUs and bereavement, reported that families felt confronted with the threat of losing a dear one. Families were distressed with uncertainty and felt left out of the care of their loved ones (Fridh, Fosberg and

Bergbom, 2009a). Although family members wanted to be close and included in decisions (Wiegand, 2006), the physical environment, critical nature of critical illness and the sophistication of medical equipment used for monitoring and supporting patient's life deterred them; this leads to the feeling of guilt. Fridh, Fosberg and Bergbom (2009a) study indicated that family members felt being cared for or 'piloted' by carers when they were welcomed, informed and trusted, and experienced togetherness. To the family, a lack of piloting meant they were not involved in caring and physically separated from the dying.

A cross sectional survey was conducted in five tertiary teaching hospital across Canada by Heyland et al. (2006) to investigate and report on what seriously ill patients and their families perceived to be the essentials of quality end-of-life care; 440 patients, 176 family members, and 160 relations were surveyed. The elements defined by participants as most important to quality end-of-life care were: 1). Having trust and confidence in the physicians taking care of patients; 2). Avoiding futile life support therapies; 3). Honest communication about patient's prognosis; 4). Having the opportunity to prepare for end of life and to say goodbye; 5). Life completion. Even though the researchers identified significant variations in the ratings among the groups, they concluded that the key to quality end-of-life care was hinged on improving relationships and communication between physicians, patients and patient's relatives and more importantly, individualised care.

Since patients' families are also at risk of distress and complicated grief, advocates recommend the concept of *'care triad,'* which is a three-way partnership or interaction involving patient, the family and nurses. Care triad acknowledges, supports, and respects the distinctive psychological, socio-demo graphic, cultural and health-related attributes of the parties involved (Cannaerts, Dierckx & Grydonck, 2004; Kolmer et al., 2008; Noome et al., 2016b). Kolmer further explains that nurses have the responsibility to explore the possibilities of family participation in patient care and to determine the boundaries of their involvement to curtail them from being overburdened physically, psychologically or socially.

Contributions from families are significant to providing optimal end-of-life care. Beckstrand et al. (2017) reported on an increase in family-related obstacles to optimal end-of-life care. This coupled with the uniqueness of each patient's family needs, calls

for attention on family care. Follow up visits to the ICU after a patient's death was recommended by Van der Klink et al. (2010), as during this time, families could have questions answered and the reassurance from carers helps to address their concerns and any challenge they may have.

2.9 PERCEPTION AND ROLE OF THE INTENSIVE CARE NURSE

Intensive Care nurses deal with dying patients and their significant others on a regular basis. Nurses may not be the ultimate decision-makers, but they are implementers of the decisions made by the physician and are involved in the aftermath of such decisions (Hov, Hedelin & Athlin, 2007). After finalising the decision on withholding or withdrawal of life-sustaining therapies, members of the multidisciplinary team practically withdraw, making the care for the dying patients and family the responsibility of the bedside nurse (Espinosa et al., 2010). Despite Intensive Care nurses' willingness to be involved, they are often left out during end-of-life decision-making (Latour, Fulbrook & Albarran, 2009; Langley et al., 2013; Kisorio & Langley, 2016). Several studies have established that Intensive Care nurses play key roles in facilitating the transition from cure to comfort care.

The role of the Intensive Care nurse is an "attempt to counter the dehumanising impact of a highly technological environment and to prioritise a peaceful death when cure is no longer possible" (Gallagher et al., 2015: 801). These have an impact on the end-of-life experiences of patients and families. Evidence shows that beneficial results, such as the achievement of closure of all the parties involved and decreased risk for prolonged grief, can be attained when nurses provide adequate end-of-life care (Fouche, 2006; Ranse, Yates & Coyer, 2012).

Hov, Hedelin and Athlin (2007) used a phenomenological approach to probe what withdrawal or withholding life-sustaining treatments meant to Intensive Care nurses. Four themes were identified; Nurses were 1). lonely executing their responsibilities, 2). either optimistic or pessimistic depending on patients' condition, 3). in a constant shadow of uncertainty, and 4). prided themselves in their professionalism despite little formal influence. Intensive Care nurses perceived their role as both fulfilling and demanding. Hov and colleagues appreciated their roles, and described them as interpreters and dedicated helps.

In a recent systematic review, Vanderspank-Write, Efstathiou and Vandyk (2018) identified four main patterns engaged by Intensive Care nurses as they cared for patients withdrawn from life supports. Nurses dealt with challenges and conflicts, provided individualised care, involved patient families and handled the emotions associated with withdrawal of treatments. It was reported that nurses are poised to do their best for patients and families despite the challenges and the complexity of the process.

In another study, Adams et al. (2011) analysed studies on the roles of nurses and strategies employed in end-of-life decision-making. They found an increasing trend in nurses' advocacy role in "challenging the status quo and helping all the parties to see the bigger picture" (Adams et al., 2011:12). By engaging families through interpretation and explanation of happenings, family members were more satisfied, able to accept patient prognosis and participated in decision-making. The researchers summarised the roles of nurses into three: being a liaison between family members and the family and other health team members, supporting and empathising with family and physicians and advocating for physicians and family. However, it was unclear how these roles were enacted.

Gallagher and colleagues (2015), through grounded theory, explored nurses' end-of-life decision-making practices across varied cultural contexts. They came up with the theory of *negotiated re-orienting,* which involves nurses interacting with patients and the families with the aim of getting them to agree and accept the need to redirect care goals from curative to comfort care. According to the authors, this approach helps patients and families to experience good death in the ICU. The study revealed that Intensive Care nurses use two core practices to facilitate the process: *1). Consensus seeking via* persuasions until the parties come to terms with reality of patients' poor prognosis and *2). emotional holding* by providing support and comfort. The authors concluded that the part nurses play in making end-of-life decisions is clear, but these roles are complicated in a medically dominated practice area.

Ranse, Yates and Coyer (2016) also established that Intensive Care nurses play an essential role in facilitating transition from cure to comfort care by giving information, listening to concerns and intervening if possible, altering the environment to make it suitable for the dying and comfortable for the family, giving emotional support, involving

patient and family in making decisions, managing symptoms and providing spiritual support.

Noome and colleagues (2016b) conducted an integrative review to determine whether nursing dying persons was related to the care triad. They found care was centred round the patient, the patient's family and the environment. Noome et al. generated four role categories, care of the ICU patient, the family, environmental aspect and organisational aspect of end-of life care. Even though the researchers could not determine how nurses carry out their roles, it was evident there was a dichotomy between the theoretical model of care triad and actual practice; relational aspect of care was missing, and patient families were inadequately cared for. The researchers recommended the need for Intensive Care nurses to be sensitive to existing relationships to help curtail or decrease post-traumatic stress disorder among families.

It is evident that Intensive Care nurses play significant roles when transitioning from cure to comfort care, however, the manner or attitudes towards these roles is unclear.

2.10 OBSTACLES TO OPTIMAL END-OF-LIFE CARE

Studies have described some factors or behaviours obstructing optimal end-of-life care in the ICU (Attia, Abd-Elaziz & Kandeel 2012; Beckstrand & Kirchhoff 2005; Iglesias, Pascual & de Bengoa Vallejo, 2013). The common themes identified are patient/family-related factors, physician-related factors, nurse-related factors and environmental or institutional factors.

2.10.1 Patient/Family factors

Some of the identified factors attributed to patients and their families include lack of advance directives and no surrogate decision-maker (Fridh, Fosberg & Bergbom, 2009b; Friedenberg et al., 2012), pain that is difficult to manage, family's unwillingness to accept patient's poor prognosis and unrealistic expectation (Espinosa, 2010; Fridh, Fosberg & Bergbom, 2009b; Iglesias, Pascual & de Bengoa Vallejo, 2013; Nelson et al., 2006). Family interruptions with persistent calls (Attia et al., 2012), disagreements among family members on the direction of care (Friedenberg et al., 2012), families attempting to overturn patient's advance directives (Iglesias, Pascual & de Bengoa

Vallejo, 2013; Nelson et al., 2006), family absence when patient is dying, and their lack of understanding of life-saving measures.

The study by Nelson and colleagues (2006) was a national survey involving 600 adult ICUs in the United States. The aim was to research ICU directors' (nurses and physicians) views and experiences on the obstacles to optimal care for dying ICU patients and to determine the type, availability and specific strategies that may enhance care. The findings revealed that barriers to optimal end-of-life care were common and frequent. Patient and family-related obstacles were the most highly rated. Approximately 50% of the directors indicated that patient and family unrealistic expectations and patients' inability to be involved in discussions hugely obstructed optimal care.

Espinosa et al. (2008) reported unrealistic family expectations as destructive, time consuming and increased stress for nurses. Intra-family fighting, conflict and indecisiveness have been found to delay the planning and actual performance of end-of-life care, thereby creating tension and distress for patients, the family and caregivers (Kramer et al., 2006).

In another study (Friedenberg et al., 2012), researchers sought to determine whether the level of healthcare training, discipline or institution impact on the perceptions of obstacles to end-of life care. Respondents indicated that lack of advanced directives, patient inability to participate in end-of-life decision process and unrealistic expectations of families presented as obstacles to care. The study confirmed that the variables had significant impact on perceptions thus recommended the development of local strategies to improve care.

2.10.2 Physician related factors

Interestingly, both physicians and nurses perceive physicians as the ones who greatly hinder optimal end-of-life care (Festic et al., 2010). Physicians are reported to be uncomfortable initiating the process because to them, a patient's death is a failure to rescue (Coombs, Addington-Hall & Long-Sugehall, 2012). Flannery, Ramjan and Peters (2016) identified indecision on futility of treatment and delay as to when to start end-of-life discussion as major interference. To nurses, continuing aggressive

treatment despite poor patient prognosis delays transition from curative to comfort care. It denies Intensive Care nurses the opportunity to provide their core mandate of providing comfort and compassionate care leading to inadequate time for optimal end-of-life care. The consequences are feelings of powerlessness, decreased job satisfaction, moral distress and high attrition rates among Intensive Care nurses (Henrich et al., 2016; Rushton, Caldwell & Kurtz, 2016).

Disagreement among physicians on patient's prognosis has also been found to hinder optimal end-of-life care (Beckstrand & Kirchhoff, 2005; Espinosa et al., 2010, Zomorodi & Lynn, 2010). Nurses are reported to struggle with end-of-life care when there is dissonance regarding treatment goals among physicians (Kirchhoff et al., 2000). Zomorodi and Lynn gave an account of how different specialist teams, such as renal, neurology or cardiology, met with patients' families on different occasions with varied opinions. These create unrealistic expectation and intra-family conflicts.

Others include physician's attitudes of either being overly optimistic to family, being evasive and avoiding end-of-life conversation with families (Attia, Abd-Elaziz & Kandeel, 2012; Iglesias, Pascual & de Bengoa Vallejo, 2013). These may be attributed to the findings of Nelson et al. (2006), which suggested that physician's inadequate training on end-of-life communication and insufficient communication between the parties involved, hinder optimal end-of-life care.

2.10.3 Nurse-related factors

The lack of adequate formal end-of-life content in the curriculum of nursing training at the various levels is reported as a huge obstacle to caring adequately for dying patients (Attia, Abd-Elaziz & Kandeel, 2012; Espinosa, 2010; Nelson et al., 2006). Consequently, nurses have difficulty with end-of-life communication (Brooks, Manias & Nicholson, 2017; Montagnini, Smith & Balistrieri, 2012), and this greatly obstructs optimal care (Flannery, Ramjan & Peters, 2016).

Evidence shows that nurses' inexperience with handling end-of-life issues and difficulty coping with nursing dying patients on regular basis hinders the provision of optimal care. Some nurses described the experience as painful, traumatic, heart breaking and

depressing. Addressing Intensive Care nurses' coping mechanisms may help them to better handle distraught family members and the stressful situations associated with nursing dying patients, thereby improving end-of-life care (Espinosa, 2010; Kisorio & Langley, 2016; Zomorodi & Lynn, 2010). The inability of Intensive Care nurses to elicit information regarding patients' values and preferences is also considered a major obstacle (Zomorodi & Lynn, 2010).

Efstathiou and Walker (2012) reported that ambiguity of nurses' responsibilities and lack of guidelines on end-of-life care practices create uncertainties, distress among nurses and impact negatively on care. Although South African nurses are reported to be more certain about which practices to employ (Langley et al., 2013), discrepancies and uncertainties about which monitors or technology to turn off and what end-of life care practices are ethically acceptable have been documented in literature (Coombs et al., 2015; Fridh, 2014; Zomorodi & Lynn, 2010). Zomorodi and Lynn indicated that, the practice of reducing technology was used by Intensive Care nurses as a strategy for providing comfort for patient family and for making the nurses themselves feel better.

2.10.4 ICU environment/Institutional practices

Studies have indicated that the physical space and the conditions that prevail there could obstruct the delivery of optimal end-of-life care. The ICU is a fast paced and stressful environment, characterised by noise from staff and alarms, monitors and machines. Even though ICU designs differ from one setting to the other, it is common to find patients sharing a room or a bigger space with curtains separating beds. Thus, many describe the ICU as not an ideal place for such care. Privacy and serene environments are acknowledged as factors that greatly optimise end-of-life care (Arbour & Wiegand 2014; Fridh, Fosberg & Bergbom, 2007; Fridh, Fosberg & Bergbom, 2009b; Zomorodi & Lynn, 2010). Suboptimal space for family meeting is reported as obstructive (Nelson et al., 2006). Attia, Abd-Elaziz and Kandeel (2012) reported poor ICU design as the second largest obstacle to end-of-life care. According to the researchers, families are denied access to the dying patient due to space limitations.

Competing nurses' time, inadequate staffing and nurses' workload have also been cited as ICU environmental factors that hinder optimal end-of-life care (Attia, Abd-Elaziz & Kandeel, 2012; Espinosa et al., 2008; Zomorodi & Lynn, 2010). Attia, Abd-Elaziz and Kandeel (2012) found the greatest obstacle to end-of-life care to be heavy workload of nurses, which causes divided attention and reduces contact time with dying patients.

In a study by Kisorio and Langley (2016), nurses portrayed noise in the ICU as a flaw to patient's comfort care. The prevailing conditions in ICUs cause nurses to engage in environmental modification practices, such as switching off alarms, dimming lights, arranging chairs around the patient's bed and drawing curtains to provide privacy, thereby supporting the presence of families and creating a peaceful environment for all (Ranse, Yates & Coyer, 2016; Zomorodi & Lynn, 2010).

Institutional practices and policies may also obstruct optimal end-of-life care. Intensive Care nurses have expressed willingness to participate in decision-making processes but are frequently left out (Espinosa et al., 2008; Espinosa et al., 2010; Kisorio & Langley, 2016; Latour, Fulbrook & Albarran, 2009). Ozden, Karagozoglu and Yildirim (2013) found that not involving nurses could lead to disagreement on treatment goals, delay the initiation of comfort care and create moral distress among Intensive Care nurses. Nurses have also expressed a feeling of abandonment and powerlessness when they are excluded from the decision process (Espinosa et al., 2010).

Ineffective cooperation and communication between caregivers, patients and their families are perceived to hinder the delivery of effective end-of-life care greatly (Books, Manias & Nicholson, 2017; Festic et al., 2010; Fridh, 2014; Friedenberg et al., 2012). In one study, nurses reported that communication problems, such as difficulty with obtaining physician orders and updates for family, as the top relational obstacle to optimal end-of-life care (Zomorodi & Lynn, 2010).

A replicate of Beckstrand and Kirchhoff's (2005) study was done by Crump, Schaffer and Schulte (2010). The top perceived obstacle items included relatives who persistently called nurses instead of the designated contact person, family not knowing the implication of life-saving measures, unconducive ICU design, nurses dealing with enraged family, and patient's relations dismissing the patient's worsening condition.

Attia, Abd-Elaziz and Kandeel (2012) adapted Beckstrand and Kirchhoff's (2005) tool. The study was conducted in four ICUs at a university hospital in Egypt, where 70 nurses were conveniently sampled. The majority of the respondents (81.4%) reported nurses' workload as the largest obstacle, followed by poor ICU design (67.1%), family not knowing the life-saving measures (65.7%) and frequent calls from families for update on patients' condition (62.9%).

In a recent comparative study, Beckstrand et al. (2017) investigated the most common and current obstacles and sought to determine whether any significant changes have occurred since the first data was collected approximately 17 years ago. Although the top five (5) reported barriers have always been in the top eight (8) over the years, the current results showed significant variations. The largest obstacles identified included family not understanding what *lifesaving* measures implied, families requesting for continuous life-saving treatments contrary to patients' advance directive, families not accepting poor prognosis, families' disagreement about the use of life support and inadequate time for end-of-life care because nurses were occupied with curative measures rather than comfort care. Conversely, the five top obstacles identified from the initial study (Beckstrand et al., 1999) were divergent physicians' opinions about patient care plan, relatives' persistent call on nurses for updates rather than the designated family member, physicians being evasive and avoiding families, nurses dealing with angry families and nurses inability to decipher patients' values regarding continuation of treatments.

After comparing both studies, the authors concluded that obstacles to end-of-life care persist. Results showed an increase in family-related items. These findings call for more attention and an individualised care approach, on the basis that every family is unique. From these two studies, one can deduce that perceptions and intensity of obstacles differ over time. Therefore, there is a need for reviews to ensure measures adopted are abreast with current practices.

2.11 FACILITATORS/HELPS TO OPTIMAL END-OF-LIFE

Teamwork, effective and open communication between the multidisciplinary team and among the caregivers and patients and/or their significant others, patient- and family-

centred care model, in addition to support for family and staff are some of the factors that enhance care for dying persons and their relations (Attia, Abd-Elaziz & Kandeel, 2012; Efstathiou & Walker, 2014; Hansen et al., 2009).

Hansen et al. (2009) sought to describe Intensive Care nurses' perceived interventions that improves of end-of-life care. Three main items were reported on, strong communication and collaboration among nurses and physicians, utilising palliative care services and supporting families and staff. The findings showed that nurses with longer Intensive Care experience were more knowledgeable and capable of providing better care. The working environment, and support for patient and staff were also cited as factors that have an impact on end-of-life care. Respondents advocated for better communication among physicians, nurses and patient families.

Festic et al. (2010) indicated that nurses are the strongest support to end-of-life care. They suggested that effectual communication and teamwork, availability of chaplaincy services for spiritual support, positive attitudes of physicians, provision of comfort care and end-of-life education and training may enhance care. Furthermore, Festic and colleagues argued that key changes needed to optimise care in the ICU included educating nurses on the phenomenon, upgraded comfort care, clear goals and advance directives, change in physician attitudes, improved ICU environment, increased nurse time devoted to dying patients and more family support.

Crump, Schaffer and Schulte (2010) found the top five perceived supportive behaviours to end-of-life care in adult ICU to be: 1). choosing one family contact person for all communications, 2). getting families to come to terms with patient's poor prognosis, setting a peaceful, dignified bedside scene for bereaved family, having physicians to be involved and agree on the direction of care and giving families enough time to be alone with the patient after death.

Attia, Abd-Elaziz and Kandeel (2012) put 19 items that facilitate end-of-life care into three categories: 1. Support for nurse, 2. Involving family in patient care and 3. Supporting family members after patients' death.

The top five rated supportive behaviours were adequate communication among physicians and nurses (94%), nurses relying on their own past experience (82.9%),

teaching families on how to behave around the dying person (78.6%), nurses supporting each other after patient demise (75.7%) and appointing one family member as liaison for all communications between the care providers and family (75.7%).

Efstathiou and Walker (2014) described experiences of nurses during end-of-life care as putting their best foot forward to ensure death is dignified and less painful. Four main and two subordinate themes were identified as facilitators to the process:

- taking care of patient and family,
- promoting family presence,
- creating room for family and patient to connect, and
- managing emotions and uncertainties.

The two subordinate ones further explained the master themes, "*reconnecting the patient and the family"* by making the ICU family friendly to enable them to get closer and be alone with patient and "*dealing with emotions and ambiguity"* by deciding what is the right thing to do in a situation where there are no clear guidelines for care.

Beckstrand and Kirchhoff's (2005) survey instrument was adapted for the current study. The original study sought to measure the views of nurses regarding how intense, and how frequent a behaviour, obstructed or facilitated end-of-life care in the ICU. Of the 6800 members of the American Association of Critical Care Nurses, 1500 were randomly sampled.

Data collection was done with a modified version of the "National Survey for Critical Care Nurses Regarding End-of-Life Care," developed in 1998 by Kirchhoff and Beckstrand. The instrument was a 72-item questionnaire composed of 29 obstacle items, 24 supportive behaviour items, four open-ended questions for nurses to add any item that was not covered in the survey, and 15 demographic questions. Respondents were asked to rate how large an item was and how frequently it was experienced. Of the 1500 sampled, 955 completed questionnaires were returned. Respondents indicated that, the top five most intense and frequently occurring items perceived as obstacles were:

- 1). Family repeatedly calling in for nurses to update them on the patient instead of contacting appointed person for such information;
- 2). Family's lack of understanding of what "life-saving measures" imply;

- 3). Different physicians taking care of one patient who differ in the plan and goal of care;
- 4). Physicians who were evasive and avoided family discussions;
- 5). Nurses preoccupied with providing curative measures instead of comfort care.

The five highest most helpful and most occurring supportive behaviours were:

- 1). giving families adequate time to be alone with patient after death;
- 2). Creating a solemn bedside scene;
- 3). Teaching the family on how to act around a patient who is dying;
- 4). Family showing appreciation for the care given;
- 5). Physicians agreeing on the goal of care.

Beckstrand and Kirchhoff concluded that the behaviour, which hindered optimal care most were related to patient and family behaviours that took nurses away from caring for the patient, behaviours that caused patients pain and prolonged suffering and disagreement among physicians regarding the plan and goal of care. The study revealed that highest rated items were not always frequent.

2.12 SUMMARY

This review has provided description of critical illness and the ICU, dying in the ICU, end-of-life care, collaboration during care, decision-making and withholding and withdrawal of life-sustaining therapies, end-of-life care practices in adult ICUs, perceptions and roles of patients' families and nurses, obstacles and helpful behaviours to end-of-life care. It is evident that Intensive Care nurses play indispensable roles in facilitating the transition from curative to comfort care, however, uncertainties about which end-of-life practices are ethically acceptable presents variations in end-of-life practices across Intensive Care settings.

Furthermore, there appears to be a strong indication that balancing between the demanding roles of using technology, addressing patient needs and the dichotomy between saving lives and improving care for dying patients puts pressure on the roles of Intensive Care nurses. These challenges hinder optimal end-of-life care. In addition,

the literature review thus far suggests there is a paucity of studies on South African Intensive Care nurses' perceptions of obstacles and supportive behaviours to optimal end-of-life care in adult ICUs. Therefore, a study to investigate nurses' perceptions on the phenomenon may provide information, and guide future studies and prompt interventions to improve care.

The following chapter presents the methodology and design used for this study.

CHAPTER THREE

RESEARCH METHODS

3.1 INTRODUCTION

This current chapter entails the research methodology and design used. The study setting, population, sample and sampling, data collection, the validity and reliability of the research instrument and data analysis are discussed. The ethical considerations observed in the study are also addressed.

3.2 RESEARCH DESIGN

A descriptive and cross-sectional survey design was utilised to identify the obstacles and supportive behaviours to optimal end-of-life care in adult ICUs. This design allows for collection of data to describe and understand the prevalence of a phenomenon at one point in time without manipulating any variable (De Vos et al., 2011).

3.2.1 Descriptive Research

Descriptive research is a type of non-experimental study where no intervention is applied. It depicts a picture of specific details of a situation. In nursing research, descriptive research is utilised to develop theory, identify problems with current practices and for determining what pertains elsewhere (Burns & Grove, 2009; Polit & Beck, 2018; Rubin & Babbie, 2008). Burns and Grove (2009) emphasised that descriptive design is suitable for identifying unknown problems within current practice. Descriptive design was therefore chosen because little is known about South African adult Intensive Care nurses' perceptions regarding obstacles and supportive behaviours in providing end-of-life care. Data was collected in participants' natural environment without intervention or manipulation of any variable in the study setting. The design helped to provide some baseline information on the prevalence of the phenomena of interest.

3.2.2 Cross sectional

A cross-sectional study or prevalence study, analyses data collected from a population or sample at a given point in time. It aims to provide data on the entire population under study. A cross-sectional study is suitable for describing the status of a phenomenon at a fixed point and helps to determine the existence and magnitude of a problem within a group of participants (De Vos et al., 2011; Polit & Beck, 2018). This study adopted a cross-sectional design because data from Intensive Care nurses' perception was captured at one-point in time.

3.2.3 Survey

Survey is an instrument used to collect verifiable data from a sample or population. It allows the collection of numeric data on hard-to-measure abstract variables, such as perception, as well as self-reported information, such as demographic factors. It is useful in describing the characteristics of a large sample (Burns & Grove, 2009; Polit & Beck, 2018). The "National Survey of Critical-Care Nurses Regarding End-of-life Care Questionnaire" devised by Beckstrand and Kirchhoff (2005) has been successfully used to collect data on the phenomenon in several studies (Attia et al., 2012; Beckstrand et al., 2009; Heaston et al., 2006). This study employed a quantitative approach and adopted total population sampling therefore a survey was chosen on the basis that surveys are easier to administer to a larger number of respondents. With survey, many questions can be asked about a subject and it gives extensive flexibility during data analysis.

3.3 STUDY SETTING

Polit and Beck (2018) define a study setting as the specific place data collection will be done and the conditions that prevail there. This study was conducted in five adult ICUs namely, cardiothoracic, coronary care, multidisciplinary, neurosurgery and trauma ICU of an academic hospital in Johannesburg. These units were chosen because patients admitted here have life-threatening illnesses or injuries and often need vital treatments such as respiratory and cardiovascular support and close haemodynamic monitoring. If options for reversing critical conditions are exhausted, life-supports may be withheld or withdrawn. The goal of care is then shifted from cure

to comfort care. These patients are cared for by a multidisciplinary team including Intensive Care nurses who offer compassionate care and offer support to dying patients and their families.

3.4 RESEARCH METHODS

A quantitative paradigm is a methodological perspective where structured guidelines are used to measure the variables of interest objectively. It is regarded as a structured approach because the research process is predetermined. This approach is deemed more appropriate for determining the extent of a problem or phenomenon as it aims at describing trends (De Vos et al., 2011).

In this study, Beckstrand and Kirchhoff's (2005) questionnaire was used to collect numeric data on the phenomenon systematically. Data analysis was also done with statistical procedures to analyse results (Polit & Beck 2018). This paradigm enabled the researcher to measure the magnitude or the extent to which selected obstacles and supportive behaviours influence the delivery of optimal end-of-life care in adult ICUs.

3.4.1 Target Population

The population for the study comprised Intensive Care nurses practicing in adult ICUs of an academic hospital in Johannesburg, cardiothoracic, coronary care, multidisciplinary, neurosurgery and trauma ICUs. The inclusion criteria for the participants were:

- Registered by the South African Nursing Council (SANC) with an additional qualification in Intensive Care nursing;
- Registered by the South African Nursing Council (SANC) as a professional nurse including permanent and agency nurses working in the selected academic hospital;
- Have more than one year of clinical experience in the chosen Intensive Care Unit.

3.4.2 Sample and Sampling Methods

Based on the nature of this study being a survey, it was decided to sample the total population of 105 (both permanent and agency staff) Intensive Care nurses working in the ICUs of the selected institution. This was done to ensure good representation of the target population. In this study, a non-probability convenience sampling method was used. The nurses who were available within the data collection period in December 2018 were invited to complete the questionnaire. Out of the 105 distributed questionnaires, 97 were returned and six uncompleted questionnaires were eliminated; 91 usable questionnaires were analysed representing a response rate of 86.7%.

3.4.2.1 Non-probability sampling

Non-probability sampling is a type of quantitative method where participants are selected by non-random methods. With this technique, the odds of selecting a participant for the research study cannot be calculated, however it has been criticised as being biased and less representative as it does not give members of a population equal chance of being selected for a study (Polit & Beck, 2018). Thus, the bias nature of non-probability sampling limits generalisation of study results, but compared to probability sampling, this technique is easy to use and feasible when there is time and resource constraints. Additionally, the aim of this study is not to generalise, but to identify and describe the phenomenon of interest within the specific study area.

3.4.2.2 Convenience sample

Convenience (accidental) sampling is a non-probability sampling method in which data is collected from members of a population who are easily accessible to the researcher. Aside from being easy, and time and cost effective, convenience sampling is considered suitable for descriptive studies to generate baseline information in new study areas thereby increasing knowledge (Burns & Grove, 2009; Polit & Beck, 2018). As little is known about South African adult Intensive Care nurses' views on the study topic, this method was chosen to help collect data to describe the status of the phenomenon within the South African context.

3.4.3 Data Collection

Quantitative data collection involves the systematic process of gathering information with the use of a measuring instrument, such as a questionnaire, to enable the researcher to answer the research question (De Vos et al., 2011). The instrument used for data collection asked Intensive Care nurses to rate the size and the frequency of selected obstacles and supportive behaviour items.

3.4.3.1 Instrument

A questionnaire designed by Beckstrand and Kirchhoff (2005), identified in literature and other published works (Heaston et al., 2006; Beckstrand et al., 2009; Attia, Abd-Elaziz & Kandeel, 2012), was employed to achieve the research objectives.

The original survey questionnaire contained 72 items divided into three sections. Section one was made up of 29 items in which the participants rated the size and how frequent the obstacle item occurred on a 5-point Likert scale; 0 (not an obstacle) to 5 (severely large obstacle). Frequency of an obstacle was also rated on a 5-point Likert scale, 0 (never occurs) to 5 (always occurs).

Section two contained 24 items in which participants rated behaviours that assisted with end-of-life care according to size and frequency on a 5-point Likert scale, where 0 meant not a help to 5; severely large help. The frequency of supportive behaviours is also rated on a 5-point Likert scale, where ‘0’ implied the behaviour never occurs, to 5 always occurs.
Four open-ended options were included to allow respondents to make any additions relating to the study that had not been included to the survey.

Section three was made up of 15 items eliciting participants’ demographic data including, gender, level of education, years of experience as Intensive Care nurse and which ICU respondents are employed in.
3.4.3.2 Validity and reliability of instrument

Face and content validity of the original survey was assessed by the developers. The interrater reliability of the instrument was reported to be 86% (Beckstrand & Kirchhoff,

2005). Furthermore, the instrument was tested on a sample of 936 Intensive Care nurses in the United States of America. Four other studies have utilised the questionnaire on independent samples of Intensive Care nurses. However, the authors did not comment on the validity and reliability of the scale items. The Cronbach alpha value for the 29 obstacle frequency items and 24 supportive behaviour frequency items were 0.86 and 0.81 respectively (Beckstrand & Kirchhoff, 2005). Thus, the questionnaire was deemed suitable for this study.

3.4.3.3 Procedure

The study was approved by the postgraduate assessors and ethics committees of the University of the Witwatersrand (Appendices E and C respectively). Approval was also given by the Chief Executive Officer and Nursing Director of the hospital (Appendix D). The respective Unit Managers also granted permission before the commencement of the study. Data collection was done within one month (December 2018). The researcher was at the respective ICUs and invited Intensive Care nurses to participate in the study. The nurses were given information letters explaining the purpose, nature and the procedures of the study (Appendix B). Prospective respondents were given the opportunity to ask for clarification and answers were given accordingly. The researcher was at the various Units during the day and night shifts to hand out the questionnaires (Appendix A). The questionnaires were self-administered by the respondents. An ethical waiver was applied in terms of consent, thus return of a completed questionnaire was accepted as informed consent. The completed questionnaires were returned in sealed envelopes and placed into sealed boxes placed in each unit. The researcher alone opened the box after the data collection period.

3.4.4 Data Analysis

Data analysis was done for closed and open-ended items. Descriptive statistics using the STATISTICA (version 13.2) software was utilised for data management and analysis of closed-ended questions. Prior to the analysis, data was cleaned; to limit data entry errors, and the raw data was captured twice onto two separate Microsoft Excel spreadsheet files. Resulting datasets were verified by comparing the two datasets and discrepancies were resolved by referring to the questionnaire for the correct responses. This step was repeated until all variations were resolved. The

dataset was then imported into the statistical software where further data cleaning was performed and invalid responses were corrected to ensure the data was of good quality.

Frequency and percentages were used to describe participant's demographic characteristics, such as age and gender. Means and medians, together with their corresponding measure of dispersion, were computed for each item under obstacles and supportive behaviours. The items were then ranked according to the size of the mean to determine largest and most occurring obstacles and supportive behaviours respectively. To achieve the first objective of this study, the product of the mean of perceived severity scores for obstacle size and frequency were calculated for each item. The same steps were repeated for supportive perceived scores to achieve the second objective.

Content analysis, using the Hsieh and Shannon (2005) approach, analysed the open-ended questions.

3.5 PILOT TESTING

Prior to conducting the main study, a mini research involving five Intensive Care nurses was done. The pilot study was done to help the researcher orientate herself to the study and evaluate the adequacy and appropriateness of the proposed methodology. The pilot study helped the researcher to address possible problems or errors that could arise in the main study to ensure a successful execution and completion of the research project (De Vos et al., 2011). The adopted instrument was pre-tested to determine how well the questions were understood, and how long it took to complete; it took approximately 25 minutes to complete the questionnaire. The respondents and results of the pilot study were not included in the main study.

3.6 VALIDITY AND RELIABILTY OF THE STUDY

The researcher adhered to the guidelines of the data-collecting instrument, as determined by the developer. Face and content validity of the instrument for the South African context was established by a small group of local domain expert nurses before commencement of data collection. The pre-testing procedure was undertaken to

determine how well the questions were understood and how long it took to complete the questionnaire. The service of a statistician was employed for data analysis and interpretation to achieve precision in statistical conclusions.

3.7 ETHICAL CONSIDERATIONS

Ethical considerations are imperative to ensure that the researcher stays within acceptable ethical principles. According to Polit and Beck (2018), ethical consideration is particularly paramount in nursing research as the boundaries between what is acceptable in nursing practice and what is stipulated for data collection in research is unclear.

The following ethical issues were observed.

3.7.1 Informed Consent

Polit and Beck (2018) describe informed consent as a means by which researchers obtain prospective respondents' or participants' agreement to voluntarily participate in a research study. The process ensures that the prospective respondents have the power of free choice, thus, they may agree to or decline participation after adequate information regarding the research has been provided. Obtaining an informed consent is an indication of respect for participant's right to self-determination (De Vos et al., 2011). Participation was voluntary and prospective respondents were made aware that they could withdraw from the study at any time without any consequences. Return of a completed questionnaire indicated consent. Prior to completing the questionnaire, they received an information letter, which explained the purpose and the procedures of the study including the possible risk of emotional distress of remembering a dying patient they may have nursed. An experienced counsellor was available for debriefing and to support nurses if emotional support was needed. Prospective respondents had the opportunity to ask questions and they were given clarifications accordingly. No incidence of emotional distress was observed or complained of during the data collection period.

3.7.2 Permission to Conduct the Study

Ethical approval and clearance were granted by all the relevant authorities: Postgraduate Assessors Committee (Appendix E), Faculty of Health Sciences Human Research Ethical Committee (Medical) of the University of the Witwatersrand (Appendix C), the Director of Nursing and the Chief Executive Officer of the Hospital (Appendix D) and the Medical and Nurse Unit Managers of the participating Intensive Care Units.

3.7.3 Anonymity and Confidentiality

Maintaining anonymity and confidentiality in research means the researcher puts in place measures to safeguard the privacy and identity of respondents and handle data in a way that limits others accessing the information. While anonymity means that no one, including the researcher, should be able to identify any subject after the data collection, confidentiality is continuation of maintaining privacy (De Vos et al., 2011; Polit & Beck, 2018). In this study, names of participants were withheld to ensure anonymity. Regarding confidentiality, only the researcher, her supervisor and the statistician could access the data.

3.7.4 Security and management of data

Paper documents were put in a lockable filing cabinet and a password was put on electronic data. As a data security measure, a backup copy of the data was kept by the researcher's supervisor. Data will be kept for at least five years, or as mandated by the University of Witwatersrand Ethics Committee and archived after all possible publications are exhausted.

3.8 SUMMARY

This chapter described the methodology of the study. The research design, study setting, research methods, population, sample and sampling, data collection, the instrument for data collection, validity and reliability of the instrument, procedure for data collection, data analysis, pretesting and pilot study, ethical consideration and validity and reliability were also addressed.

The next chapter presents the data analysis and discussion of study results.

CHAPTER FOUR

RESULTS OF THE STUDY

4.1 INTRODUCTION

This chapter describes the approach to data analysis and details of study results. Descriptive information of study participants and their perceptions on the phenomenon of interest were analysed.

4.2 RESULTS

4.2.1 Response Rate

By the end of the data collection period of one month, 97 out of 105 questionnaires were returned. Six questionnaires were incomplete leaving 91 surveys (response rate of 86.7%) available for analysis.

4.2.2 Demographic Characteristics of the Respondents

Table 4.1 Demographic characteristics of the respondents (n = 91)

Statement	Frequencies	Percentage
Gender		
- Male	12	13.2%
- Female	79	**86.8%**
Age (in years)		
- 20 to 29 years	13	14.3%
- 30 to 39 years	34	**37.4%**
- 40 to 49 years	23	25.3%
- 50 to 59 years	21	23.0%
Highest level of education		
- Diploma in nursing	77	**84.6%**
- Bachelor's degree	11	12.1%
- Master's degree	3	3.3%
- Doctoral degree	-	-
- Other	-	-

Patients nursed in end-of-life care		
- Less than 5	9	9.9%
- Between 5 and 10	13	14.3%
- Between 11 and 20	15	16.5%
- Between 21 and 30	4	4.4%
- More than 30	39	**42.9%**
- Other	11	12.1%
Type of ICU primarily employed		
- Cardiothoracic	10	10.9%
- Coronary Care	8	8.8%
- Multidisciplinary ICU	37	**40.7%**
- Neurosurgical ICU	17	18.7%
- Trauma ICU	19	20.9%
Current position		
- Direct care/bedside nurse	47	**51.6%**
- Clinical nurse specialist	40	44.0%
- Charge nurse/unit manager	2	2.2%
- Other (please specify)	2	2.2%
	Mean	**SD**
Years of experience as a RN	10.41 (Me 8.0)	7.88
Years of ICU experience	7.01 (Me 5.0)	6.62

Key: Me= median

Table 4.1 presented the results on demographic characteristics. Females accounted for 86.8% (n = 79) of the total sample (n = 91). The largest group (37.4%: n = 34) were aged between 30 to 39 years and followed by 25.3% (n = 23), 23.1% (n = 21) and 14.3% (n = 13) were in the 40 to 49, 50 to 59 and 20 to 29 age categories, respectively. The average years of experience in nursing was 10.41 (SD = 7.88), whereas on average, the years of ICU experience was 7.01 (SD = 6.62) for the total sample (n = 91).

In this study, the majority (84.6%: n = 77) of the respondents had a diploma as the highest qualification in nursing, only 12.1% (n = 11) had a bachelor's degree, and 3.3% (n = 3) a master's degree.

A close majority (42.9%: n = 39) of the respondents had experience in the category of “more than 30” situations of giving end-of-life care.
In this study, most (40.7%: n = 37) of the respondents worked in a Multidisciplinary ICU, followed by 20.9% (n = 19) in Trauma ICU.

A close majority (50.6%: n = 46) of the respondents provided direct care/bedside nursing, and 44.0% (n = 40) were clinical nurse specialists. Only a marginal (2.2%: n = 2) number of the respondents held positions as unit manager or clinical facilitator, respectively.

4.2.3 Obstacles to End-of-life Care

4.2.3.1 Obstacle Size (Intensity)

Table 4.2: Averages for obstacle size reported regarding end-of-life care

Item	Statement	Size (intensity)		
		Mean	SD	n
1	Physicians who are overly optimistic to the family about the patient surviving.	2.54	1.54	91
2	Families not accepting what the physician is telling them about the patient's poor prognosis.	3.19	1.64	91
3	The nurse having to deal with distraught family members while still providing care for the patient.	3.69	1.44	91
4	Intra-family fighting about whether to continue or stop life support.	2.54	1.70	91
5	The nurse knowing about the patient's poor prognosis before the family is told.	2.48	2.13	91
6	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.	2.79	1.80	91
7	Poor design of units, which do not allow for privacy of dying patients or grieving family members.	3.07	1.81	91
8	Unit visiting hours that are too restrictive.	2.41	1.76	91

9	The patient having pain that is difficult to control or alleviate.	2.16	1.57	91
10	Dealing with the cultural differences that families employ in grieving for their dying family member.	2.68	1.60	91
11	No available support person for the family, such as a social worker or religious leader.	2.74	1.69	91
12	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	1.78	1.64	91
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.	2.93	1.80	91
14	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.82	1.75	91
15	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	2.31	1.64	91
16	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.	4.07	1.27	91
17	Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.56	1.63	91
18	Caring for a patient who has been declared brain dead and is soon to become an organ donor.	2.67	1.75	91
19	The unavailability of an ethics board or committee to review difficult patient cases.	3.02	1.94	91
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.	3.23	1.63	91

21	Unit or hospital visiting hours that are too liberal.	1.98	1.51	91
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 break during chest compression.	3.33	1.53	91
23	The nurse not knowing patient’s sentiments regarding continuing with treatment and tests because of the inability to communicate due to patients’ depressed neurological status or due to pharmacologic sedation.	1.90	1.65	91
24	The nurse having to deal with angry family members.	3.67	1.31	91
25	The family, for whatever reason is not with the patient when he or she is dying.	3.15	1.61	91
26	Physicians who are evasive and avoid having conversations with family members.	2.47	1.67	91
27	Multiple physicians, involved with one patient, who differ in opinion about the direction in which care should go.	2.48	1.35	91
28	Continuing to provide advanced treatment to dying patients because of financial benefits to the hospital.	1.86	1.72	91
29	When the nurses’ opinion about the direction patient care should go is not requested, not valued, or not considered.	2.68	1.69	91

Table 4.2 illustrates the mean (M) and SD of the intensity of obstacle size as rated by respondents. On a scale of 0 to 5, 0 was not an obstacle and 5, an extremely large obstacle.

The mean of obstacle intensity scores ranged from 1.78 to 4.07. The top five rated obstacles were:

- “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” (M = 4.07);

- “the nurse having to deal with distraught family members while still providing care for the patient (M = 3.69);
- the nurse having to deal with angry family members” (M = 3. 67);
- “family members not understanding what life-saving measures really mean” (M = 3.33);
- “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” (M = 3.23).

The three lowest obstacles were “employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment” (M = 1.78), “continuing to provide advanced treatment to dying patients because of financial benefits to the hospital” (M = 1.86), and the “nurse not knowing patient’s regarding continuing with treatment and tests because of the inability to communicate due to patients’ depressed neurological status or due to pharmacologic sedation” (M =1.90).

4.2.3.2 Obstacle Size (frequency)

Table 4.3: Averages for obstacle frequency reported by respondents about end-of-life care

Item	Statement	Size (frequency)		
		Mean	SD	N
1	Physicians who are overly optimistic to the family about the patient surviving.	2.14	1.45	91
2	Families not accepting what the physician is telling them about the patient's poor prognosis.	3.20	1.49	91
3	The nurse having to deal with distraught family members while still providing care for the patient.	3.62	1.32	91
4	Intra-family fighting about whether to continue or stop life support.	2.25	1.70	91
5	The nurse knowing about the patient's poor prognosis before the family is told.	4.19	1.31	91
6	Not enough time to provide quality end-of-life care because the nurse is consumed	2.84	1.79	91

	with activities that are trying to save the patient's life.			
7	Poor design of units, which do not allow for privacy of dying patients or grieving family members.	3.12	1.79	91
8	Unit visiting hours that are too restrictive.	2.53	1.80	91
9	The patient having pain that is difficult to control or alleviate.	2.22	1.45	91
10	Dealing with the cultural differences that families employ in grieving for their dying family member.	2.98	1.37	91
11	No available support person for the family, such as a social worker or religious leader.	3.07	1.62	91
12	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	1.85	1.50	91
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.	3.03	1.68	91
14	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.88	1.81	91
15	Continuing treatment for a dying patient even though the treatments cause the patient pain or discomfort.	2.36	1.66	91
16	Family and friends who continually call the nurse for an update on the patient's condition rather than calling the designated family member for information.	4.18	1.10	91
17	Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.68	1.56	91
18	Caring for a patient who has been declared brain dead and is soon to become an organ donor.	2.64	1.64	91
19	The unavailability of an ethics board or committee to review difficult patient cases.	3.04	1.84	91

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.	3.53	1.43	91
21	Unit or hospital visiting hours that are too liberal.	1.95	1.56	91
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 break during chest compression.	3.52	1.48	91
23	The nurse not knowing patient’s sentiments regarding continuing with treatment and tests because of the inability to communicate due to patients’ depressed neurological status or due to pharmacologic sedation.	2.51	1.59	91
24	The nurse having to deal with angry family members.	3.54	1.27	91
25	The family, for whatever reason is not with the patient when he or she is dying.	3.47	1.41	91
26	Physicians who are evasive and avoid having conversations with family members.	2.70	1.62	91
27	Multiple physicians, involved with one patient, who differ in opinion about the direction in which care should go.	2.68	1.30	91
28	Continuing to provide advanced treatment to dying patients because of financial benefits to the hospital.	1.86	1.72	91
29	When the nurses’ opinion about the direction patient care should go is not requested, not valued, or not considered.	2.86	1.68	91

Table 4.3 shows the mean and SD of frequently occurring obstacles. On a scale of 0 = never occurs to 5 = always occurs, the mean frequency scores for obstacles to end-of-life care ranged from 1.72 to 4.19. The five most frequent obstacles were:

- “The nurse knowing about the patient's poor prognosis before the family is told the prognosis” (M = 4.19);

- “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” (M = 4.18);
- “The nurse having to deal with distraught family members while still providing care for the patient” (M = 3.62);
- “The nurse having to deal with angry family members” (M =3.45);
- “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” (M = 3.53)

The three least occurring obstacles were: (1) “Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment” (M = 1.85); (2) “Continuing to provide advanced treatment to dying patients because of financial benefits to the hospital” (M = 1.86); (3) “Unit or hospital visiting hours that are too liberal” (M = 1.95).

4.2.3.3 Perceived obstacle Magnitude (POM)

Table 4.4: Perceived severity scores for obstacles size and frequency in end-of-life care

	Obstacle statement	Intensity			Frequency			Perceived obstacle magnitude
		Mean	SD	Rank	Mean	SD	Rank	
1	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.	4.07	1.27	1	4.18	1.10	2	**17.01**
2	The nurse having to deal with distraught family members while still providing care for the patient.	3.69	1.44	2	3.62	1.32	3	**13.36**

3	The nurse having to deal with angry family members.	3.67	1.31	3	3.54	1.27	4	**12.99**
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 won’t allow the patient to talk or that ribs may break during chest compression.	3.33	1.53	4	3.52	1.48	6	11.72
5	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.	3.23	1.63	5	3.53	1.43	5	11.40
6	The family, for whatever reason is not with the patient when he or she is dying.	3.15	1.61	7	3.47	1.41	7	10.93
7	The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	2.48	2.13	20	4.19	1.31	1	10.39
8	Families not accepting what the physician is telling them about the patient's poor prognosis.	3.19	1.64	6	3.20	1.49	8	10.21
9	Poor design of units, which do not allow for privacy of dying patients or grieving family members.	3.07	1.81	8	3.12	1.79	9	9.58
10	The unavailability of an ethics board or	3.02	1.94	9	3.04	1.84	11	9.18

	committee to review difficult patient cases.							
11	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.	2.93	1.80	10	3.03	1.68	12	8.88
12	No available support person for the family, such as a social worker or religious leader.	2.74	1.69	13	3.07	1.62	10	8.41
13	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.82	1.75	11	2.88	1.81	14	8.12
14	Dealing with the cultural differences that families employ in grieving for their dying family member.	2.68	1.60	14	2.98	1.37	13	7.99
15	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.	2.79	1.80	12	2.84	1.79	16	7.92
16	When the nurses' opinion about the direction in which patient care should go is not requested, not valued, or not considered.	2.68	1.69	15	2.86	1.68	14	7.66
17	Caring for a patient who has been declared brain dead and is soon to become an organ donor.	2.67	1.75	16	2.64	1.64	20	7.05

18	Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.56	1.63	17	2.68	1.56	18	6.86
19	Physicians who are evasive and avoid having conversations with family members.	2.47	1.67	22	2.70	1.62	17	6.67
20	Multiple physicians, involved with one patient, who differ in opinion about the direction in which care should go.	2.48	1.35	21	2.68	1.30	19	6.65
21	Unit visiting hours that are too restrictive.	2.41	1.76	23	2.53	1.80	21	6.10
22	Intra-family fighting about whether to continue or stop life support.	2.54	1.70	19	2.25	1.70	24	5.72
23	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	2.31	1.64	24	2.36	1.66	23	5.45
24	Physicians who are overly optimistic to the family about the patient surviving.	2.54	1.54	18	2.14	1.45	26	5.44
25	The patient having pain that is difficult to control or alleviate.	2.16	1.57	25	2.22	1.45	25	4.80
26	The nurse not knowing patient's sentiments regarding continuing with treatment and tests because of the inability to communicate due to patients' depressed	1.90	1.65	27	2.51	1.59	22	4.77

	neurological status or due to pharmacologic sedation.							
27	Unit or hospital visiting hours that are too liberal.	1.98	1.51	26	1.95	1.56	27	3.86
28	Continuing to provide advanced treatment to dying patients because of financial benefits to the hospital.	1.86	1.72	28	1.86	1.72	28	3.46
29	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	1.78	1.64	29	1.85	1.50	29	3.29

After calculating the product of averages of each obstacle item's intensity and frequency, the POM was presented in **Table 4.4.** The scores ranged from 3.29 to 17.01. The largest POM was "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" (POM = 17.01). There was a margin of 3.65 difference between the first POM score and the second. This margin was also the widest between any two POM scores. The POM score of 9, other highly rated items following the largest obstacle, included: (1) "Nurse having to deal with distraught family members" (POM = 13.36); (2) "Nurse having to deal with angry family members" (POM = 12.99); (3) "Family not understanding what life saving measures and its implications" (POM = 11.72); (4) "Nurse being called away from patient and family to perform other duties" (POM = 11.40); (5) "The family, for whatever reason is not with the patient when he or she is dying" (POM= 10.93); (6) "The nurse knowing about the patient's poor prognosis before the family is told" (POM= 10.39); (7) "Families not accepting what the physician is telling them about the patient's poor prognosis" (POM= 10.21); (8) "Poor design of units, which do not allow for privacy of dying patients or grieving family members" (POM= 9.58); (9) " The unavailability of an ethics board or committee to review difficult patient cases" (POM= 9.18).

The three lowest POM were “Employing life sustaining measures at the families’ request even though the patient had signed advanced directives requesting no such treatment” (POM = 3.29), “Continuing to provide advanced treatment to dying patients because of financial benefits to the hospital” (POM = 3.46) and “Unit or hospital visiting hours that are too liberal” (POM = 3.86).

4.2.4 Supportive behaviours to providing end-of-life care

4.2.4.1 Supportive behaviours size (intensity)

Table 4.5**:** Averages for supportive behaviours size reported by the respondents regarding end-of-life care

Item	Statement	Size (intensity)		
		Mean	SD	n
31	Having one family member be the designated contact person for all other family members regarding patient information.	3.59	1.66	91
32	Having enough time to prepare the family for the expected death of the patient	3.26	1.53	91
33	A Unit designed so that the family has a place to go to grieve in private	3.43	1.59	91
34	Having the physicians involved in the care of the patient agree about the direction care should go	3.65	1.49	91
35	Having a Unit schedule that allows for continuity of care of the dying patient by the same nurse(s).	2.42	1.68	91
36	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	2.69	1.59	91
37	Having the family physically help with care of the dying patient.	2.12	1.81	91
38	Talking with the patient about his or her feelings and thoughts about dying.	1.97	1.86	91
39	Letting the social worker or religious leader take primary care of the grieving family.	2.58	1.82	91

40	Teaching families how to act around the dying patient such as saying to them, "She can still hear you … it is OK to talk to her."	4.07	1.18	91
41	Allowing families' unlimited access to the dying patient, even if it conflicts with nursing care at times.	3.78	1.24	91
42	Providing a peaceful, dignified bedside scene for family members once the patient has died.	4.10	1.40	91
43	Allowing family members adequate time to be alone with the patient after he or she has died.	4.18	1.19	91
44	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	3.67	1.46	91
45	Having a fellow nurse put his or her arm around you hug you, pat you on the back or give you some other kind of brief physical support after the death of your patient.	2.91	1.72	91
46	Having fellow nurses take care of your other patient(s) while you get away from the Unit for a few moments after the death of your patient.	3.24	1.70	91
47	Having a support person outside of the Unit setting who will listen to you after the death of your patient.	2.54	2.00	91
48	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.43	1.46	91
49	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	2.22	1.85	91
50	Having family members accept that the patient is dying.	3.16	1.54	91
51	After the death of the patient, having support staff compile for you the necessary paper work, which must be signed by the family before they leave the Unit.	3.16	1.66	91
52	Physicians who put hope in real tangible terms by saying to the family that, for	2.88	1.58	91

	example, only l out of 100 patients in this patient's condition will completely recover.			
53	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done	4.09	1.38	91
54	Having un-licensed personnel available to help care for dying patients.	1.01	1.67	91

Table 4.5 presents the mean and SD of items on supportive behaviours. On a scale of 0 = no help, to 5 = extremely large help, mean intensity scores ranged from 1.01 to 4.18. The five top supportive behaviours were: (1) “Allowing family members adequate time to be alone with the patient after he or she has died” (M = 4.18); (2) “Providing a peaceful, dignified bedside scene for family members once the patient has died” (M = 4.10); (3) “Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done” (M = 4.09); (4) “Teaching families how to act around the dying patient such as saying to them, she can still hear you … it is OK to talk to her." (M = 4.07); (5) “Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times” (M = 3.78).

The three lowest supportive behaviours were “Having un-licensed personnel available to help care for dying patients” (M = 1.01), “Talking with the patient about his or her feelings and thoughts about dying” (M = 1.97) and “Having the family physically help with care of the dying patient” (M = 2.22).

4.2.4.2 Supportive behaviours frequency

Table 4.6: Averages for supportive behaviours size regarding end-of-life care

Item	Statement	Size (frequency)		
		Mean	SD	n
31	Having one family member be the designated contact person for all other family members regarding patient information.	3.12	1.42	91
32	Having enough time to prepare the family for the expected death of the patient	3.02	1.35	91

33	A Unit designed so that the family has a place to go to grieve in private	3.52	1.51	91
34	Having the physicians involved in the care of the patient agree about the direction in which care should go	3.57	1.38	91
35	Having a Unit schedule that allows for continuity of care of the dying patient by the same nurse(s).	2.59	1.67	91
36	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	2.85	1.56	91
37	Having the family physically help with care of the dying patient.	1.74	1.61	91
38	Talking with the patient about his or her feelings and thoughts about dying.	1.64	1.54	91
39	Letting the social worker or religious leader take primary care of the grieving family.	2.05	1.78	91
40	Teaching families how to act around the dying patient such as saying to them, "She can still hear you … it is OK to talk to her."	3.68	1.29	91
41	Allowing families' unlimited access to the dying patient even if it conflicts with nursing care at times.	3.58	1.38	91
42	Providing a peaceful, dignified bedside scene for family members once the patient has died.	4.04	1.41	91
43	Allowing family members adequate time to be alone with the patient after he or she has died.	4.40	0.85	91
44	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	3.21	1.42	91
45	Having a fellow nurse put his or her arm around you hug you, pat you on the back or give you some other kind of brief physical support after the death of your patient.	2.64	1.69	91
46	Having fellow nurses take care of your other patient(s) while you get away from the Unit for a few moments after the death of your patient.	3.10	1.78	91

47	Having a support person outside of the Unit setting who will listen to you after the death of your patient.	1.87	1.98	91
48	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.62	1.29	91
49	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	1.59	1.73	91
50	Having family members accept that the patient is dying.	2.88	1.34	91
51	After the death of the patient, having support staff compile for you the necessary paper work which must be signed by the family before they leave the unit.	3.01	1.41	91
52	Physicians who put hope in real tangible terms by saying to the family that, for example, only l out of 100 patients in this patient's condition will completely recover.	2.66	1.52	91
53	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done	3.79	1.52	91
54	Having un-licensed personnel available to help care for dying patients.	0.95	1.71	91

Table 4.6 exhibits the mean and SD of the frequency of supportive behaviours. On a scale of 0 = never occurs to 5 = always occurs, the mean (M) scores ranged from 0.95 to 4.40. The five top most frequent items were: (1) “Allowing family members adequate time to be alone with the patient after he or she has died” (M = 4.40); (2) “Providing a peaceful, dignified bedside scene for family members once the patient has died” (M = 4.04); (3) “Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done” (M = 3.79); (4) “Teaching families how to act around the dying patient” (M = 3.68); (5) “Having family members thank you or in some other way show appreciation for your care of the patient who has died” (M = 3.62).

The least frequent supportive behaviours were “Having un-licensed personnel available to help care for dying patients” (M = 0.95), “Talking with the patient about his or her feelings and thoughts about dying” (M = 1.64) and “Having the family physically help with care of the dying patient” (M = 1.74).

4.2.4.3 Perceived supportive behaviours magnitude (PSBM) score

Table 4.7: Perceived intensity scores for supportive behaviours size and frequency in end-of-life care

	Supportive behaviour statement	Intensity			Frequency			Perceived supportive behaviour magnitude
		Mean	SD	Rank	Mean	SD	Rank	
1	Allowing family members adequate time to be alone with the patient after he/she has died.	4.18	1.19	1	4.40	0.85	1	**18.39**
2	Providing a peaceful, dignified bedside scene for family members once the patient has died.	4.10	1.40	2	4.04	1.41	2	**16.56**
3	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done	4.09	1.38	3	3.79	1.52	3	**15.50**
4	Teaching families how to act around the dying patient such as saying to them, "She can still hear you … it is OK to talk to her."	4.07	1.18	4	3.68	1.29	4	**14.98**
5	Allowing families unlimited access to the dying patient even if it	3.78	1.24	5	3.58	1.38	6	13.53

	conflicts with nursing care at times.							
6	Having the physicians involved in the care of the patient agree about the direction in which care should go	3.65	1.49	7	3.57	1.38	7	13.03
7	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	3.43	1.46	10	3.62	1.29	5	12.41
8	A Unit designed so that the family has a place to go to grieve in private	3.43	1.59	9	3.52	1.51	8	12.07
9	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	3.67	1.46	6	3.21	1.42	9	11.78
10	Having one family member be the designated contact person for all other family members regarding patient information.	3.59	1.66	8	3.12	1.42	10	11.20
11	Having fellow nurses take care of your other patient(s) while you get away from the Unit for a few moments after the death of your patient.	3.24	1.70	12	3.10	1.78	11	10.04
12	Having enough time to prepare the family for the expected death of the patient	3.26	1.53	11	3.02	1.35	12	9.85
13	After the death of the patient, having support staff compile for you the	3.16	1.66	14	3.01	1.41	13	9.51

	necessary paper work which must be signed by the family before they leave the Unit.							
14	Having family members accept that the patient is dying.	3.16	1.54	13	2.88	1.34	14	9.10
15	Having a fellow nurse put his or her arm around you hug you, pat you on the back or give you some other kind of brief physical support after the death of your patient.	2.91	1.72	15	2.64	1.69	17	7.68
16	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	2.69	1.59	17	2.85	1.56	15	7.67
17	Physicians who put hope in real tangible terms by saying to the family that, for example, only l out of 100 patients in this patient's condition will completely recover.	2.88	1.58	16	2.66	1.52	16	7.66
18	Having a Unit schedule that allows for continuity of care of the dying patient by the same nurse(s).	2.42	1.68	20	2.59	1.67	18	6.27
19	Letting the social worker or religious leader take primary care of the grieving family.	2.58	1.82	18	2.05	1.78	19	5.29
20	Having a support person outside of the Unit setting who will	2.54	2.00	19	1.87	1.98	20	4.75

	listen to you after the death of your patient.							
21	Having the family physically help with care of the dying patient.	2.12	1.81	22	1.74	1.61	21	3.69
22	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	2.22	1.85	21	1.59	1.73	23	3.53
23	Talking with the patient about his or her feelings and thoughts about dying.	1.97	1.86	23	1.64	1.54	22	3.23
24	Having un-licensed personnel available to help care for dying patients.	1.01	1.67	24	0.95	1.71	24	1.73

Table 4.7 shows the scores for perceived supportive behaviour magnitude (PSBM). PSBM scores ranged from 1.73 to 18.39. The top 10 most perceived help to end-of-life care were: (1) “Allowing family members adequate time to be alone with the patient after he or she has died” (PSBM= 18.39); (2) “Providing a peaceful, dignified bedside scene for family members once the patient has died” (PSBM= 16.56); (3) “Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done” (PSBM = 15.50); (4) “Teaching families how to act around the dying patient” (PSBM=14.98); (5) “Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times” (PSBM = 13.53); (6) “ Having the physicians involved in the care of the patient agree about the direction in which care should go” (PSBM= 13.03); (7) “Having family members thank you or in some other way show appreciation for your care of the patient who has died” (PSBM=12.41); (8) “A Unit designed so that the family has a place to go to grieve in private” (PSBM= 12.07); (9) “Having a fellow nurse tell you that, ‘You did all you could for that patient,’ or some other words of support” (PSBM=11.78); (10) “Having one

family member be the designated contact person for all other family members regarding patient information" (PSBM= 11.20).

The three lowest supportive behaviours were "Having un-licensed personnel available to help care for dying patients" (PSBM = 1.73), "Talking with the patient about his or her feelings and thoughts about dying" (PSBM = 3.23) and (3) "Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later" (PSBM = 3.53).

4.2.5 Open-ended statements for obstacles to end-of-life care (item 30)

Seven respondents responded to the open-ended question regarding additional perceived obstacles to end-of-life care. Three of the responses were excluded because they were duplicates of obstacle items on the questionnaire. The additional perceived obstacles were put under three headings:

1. Physician related:
    - "*Most of the time if doctors fail to save life of the patient, they put blame to the nursing staff.*"

2. Patient family related:
    - *Family members threatening the nursing staff and physicians about taking legal actions and physical violence (5) Occurrence (3)."*

3. The ICU environment:
    - "*Not involving patients' family in end of life decision making."*
    - *"Inadequate communication and lack of support for patient family*."

4.2.6 Open-ended statements for supportive behaviours to providing care (item 55).

There was one response to item 55 on the questionnaire, which asked respondents to add any perceived supportive behaviour to providing end-of-life care not included in the survey. The respondent expressed a feeling of emotional distress and indicated

the need to support nurses**. "***As nurses, I feel we need debriefing after one has lost a patient. I personally still find it difficult to care for a patient with poor prognosis. I find myself still thinking about that patient even days after they have passed. Counselling is important and there is none given to nurses."*

4.2.7 Open-ended responses on change needed regarding end-of-life care (item 56).

Ten respondents responded to the question on which aspect of end-of-life care they would change if they had the ability. The responses were put under three headings:

1. Patient support
   - "*Some sedation for support.*"

2. Family support
   - *"Taking care of the families as well."*

3. ICU practices/Policies
   - "*No junior nurses to be allowed to look after patients on end-of-life care by themselves, even when supervised. Debriefing sessions to be given to all nurses after patient has passed on."*
   - *"More unison discussion and agreeing with regard to end-of-life care between management.*"
   - "*To stop continuity of care for patients with poor prognosis and suffering to end life pain free."*
   - *"Advocate for the presence of social worker during counselling."*

4.3 SUMMARY OF RESULTS

Ninety-one (n = 91) nurses, mainly women participated in the current study. The largest age group was between 30 to 39 years. The majority of respondents held a diploma as the highest nursing qualification. Most of them were professional nurses involved in direct care, and all respondents had experienced end-of-life care; a close majority worked in the General ICU. Overall, their mean years of experience in nursing was

10.41 (SD = 7.88), whereas the mean years of experience in ICU nursing was 7.01 (SD = 6.62).

The most rated perceived obstacles and supportive behaviours were related to patient's family items. The greatest obstacle was family who persistently called on nurses for updates instead of the designated contact person. The least obstacle was providing life-sustaining interventions at the request of the family against patient's advanced directive. The most supportive behaviour item was permitting patient's family to have enough time alone with patient after death. The least supportive behaviour was utilising the services of an un-licenced nurse to care for dying patients. Regarding open-ended questions, the additional obstacle related to physicians, patients' family and communication issues, while the supportive behaviour related to support for nurses during and after end-of-life care.

4.4 SUMMARY

This chapter presented the results of the study. The next chapter discusses the findings of this study in relation to relevant literature. The study limitations, recommendations for nursing practice, education, management and further research are also addressed.

CHAPTER FIVE

DISCUSSION OF FINDINGS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This final chapter presents discussions of the study results, summary of the study, limitations and recommendations for clinical practice, nursing education and for further research. This study identified the perceived items that were obstacles and support to the provision of optimal end-of-life care in adult ICUs. The major findings are discussed according to the research questions posed in the study.

5.2 DISCUSSION OF FINDINGS

5.2.1 Demographic data of respondents

Ninety-one Intensive Care nurses were involved in this current study. Most of the respondents (n= 79), representing 86.8%, were females and 12 (13.2%) were males; generally, the nursing profession is dominated by females. Literature suggests that male nurses may exhibit some different caring behaviours from their female counterparts due to the innate internal conflict between masculinity and caring concepts (Lee, Chen & Yang, 2010). Male nurses are reported to cope better with stresses associated with end-of-life care (Wu et al., 2015), thus, the high prevalence of moral distress among Intensive Care nurses may be attributable to the female gender dominance in the ICU. However, this is beyond the scope of this study.

The largest group of respondents (37.4%; n = 34) were aged between 30 to 39 years, followed by 25.3% (n = 23), 23.1% (n = 21) and 14.3% (n = 13) in the 40 to 49, 50 to 59, 20 to 29 age categories, respectively. The average years of experience in nursing was 10.41 (SD = 7.88), whereas on average, the years of ICU experience was 7.01 (SD = 6.62) for the total sample (n = 91). All respondents had experienced end-of-life care with a close majority (n=39: 42.8%) having provided end-of-life care to over 30 patients and their families. The above results show that majority of the respondents in this study are older, have considerable experience in ICU and have skills for caring for

dying patients and their relatives. These traits make their views on end-of-life care valuable to this study. A study by Abu Hasheesh et al. (2013) revealed that nurses' characteristics, such as age and years of experience, have an impact on their attitudes towards end-of-life care. The authors concluded that older registered nurses with more experience had a more positive attitude to death and caring for dying patients. This finding may back the call for junior nurses to be exempted from providing end-of-life care, as indicated by one respondent in this study.

Additionally, a close majority (50.6%: n = 46) of the respondents provided direct care/bedside nursing, and 43.9% (n = 40) were clinical nurse specialists. Only a marginal (2.2%: n = 2) number of the respondents held positions as unit manager or clinical facilitator, respectively. This indicates that most of the respondents were abreast with what happens in their respective Units and thus their views reflect the current end-of-life practices.

The results reveal the majority of respondents (n= 77: 84.6%) had diploma in nursing as highest level of qualification, 11 (12.1%) had a bachelor's degree and three (3.3%) had a master's degree. Unfortunately, this does not clearly indicate whether the respondents had had additional training in ICU or not, which may be a limitation of the adapted survey. During data collection, the questionnaires were given to Intensive Care nurses. Studies have shown that there is a positive correlation between end-of-life education and practice (Brooks, Manias & Nicholson, 2017; Montagnini, Smith & Balistrieri, 2012). However, the researcher could not find a South African study that had evaluated the end-of-life care component in Intensive Care nurses' curriculum.

All five ICUs, multidisciplinary (n=37; 40.7%), trauma (n= 19; 20.9%), neurosurgical (n=17; 18.7%), cardiothoracic (n= 10; 10.9%) and coronary care (n=8; 8.8%) were represented in the study. The findings from the study can therefore be applied to the selected institution.

5.2.2 Perceived obstacles to end-of-life care

Persistent calls from family requesting for updates on the patient's condition rather than the designated family member for such information was the largest perceived obstacle in this study, with a POM score of 17.1; this was rated as the 1st (M= 4.07); large

obstacle, and 2nd (M= 4.18) very often occurs obstacle item, respectively. Even though the POM scores of earlier studies were lower than that of this current study, Beckstrand and Kirchhoff (2005) and Crump, Schaffer and Schulte (2010) also found this item to be the greatest obstacle (POM= 14.83) and (POM= 15.60) in their respective studies. Attia, Abd-Elaziz and Kandeel (2012) found it to be the fourth largest obstacle (62.9% severe).

It is reported that family members appreciated having conversations about the patient's condition with Intensive Care nurses (Noome et al., 2016) because it took away the feeling of loneliness (Lind et al., 2012). Effective communication with family regarding the patient's condition is necessary and improves end-of-life care (Noome et al., 2016; Truog et al., 2008). However, frequent calls interrupt care delivery and takes the nurses away from the patient. As indicated earlier in the literature review, the period for end-of-life care can be short, and frequent interruptions do not only put extra burden on nurses but also compromise care, as it limits the time available for nurses to provide adequate care to the dying patient. Fridh, Fosberg and Bergbom (2009b) indicated that nurses attend to families better after ensuring that the patient is comfortable. Channelling all calls to the designated person would spare the nurse some time to attend to the patient and other aspects of end-of-life care. Communication guidelines or protocols for end-of-life care communication could be employed to minimise the interruptions.

Intensive Care nurses in this study indicated that the second largest obstacle was nurses having to attend to family members who were distraught (POM= 13.36). In terms of intensity size and how often it occurs, the nurses rated it as 2nd (M= 3.69) fairly large obstacle and 3rd (M= 3.62) very often occurs obstacle, respectively. Beckstrand and Kirchhoff (2005) and Crump, Schaffer and Schulte (2010) reported the second largest obstacle in this current study as 8th (POM= 10.40) and 8th (POM= 10.40) respectively. Attia, Abd-Elaziz and Kandeel (2012) did not report on this item, they adapted the survey instrument and reduced the obstacle items from 29 to 25, thus this item was excluded.

The acute nature of ICU admissions, unfamiliar ICU environment in addition to the thought of losing a loved one puts so much stress on a patient's family (Coombs et al., 2015). A South African study, by Kisorio and Langley (2016), on family experience

regarding end-of-life care in the ICU revealed that the family were inadequately cared for. Patients' families felt they were left in the dark and indicated they needed emotional and spiritual support. The authors indicated that families were not satisfied with the level of communication and information shared between them and the nurses. This situation causes despair and may lead to anger, which may be responsible for the physical violence and threats of legal suits against nurses as expressed by one respondent in the open-end questions. Therefore, it is not surprising to find that Intensive Care nurses deal with distraught family members. When concerns of a patient's family are not addressed adequately, they run the risk of having depression, anxiety or post-traumatic stress disorder (Noome et al., 2016a).

As confirmed by one respondent in this study, and in other studies (Beckstrand et al., 2017; Kisorio & Langley, 2016), Intensive Care nurses are challenged and have psychological and emotional difficulty when nursing a dying patient. An additional burden, such as dealing with distraught family, compounds their plight because patients' family issues are more difficult to resolve (Beckstrand et al., 2017). The situation also denies nurses the ability to provide compassionate care, which is a valued nursing practice. Consequently, nurses become morally distressed and burnout, which negatively affects care (Henrich et al., 2017; McAndrew, Leske & Schroeter, 2015; Langley, Kisorio & Schmollgruber, 2015). Supporting Intensive Care nurses in this regard will help them to improve their care for dying patients and the family.

The third largest perceived obstacle in this study was the nurse having to deal with angry family members (POM= 12.99). It was rated as the 3rd (M= 3.67) large obstacle and 4th (M= 3.45), very often occurs, most intense and frequently occurring obstacle respectively. Similar studies by Beckstrand and Kirchhoff (2005), Crump, Schaffer and Schulte (2010) and Attia, Abd-Elaziz and Kandeel (2012) reported the 3rd perceived obstacle item in this study as the 7th (POM= 10.43), 4th (POM= 12.70) and 15th (34.3%, severity of the obstacle) respectively. Some patients' families may have unrealistic expectations (Friedenberg et al., 2012; Nelson et al., 2006), others may feel inadequately cared for (Kisorio and Langley, 2016), all of which could cause frustration and anger. As nurses are the ones who are by the patient, it is common for families to blame them and displace their negative emotions on the nurses. These negative emotions create tension, and distresses both patients and nurses (Kramer et al., 2006).

There is high litigation in South African ICUs, which impacts on Intensive Care nurses' ability to provide care. Therefore, dealing with angry family members could be burdensome, destructive and time consuming (Espinosa et al., 2008; Schmollgruber, 2006), and consequently, the nurses are not able to deliver optimal end-of-life care.

As illustrated in **Table 4.4**, patient family-related items were those with the most POM. These items included nurses dealing with: (1) Frequent calls from family; (2) Distraught family members; (3) Enraged family members; (4) Family members not knowing the implications and meaning of "life-saving measures;" (5) Family absence when patient is dying and (6) Family refusing the fact the patient cannot get better. These obstacle items were rated 1st, 2nd, 3rd, 4th, 6th and 8th most POM respectively. Even though the obstacle items and their ratings were not the same, the finding that patient family-related obstacles were the most highly rated is comparable to Beckstrand et al. (2017), who also found six patient family-related items dominating the top 10 obstacles. These were: (1) Family lack of understanding of what life-saving measures are; (2) Family desire to overturn patient advance directive: (3) Frequent calls from family; (4) Family rejecting patient's poor prognosis; (5) Nurses handling angry family members; (6) Intra family fighting and indecision on the direction of care. These were rated 1st, 3rd,4th ,5th, 7th and 8th most POM respectively.

Contrary to the current study, other authors reported that physician-related obstacle items, such as indecision to initiate end-of-life care, disagreement among physicians about the goal of care, physicians who did not want to engage patient relatives and avoided discussions with them and attitudes of giving so much hope to the family were considered as the greatest obstacles (Brooks, Manias & Nicholson, 2017; Festic et al., 2010; Iglesias, Pascual & de Bengoa Vallejo, 2013). Attia, Abd-Elaziz and Kandeel (2012), conversely, found ICU environmental factors such as nurses' heavy workload, ICU design and liberal Unit visiting hours as the most highly rated perceived obstacles in their study.

Intensive Care nurses in this study rated "Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment" as the least perceived obstacle to end-of-life care. The mean intensity size was 1.78 (small obstacle), frequency score was 1.85 (sometimes occurs) and a POM score of 3.29. This current finding does not support findings of earlier

studies (Beckstrand et al., 2017; Iglesias, Pascual & de Bengoa Vallejo, 2013; Nelson et al., 2006), which found this obstacle item as a huge obstacle to end-of-life care.

South Africa has an ethical framework for withholding and withdrawal of life-sustaining treatments. The physician in charge of the patient may override family demand to keep a dying patient on life-sustaining measures. This may help resolve any conflict arising from such family demands and thus may not pose as much a challenge to the nurses.

Interestingly, Intensive Care nurses perceived nurses having prior knowledge about patient's worsening condition before the family as the 7th largest obstacle.
This item has not been reported among the top 10 obstacle items in previous studies. Nurses knowing about patient's prognosis before the family is a common phenomenon. Intensive Care nurses are the ones who closely monitor the patient's condition and spend the most time by the patient. Thus, they are more likely to know about the patient's poor prognosis before the family. One would think that it is better for nurses to have prior knowledge of patient's condition so that the nurses could plan and know what to communicate to the family when needed. It is uncertain why this will obstruct care delivery. Therefore, as we explore opportunities to improve end-of-life care in the ICU, it is imperative to do a qualitative study to probe into this finding. Clearly, most perceived obstacle items vary across settings.

5.2.3 Perceived supportive behaviours to end-of- life care

The highest ranked perceived supportive behaviour was "Allowing family members adequate time to be alone with the patient after he or she has died," with a perceived supportive behaviour magnitude (PSBM) score of 18.30. This was also rated as the 1st (M = 4.18), large help and the 1st most frequently occurring help (M= 4.40), very often occurs.
The second highest perceived supportive behaviour was "Providing a peaceful, dignified bedside scene for family members once the patient has died." The PSBM score was 16.56. Intensive Care nurses rated it as the 2nd (M= 4.10): large help and 2nd (M= 4.04): very often occurs supportive behaviour.

The top two-ranked perceived supportive behaviours in this study were ranked the same in Beckstrand and Kirchhoff's (2005) study and rated as the 5th and 3rd by Crump, Schaffer and Schulte (2010).

The need to create a conducive environment and allow families adequate time to be with the dead is supported by Langley et al. (2013), which highlighted that there are different believes and attitudes towards death and dying. Providing privacy and giving families enough time alone with the dead, offers them the opportunity to pay their last respects and to perform any rituals as they deem appropriate. Fridh, Fosberg and Bergbom (2009b) reported that privacy at the bedside afforded the family the opportunity to keep vigil and express their full sorrow. These may help the family to attain closure and curtail prolonged grieving and its associated complications (McAdam & Erickson, 2016).

Thirdly, the nurses indicated, "Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done" (PSBM =15.50) served as a great help. The item was rated 3rd intense and frequently occurring help with average scores of 4.09: large help and 3.79: very often occurs respectively. Beckstrand and Kirchhoff found (2005) that although this item was considered a large help (M= 4.14), it rarely (1.90) occurred, thus, it was not rated among the top perceived supportive behaviours (PSBM= 7.87). Intensive Care nurses in Crump, Schaffer and Schulte (2010) study also considered the item as a large help (M= 4.04) but it seldomly occurred (M= 1.84). Attia, Abd-Elaziz and Kandeel (2012) did not report on this item.

Deduction from these findings suggest that Intensive Care nurses in this study were supported by physicians with end-of-life communication. Several studies (Attia, Abd-Elaziz & Kandeel, 2012; Brooks, Manias & Nicholson, 2017; Espinosa, 2010; Montagnini, Smith & Balistrieri, 2012; Nelson et al., 2006) have attributed nurses' difficulty with end-of-life communication to inadequate end-of-life content in their curriculum at the undergraduate and graduate levels. Kisorio and Langley (2016) reported that Intensive Care nurses in South Africa prefer referring the family to the physician due to the challenges they have when handling end-of-life communications. Another reason why South African nurses may prefer physicians to communicate to the bereaved family could be that the nurses do not feel empowered to do so. Langley, Kisorio and Schmollgruber (2015) demonstrated that the situation that prevails in South

African ICUs, due to their history, constrains the autonomy and accountability traits of Intensive Care nurses. Additionally, even though McAdam and Erikson (2016) suggested that both Intensive Care nurses and physicians feel unqualified to render support for bereaved families, Moss et al. (2005) argued that physicians are more confident with end-of-life communications. This may account for why nurses would advocate for physicians to communicate with bereaved families.

The least perceived supportive behaviour to end-of-life care was “Having un-licensed personnel available to help care for dying patients” (PSBM= 1.73). This item was also rated the least help and the almost never occurring behaviour with mean intensity and frequency scores of 1.01 and 0.95 respectively. Attia, Abd-Elaziz and Kandeel (2012) also found this supportive behaviour as the least perceived help (1.4% help).

As presented in **Table 4.7,** the highest ranked perceived helpful behaviours to end-of-life care were related to supporting patient family, which was identified in earlier studies as significant help (Efstathiou & Walker, 2014; Kirchhoff & Beckstrand, 2000). Kisorio and Langley (2016) indicated Intensive Care nurses were usually busy during end-of-life care. Findings of this study support recommendations for inter-professional collaboration (Espinosa et al., 2010; Festic et al., 2012; Montagnini, Smith & Balistrieri, 2012) in end-of-life care.

What is unclear about the findings in the study is that deductions from the scores; supportive behaviour size, and how frequently these helps are given, gives the impression that Intensive Care nurses are frequently given support with patient family issues, and yet patient family-related items are the most highly rated obstacle items. The peculiarity of each family’s needs may account for this. Beckstrand et al. (2017) suggested that unlike nurses who deal with patients at the end of their lives on a regular basis, such ICU experience may be the first for families, thus one cannot predict their reactions. Adopting one approach for all families will not work hence the need for individualised care models.

5.3 SUMMARY OF THE STUDY

The purpose of the study was to identify and describe Intensive Care nurses' perceptions of behaviours that are obstacles to or support the provision of effective end-of-life care in adult ICUs of an academic hospital in Johannesburg.

The study objectives were to identify and describe nurses' perceptions of behaviours that are obstacles to end-of-life care and their perceptions of supportive behaviours, which facilitate the care.

After attaining the necessary clearance and permission to conduct this study, a pilot study was undertaken, which helped to refine the methodology and scale down the questionnaire. To make the study more representative, the total population of 105 Intensive Care nurses were invited. Data was collected in December 2018, with an 86.7% response rate. Descriptive statistics, such as measures of central tendency and dispersion, were used to describe results from the study.

The highly rated perceived obstacles and supportive behaviours to optimal end-of-life care were related to patient family items.

5.4 LIMITATIONS OF THE STUDY

The study had some limitations regarding generalisation of results and the survey instrument. Firstly, despite the high response rate of 86.7%, the study was done at only one academic hospital in Johannesburg. Intensive Care nurses from other institutions might have different perceptions, therefore the results may not be applicable to other adult ICUs. This prevents the generalisation of the current study.
Secondly, concerns could be raised about the eligibility of the majority of the respondents. Intensive Care nurses have, at least, a post basic qualification, however, results of this study show most of the respondents had a diploma as the highest qualification. This could be because responses to item 5 on the questionnaire (demographic section) did not include a post basic level.

Furthermore, the closed-ended nature of the items on the questionnaire did not allow for depth in the identified obstacles and helpful behaviours. A qualitative study is

needed to probe into the highly rated perceived obstacles and supportive items to gain more in-sight into nurses' perceptions.

Lastly, most of the additional obstacle and supportive behaviour items suggested by respondents were duplicates of items on the questionnaire. This could be attributed to the wording of the questions or the lengthiness of the questionnaire and as such, respondents could not understand the question or may have forgotten they had responded to a similar item. Three respondents mentioned in the comments section that the questionnaire was complex and long.

5.5 RECOMMENDATIONS ARISING FROM THE STUDY

5.5.1 Clinical Practice

Support for nurses

The highest perceived obstacle was frequent calls from families. Nurses could limit the interruptions by giving regular updates on the patient to a designated contact person and redirecting all calls to that person. This approach would be effective if the designated person was up to date with what was happening with the patient.

Intensive Care nurses in this study considered it helpful when physicians were the ones speaking to families after the patient had died. Going forward, nurses should actively participate in physician and patient family meetings, as nurses would be aware of what had been communicated and could give the same message to other family members if the need arose; contradicting information could fuel distrust and anger among the families. As the nurses participate and observe how the communication process is conducted, they would in turn learn and gradually improve their skills and confidence. Intensive Care nurses must re-examine their end-of-life practices and enforce effective communication measures. Having an end-of-life communication protocol could go a long way to lessen this challenge. The nurses could also benefit from formal training on how to communicate during such situations.

Due to the peculiarity of each family's needs and the short period for end-of-life care, dealing with distraught and angry family members compounds the challenges Intensive

Care nurses face. The concerns of families may not be adequately addressed by the same nurse caring for the dying patient. Therefore, team collaboration must be enforced throughout the process. Withdrawal of other members of the multidisciplinary team after life-support has been withdrawn should be discouraged; for example, physicians or a clinical psychologist should be around to address the concerns of the family to ease the burden on nurses. An end-of-life communication protocol by the multidisciplinary team could also provide a framework for communication, which may prevent the aggravation of distress among the nurses thereby improving overall health outcome. The nurses themselves need to be supported to enable them to provide better care for the dying patient and to address the concerns of the family.

As indicated by one respondent, Intensive Care nurses have bereavement needs. Some nurses grieve after the death of a patient, and this affects their emotional and psychological wellbeing. Debriefing and counselling sessions for nurses after a patient has died may help them to cope with end-of-life issues.

Support for patient family

When concerns of family members are not adequately resolved, they are aggrieved. To curtail this and to limit the obstruction this creates for caregivers, nurses should coordinate the care of the patient with the family by adopting an individualised patient and family care model. Bereavement services, such as a follow up appointment at the ICU, may help prevent or decrease the prevalence of post-trauma stress disorder among bereaved families.

5.5.2 Nursing Management

Results from the study indicate that Intensive Care nurses appreciate supportive behaviours related to patient's family. Stakeholders could use the information to better understand some of the concerns of the nurses and develop local strategies, such as ensuring Intensive Care nurses actively participate in the decision-making process, in-service training and education on emerging end-of-life issues, develop a communication protocol (consultative), enhancing collaboration among the multidisciplinary team and periodic evaluation of end-of-life practices.

5.5.3 Nursing Education

It is evident that Intensive Care nurses in this study have end-of-life communication challenges. Other authors have attributed this to the lack of, or insufficient, end-of-life content in nursing education and training. It could also be that educators are not up to date with current practices. Nursing training curriculum could be reviewed to include or add to end-of-life communication content. Additionally, educators may need to engage with clinical practice by attending Unit ward rounds and engaging nurses at the bedside.

5.5.4 Further Research

Due to the reasons limiting the generalisation of the findings of this study, an extension of the study to other hospitals could give a broader view of the phenomenon. A qualitative study on this topic may help to get more depth into items that could not be explained quantitatively.

As one explores ways of improving end-of-life care, a study to ascertain the quality of such care in adult ICUs may help attain information to upgrade end-of-life practices.

5.6 CONCLUSIONS

Identifying the perceptions of Intensive Care nurses about the challenges they face when taking care of dying patients and their relatives is key to finding or developing strategies to lessen the stresses nurses go through. Studies that examined obstacles and supportive behaviours to end-of-life care of South African nurses working in Intensive Care Units are scarce. However, this study's findings support the conclusions of most studies that highlighted and reported on end-of-life care obstacles and behaviours that support the course. This current study confirms the findings that challenges to providing this type of care in ICUs persist Therefore, Intensive Care nurses must be supported, given a voice and empowered to carry out their mandate to improve end-of-life practices in adult ICUs.

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APPENDIX A

INTENSIVE CARE NURSES PERCEPTION OF END-OF-LIFE CARE QUESTIONNAIRE

End-of-life is currently regarded an important phase of life. Intensive Care nurses are frequently responsible for care of patients at the end-of-life and dying. Care dilemmas arise for nurses, because dying patients are placed in an environment created to support and sustain life.

SECTION 1: PERCEPTIONS OF POSSIBLE OBSTACLES TO END-OF-LIFE CARE

The following items pertain to your perceptions of possible obstacles to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterises how **large an obstacle** you have found each item to be, then mark the square box for how **frequently** you have experienced the obstacle as you have cared for dying patients.

How Large an obstacle	**How frequently?**
0 = Not an obstacle	0 = Never Occurs
1 = Extremely Small Obstacle	1 = Almost Never Occurs
2 = Small Obstacle	2 = Sometimes Occurs
3 = Medium Obstacle	3 = Fairly Often Occurs
4 = Large Obstacle	4 = Very Often Occurs
5 = Extremely Large Obstacle	5 = Always Occurs

		Indicate how large obstacle is	**Indicate how often obstacle occur**
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 patient's 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.	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 patient's 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 dying 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 □ □ □ □ □ □
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 admit 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 designated 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	Caring for a patient who has been declared brain dead and is soon to become an organ donor.	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 or hospital 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 break during chest compression.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
23	The nurse not knowing patient’s sentiments regarding continuing with treatment and tests because of the inability to communicate due to patients’ depressed neurological status or 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 when 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 in which care should go.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
28	Continuing to provide advanced treatment 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 in which 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 large each obstacle is and how frequently it occurs.

_____

_____

_____

_____

_____

TURN TO THE NEXT PAGE

SECTION 2: PERCEPTIONS TO PROVIDING END-OF-LIFE CARE

The following items pertain to your perceptions to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterises how **large a help** you have found each item to be, then mark the square box for how **frequently** you have experienced the helpful behaviour as you have cared for dying patients.

0 = Not a Help	0 = Never Occurs
1 = Extremely Small Help	1 = Almost Never Occurs
2 = Small Help	2 = Sometimes Occurs
3 = Medium Help	3 = Fairly Often Occurs
4 = Large Help	4 = Very Often Occurs
5 = Extremely Large Help	5 = Always Occurs

		Indicate how large of help you found each item	**Indicate how often you experienced this**
31	Having one family member be the designated contact person for all other family members regarding patient information.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
32	Having enough time to prepare the family for the expected death of the patient.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
33	A Unit designed so that the family has a place to go to grieve in private.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
34	Having the physicians involved in the care of the patient agree about the direction care should go.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
35	Having a Unit schedule that allows for continuity of care of the dying patient by the same nurse(s).	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
36	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
37	Having the family physically help with care of the dying patient.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
38	Talking with the patient about his or her feelings and thoughts about dying.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □

39	Letting the social worker or religious leader take primary care of the grieving family.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
40	Teaching families how to act around the dying patient such as saying to them, "She can still hear you … it is OK to talk to her."	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
41	Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
42	Providing a peaceful, dignified bedside scene for family members once the patient has died.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
43	Allowing family members adequate time to be alone with the patient after he or she has died.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
44	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
45	Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give you some other kind of brief physical support after the death of your patient.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
46	Having fellow nurses take care of your other patient(s) while you get away from the Unit for a few moments after the death of your patient.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
47	Having a support person outside of the Unit setting who will listen to you after the death of your patient.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
48	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
49	Having an ethics committee member routinely attend Unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
50	Having family members accept that the patient is dying.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
51	After the death of the patient, having support staff compile for you the necessary paper	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □

	work which must be signed by the family before they leave the Unit.		
52	Physicians who put hope in real tangible terms by saying to the family that, for example, only one out of 100 patients in this patient's condition will completely recover.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
53	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □
54	Having unlicensed personnel available to help care for dying patients.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 □ □ □ □ □ □

55. Please describe any missing helpful behaviour in detail. Indicate how **large** the help is and how **frequently** it occurs.

56. 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?

SECTION 3: DEMOGRAPHIC DATA

1	How many years of experience do you have as an RN? yrs			
2	How years of ICU experience do you have? yrs			
3	What is your gender?			
	Male			
	Female			
4	**What is your age group in years?**			
	20-29 years			
	30-39 years			
	40-49 years			
	50-59 years			
	Other……..			
5	What is your highest completed level of education?			
	Diploma in nursing			
	Bachelor's degree			
	Master's degree in nursing			
	Doctoral degree in nursing			
	Other……..			
6	Over your nursing career, to how many ICU patients have you given immediate end-of-life care?			
	Less than 5		Between 21 and 30	
	Between 5 and 10		More than 30	
	Between 11 and 20		Other……	
7	In which type of ICU are you primarily employed?			
	Cardiothoracic			
	Coronary Care			
	Multidisciplinary ICU			
	Neurosurgical ICU			

	Trauma ICU	
8	The position you hold at the facility is…	
	Direct care/Bedside nurse	
	Clinical nurse specialist	
	Charge nurse/ Unit Manager	
	Other (Please specify) ……	

Do you have any further comments you wish to make about this study?

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

APPENDIX B

OBSTACLES AND SUPPORTIVE BEHAVIOURS TO END-OF-LIFE CARE IN ADULT ICUS: PERCEPTION OF INTENSIVE CARE NURSES.

NURSES INFORMATION LETTER

Dear Colleague,

My name is Patricia Dorsaa, a student at the University of Witwatersrand, pursuing Master of Science in Nursing (Intensive Care) at the Department of Nursing Education. I would like to invite you to consent to my including you in the sample of nurses I hope to study in adult Intensive Care Units. The study aims to identify and describe the obstacles and supportive behaviour in providing optimal end-of-life care to dying patients and their families.

Should you agree to participate in this study, you will be asked to complete a questionnaire, which will be given to you on your next shift. The questionnaire is in three parts. The first and second parts are selected items on obstacles and supportive behaviours respectively. You will be asked to rate the magnitude and frequency of selected items. The third part is about respondents' demographic data. In order to maintain anonymity, please do not write your name. It will take approximately 25 to 30 minutes to complete the questionnaire. Completed questionnaires must be placed in the envelope and posted in the sealed box provided in your respective Units.

Participation in this study is voluntary. Your decision not to participate will not attract any penalty and you can withdraw at any time. All questionnaires will be handled by me and will be kept in a locked filing cabinet with limited access. There may be a small risk that in completing the questionnaire you may be reminded a dying patient you nursed and evoke feelings of emotional distress. I will arrange for a counsellor for debriefing.

The appropriate people and research committees of the University of Witwatersrand, Gauteng Department of Health and the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) have approved the study and its procedures. Should you require further information regarding this research study, you may contact the Chairperson of this Committee Dr Clement Penny, who may be contacted on 011 717 2301, or by e-mail on clement.penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the email addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za .

Thank you for taking time to read this information letter. Should you require more information regarding the study or your rights, you are free to contact me in the Department of Nursing Education, or on the following telephone number: 061 294 3750.

Yours Sincerely,

Ms Patricia Dorsaa.
MSc Nursing Student

Supervisor:Professor Shelley Schmollgruber email: shelley.schmollgruber@wits.ac.za

APPENDIX C

Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms Patricia Dorsaa

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180746

NAME: (Principal Investigator)	Ms Patricia Dorsaa
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Obstacles and supportive behaviours to end of life care in an adult intesive critical care: perceptions of intensive care nurses
DATE CONSIDERED:	27/07/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Shelley Schmollgruber
APPROVED BY:	Dr C Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	23/11/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed July and will therefore be due in the month of July each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX D

Hospital Permission to Conduct Research

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. G. Ngwenya
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
26 November 2018

Ms. Patricia Dorsaa
Department of Nursing Education
University of Witwatersrand
NHRD REF: GP_201809_007

Dear. Patricia Dorsaa

RE: **"Obstacles and supportive behaviours to end of life care in adult intensive care units: perceptions of intensive care nurses"**

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / ~~not supported~~

Ms. M.M Pule
Nursing Director
Date: 26/11/2018

Approved / not approved

Ms. G. Bogoshi
Chief Executive Officer
27.11.2018

APPENDIX E

Postgraduate Approval of Study

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

11 September 2018
Person No: 1562761
PAG

Miss P Dorsaa
Earlsmere Building
11 Princess Pl
Brendthurst, Parktown
2193
South Africa

Dear Miss Patricia Dorsaa

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Obstacles and supportive behaviours to end of life care in adult intensive care units: Perceptions of intensive care nurses* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX F

Permission to use Research Instrument

From: Renea Beckstrand [mailto:Renea_Beckstrand@byu.edu]
Sent: 13 March 2019 21:51
To: Shelley Schmollgruber <schmoll@iafrica.com>
Subject: RE: request for permission to use survey questionnaire

Here you go, best wishes. Renea

From: Renea Beckstrand [mailto:Renea_Beckstrand@byu.edu]
Sent: 13 March 2019 17:27
To: Shelley Schmollgruber <schmoll@iafrica.com>
Subject: RE: request for permission to use survey questionnaire

I have many versions of the Obstacles and Helpful Behaviors instrument: critical care nurses, oncology, emergency department, peds, NICU.

Which one are you interested in and my stipulations are that you send me any translations of the instrument, that the instrument is used only once and never with a U.S.A. sample, and that you notify me of any publications from the study.

Renea L. Beckstrand, PhD, RN, CCRN, CNE
Professor
Brigham Young University, College of Nursing
P.O. Box 89, KMBL
Provo, UT 84602
801 422-3873
renea@byu.edu

From: Shelley Schmollgruber <schmoll@iafrica.com>
Sent: Wednesday, March 6, 2019 10:37 AM
To: Renea Beckstrand <Renea_Beckstrand@byu.edu>
Cc: 'Shelley Schmollgruber' <Shelley.Schmollgruber@wits.ac.za>
Subject: request for permission to use survey questionnaire

Dear Professor Beckstrand,
My name is Shelley Schmollgruber, I am the Postgraduate Research Coordinator for the Department of Nursing Education in the Faculty of Health Sciences at the University of the Witwatersrand.
I am currently supervising a MSc Nursing Student who is interested in looking at end of life care. The student has identified your work as very interesting for her study in order to advance our understanding of the obstacles and supportive behaviours in adult intensive care units in South Africa.

The student is expected to conduct the data collection phase of the study over three months. She is expected to write one paper for publication in fulfilment of the degree award.
We hereby request your permission to use your Obstacles and Supportive behaviours questionnaire for end of life care in our South African Study.
Our ethics committee does require written permission to be obtained from the original developer of the instrument. This does not have to be a long letter but an email response would also suffice.

Kind regards
Shelley Schmollgruber

Prof Shelley Schmollgruber (PhD)
Associate Professor.
Specialisation: Intensive and Critical Care Nursing, Trauma and Emergency Nursing.
e-mail: shelley.schmollgruber@wits.ac.za
Tel: +27 (0) 11 488 4271
address: 7 York Road, Parktown, Johannesburg, South Africa, 2193.



APPENDIX G

Language Editing and Proofing

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 Email: moramist@vodamail.co.za

Work Certificate

To	Prof. Shelley Schmollgruber
Address	Wits Dept of Nursing Education
Date	10/03/2019
Subject	OBSTACLES AND SUPPORTIVE BEHAVIOURS TO END-OF-LIFE CARE IN ADULT INTENSIVE CARE UNITS: PERCEPTIONS OF INTENSIVE CARE NURSES
Ref	SS/GS/29

I certify that I have edited the following research report for language, grammar and style,

Forward, Chapters 1 to 5 and Appendices: Obstacles and supportive behaviours to end-of-life care in adult Intensive Care Units: perceptions of Intensive Care Nurses, by P. Dorsaa

to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies