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Intensive care unit nurses' experiences regarding withdrawal of treatment and end of life care

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2022

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INTENSIVE CARE UNIT NURSES' EXPERIENCES REGARDING WITHDRAWAL OF TREATMENT AND END OF LIFE CARE

Shenaz Hussein

A research report submitted to the

Faculty of Health Sciences, University of the Witwatersrand, Johannesburg

in partial fulfilment the requirements for the degree

of

Master of Science in Nursing

Johannesburg, 2022

DECLARATION

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



.....

Shenaz Hussein

Signed at Johannesburg

On the ...30th..... day of .....August..... 2022

Protocol number: M190640

DEDICATION

I dedicate this work to God because without his grace none of this would have been possible, my family and friends who has been my pillar of strength and motivation, my colleague's fellow ICU nurses and doctors it is through you I have remained steadfast. You have been my strength and comfort through many a difficult day regarding end-of-life care and the withdrawal of treatment. Thank you for your love and support, your belief in what we do as healthcare professionals and for being strong as a team. It is through us that families and patients find healing and comfort. Lastly, I dedicate this work to the families and patients I have worked with your strength and faith has taught me how precious life is.

ACKNOWLEDGEMENTS

I would like to acknowledge God for making all of this possible by his grace.

I would like to give a special thanks to those people who have encouraged me and stood by me to ensure that this journey was a successful endeavour.

To my supervisor Dr Ntombifikile Klaas who sacrificed her time and showed me nothing but encouragement and motivation to get through this difficult journey I am deeply grateful.

To my wonderful family and friends especially my daughter Iman and my life coach Thabang I thank you for your patience and belief in me and for continuously supporting me and encouraging me throughout this journey.

To my fellow Transplant ICU colleagues and managers thank you for being the wonderful team that you are thank you for the love, care, hard work, kindness and empathy. Thank you for believing in me and supporting my endeavour.

ABSTRACT

Background: The withdrawal of treatment and End of Life Care (EOLC) in the intensive care setting is a process that often has many challenges. This process can cause the intensive care nurse involved in the process to have many conflicting feelings. These feelings can affect the nurse and the process both negatively and positively. It can cause emotional distress and frustration resulting in poor decision-making and poor communication. It can also cause a feeling of relief that the patient will suffer no more. On the other hand, prolonging death can lead to patient suffering or ending the life of a patient too soon can result in anxiety and self- blame.

Aim: The aim of the study was to describe the ICU nurses' experiences with regard to withdrawal of treatment and EOLC in the adult intensive care units of a university affiliated public hospital in Gauteng.

Methods: A qualitative descriptive design was used in this study. Purposive sampling method was utilized to select the sample of 15 (n=15) registered nurses working in the four ICUs of an academic hospital in the Gauteng province. In - depth semi- structured interviews were used to collect data. Braun and Clarke's thematic analysis approach was utilized to analyse the transcribed interviews.

Results: Three broad themes emerged from the study. These included *obstacles to withdrawal of treatment and EOLC, emotional burden and coping mechanisms.*

Conclusion: For more than three decades ICU nurses face many challenges within the working environment while providing care to the dying patients and supporting their family members. It was evident from literature as well as from the study's findings several obstacles concerning withdrawal of treatment and EOLC exist. These concerns are related to inadequate training for nurses, lack or inadequate support systems for nurses, the unfavourable nature of the ICU, nurses' lack of or inconsistent involvement in decision-making, lack of communication and teamwork among the ICU team members. Despite the multi-cultural and diversified societies, and differences in EOLC practices globally, all ICU nurses experience similar obstacles to EOLC.

Keywords: End of life care, experiences, Intensive care unit, and withdrawal of treatment.

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LIST OF ABBREVIATIONS

ICU	Intensive Care Unit
ICU Nurse	Intensive Care Unit Nurse
EOLC	End of Life Care
DNR	Do not resuscitate

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This chapter presents an overview of the study. The chapter incorporates the background information for the research problem, the purpose, and objectives of the study, the research question, the significance of the study, paradigmatic perspectives and definition of key terms. It also presents a brief overview of the research methods, ethical considerations, and measures to ensure trustworthiness.

1.2 BACKGROUND OF THE STUDY

Rates and patterns of death and dying in the intensive care unit (ICU) vary worldwide. These rates are dependable on patient demographics, patterns of disease and sociological influences (Myburgh *et al.*, 2016). Of all deaths, 20% occur in ICU. The majority of these patients spend the last month of their life in ICU and therefore, ICU nurses need to provide holistic and high-quality end-of-life care.

The intensive care unit is a highly technological environment that needs nurses to care for patients with severe injuries and illnesses that are life threatening. Even though intensive care nurses are in partnership with doctors in patient care, they still need to have critical decision-making skills and vast knowledge of illnesses, injuries and management of these aspects. They must be a source of comfort and support to families and patients during a very vulnerable time (De Beer, Brysiewicz & Bhengu, 2011).

End-of-life care has become an extremely important subject in respect of the appropriate management of patients and their families. Withholding and withdrawal of life-sustaining treatment while ensuring the alleviation of suffering, within diverse cultural and religious belief systems is complex (Myburgh *et al.,* 2016). The withdrawal of treatment refers to the termination of life-sustaining interventions given to the dying and critically ill patient, as it will not benefit the patient (Crowe & Macfarlane, 2013).

It is reported that the common occurrence of death due to the withdrawal of life-sustaining treatment ranges between 0 and 84.1% with a standard deviation of 23.7%, thus leaving a need for further research on withdrawal of treatment and end of life care (Mark *et al.,* 2015).

The withdrawal of treatment and EOLC in the intensive care setting is a process that often has many challenges. This process can cause the intensive care nurse involved in the process to have many conflicting feelings. These feelings can affect the nurse and the process both negatively and positively. It can cause emotional distress and frustration resulting in poor decision-making and poor communication. It can also cause a feeling of relief that the patient will suffer no more. On the other hand, prolonging death can lead to patient suffering, or ending the life of a patient too soon can result in anxiety and self-blame.

In the South African context, HIV and AIDS as well as injuries add to the quadrupling burden of disease. An ICU mortality rate of 31.5% shows that death and dying is a common occurrence in this setting (Kisorio & Langley, 2016).

The idea of death and dying alone can evoke many feelings such as sadness, grief, emotional distress and a feeling of failure in the nurse.

Ranse *et al*. (2012) illustrated how nurses experience grief and distress every day because of having to care for critically ill patients with disturbing injuries. Support services are either not readily available or not easily accessed or utilized and is lucrative to maintaining the health of nurses psychologically. Participants in this study mentioned that external support services to aid nurses psychologically were available but not utilized. With a high occurrence of death post-withdrawal of treatment and dealing with death itself this often results in conflicting feelings on whether or not to withdraw treatment. However, even after the decision to withdraw the treatment has been made, the nurse wants to distance herself or himself from the process.

Borhani *et al.* (2015) highlighted that continuing with life-sustaining treatment helped some patients' health status to improve despite the expectation that they would not. This made nurses more aware of their commitment to continuing life-sustaining therapy with the idea that they would allow a patient to die too early whereas the patient could be saved.

Another challenge for nurses is religious beliefs and personal feelings that are often against death, hence making the withdrawal of treatment to seem like an unethical aspect to consider or carry out. According to the findings of an Australian study by Halcomb *et al.* (2004), most nurses found themselves moving away from the process of withholding or withdrawing treatment because of religious beliefs that are against death. The nurses stated that they were feeling defeated in terms of saving patients' lives and they experienced emotional turmoil during this time.

Due to the aforementioned factors, problems arose concerning principles of right and wrong behaviour concerning the nurses' role during and after withdrawal of life-sustaining treatment.

According to the findings of a South African study by Langley *et al.* (2013), on critical care

nurses' views on end-of-life decision making and practices 63- 68% of the nurses expressed fear of legal action during EOLC. The Japanese nurses, however, placed no significance on legal action, as they perceived all the responsibility being that of the doctors during this process (Kinoshita & Miyasita, 2011).

A study carried out by Coombs *et al.* (2015), emphasized that there is complexity of a high degree concerning different opinions regarding the do's and don'ts of EOLC once life support is discontinued or not initiated. Examples of the above difference of opinions are that 41% of participants stated that patients should be deeply sedated, 43% agreed to the continuation of fluid replacements and 41% disagreed with nutrition being continued. According to Holms *et al*. (2014), staff distress was frequently related to lack of experience, challenges with communication, insufficient training and lack of support, and lack of involvement in decision-making.

Brooks *et al*. (2017) reported that junior nurses and doctors had trouble communicating about EOLC and having conversations. This could be due to their lack of experience, support and training. This is supported by Ranse *et al.* (2012) and further added that junior colleagues do not have support from their senior colleagues as they have not established such relationships yet and this further adds to them having lack of support.

In a study by Halcomb *et al*. (2004), the nurses expressed that withdrawal of treatment is complex and a difficult situation due to many factors such as obligations and responsibilities to multiple facets.

The nurses raised a concern that they were expected to carry out end-of-life care alone after the

doctors have made the decisions.

They added that they also have a responsibility to support the patient and the family during this time as well as to carry out their professional obligations to their profession and their employer, the hospital (Halcomb *et al.*, 2004). The nurses stated that they have difficulty when it comes to handling both their feelings and professional expectations and often end up questioning whether what they did was the correct thing to do or not (Kisorio & Langley, 2016).

Nurses expressed many negative emotions when they are not part of making the choice on EOLC. The timing of doctors in terms of making decisions to withdraw treatment is an issue and was often prolonged and often causes moral distress to nurses. In a study conducted by Langley *et al.* (2013), on moral distress experienced by intensive care nurses, 33% of the nurse participants felt that decisions to withdraw active treatment were made too late. Communication between the doctor and the nurse is often considered a problem. Nurses feel that they are often asked to carry out orders without being involved in making the choice to discontinue or not initiate life support measures.

Communication between the nurse and the family was reported as a major concern. Good communication is needed to facilitate optimal EOLC and where there is family involvement to a large degree. Nurses reported being unhappy regarding the conflict with other members of the multidisciplinary team (Halcomb *et al.,* 2004). Flannery *et al.* (2015) reported that nurses were cold towards communicating with the family due to negative feelings caused by the dispute between nurses and doctors. This increased the risk of both the family of the patient and the nurses feeling secluded.

Poor communication may prolong the pain and suffering of all involved during EOLC. Therefore,

it is of great importance to have good cultural communication.

An example of this is explaining the critical condition of the patient in a culturally acceptable way considering the patient and family's religious views and cultural beliefs and practices.
This can promote more understanding, acceptance and agreement (Powazki *et al.*, 2014).
Clinicians often have poor cultural communication with families and patients. Nurses take a critical forefront role in helping and informing patients families about the withdrawal of treatment and they view this as an area of importance. Nurses communicate and support EOLC where families are concerned (Powazki *et al.*, 2014). According to the findings of a study by Adams *et al*. (2011), 98% of nurses counsel family members of the dying patient.

Participants in a study by Brooks *et al*. (2017) were dissatisfied with the environment in which treatment is withdrawn. Nurses' views on the matter are that many aspects of the ICU environment affect EOLC negatively. This included lack of privacy, noise levels from alarms of monitors and ventilators (Brooks *et al.*, 2017). To improve the ICU environment, especially during EOLC some suggestions were made. These included the availability of beds for the family, food, showering facilities, soothing music, a quiet place for prayer, meditation and family gatherings (Beckstrand *et al*., 2006).

Even though end-of-life care is a multidisciplinary responsibility, ICU nurses remain the primary care providers to patients and their families in the ICU at the end of life. This cadre of healthcare professionals is faced with diverse perceptions and emotions while providing care for patients whose active treatment has been withdrawn.

They are at the patient's bedside 24 hours a day. This puts them under tremendous distress in

providing end-of-life care to dying patients and their families. As a result, nurses struggle and harbour fears talking about death and dying in the ICU. Therefore, this study intends to describe the experiences of intensive care nurses regarding the withdrawal of treatment and EOLC.

1.3 PROBLEM STATEMENT

Intensive care nurses' experiences of withdrawal of treatment and EOLC for patients and family members have been well described in the literature using varying research approaches and within varying multi-cultural societies and geographical locations (Efstathiou & Walker 2014; Kisorio & Langley, 2016; Rafii *et al.,* 2016). It is evident in the literature that nurses face many challenges within the working environment while providing care for patients and family members. ICU nurses' experiences regarding the withdrawal of treatment and EOLC are complex and can affect the process and outcomes both negatively and positively.

Even though the South African mortality rate in ICU has increased significantly when compared to the past due to the poor prognosis, change in disease profile, the HIV and AIDS epidemic and high prevalence of multiple traumas resulting from motor-vehicle accidents and high levels of violence (Brysiewicz & Bhengu, 2010; Langley *et al*., 2013).

According to a survey study conducted in the South African context on moral distress experienced by ICU nurses, it was found that ICU nurses experienced considerable moral distress when dealing with the withdrawal of life-sustaining treatment and EOLC (Kisorio & Langley, 2016). A better understanding of their experiences will assist in providing support to the nurses.

The study attempted to answer the following research question:

What are ICU nurses' experiences regarding the withdrawal of treatment and EOLC?

1.4 PURPOSE OF THE STUDY

The purpose of this study was to describe the ICU nurses' experiences with regard to withdrawal of treatment and EOLC in the adult intensive care units of a university-affiliated public hospital in Gauteng.

1.5 OBJECTIVE

The objective of the study was to explore and describe the ICU nurses' experiences with regard to withdrawal of treatment and EOLC.

1.6 SIGNIFICANCE OF THE STUDY

This study intended to explore the experiences of ICU nurses when caring for EOLC patients. It was envisaged that knowing this information would create insight into nurses' positive and negative experiences. Knowing this information would help individualize care and provide comfort for the patient and family. This study will build on the previous research conducted in South Africa.

1.7 PARADIGMATIC PERSPECTIVE

A paradigm is a general perspective on the complexities of the world, or the worldview of a phenomenon (Polit & Beck, 2018). It is a philosophical stance, which guides qualitative research as it informs the question to be asked, an observation made and how the data is interpreted. A paradigm helps in guiding the researcher's enquiry. In this study, the researcher's enquiry is based on meta-theoretical, theoretical and methodological assumptions.

1.7.1 Meta-theoretical Assumptions

According to Polit and Beck (2018), metatheory explores the theoretical foundations on which the study is based. The person, the environment, health and nursing are the four meta- theoretical assumptions in nursing.

- **The person**

The person in this context is the intensive care nurse who has specialised advanced skills to care for critically ill patients in the intensive care unit and is involved in end-of-life care with the rest of the multidisciplinary team involved in the EOLC process.

- **The environment**

The environment refers to the internal as well as the external factors which affect the person. The external aspects are the surroundings or conditions within which a person functions or where a particular activity is carried out. The internal environment refers to the person's response to the particular surrounding (Nikfarid, *et al*., 2018). In this study, the environment refers to the intensive care unit, a designated area in a hospital with specialized equipment and skilled personnel caring for patients during the end-of-life care process.

- **Health**

Health is the state of being physically and psychologically well and it does not necessarily mean the absence of disease. It is said to be a balance between the person and the environment (Svalastog *et al*., 2017).

In the context of this study, health refers to the critically ill patient's holistic well-being during end-of-life care for them to attain comfort care regardless of their prognosis in the ICU.

- **Nursing**

Nursing refers to a profession of caring for sick individuals by people regulated by the profession to render healthcare to those in need of it. Nursing entails providing support, hope and treating someone with dignity and respect until death (South African Nursing Council, 2005). Intensive care nursing is a speciality that involves the care of critically ill patients during the end of life (De Beer *et al.,* 2011).

1.7.2 Theoretical Assumptions

Theoretical assumptions are theoretical notions used as a point of departure in a study (Polit & Beck, 2018). These include the operational definitions used in a study.

1.7.2.1 Operational definitions

Operational definitions define a variable by stipulating what actions are needed to measure it (de Vos *et al*., 2011). Definitions for the study were as follows:

- **Intensive Care Unit**

An intensive care unit is a highly technological environment that needs nurses to care for patients with severe injuries and illnesses that are life-threatening (De Beer *et al*., 2011). In this study, intensive care unit refers to specialised sections in the hospital, staffed and managed by specialised health professionals using specialised equipment to rescue patients with life-threatening illnesses.

- **Intensive care nurse**

Intensive care nurse refers to a professional nurse who has undergone advanced training with an accredited institution and is registered with the South African Nursing Council. In this study, intensive care nurse refers to a nurse who has critical decision-making skills and vast knowledge of illnesses injuries and management of these aspects as well as they must be a source of comfort and support to families and patients during end-of-life care (De Beer *et al*., 2011).

- **Withdrawal of treatment**

The withdrawal of treatment refers to removing or the prevention of initiation and maintaining of treatment and medication and applied science and procedures that support life unnaturally (Crowe & Macfarlane, 2013). In this study, the withdrawal of treatment is not initiating treatment or therapy that supports life unnaturally or stopping such treatment or therapy.

- **End of life care (EOLC)**

According to the National Cancer Institute (NCI), EOLC is holistic care which is to facilitate supporting and giving comfort to dying patients and their families during and after the withdrawal of life supportive treatment and curative treatment. It includes aspects such as pain management with regard to the dying patient (NCI, 2019). In this study, it refers to giving support and care to the patient and family during the withdrawal of treatment and the dying process.

- **Experiences**

Experience is defined as direct observation of or participation in events as a basis of knowledge (Webster, 2019). In this study, this will be experiences of ICU nurses who participate in the withdrawal of treatment and end-of-life care in the ICU.

1.8 OVERVIEW OF THE RESEARCH METHODOLOGY

This section presents an overview of the research methodology. Detailed information will be discussed in chapter 3. A qualitative descriptive design was used in the study to describe ICU nurses' experiences regarding the withdrawal of treatment and EOLC.

This design was chosen to facilitate a comprehensive summarization of all events experienced by ICU nurses with regards to withdrawal of treatment and EOLC. The study setting was four intensive care units (Trauma, Medical-surgical, Cardiothoracic and Neurosurgical ICU) of a university-affiliated academic hospital in the Gauteng province.

The study population consisted of registered nurses with an additional qualification in intensive care or trauma and emergency nursing working in trauma, medical, surgical, cardiothoracic and neurosurgical ICU. Fifteen (n=15) participants were purposively selected.

Before commencement of the study, ethical clearance from the Human Research Ethics Committee of University of Witwatersrand was obtained. Permission to conduct the study was obtained from the hospital management. Permission was also obtained from the respective nurse unit managers to conduct the study in the units. Data was collected using semi-structured interviews using an interview guide.

Data collection was continued until saturation of information was achieved. The interviews were transcribed verbatim. Braun and Clarke's six-phase framework for thematic analysis was used (Braun & Clarke, 2006; Clarke & Braun, 2013).

1.9 ETHICAL CONSIDERATIONS

The following ethical considerations were adhered to in this study:

- The protocols were submitted for peer review to the Department of Nursing Education to assess the feasibility of the study.
- Protocols were submitted to the University Postgraduate Committee for permission to conduct the study, and ethics approval was obtained.
- Permission from the Gauteng Department of Health and hospital management was obtained.
- Informed consent was obtained from the participants and permission for audio recording was obtained.
- Confidentiality and anonymity of participants was ensured by the use of pseudo names.
- Participants were informed that participation is voluntary, and that they may withdraw from the study at any time, without penalty.

1.10 LAYOUT OF THE STUDY

The layout of the study is as follows:

Chapter One: Overview of the study

Chapter Two: Literature Review

Chapter Three: Research design and methods

Chapter Four: Presentation and discussion of findings

Chapter Five: Summary of main findings, limitations, recommendations and conclusions

1.11 SUMMARY

This chapter provided an overview of the study which included the introduction and background, the problem statement, purpose, and objective of the study. It also set out the significance of the study, the researcher's assumptions and operational definitions were included. The next chapter will focus on the literature review of the study in question.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents the literature reviewed for this study. A literature review is a written summary of journal articles, books, and other documents that describes the past and current state

of information on the topic of your research study. It also organizes the literature into subtopics and documents the need for a proposed study (Polit & Beck, 2018).

The chapter is a general review of intensive care unit nurses' experiences regarding withdrawal of treatment and end-of-life care and the effects it has on the process and the nurses' wellbeing. It includes the concept of death and dying, the withdrawal of treatment and end of life care concept, the role of ICU nurses during withdrawal of treatment and EOLC, the effect of EOLC on the ICU nurse, perceived barriers to withdrawal of treatment and EOLC and the summary. The search was conducted using electronic databases available through the University of Witwatersrand Academic Library - Clinical Key, Medline, PubMed, Cochrane Library, EBSCO host, Science Direct and Wiley Online Library.

2.2 THE CONCEPT OF DEATH AND DYING

In the twenty-first century, both the layperson and the healthcare providers perceive death differently from how it was perceived in the 18th century. Throughout history families, friends and religious groups cared for dying patients in their homes. Death was perceived as a natural part of life. There was a clear distinction between life and death because dying was accepted as a process in the continuum of life (Ferrell, 2006; O'Mahoney *et al*., 2010; Mark *et al*., 2015).

Significant advancements in science and medical technology, preventive care, early detection and treatment of diseases, use of vaccinations and widespread use of antibiotics have provided many benefits for society and have created challenges (Ferrell & Coyle, 2008). Instead of dying abruptly at home from a terminal illness many patients choose to undergo medical treatment and die either in a hospice or in the ICU after enduring a lengthy, progressive end-stage illness or multiple system organ failure (Ferrell, 2006). These advancements in medical technology have increased

life expectancy and patients with multiple chronic illnesses and life-threatening conditions are living longer (Ferrell, 2006; O'Mahoney *et al*., 2010; Mark *et al*., 2015).

2.3 WITHDRAWAL OF TREATMENT AND END OF LIFE CARE

The intensive care unit is a designated unit within a hospital setting that has a patient population that requires curative and aggressive medical treatment for critical and life-sustaining illnesses (American Association of Critical-Care Nurses, 2012).

Despite these continuing technological and medical advances mortality following intensive care admission is approximately 20% with 60-70% of these deaths occurring after the decision to withdraw treatment (Sprung *et al*., 2003; Truog *et al*., 2008). Withdrawal of treatment and EOLC is a common occurrence especially in an intensive care environment.

The withdrawal of treatment refers to removing or the prevention of initiation and maintaining of treatment, medication, applied science, and procedures that support life unnaturally (Crowe & Macfarlane, 2013).

The prevalence of withdrawal from active treatment is between 0 and 84% and this varies based on culture, geographical location, religion, different attitudes of healthcare professionals, legal factors, and institutional characteristics (Azoulay *et al*., 2009; Myburgh *et al*., 2016).

According to the findings of a Canadian study by Turgeon *et al.* (2011), on mortality associated with withdrawal of life-sustaining therapy for patients with severe traumatic brain injury most

deaths (70.2%–75.7%) were associated with withdrawal of life-sustaining therapy. This can be expected as the ICU environment is saturated with critically ill patients whose illnesses and or injuries are life threatening. There is evidence that approximately 20% of ICU patients die in this setting each year (Ranse *et al.,* 2012). Although patient death in ICU may occur suddenly many of these deaths involve withholding or withdrawing life-sustaining therapies and in these situations the role of ICU nurses shifts from providing life sustaining measures to EOLC. HIV and AIDS as well as injuries add to the quadrupling burden of disease in the South African context. An ICU mortality rate of 31.5% shows that death and dying is a common occurrence in this setting (Kisorio & Langley, 2016).

The underlying reasons to withdraw treatment centre on the further deterioration of a patient's condition despite best therapy. An overwhelming poor functional outcome results in severe functional disability and coexisting severe systemic diseases (Halevy *et al*., 1996; Truog *et al*., 2008). The majority of deaths in the ICU are often preceded by the decision to withdraw active treatment.

Withdrawal of treatment has therefore become a common event in the ICU but is an area that is plagued with inconsistencies, ethical dilemmas and challenges, especially related to the quality of care rendered to the dying patient and the family after treatment is withdrawn.

According to the National Cancer Institute (NCI), EOLC is holistic care that is aimed at facilitating, supporting and giving comfort to a dying patient and their family during and after the withdrawal of life supportive treatment and curative treatment. It includes aspects such as pain management for the dying patient (NCI, 2019). Badir *et al*. (2016), defines EOLC as the total and supportive care rendered to patients at the end of life and their families, as curative therapies become physiologically inappropriate. The emphasis is on relieving suffering, promoting comfort

and a dignified death. This special care begins with multi-disciplinary discussions and a decision to withdraw treatment.

Ideally decisions surrounding treatment withdrawal and transition from curative to end-of-life care remain a shared responsibility of a multidisciplinary ICU team with the involvement of patients and their families (Sprung *et al.,* 2014). Unfortunately, communication and teamwork among these groups are suboptimal despite the recognition by various research evidence as an integral part of intensive care practice (Efstathiou & Walker, 2014).

2.4 THE ROLE OF INTENSIVE CARE NURSES

Critical care nursing is a specialty dealing with human responses to life-threatening problems. An intensive care unit is a highly technological environment that needs nurses to care for patients with severe injuries and illnesses that are life threatening. The literature clearly describes nursing as a caring and nurturing profession with a unique perspective with caring for patients at the end of life being an integral part of nursing practice. Nurses are uniquely positioned to change the way EOLC is provided for patients and their families (Fournier, 2017; Miller, Forbes & Boyle, 2001; Ciccarello, 2003).

As a result, their perspectives on the quality of care provided after the withdrawal of treatment in the ICU are important in addressing the current challenges faced in intensive care practice.
Nurses play a vital role in supporting both patients and their families along the EOLC. Even though ICU nurses are in partnership with doctors in patient care they still need to have critical decision-making skills and vast knowledge of illnesses, injuries and management of these aspects as well as they must be a source of comfort and support to families and patients during a very

vulnerable time. Intensive care nurses are the primary care providers to critically ill patients and their families (De Beer *et al.*, 2011).

There is no set professional role of a nurse during the withdrawal of treatment and EOLC. This is because the end-of-life process and withdrawal of treatment process are very different in every situation. Several research groups and critical care communities have, over the years, developed and published guidelines and recommendations to help guide the provision of EOLC in the ICU (Downar *et al*., 2016; Truog *et al*., 2008; Sprung *et al*., 2014). Due to the multi-cultural and diversified societies and differences in EOLC practices globally, not all of these recommendations have entirely addressed the issues associated with the provision of EOLC, especially in low and middle-income countries where non-western cultures exist. Patients' prognosis and needs differ from patient to patient no two patients are the same thus making EOLC and the withdrawal of treatment and the institution of universal guidelines in this regard, difficult (Baggs *et al*., 2012; Ranse *et al.*, (2012).

2.4.1 Care and caring

Care and caring are very important functions of a nurse toward the patient who is dying and their family. It is also a very emotionally draining exercise for the nurse and has a high level of difficulty. According to (Ranse *et al.*, 2012), the caring role during EOLC includes emotional care of the family and physical care of the patient. Nurses experience emotional exhaustion and find difficulty when it comes to caring during EOLC (Efstathiou & Walker, 2014).

2.4.2 Comfort and supportive care

Comfort and supportive care regarding the dying patient are critical points during EOLC and withdrawal of treatment. It involves making sure that the patient is comfortable, free of pain and

that those unnecessary interventions are in cessation. Comfort and support are very important during the withdrawal of treatment and EOLC so that suffering is minimized, and the dignity of the patient is maintained. Nurse's view providing comfort to patients and support to the family after the withdrawal of treatment as being very important (Vanderspank-Wright *et al*., 2018).

2.4.3 Comfort care

According to Thelen (2005), sedation and pain medication which is giving the patient comfort care is the next step in the process of the withdrawal of treatment. In addition, the integral parts of comfort care are bathing, haircare, pressure injury prevention, giving of medication to loosen secretions from the lungs as well as spiritual care (Ranse *et al*., 2012).

Pain control is considered as often inadequate during the withdrawal of treatment. According to the findings of a study by Halcomb *et al*. (2004), on insight into Australian nurses' experience of withdrawal/withholding of treatment in ICU, 78% of the participants reported that pain control was often insufficient.

Beckstrand *et al*. (2006), emphasised that patients suffering be brought to a minimum by using adequate comfort measures.

They suggested the administration of intravenous pain medication and the cessation of interventions such as the use of vasopressors or haemodialysis. Many nurses also experienced emotional tension over aggressive interventions that were being continued despite the poor chance of patient survival.

2.4.4 Being There

A nurse needs to be present for the family and patient during EOLC and withdrawal of treatment. A nurse who has experienced this scenario before can help ease the process and provide emotional and physical support. A nurse's continuous bedside presence always promotes the provision of warm and compassionate care. In a study by Jones and Fitzgerald (1998), nurses through many different narrations made it clear that the need to be there for the patient and family during the withdrawal of treatment and EOLC both emotionally and physically is very important.

2.4.5 Advocacy

One of the primary responsibilities of a nurse is advocacy. It is his or her responsibility to make sure that the patients' best interests are carried out and that the patient does not have prolonged suffering or that the withdrawal of treatment is carried out too early when there is a chance of survival. In a study by McAndrew and Leske (2015), on experiences of nurses and physicians when making end-of-life decisions in intensive care units, nurses believed they are advocates for the patient and the family during EOLC.

Patient advocacy is speaking up for the patient in terms of what is good for their wellbeing. In the case of EOLC and withdrawal of treatment nurses often experience a moral dilemma where there is a fine line between deciding to continue with life-sustaining treatment to save life or to stop treatment to ensure less suffering and maintain the dignity of the patient. This dilemma stems from the ambiguity of the prognosis of patients' condition (van Rooyen *et al.*, 2005).

2.4.6 Ethical and legal obligations

Ethical obligations and possible legal repercussions due to the withdrawal of treatment may also be a cause of concern. A major ethical concern is to not cause harm to the patient or the family. In a study by Halcomb *et al*. (2004), nurse participants saw continuing treatment as causing unwanted unpleasant experiences to the patient.

These participants pointed out that their wish was to not hurt the patient or family. A South African study by Langley *et al*. (2013), on South African critical care nurses' views on EOLC decision making and practices, projected results that nurses' fear of legal action is of great significance during EOLC. The Japanese nurses, however, placed no significance on legal action, as they perceived all the responsibility being the doctors' during this process (Kinoshita & Miyasita, 2011).

2.5 THE EFFECT OF WITHDRAWAL OF TREATMENT ON ICU NURSES

The nursing profession has been recognized as a very stressful occupation. The idea of death and dying alone can evoke many feelings such as sadness, grief, emotional distress and a feeling of failure in the nurse. The ICU environment is physically demanding, involves intensive work with patients and their families, and requires ICU nurses to be competent in nursing care and the use of advanced technical equipment.

The combined challenges of caring for critically ill patients and facing the demands of families and colleagues help to create a high level of work-related stress for ICU nurses.

ICU nurses encounter ethical dilemmas as they care for dying patients who receive life-prolonging medical interventions in an intensive care unit (Ferrell, 2006). Ranse *et al.*(2012) confirms this by mentioning how nurses experience grief and distress every day because of having to care for critically ill patients with disturbing injuries. With a high occurrence of death post-

withdrawal of treatment and dealing with death itself this often results in conflicting feelings on whether or not to withdraw treatment even after the decision is ordered by the doctor the nurses want to distance themselves from the process.

Repeated exposure to intensive work environments may lead to burnout and stress, which affect the emotional, mental, physical, psychological, and spiritual health of ICU nurses. Burnout results from prolonged exposure to work environments that are emotionally demanding and create physical, emotional, and mental exhaustion (Ferrell, 2006).

Nurse participants in a study by van Rooyen *et al.* (2005), expressed feelings of frustration, helplessness, and being emotionally drained during the withdrawal of treatment process. Holms *et al.* (2014) shares the same view. The highest level of moral distress was observed by ICU nurses in comparison to other wards as well as it was closely linked to the futility of care as explained in a study by (Borhani *et al.*, 2015).

2.6 PERCEIVED BARRIERS TO WITHDRAWAL OF TREATMENT AND EOLC

Nurses experience distress and hardship during EOLC and withdrawal of treatment because of factors they perceive to be burdensome.

The common barriers included knowledge and training, involvement in decision-making, the environment, communication, attitudes, beliefs and practices, shortage of staff, and lack of support (Holms *et al.*, 2014).

A study carried out by Coombs *et al*. (2015), emphasised that there is complexity of a high degree concerning different opinions regarding the dos and don'ts of EOLC once life support is discontinued or not initiated. Examples of this are 41% of participants stated that patients should be deeply sedated, the continuation of fluid replacements was agreed to by 43% and disagreed to by 41% and 56% of participants disagreed to nutrition being continued. According to Holms *et al*. (2014), staff distress frequently mentioned lack of experience, challenges with communication, insufficient training and lack of support and lack of involvement in decision making.

2.6.1 Knowledge and training

Although ICU nurses are expected to provide quality care to more dying patients in intensive care units, they often feel unprepared because their education and training or clinical experiences have not prepared them to help patients and their families during the dying process (Thelen, 2005).

Knowledge and training or a lack thereof can cause many hindering situations during EOLC and withdrawal of treatment. In a study by Brooks *et al.* (2017), what was considered a point of reference is that junior nurses and doctors had trouble communicating about EOLC and having conversations. This could be due to their lack of experience, support and training. Ranse *et al.* (2012) stated that junior colleagues do not have support from their senior colleagues as they have not established such relationships yet and this further adds to them having lack of support.

According to the findings of a study by Beckstrand *et al*. (2006), nurses portrayed the view that doctors should be taught when it is okay to allow patients to die with dignity. Insufficient training

is given to ICU clinicians in areas of importance that need to be addressed during EOLC and withdrawal of treatment. This includes pain, discomfort, depression, unsatisfied hunger and thirst Carlet *et al.*(2004). Forte *et al.* (2012), further state that doctors who are inexperienced and who lacked education and training refrained from making decisions regarding end-of-life care thus prolonging the suffering of the patient and causing conflict with the nurses. Naidoo and Sibiya (2014) raised a concern that critical care nurses are not being sufficiently equipped with skills and knowledge to deal with death and dying in their professional practice

2.6.2 Involvement in decision making

Nurses need to be involved in decision-making regarding EOLC and withdrawal of treatment as they spend most time with the patient during this time. In the study by Halcomb *et al.* (2004), nurses felt they were left alone to manage the death process once the choice has been made to discontinue or not initiate life-supportive care. They also expressed lack of involvement in decision-making.

Nurses feel many negative emotions when they are not part of making the choice on EOLC and withdrawal of treatment. The timing of doctors in terms of making decisions to withdraw treatment is an issue, was often prolonged, and often causes moral distress to nurses.

In a South African study by Langley *et al.*(2013), on moral distress experienced by intensive care nurses 33% of the nurse participants felt that decisions to withdraw active treatment were made too late. Not including any member of the multidisciplinary team during the decision-making process may result in dissatisfaction Carlet *et al.*(2004).

Timing is very important in the withdrawal of treatment process. Poor timing can have negative repercussions such as prolonging the patients suffering or withdrawing treatment too early whereas there could be a chance of survival for the patient. Only 29% of nurses in the study by Langley *et al.* (2013), agreed that the decision to withdraw treatment was made at the right time the rest either thought it was done too early or too late. Poor timing may prolong the patients' and families' suffering. Poor timing of the withdrawal of treatment or prolonging the process is often a cause of emotional tensions and frustration. According to a study by Ranse *et al*. (2012), this can be due to family not being ready to let go.

2.6.3 The ICU environment

ICU represents a setting where decisions about managing the dying and death of patients are made frequently. These decisions involve communication among the members of the multidisciplinary team, the patient as well as the family members. The ICU environment needs to be therapeutic to the family and patient during EOLC to grant an atmosphere of peace and ease during this process.

According to the findings of a study by Brooks *et al.* (2017), nurses were dissatisfied with the environment in which treatment is withdrawn. Nurses' views on the matter are that many negative aspects of the ICU environment affect EOLC negatively. These include lack of privacy, noise from alarms of monitors and ventilators (Brooks *et al*., 2017). To improve the ICU environment, especially during EOLC some suggestions made included: beds for the family, food, showering facilities, soothing music, a quiet place for prayer, meditation and family gatherings (Beckstrand *et al*., 2006). Another important point emphasised by these authors was that a patient should never have to face death alone and so should be with family during EOLC.

2.6.4 Communication

Communication facilitates understanding and smooth transition of the process for the family, nurse and the rest of the multidisciplinary team. Nurses communicate information to the multidisciplinary team regarding the patient and the patient's family. They also communicate to the family about the patient and coordinate discussions regarding EOLC between the multidisciplinary team and the family (Adams *et al.,* 2011).

Communication between the doctor and the nurse is often considered a problem and nurses feel that they are often asked to carry out orders without being involved in making the choice to discontinue or not initiate life support measures. Communication between the nurse and the family is also an issue. Effective communication is needed to facilitate optimal EOLC and care where there is family involvement to a large degree. Nurses reported being unhappy regarding the conflict with other members of the multidisciplinary team (Halcomb *et al.,* 2004).

Flannery *et al*. (2015), reported that nurses were cold towards communicating with the family due to negative feelings caused by the dispute between nurses and doctors and this increased the risk of both the family of the patient and the nurses feeling secluded. Powazki *et al*. (2014), illustrated that clinicians have poor cultural communication with families and patients.

Nurses take a critical forefront role in helping and informing patients' families about the withdrawal of treatment and they view this as a huge area of importance. Nurses communicate and support EOLC where families are concerned. Carlet *et al*. (2004), reported that poor communication between family and ICU staff is a problem and affected the way the prognosis, diagnosis and treatment of the patient was to be carried out accordingly.

Good communication is a crucial point with regard to family-centred care, which is seen as a huge catalyst for the delivery of quality end-of-life care (Ranse *et al*., 2012). Thelen (2005), supported this idea and further added that communication is efficient when it is done frequently and early.

2.6.5 Attitudes, beliefs and practices

Nurses' feelings, beliefs and practices can affect the EOLC process negatively. It can prolong the process as well as increase its level of difficulty in terms of carrying out the process. It includes factors such as being against death, relating to the patient on some level of similarity. This makes it difficult to let go.

The difficulties felt by ICU nurses providing EOLC may lead to negative attitudes toward caring for dying patients (Tirgari *et al*., 2016). Another challenge for nurses is religious beliefs and personal feelings that are often against death hence making the withdrawal of treatment seem like an unethical aspect to consider or carry out. According to the findings of a study by Halcomb *et al.* (2004), on nurses' experiences during the withdrawal of treatment in ICU, most nurses found themselves moving away from the process of withholding/withdrawing treatment because of religious beliefs that are against death. The nurses stated that they were feeling defeated in terms of saving patients' lives and they experienced emotional turmoil during this time.

Due to the aforementioned factors problems arose concerning principles of right and wrong behaviour in this case with regards to the nurse's role Halcomb *et al.*(2004). Nurses also find it more difficult to actively withdraw treatment with regards to certain patients. For example, a young patient or a patient they can relate to on some level (McMillen, 2008).

2.6.6 Shortage of staff

Shortage of staff during the withdrawal of treatment and death process brought out a negative response from nurses. In a study by Beckstrand *et al.* (2006), having insufficient nurses was seen as the catalyst for not having sufficient time to nurse patients during EOLC and to give support to the family. The participants in this study expressed frustration because they strongly believed that the patient-staff ratio of a dying patient should be 1:1 to ensure that the family and patient are cared for adequately. Tirgari *et al*. (2016) identified the shortage of nurses that contributes to a lack of time to care for dying patients as a barrier to providing a good death in ICUs.

2.6.7 Support

Emotional and psychological support is of utmost importance during and after the EOLC process. The family and nurses and other members of the multidisciplinary team experience immense emotional and psychological distress due to the experience of the patient's imminent death and passing.

Emotional support for nurses involved in EOLC is either not readily available or easily accessed or utilized. Participants in a study by Ranse *et al*. (2012), recognised that external support services to aid nurses psychologically were available but not utilised. The family receives support from the nursing staff who spend a lot of time with them.

Spiritual support is a fundamental factor to help comfort and bring peace to the family, patient and nurse during this very distressing time of EOLC and the withdrawal of treatment. Kisorio and Langley (2016), mentioned that it was sometimes difficult to get spiritual support when needed during EOLC and the withdrawal of treatment. Gonzalez-Rincon *et al.* (2018), further mentioned

and support the need for spiritual support during EOLC and the withdrawal of treatment and brings to the fore the findings that tending to spiritual needs was important to ensure a peaceful death.

2.7 COPING MECHANISMS OF NURSES

Coping mechanisms are strategies utilized to reduce unpleasant emotions, which are often experienced during end-of-life care. They can be conscious or subconscious, or they may be negative or positive to ones being, overall professional growth and progress.

Negative coping mechanisms can be harmful to ones being and can result in being dysfunctional. In a study by Van Rooyen *et al*. (2005), the nurses explained that at times they withdrew from patients emotionally by creating distance or by avoiding being involved. Also mentioned was that nurses used self-control where they remained professional and tried to avoid all emotions to try and deal with the situation of EOLC and the withdrawal of treatment.

Positive coping mechanisms are a necessity to maintain good overall well-being especially during an intense emotional process such as EOLC and it helps the nurse deal with the situation and aftermath positively. Participants mentioned sharing, talking, debriefing as well as praying and partaking in activities that they like which bring about relief and happiness.

In a study by Van Rooyen *et al*. (2005) participants coped by turning to a colleague who had been through similar situations for comfort and empathy other participants engaged in certain activities that helped them relieve tension such as going home and crying. Nurses also used intellectualization where they focused on theoretical information that allows them to have a rational explanation for the situation that helps them cope with anxiety.

2.8 SUMMARY

This chapter discussed the literature that was reviewed for this study. The literature provided the concept of death and dying, the withdrawal of treatment and end of life care concept, the role of ICU nurses during withdrawal of treatment and EOLC, the effect of EOLC on the ICU nurse, perceived barriers to withdrawal of treatment and EOLC as well as coping mechanisms. The next chapter will discuss the methodology and research design of the study in detail.

CHAPTER THREE

RESEARCH METHODS

3.1 INTRODUCTION

This chapter provides a description of the research methods utilized to describe ICU nurses' experiences regarding withdrawal of treatment and end-of-life care. It includes the research design and methods, study setting, sampling, data collection, and data analysis. This chapter also describes ethical considerations and measures to ensure trustworthiness.

3.2 PURPOSE OF THE STUDY

The purpose of the study was to describe the ICU nurses' experiences with regard to withdrawal of treatment and EOLC in the adult intensive care units of a university-affiliated public hospital in Gauteng.

3.3 OBJECTIVE OF THE STUDY

The objective of this study was:

- To explore and describe the experiences of ICU nurses with regard to withdrawal of treatment and EOLC.

3.4 STUDY SETTING

The setting is the physical location of the research, for instance, a ward in a hospital, a clinic or the community (Holloway & Wheeler, 2015).

This study was undertaken in a natural setting, namely the intensive care units. The hospital has a bed capacity of 1100 beds and comprises of six ICUs. Data was collected in four ICUs (Trauma, Medical- surgical, Cardiothoracic and Neurosurgical ICU) of a university-affiliated tertiary hospital in Gauteng province. These ICUs were purposively selected because of the severity of illness and the length of stay of the critically ill patients. The average level of illness severity (SAPS II score) of patients admitted to these units is 34.72 (SD 12.53), and an average length of stay is 8.54 (SD 17.01) days (Schmollgruber, 2015). A high level of specialised care for patients with more than one organ failure is provided in these ICUs. The health personnel who are members of the multidisciplinary team in these units comprises of nurses, intensivists, medical and surgical specialists, physiotherapists, occupational therapists, dieticians, anaesthetists, psychologists and social workers. The nurse-patient ratio in this unit is one nurse to one patient.

3.5 RESEARCH DESIGN

A research design is a plan, which helps the researcher in planning and implementing the study to achieve the desired objective. A research design usually includes the main methods and the theoretical framework. Researchers briefly describe the methodology they adopt and the reasons

and justification for it. They also explain the fit between the research question and methodology (Holloway & Wheeler, 2015). For this study, a qualitative, exploratory and descriptive design was used to explore and describe the ICU nurses' experiences regarding the withdrawal of treatment and EOLC. The design facilitated a comprehensive summarization of all events experienced by ICU nurses with regards to withdrawal of treatment and EOLC.

3.5.1 Qualitative design

A qualitative design is a method of exploring meaning, describing and providing an in-depth understanding of life experiences. It deals with a direct description of a phenomenon from people's perspectives (Polit & Beck, 2018). For the purpose of this study, the qualitative approach was utilized, as little knowledge is known of the experiences of ICU nurses on withdrawal of treatment and end-of-life care. This method thus helped the researcher to gain understanding and receive a rich description of the experiences of ICU nurses on withdrawal of treatment and end-of-life care.

3.5.2 Exploratory design

An exploratory design seeks to gain new insight, discover new meaning, or increase knowledge about a phenomenon in the field of study. This also refers to the design, which explores the full phenomenon under study (Polit & Beck, 2018). An exploratory design was chosen for this study because of the lack of knowledge about the topic under study.

3.5.3 Descriptive design

A descriptive design is employed to gain an in-depth knowledge of the phenomenon under study and it does not give room for manipulation of the variables (Polit & Beck, 2018). It entails the collection of information from a representative of the population. A descriptive design was employed as the main aim of the study was for the ICU nurses to describe their experiences regarding withdrawal of treatment and end-of-life care.

3.6 RESEARCH METHODS

This is a strategy of enquiry, which proceeds from underlying assumptions to research design and data collection. It allows the researcher to collect data and find a solution to the problem at hand (Polit & Beck, 2018).

The research methods include the population, sample and sampling procedures, data collection and data analysis.

3.6.1 Population

Population refers to the entire aggregation of the participants in which a researcher is interested (Polit & Beck, 2018). According to Holloway & Wheeler (2015), there are two types of populations, namely the target and study population. The target population has particular experience or knowledge of the phenomenon that the researcher is seeking to explore. The study population had the same attributes as the target population however in addition were available to the researcher. In this study, the study population consisted of registered nurses with additional qualifications in intensive care or trauma and emergency nursing working in trauma, medical-surgical, cardiothoracic and neurosurgical ICU. There were approximately 80 (N= 80) registered

nurses with additional qualifications in intensive care or trauma and emergency nursing practising in these units.

3.6.2 Sample and Sampling Methods

A sample is the subset of the population (Polit & Beck, 2018). In this study, the sample constituted of registered nurses with an additional qualification in intensive care or trauma and emergency nursing who had worked in ICU for a minimum of one year.

Sampling refers to the process of selecting the participants to represent the entire population so that inferences about the population can be made (Polit & Beck, 2018). In this study, a purposive sampling method was chosen to obtain in-depth information and an understanding of the participants' experiences on withdrawal of treatment and EOLC. Purposive sampling is where sampling units are selected for a specific purpose on which the researcher “decides” (Holloway & Wheeler, 2015).

The inclusion criteria for prospective nurse participants were:

- Registered nurses with an additional qualification in intensive care or trauma and emergency nursing.
- Working in ICU for at least a year or more

The registered nurses with an additional qualification in intensive care or trauma and emergency nursing and a minimum of a year working in ICU were included were considered to have developed a level of competency in the intensive care unit and are more aware of the needs of critically ill patients (Benner *et al.,* 1996).

The exclusion criteria in this study were enrolled nurses and enrolled nursing assistant nurses

because they work under the direct supervision of the registered nurse. Enrolled nurses would not be handed the task of withdrawal of treatment in an ICU setting as it above their scope of practice. Registered nurses without an additional qualification and less than a year of experience working in the ICU setting were excluded because their experience with withdrawal of treatment and EOLC could be insufficient to add valuable feedback required for this study.

3.6.3 Data Collection

Data collection refers to the gathering of information to address a research problem. In a qualitative study, an interview is one of the most commonly used methods of data collection (Polit & Beck, 2018). Semi-structured individual interviews were undertaken using one open-ended question and probes to explore the experiences of ICU nurses about withdrawal of treatment and EOLC.

An interview guide was used (**Appendix A**) during data collection.

According to Creswell, there are five steps when collecting qualitative data. This includes identifying participants and sites, gain access, determine the types of data to collect, develop data collection forms, and administer the process in an ethical manner (Creswell, 2018).

3.6.4 Procedure

After receiving approval to conduct the study from the Research and Postgraduate Committee (**Appendix H)** and ethical clearance from the Human Research Ethics Committee (HREC) of the University of the Witwatersrand (**Appendix G**) and approval from the Chief Executive Officer of the hospital (**Appendix F**), the researcher approached the unit managers of each of the ICUs.

After the unit manager gave permission, the research explained the aim purpose of the study. The participants who met the inclusion criteria were invited to participate in the study. The information sheet (**Appendix C**) with all the details of the study was given to the participants. Voluntary participation in the study was stressed to the participants and those who intended to participate were given the audio taping informed consent (**Appendix E**) to be signed.

The researcher and the participant agreed upon a convenient time for the interview, and the unit manager was informed of the decision and the approximate time of the interview. **Table 3.1** below summarises the number of participants recruited from each ICU.

Table 3.1: Overview of the recruited participants

Type of Intensive Care Unit	Number of recruited participants
Cardiothoracic	3
Trauma	4
Medical-surgical	5
Neuro surgical	3

At the beginning of the interviews, participants were asked to relax and reminded that participation in the study was voluntary, the study had no intention to harm, and they could withdraw from the interview at any time. The researcher did not implicate her feelings or interfere with data from the participants.

An interview guide with one central question and probing questions were used to keep the interview focused. This allowed the researcher to collate detailed data and allowed the participants to talk about their experiences as they wished. The contact details of participants were

taken should a follow-up interview be required for clarification purposes. They were also informed that psychological support was available should a need arise.

Fifteen interviews were conducted in this study. Data was collected until no new information emerged, indicating the data were saturated (Polit & Beck, 2018).

In-depth, semi-structured interview questions were used to explore ICU nurses' experiences regarding withdrawal of treatment and EOLC. After the interview, the researcher highlighted as much of the conversation as possible and included striking themes as well as non-verbal responses.

The interviews were tape-recorded and transcribed using pseudonyms to ensure anonymity and confidentiality, and field notes were taken. Field notes are a written account of the things that a researcher hears, sees experiences and thinks in the course of collecting the data or reflecting on the data obtained during the study (Polit & Beck 2018). The interviews were conducted in a small office in the hospital near the ICU. At the end of the interviews, all participants were thanked for their participation, cooperation and for being open during the interview. The audiotapes and field notes were kept safe under lock and key and only accessed by the researcher.

The pilot test is a small-scale version of the main study. It consisted of 2 participants from cardiothoracic ICU. The purpose of the pilot interview was to gather the information used to improve the feasibility of the study and allow the researcher to clarify questions and her interviewing technique. No challenges were encountered. The results of the pilot interviews were included in the main study.

3.7 DATA ANALYSIS

Qualitative data analysis is an iterative activity were researchers move back and forth from

collection to analysis to back again refining the questions they ask from the data. It is a complex non-linear process but also systematic, orderly and structured (Polit & Beck, 2018).

Data analysis was initiated after each participant was interviewed. The interviews were transcribed verbatim. Braun and Clarke's six-phase framework for thematic analysis was used (Braun & Clarke, 2006; Clarke & Braun, 2013). These steps will be discussed below and the related practical approach utilised during analysis.

- Reading all transcripts and field notes thoroughly to get an overview. Highlighting important ideas.
- Reading each interview and questioning the objective and underlying meaning.
- Distinguishing between main, unique and other themes.
- Coding themes and highlighting themes throughout the text.
- Describing and categorising themes and identifying relationships between them.
- Assembling data from text into identified categories.

The interviews were crosschecked with the original audiotape recording before data analysis was commenced to ensure the accuracy of information. **Table 3.2** displays the steps that were followed in the study.

Table 3.2: Summary of thematic analysis steps

Steps	**Description of the steps**
1. Reading transcriptions and field notes deeply, noting significant ideas	Reading and re-reading or transcribing data and noting the significant ideas.

2. Reading each interview, questioning the objective and underlying meaning	Identifying data with the same features and organising it according to relevance with ideas.
3. Distinguishing the different types of themes	Identifying similar codes of data available takes place in this phase. This phase concludes by relating all coded data significant for each theme.
4. Coding themes and highlighting them throughout the text	Thematic map of data analysis is being generated in this phase. The researcher provides a description of the themes and states whether the themes are giving a concrete story about the data and the relationship in themes.
5. Describing, categorising and identifying relationships of themes	Identifying the specifications of each theme and naming themes. It is all about getting the essence of a specific theme for the researcher to name it.
6. Report writing	The researcher looks at the whole analysis, relating it to the main research question and the literature review of the study, then produces the report.

The researcher's ideas, opinions, and assumptions regarding the subject being studied were bracketed to avoid bias with regard to the data being studied. Coding was used to categorize data. The reliability of coding was checked by the supervisor as well an independent co coder who is an experienced qualitative researcher. Encoding the data and manual analysis were utilised to have a thorough review of all information in the transcripts of the interviews.

3.8 ETHICAL CONSIDERATIONS

In all studies, ethical issues must be reviewed so that the relevant principles may be applied by the researcher to protect participants from harm and risk.

The researcher needs to utilize ethical principles and rules to maintain an equilibrium (Holloway& Wheeler, 2010). Ethical principles were observed following the South African Nursing Council Code of Ethics for nursing practitioners.

The nurses were informed that they can participate in the study voluntarily and can withdraw from the study at any time with no repercussions. The researcher ensured that all participants are psychologically protected by arranging psychological support should any of the participants experience psychological discomfort.

3.8.1 Informed Consent

Informed consent means that all participants in the research must be given full information regarding the research study and must voluntarily consent to participate (Holloway &Wheeler, 2010). Informed consent was obtained in writing for participating in the study (**Appendix D**) and for the audio recording of the interviews (**Appendix E).**

3.8.2 Permission to Conduct Research

The following steps were taken to obtain clearance to conduct the study:

- Protocols were submitted for peer review to the Department of Nursing Education to assess the feasibility of the study.
- The protocol was submitted to the University of Witwatersrand's Research and Postgraduate Committee via the School of Therapeutic Sciences assessor group. Written approval was obtained before the commencement of the study (**Appendix H**).
- Ethical clearance was applied for from the University of Witwatersrand Human Research Ethics Committee (Medical).

- Written approval and clearance were obtained before the commencement of the study (**Appendix G)**.

- Upon receipt of ethics permission, approval to conduct the study was sought from the hospital authorities, where the study was to be carried out (**Appendix F)**. Permission to conduct the research in the Intensive Care Units was also sought from the Unit Managers to gain access to the participants.

3.8.3 Anonymity and Confidentiality

Anonymity, in this study, was ensured by the use of codes during data collection, and to maintain confidentiality, the following procedures were ensured:

- The transcribed interviews were saved with a password known only to the researcher
- Codes and integration of identifiable data were used.
- Identifiable written scripts were kept in a sealed envelope in a safe with the supervisor (password protected).

All data including voice recordings, field notes, and transcripts were only accessed by the researcher and the research supervisor and were locked away securely.

3.9 MEASUREMENT OF TRUSTWORTHINESS

The researcher followed the model of Lincoln and Guba (1985) to ensure the trustworthiness of this study. Trustworthiness involves establishing the study findings. Trustworthiness strategies are discussed below:

3.9.1 Credibility

Credibility refers to the trust that the data received by all contributors in the study are correct and honest in nature (Polit & Beck, 2018). Credibility was ensured by providing feedback to the participants after emerging interpretations and obtaining participants' responses regarding the credibility of the collected data. The transcripts were reviewed against the developed themes by the supervisor.

3.9.2 Dependability

A study is dependable when the findings are consistent and can be repeated (Polit & Beck, 2018). Dependability was ensured by discussing transcriptions with the supervisor to verify the authenticity and accuracy of the actual data as recorded during the interviews.

3.9.3 Conformability

Conformability refers to objectivity, accuracy, relevance or meaning of data (Polit & Beck, 2018). Conformability was exercised by recording the interviews to demonstrate that the findings were the results of the participants' own experiences as told by them and by a rigorous audit trail.

3.9.4 Transferability

Transferability is when the findings of a study can be utilised in similar situations. According to Polit and Beck (2018), transferability refers to the generalisability of the data. Transferability was ensured by documenting thick, detailed descriptions of data collection and analysis. The findings were documented in detail so that readers will be able to understand and transfer the findings to another situation.

Table 3.3 Summary of the measures used to ensure trustworthiness

Strategy	**Criteria**	**Application**
Credibility	Peer examination	Peer examination was done by discussing the research process with the supervisor Ensuring availability of the analysed data in the report
	Prolonged engagement	Follow-up visits after the initial data collection process. Interviews were conducted in the participants' working environment while at the same time observing their day-to-day activities in their natural setting
Dependability	Description of data	A detailed description of the processes, research method and design used was provided
	Peer examination	The research plan and implementation were examined by the supervisor Coding and re-coding was done with the supervisor. Independent co-coding
Conformability	Verbatim transcription	All audio-taped interviews were transcribed verbatim Bracketing to avoid contamination of data. The richness of the data is preserved by using quotations.
	Audit trail	Detailed methodological description
Transferability	Detailed description	A detailed description of the phenomenon under study, the analyzed data and method were presented in the report for proper understanding. Using various data collection methods like

		interviews, field notes and tape recording.

3.10 SUMMARY

This chapter provided an outline of the research methodology used in this study. It included research design and methods, study setting, sample and sampling procedure utilized, ethical considerations and measures of trustworthiness.

The next chapter will describe the findings of the experiences of ICU nurses regarding EOLC care and the withdrawal of treatment.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

This chapter outlines the study findings on the experiences of ICU nurses regarding withdrawal of treatment and end-of-life care at an academic hospital in Gauteng. The demographic data as well as the themes and sub-themes that emerged in this study are presented and discussed. Discussion, integration and referencing of the existing literature are done in line with the themes and sub-themes discovered in this study to support the research findings.

In-depth, semi-structured interviews of fifteen (N=15) ICU nurses were undertaken using an interview guide. One central question and probes were used to explore the experiences of ICU nurses regarding withdrawal of treatment and EOLC. The interviews were transcribed verbatim on the same day. Data analysis was undertaken using Braun and Clarke's six-phase framework for thematic analysis (Braun & Clarke, 2006; Clarke and Braun, 2013).

4.2 DEMOGRAPHIC DATA

This section is related to the participants' demographic data, which is comprised of five items. Items included gender, age, highest nursing qualification, years of experience and current position. Fifteen (n=15) ICU nurses with an additional qualification in Intensive Care or Trauma and Emergency nursing made up the sample size. **Table 4.1** provides an overview of the results.

Table 4.1: Summary of the demographic data of the participants (n=15)

Demographic Variable	**Frequency (n)**	**Percentage %**
Gender		
Male	2	13.3
Female	13	**86.7**
Age in years		
20-29	2	13.3
30-39	3	**20**
40-49	3	**20**
50-59	3	**20**
60-65	3	**20**
>65	1	6.7
Highest Nursing Qualification		
Advanced Diploma/Degree	11	**73.3**
Masters	3	20
Doctorate	1	6.7
Years of experience		
1-5 years	6	**40**
6-10 years	2	13.3
11-15 years	2	13.3
16-20 years	0	0
<21 years	5	33.3
Current Position		
ICU or Trauma trained	9	**60**
Professional Nurse	0	0
Shift leader	5	33.3
Charge nurse	0	0
Nurse manager	1	6.7

Clinical educator	0	0

Table 4.1 presented these results. Females accounted for 86.7% (n = 13) and males 13.3% (n = 2) of the total sample (n = 15). The highest responses (20%; n=3) were from age categories 30 to 39; 40 to 49; 50 to 59 years and 60 to 65 followed by 13.3% (n = 2) aged between 20 to 29 years and 6.7% (n=1) in the age category above 65. Most of the participants (73.3%; n=11) held an advanced diploma or degree qualification, followed by 20% (n=3) of the nurses who held a Masters degree and 7% (n=1) held a Doctorate degree. Most participants held a current position as ICU or Trauma trained nurse 60% (n=9). The shift leader position was held by 33.3% (n=5) and the nurse manager position was held by 6.7% (n=1). The largest group of participants 40% (n=6) had between 1 and 5 years of ICU experience, followed by 33.3% (n=5) for greater than 21 years, and 13.3 % (n= 2) between 6 to 10 years and 11 to 15 years.

4.3 EMERGENT THEMES

This section consists of a presentation of the findings and relevant literature regarding ICU nurses' experiences regarding end-of-life care and the withdrawal of treatment. Three broad themes emerged from the study, with 13 sub-themes. These themes were obstacles to effective withdrawal of treatment and EOLC, emotional burden and coping mechanisms of nurses. The core structure of the findings was based on these themes. These themes were further explained and verbatim quotations regarding the participants' experiences were used to corroborate the themes to make them more significant. These verbatim quotations were presented in italics under each theme and subtheme so that the aspect being discussed was corroborated. Pseudonyms were utilized regarding the nurses who took part in the interviews. The relevant literature was also included to support the research findings. An overview of the themes and sub-themes from the interviews with the participants is provided in **table 4.2.**

Table 4.2: Summary of the themes and sub-themes

Themes			Subthemes
4.3.1	Obstacles to withdrawal of treatment and EOLC	4.3.1.1 4.3.1.2 4.3.1.3 4.3.1.4 4.3.1.5 4.3.1.6 4.3.1.7	Psychological support Spiritual support Policies and protocols Lack of resources Nurses' knowledge and education on EOLC Involvement in decision making Environmental factors
4.3.2	Emotional Burden	4.3.2.1 4.3.2.2 4.3.2.3	Nurses' feelings of withdrawal of treatment and EOLC Nurses' perspectives on family feelings Nurses' perspectives of patient feelings
4.3.3	Coping mechanisms	4.3.3.1 4.3.3.2 4.3.3.3	Negative coping mechanisms Positive coping mechanisms Lack of coping mechanisms

THEME ONE: OBSTACLES TO WITHDRAWAL OF TREATMENT AND EOLC

Obstacles to withdrawal of treatment and EOLC emerged as the first theme in this study. An obstacle is defined as something that blocks movement, going forward or action is prevented or made more difficult (Cambridge dictionary, 2022). All the participants in this study highlighted several obstacles that make the process more difficult to handle and in turn it evokes many challenges and emotions.

4.3.1.1 Psychological support

The end-of-life care process is a very emotionally burdening process substantiating the need for, psychological support and counselling. Debriefing following the death of a patient was considered beneficial but factors such as time constraints due to institutional demands, such as bed filling and paperwork, meant that nurses had to carry on without debriefing and moved on to the care of the next patient quickly after the preceding death. Some of the participants expressed that psychological support was either unavailable or perceived that it was not important to utilize.

The following statements from participants support the above-mentioned hypothesis:

"Nothing, you don't get support from anyone counselling nothing I wish we were getting counselled as nurses from time to time." Ivy

“Maybe they do have, just that we are in ICU there is no time for you to attend those sessions life has to go on, you have to admit a new patient holistically, forget about what happened move on with your life.” Dianna

"I must just accept though accepting is very tough I must go on with life that's how I am I don't need to go to other people for counselling I can counsel myself even better I have my own way of counselling myself." Brianna

"No, no we don't need support it's just like you know throwing away a bag of potatoes and you just face going the other way, there isn't much support as that we really need support time and again, we should have counselling or maybe the social worker is coming to see us talk about the situation." Lisa

“No each man for himself here, no support whatsoever, you have to deal with your emotions and at the end of the day you have to work continuously.” Ivy

“There is no time where they can say go and consult unless you do it on your own.” Kim

The current study's findings are similar to those of Carlet *et al.* (2003). These authors emphasize that major problems such as psychological issues related to withdrawal of treatment and EOLC were not adequately addressed.

The need for emotional support during the withdrawal of treatment and EOLC was expressed as vital (Halcomb *et al*., 2004; Van Rooyen *et al.*, 2005; Ranse *et al.*, 2012). However, these services were either not available Halcomb *et al*. (2004) or the participants did not see the need to access psychological support (Halcomb *et al*., 2004; Thompson *et al*., 2011), instead, they relied on their colleagues (Ranse *et al.*, 2012) for psychological support. The findings of a South African study by Naidoo and Sibiya (2014) highlighted that there were no established support systems and supportive strategies in place for nurses. Often, they made use of their previous experiences to provide EOLC for patients and families (Naidoo & Sibiya, 2014). On the other hand, the novice nurses without previous experience end up being more negative about EOLC, which affects their ability to provide quality care for dying patients (Attia *et al*., 2012). It was further highlighted that nurses found it difficult or inappropriate to display their emotions, and as a result suffered alone, while the emotional impact lingered for a considerable time following the death of the patient.

4.3.1.2 Spiritual support

Spiritual support is a fundamental factor to help comfort and bring peace to the family, patient and nurse during this very distressing time. Participants mentioned that this support during EOLC and the withdrawal of treatment process is unavailable. The following statements bear evidence:

"Nothing is being done culturally the family just comes for those few minutes…" Ivy
"I was expecting spiritual support because there is a limitation as to how far I can go…" Nicki

"Something should be put into place with regards to spiritual care I can tell you that no psychologist came to see the patient or other patients, no psychologist no spiritualist." Nicki

We don't have structures in place in that regard we don't have structures that when the patient is not coping, we call in pastors and imams, their spiritual leaders…. Nicki

Kisorio and Langley (2016) support the above-mentioned statements and further added that sometimes it is difficult to get the needed spiritual support when needed during the withdrawal of treatment and EOLC. Gonzalez-Rincon *et al*. (2018) further mention and supports the need for spiritual support during the withdrawal of treatment and EOLC and bring to the fore that attending to spiritual needs was important to ensure a peaceful death.

4.3.1.3 Policies and protocols

Policies and protocols make provision for guidance on how to manage the tasks of withdrawal of treatment and EOLC. The lack thereof often results in inconsistencies and ineffective end-of-life care. This in turn causes conflicting feelings, moral dilemmas and delays in terms of decision making and carrying out of the proposed management.

The participants in this study expressed a concern that there were no policies and protocols on withdrawal of treatment. This leads to inconsistencies and debates between the doctors and nurses during EOLC.

They reported that this makes the withdrawal of treatment and EOLC process to be confusing, inconsistent, longer and emotionally draining. They added that if they had guidelines to refer to, it would make the EOLC and withdrawal of treatment process simpler to manage.

This can be corroborated by the quotes below:

"There is no protocol; the first doctor said that we shouldn't intubate the other one felt nah instead of him dying like that. It was really much of a debate but eventually, the patient was ventilated I felt as if we wasted time. With this certain consultant, I know she will go all out… So, I also know other doctors are like if it's their week there is nothing, they can do so he actually won't do anything." Anne

"The policy will have to help because it will be like there will be criteria to follow you know to guide people not to do the wrong things." Faith

"We've never written any policy here we've never referred to any policy we just follow what they say and that's it, we've never referred to any policy" Ivy

It's a bit of a dilemma if they were considering treatment, you feel like you are in a catch-22 situation the fact that they don't know if the patient is really going to demise." Lisa

Ranse *et al.* (2012) also reported that there were no policies or protocols available to guide end-of-life care. This led to uncertainty and ambiguity regarding the prognosis of the patient and EOLC decision-making. Even when the decision to withdraw treatment was made there was a delay in executing that decision, practically this was observed with increased waiting times even after the decision to withdraw treatment was made.

Over the years, several research groups and critical care communities have developed and published clinical guidelines and recommendations to help guide the provision of EOLC in the ICU (Downar *et al.,* 2016; Truog *et al*., 2008; Sprung *et al*., 2014).

Due to the multi-cultural and diversified societies and differences in EOLC practices globally, not all of these recommendations have entirely addressed the issues associated with the provision of EOLC, especially in low- and middle-income countries where non-western cultures exist.

Most of these research works and initiatives on EOLC care have been done in developed countries. Applying such strategies and concepts to the developing countries may be inappropriate, unrealistic and liable to fail due to the disease profile, the epidemiological context of death, life expectancies, cultural and religious differences.

4.3.1.4 Lack of resources

Lack of resources was also mentioned by participants to be a huge factor that influenced EOLC negatively. Resources such as beds in the ICU setting are never enough for the patients at hand. They further added that the resources were allocated based on who has a better prognosis or chances of survival.

This is illustrated in the quotes from participants in the study mentioned below:

"They talk about resources, just a waste of resources, why keep that person whereas there is someone in casualty who needs, a younger person who has a higher chance of survival who needs that ICU bed, and they are keeping that person who according to them shows no chance of progress." Dianna

"Beds are closed and locked some patients need to give others space and we feel that decisions are made hastily because of the situations we have in our hospitals and provinces and so on." Glen

Shortage of staff was reported as a huge barrier to providing EOLC (Beckstrand *et al.*, 2006). These compromised the time nurses spent caring for the dying patient and giving support to the family.

The participants in this study expressed frustration because they strongly believed that the patient-staff ratio of a dying patient should be 1:1 to ensure that the family and patient are cared for adequately.

Participants also mentioned that agency and floating staff were given these patients to nurse as they were seen as lower priority. The participants (nurses) viewed this as a barrier to facilitate a good death.

4.3.1.5 Nurses' knowledge and education on EOLC

Lack of education and training was perceived as a hindrance to effective EOLC. Managing the withdrawal of treatment and EOLC process efficiently requires knowing how to care for and attend to the needs of the dying as well as the family. Participants mentioned that there is limited knowledge and provision regarding how to carry this out efficiently enough to meet the needs of the patient and family. It was noted that all the participants had more than two years of working in ICU and the inclusion criteria was an additional qualification in Intensive care nursing and Trauma and Emergency Nursing.

This was expressed in extracts below:

"You can do an entire 3 or 4 years for us at Masters level there are a few sessions on end-of-life care and palliative care." Morris

"When someone is dying, we have a limited knowledge on how to care for the dying." Morris

Lack of education and training regarding EOLC, and the withdrawal of treatment was first reported more than three decades ago (Thomson, 1988).

This author reported that nurses felt ill equipped to deal with dying patients and they avoided conversations about death. What was recommended was more supervision for nursing students and additional specialist nurses in acute hospitals, who should be better educated in the care of the dying and the bereaved. This recommendation does not apply to this study because all the participants had more than two years of working in ICU, and they all had additional qualifications in either intensive care nursing or trauma and emergency nursing.

In studies conducted in the past two decades, nurses still report on insecurity and lack of education (Carlet *et al.*, 2003; Beckstrand *et al.*, 2006; Van Rooyen *et al.*, 2005; Crump *et al*., 2010; Attia *et al*., 2012; Holms *et al.*, 2014; Naidoo & Sibiya, 2014) in EOLC. These authors reported that training received by critical care nurses on EOLC is often inadequate, informal or non-existent. This ideology reported in these studies is consistent with the current study findings. The content on EOLC has been added to intensive care textbooks and clinical guidelines and recommendations for holistic EOLC and symptomatic alleviation have been published (Downar *et al.*, 2016; Truog *et al*., 2008; Sprung *et al*., 2014).

Inexperienced and novice nurses are not adequately prepared to provide skilled and competent care to dying patients in a chaotic and complex environment supercharged with advanced technology, increased demands from patients and families, and high expectations of performance from colleagues and managers. Vanderspank-Wright *et al*. (2011) added that nurses with fewer than two years of experience working in an ICU clinical environment frequently experienced fear and guilt because they felt their limited experience had contributed to a patient's death.

What is of concern is that in this study, the inclusion criteria were all registered nurses who have worked for more than one year in ICU and an additional qualification in Intensive care or Trauma and Emergency Nursing. All the participants had more than two years of working in ICU, yet they still expressed inefficient knowledge of EOLC.

The participants in a South African study by Van Rooyen *et al.* (2005) expressed the need for knowledge regarding the EOLC and withdrawal of treatment process, specifically relating to the ethical aspects and the need for skills to help patients and families during the process. This finding was similar to an Egyptian survey where 60% of the ICU nurses perceived lack of education and training on family grieving and EOLC as a barrier to quality care (Attia *et al*., 2012).

4.3.1.6 Involvement in decision-making

Decision-making should be a team effort to offer a holistic informed decision that will benefit all parties regarding the withdrawal of treatment and EOLC. Most nurses that partook in this study felt very strongly about not being involved in the decision-making process. They described their relationship with the doctors as authoritative because they were just "simply carrying out orders". They expressed feeling undervalued and that nursing as a profession is undervalued by doctors. Emotions expressed included anger, frustration and powerlessness.

Below are direct quotes from participants that support these findings:

"We stood the whole day, and someone will just come with a quick overview of the chart and a few investigations and says guys we are not going to do anything for him. You can't tell a professor that we need to resuscitate a patient when they tell you that you cannot resuscitate." Glen

"You just have to do whatever because these are the orders." Emma

"They just write on the chart DNR then we nurse's when we hand over, we see this on the chart this DNR others don't know, at least we know maybe if the doctors can call the shift leader or the sister in charge and discuss it." Henrietta

"They just give us orders so if they want us to stop the treatment, they just tell us. It makes me

feel useless it makes me feel like doctors sometimes they don't respect nursing as a profession because I feel like they should involve us in every decision they make about the patient because we are the ones that spend 24 hours with the patient, we know the patient way better than they do." Ivy

"Maybe if we as nurses, as specialist practitioners in this speciality we can at least be allowed to voice our opinions, to take part may be in the decision making and voice maybe your feelings and be taken into consideration." Lisa

"The doctor came in; you know there was no discussion with the nurses on whether to withdraw they just came in and wrote on the ICU chart stop that and that and that and I was there looking at a fellow human being just on a bed dying without someone around it was very emotional." Morris

"Nurses, they are good at executing the plan, but they are not a part of the people who make the plan and that makes the scene like we don't feel a part of what is happening to the patient even though you do all the nursing stuff you don't feel a part of it. You are just there to follow procedures you are there to tick boxes someone already has the template." Morris

The findings of this study are substantiated and supported by a South African study by Langley *et al*. (2013), where only 35% of nurses stated that they were actively involved in EOLC discussions with physicians. Nurses have expressed dissatisfaction with not being involved in the decision-making process. They felt they spent the longest time with the patient and could contribute to decision making regarding patient care, instead they were just told about decisions that were made (Carlet *et al.*, 2003; Halcomb *et al.*, 2004; Kisorio & Langley, 2016).

Jordan and Pheiffer (2017) raised a concern that withdrawal of life-support treatment by nurses is based on verbal orders. These authors highlighted the importance of having orders written to make the process more legal.

According to Flannery *et al.* (2016), nurses spend most of their time with the patient and are

therefore in a unique position as the family and or patient often discuss their EOLC wishes with them. The Australian and New Zealand Intensive Care Society stated that although the intensivist leads the decision-making process it should always remain a shared decision-making process. Nurses expressed feeling undervalued and that nursing as a profession is undervalued by the doctors (Flannery *et al*., 2019).

It was further mentioned that nurses are either excluded or inconsistently included in the decision-making process. This leads to lack of uniformity and ambiguity for nurses (Latour *et al*., 2009). According to the findings of a study by McAndrew *et al.* (2015), nurses experienced moral distress related to the inability to influence end-of-life decisions. Thelen *et al*. (2005), emphasised the importance of collaborative decision-making between physicians and nurses when dealing with EOLC issues in the ICU as this may decrease the moral distress experienced by each group.

4.3.1.7 Environmental factors

Environmental factors play a huge part in the delivery of efficient EOLC during a very distressing time. A conducive environment creates peace, calm and comfort for everyone involved in the EOLC process.

COVID 19 and the lockdown restrictions such as isolation, social distancing and the family not being allowed to visit the dying patient had negative repercussions on the ICU nurses, the family as well as the dying patient. Some of the participants in this study raised this concern since they had to watch patients dying alone in the cubicles. The following quotes from participants support these statements:

"No, the family was not there it was during the lockdown last month." Anne

"Before Covid at least you were able to hold them but now it's difficult you can't even give them a hug." Emma

"It's during Covid no family member is allowed to come here and the patient is dying so you can imagine no visitors are allowed here so the patient is just going to die by themselves on their own." Ivy

"One thing that has affected us most is this Covid thing…" Jessica

"We leave these patients in those cubicles with nothing visual to them some patients coming from all walks of life they may have interest in let's say playing music some may have interest in let's say family members rubbing their hands." Morris

"Another component normally in ICU, this noise coming from the alarms and monitors…" Morris

"ICU is very busy whilst sometimes in a cubicle you have two patients you attending to..." Morris

This study's findings are similar to those of a Canadian study on critical care nurses' experience during the early phases of the COVID-19 pandemic.

These participants expressed anxiety, concern and distress related to meeting patient care needs in new ways while staying safe and managing personal commitments to self and family. They experienced a high degree of psychological distress when working during the early phases of the COVID-19 pandemic (Crowe *et al.*, 2021).

Holms *et al.* (2014) perceived the ICU environment as not conducive to the dying patient as well as the grieving family because of lack of peace, privacy and space. Kisorio & Langley 2016) reported that a huge flaw found was that noise had become normal in the ICU setting and this flaw needed to be rectified.

Gonzalez-Rincon *et al.* (2018) highlighted the importance of the presence of the family and the ICU nurses to make sure that the dying patient has a peaceful death and further added that no patient should die alone.

THEME TWO: EMOTIONAL BURDEN

Emotional burden emerged as the second theme in this study. All the participants in this study expressed mixed emotions related to caring for the dying patient and the obstacles encountered during the withdrawal of treatment and end-of-life care.

4.3.2.1 Nurses' feelings regarding withdrawal of treatment and EOLC

Negative emotions and feelings are rife during the EOLC process, the negative emotions and feelings of nurses who witness and are part of the process of patients dying are observed to be intense in this study resulting in an emotional burden on the ICU nurse.

These emotions ranged from being scared and feeling guilty, sad and depressed and within the midst of a moral dilemma, which affects the nurse holistically to much more intense change in attitudes such as becoming emotionally blunt and not being scared of death. Some of the participants expressed regret for choosing to work in the ICU.

The following are quotes of participants related to the above-mentioned nurses' feelings regarding withdrawal of treatment and EOLC:

"So, we just had to watch him die so to me that was very traumatizing to the point that I didn't want to be around the patient anymore…" Anne

"You get used to it… he'll die anyway so you try to treat them with care and make them

comfortable… I feel like I shouldn't have that attitude." Anne

"Spiritually it's actually draining. It made me feel like I was nursing a corpse, honestly, I felt like I was nursing a corpse especially since I knew this person from when he used to speak, from when he would tell me he's been sick, he had a history…" Anne

"It was so painful to me I was like I can't! it's painful there's nothing more we can do. When I came on duty, he was on adrenalin but they said they are stopping they are not going to do anything so it was frustrating too because he was awake, that's what was frustrating me more he was awake." Carla

"We are failing them these people are here for us to help and we failing them we are ending their life we are supposed to be helping but then again, we are not God it's like we are supposed to do more but we are failing them. It's scary and so difficult and depressing." Carla

"It was bad, very bad I used to cry every day. You feel sad when you are there you feel very sad yes, every time you end of life you know you feel sad," Emma

"It's very sad, I feel very sad when I have to get to that point whereby, I am told please don't bother giving him any more treatment. I'm trained to save life; I'm trained to do something about it and here we are being told to do nothing for the patient. Glen

With me, with the time I've been in ICU this happened quite a lot of times so my feelings were not the same throughout, in the earlier stages this would depress me a lot, yes depress me a lot…" Glen

"As time goes on you ended up becoming even somewhat blocking feelings and doing things like a robot… I've become cold…" "I can say when people now can see that situations are dangerous, I don't have that natural sympathy for life." I'm no longer afraid of death." Glen

"Guilt, we are most of the time feeling guilt, also maybe for this to go to poor prognosis, we on our side, me as the nurse, did I do everything to keep the prognosis from progressing? Did I give the medication at the right time?" Glen

“It’s scary, very scary for me like I said I believe that everyone should be given a chance to live despite the prognosis the scariest part is stopping the life support.” Ivy
“It has broken my heart so much and it makes me feel helpless because there is absolutely nothing I can do.” Ivy

“It's a bit of a dilemma if they were considering treatment, you feel like you are in a catch-22 situation the fact that they don't know if the patient is really going to demise." Lisa
“Like you feel you have constraints like you can’t do anything.” Lisa

“You still feel it emotionally, but you still have to do what you need to do physically. It is a traumatic experience, the post-traumatic stress. You always want to quickly wrap up and hand over the patient to another person because you don’t want to go through that experience anymore.” Morris

“Physically I was stressed, stress is a major effect the stress of being around your patient the stress of making sure this patient is comfortable. Gradually I would get exhausted and frustrated and you know sometimes I will feel like why am I in Intensive care why didn’t I go for another speciality intensive care is draining.” Nicki

"I've seen some nurses those that are more experienced than I am I see them it looks as if this patient is not human it's just another patient, I don't see the human aspect. We cry, we get too emotional.” Nicki

“It has made me not to like my job… I regret maybe doing ICU… I don’t see myself in ICU in the next two-three years no… I would feel like I can't go to work…" Ophelia

The following literature reiterated that the withdrawal of treatment and EOLC process is rife with emotions and causes emotional burdens on the nurse. Mcmillen (2007) relays the message that ICU nurses had trouble when taking care of patients whose treatment was withdrawn. It was a bad or upsetting experience and there was a strong sense of emotional labour. Kisorio and Langley

(2016) refers to psychological and emotional challenges that were considered painful, traumatic, heart-breaking, depressing disturbing and stressful by participants.

All nurses' experiences were explained to involve emotions, nurses who got to know their patients and family felt sad and upset because of the withdrawal of treatment and took it personally (Halcomb *et al*., 2004). A participant in the above-mentioned study inferred that withdrawing or not starting treatment in EOLC felt like they were giving up hope and failing as a nurse. Halcomb *et al*. (2004) goes further to mention that involvement with patients and their family in-depth lead to an emotional cost to nurses involved in the process. Many nurses also experienced emotional tension over aggressive interventions that were being continued despite the poor chance of patient survival (Beckstrand, 2006).

The nurses' feelings of guilt and sadness, helplessness, anger, sadness and frustration and despondency because no matter what was done, death was still inevitable were reiterated (Van Rooyen *et al*., 2005; Holms *et al.,* 2004). The nurse involved in taking care of the dying patient and the family is emotionally drained (Holms *et al*., 2004).

Vanderspank-Wright *et al*. (2011) support this study's findings by reporting that nurses with fewer than two years of experience working in ICU frequently experienced fear and guilt because they felt their limited experience had contributed to a patient's death. The resulting conflicted values, emotional turmoil, exhaustion, burnout, job dissatisfaction, and low morale may cause nurses to leave the nursing profession (Ferrell, 2006; O'Mahony *et al*., 2010).

4.3.2.2 Nurses' perspective on family feelings

The participants who partook in this study expressed their observations of families of the dying patients. They perceived family members as individuals that cannot accept that their loved one is

dying, in denial, being distressed and blamed healthcare professionals for the deaths being distressed and emotional.

Below are quotes from participants shedding light on their emotional burden:

"It affects them in a very painful manner and indescribable." Anne

"They were in big, big denial…" Briana

"They think we are the ones who killed him, who switched off the machines." Carla

You call them and explain they are in denial they don't accept what you are telling them they tell you no he will be fine." Dianna

"How they feel they don't express…" Emma

"It's difficult for the family…" Faith

"For the family it's sad I've seen people breaking down…" Glen

"I feel they (the family) become more distressed than any other person here, imagine being told that your child or relative is dying and there is nothing that you can do that must be very, very scary." Ivy

"It's difficult for them to accept even if they have been informed about the poor prognosis…" Kim

"Some of them can understand because maybe the patient has been sick for some time but with others, they don't even want to accept the fact that we assisted the patient slowly going into demise." Lisa

"More often than not family members don't have any clue of what is happening they are not told the reasons why we are stopping all that we say is that we are trying our best." Morris

Care of the family has been identified as important to EOLC. Nurses provide support to family members through their physical presence and the provision of information (Halcomb *et al*., 2004; Ranse *et al*., 2012; Powazki *et al.*, 2014). Thelen (2005) described making end-of-life decisions as being surreal, overwhelming and devastating. They expressed feelings of guilt for letting their loved ones suffer if decisions were not made or carried out soon enough. The participants in a study by Kisorio and Langley (2016), expressed distress that they thought their loved ones would get better. They found the news that their family member would not survive hard to believe and held on to the hope of recovery.

Stokes *et al.* (2019) supported the current study findings. The nurses in this study expressed that being there for the dying patients and their families was meaningful and part of providing a good death. They emphasized that nobody should die alone and that family presence at the bedside was extremely vital.

4.3.2.3 Nurses' perspective of patient feelings

Dying patients have a lot to deal with holistically, mentally, emotionally, spiritually and physically. The nurses in this study perceived accepting that one is about to die as a mammoth task. They further added that their observations were that most of the dying patients had mixed feelings, which included sadness, aggression, giving up and being helpless. The ICU nurses expressed that they were feeling helpless when caring for a dying patient. However, one participant had a different view to mention that dying patients do not feel anything.

Below are direct quotes from participants in the study validating the above sub-theme:

"His limbs are not working and it's depressing all of us in the unit, all of us who are nursing him, he's talking, he's responding but he knows he cannot feel anything. They are scared they sometimes become aggressive…" Carla

"You find them crying and sobbing like my patient he is a gunshot c-spine and he is quadriplegic and doctor told him about his condition and he was sobbing…Once you tell them it affects them there is no way out or there are no chances of survival and then they tend to give up." Dianna

"The same frustration, unanswered questions you know but most of the time anxiety is always there for them." Glen

"It must be very stressful as well because the patient is helpless and hopeless…" Ivy

"The patient doesn't feel anything he's just lying there he does not feel anything." Jessica

The nurses in a study by Stokes *et al*. (2019) perceived their presence as a sense of obligation and duty to patients while they were dying. The importance of little actions like holding the patient's hand, talking to them was a way of providing reassurance and comfort.

They ensured everything to preserve human dignity and peacefulness during EOLC. Spirituality and religion were associated with peacefulness and were described as important aspects of a good death (Stokes *et al.,* 2019).

Nurses have a responsibility to support the patient and the family during withdrawal of treatment and EOLC as well as to carry out their professional obligations to their profession and their employer, the hospital (Halcomb *et al.*, 2004). The participants in a South African study raised a concern that they have difficulty when it comes to handling both their feelings and professional expectations. They often end up questioning whether what they did was the correct thing to do or not (Kisorio & Langley, 2016). Many nurses also experienced emotional tension over aggressive

interventions that were being continued despite the poor chance of patient survival.

THEME THREE: COPING MECHANISMS

The third theme that emerged in this study was coping mechanisms. Coping mechanisms are strategies utilized to reduce unpleasant emotions which are often experienced during end-of-life care. They can be conscious or subconscious; however, they may be negative or positive to ones being, overall growth and progress holistically. The participants in this study expressed different coping mechanisms.

4.3.3.1 Negative coping mechanisms

Negative coping mechanisms can be harmful and can result in one being dysfunctional. Participants that partook in this study mentioned negative coping mechanisms that can affect them badly in the long run.

Some of these coping mechanisms that were mentioned included the consumption of alcohol, ignoring, blocking out or avoiding the situation of EOLC and becoming emotionally blunt.

Direct quotes that substantiate the use of and occurrence of negative coping mechanisms are as follows:

"Sometimes you end up at home you got your glass of wine and drink and sleep that's what we do sometimes." Carla

"I've experienced myself having a little more than what I used to drink at some stage…" Glen

"I am not necessarily thinking about the patient and he is dying I could be at work enjoying movies in the time allocated for me to do work I don't have to be looking at the chart or the patient I will just be waiting for the alarm to tell me asystole." Glen

"When I came here, I was emotionally weak now I am emotionally blunt." Ivy

"There are some sessions where you tend to avoid the situation…" Morris

In a study by Van Rooyen *et al.* (2005), the nurses explained that at times they withdrew from the dying patients emotionally by creating distance or avoiding being involved. Also mentioned was that nurses used self-control where they remained professional and tried to avoid all emotions to try and deal with the situation of EOLC and the withdrawal of treatment.

4.3.3.2 Positive coping mechanisms

Positive coping mechanisms are a necessity to maintain good overall well-being, especially during an intense emotional process such as EOLC and it helps the nurse deal with the situation and aftermath positively. Participants in this study mentioned sharing, talking, debriefing as well as praying and partaking in activities that they like which bring about relief and happiness.
The following quotes bear evidence:

"How I manage it is by talking to other colleagues…It's therapeutic on my part I also speak to my family… I also pray about it…" Anne

"You talk about it; we do talk about it… During teatime we do talk about it after its happened then it's a part of venting it out, debriefing." Dianna
"We do talk about it…" Emma

"I'm a praying woman I believe in God so everything I give to my God; I give it to him so he can help me deal with such issues." Faith

"Maybe prayer, God makes me strong to take care of these patients…" Emma

"My colleagues are there we talk…" Jessica

"You normally tend to externalise your feelings to people just to listen to their answers and basically you realize you are not alone majority of nurses are going through that. Sometimes you stick to things you love doing, watching a movie, you know after coming back from watching a movie, speaking to family, doing something different, going for hiking…" Morris

"I talk about it I take it home and I tend to talk about it with my husband when I get home…" Nicki

In a study by Van Rooyen *et al.* (2005), participants coped by turning to a colleague who had been through similar situations for comfort and empathy. Other participants engaged in certain activities that helped them relieve tension such as going home and crying. Intellectualization was also used by nurses where they focused on theoretical information that allows them to have a rational explanation for the situation that helps them cope with anxiety.

4.3.3.3 Lack of coping mechanisms

A few participants in this study felt that they needed to be strong and carry on working because there was work to be done and patients to take care of. They completely ignored their own needs to deal with the process of EOLC and how it affected them and one participant even mentioned that a result of doing that was snapping eventually which is a very unhealthy result of not coping.

"You don't vent you keep it to yourself and then you experience all the traumatic things happening then at the end of the day you bottle up things and as time goes by you just it happens once in a while you snap you know…" Dianna

"You tell yourself that you made a pledge as a nurse to be there for a patient, so you have to chill out and be strong about it…" Dianna

"For that moment you will feel sad but you see there are other patients that need your help."

Emma

"I'm coping, it's okay I'm coping like I'm here you can see I'm working." Emma

"I just tell myself that this is a professional environment this is a job that I have to do I have to learn to separate my emotions from my work." Ivy

4.4 SUMMARY

The findings of this study were presented in this chapter. Three themes and thirteen sub-themes emerged and were corroborated with direct quotes from the participants. These findings were then discussed in relation to the relevant literature. This chapter brought to light the intensity of withdrawal of treatment and EOLC as well as the impact of the process on the ICU nurses and family members. The next chapter focuses on the summary of findings, the study limitations and the recommendations.

CHAPTER FIVE

SUMMARY OF FINDINGS, LIMITATIONS, AND RECOMMENDATIONS

5.1 INTRODUCTION

The chapter focuses on the summary of the study findings, limitations and recommendations for practice and future research.

5.2 SUMMARY OF THE STUDY

The purpose of this study was to describe the ICU nurses' experiences with regard to withdrawal of treatment and EOLC in the adult intensive care units of a university-affiliated public hospital

in Gauteng.

To achieve the purpose of the study, the following objective was set.

- To explore and describe the ICU nurses' experiences with regard to withdrawal of treatment and end-of-life care.

A qualitative descriptive design was used in the study to describe ICU nurses' experiences regarding the withdrawal of treatment and EOLC. The design facilitated a comprehensive summarization of all events experienced by ICU nurses with regards to withdrawal of treatment and EOLC. Purposive sampling was utilised to recruit 15 registered nurses who met the inclusion criteria. The sample was recruited from a total population of 80 registered nurses working in the 4 ICUs of a university affiliated academic hospital in the Gauteng province.

In-depth semi-structured interviews were undertaken using one open-ended question. Probes were used to explore the experiences of ICU nurses about withdrawal of treatment and EOLC.

Data analysis was initiated after each participant was interviewed. Data saturation was achieved after 15 interviews. The audiotaped interviews were transcribed verbatim. Braun and Clarke's six-phase framework for thematic analysis were used (Braun & Clarke, 2006; Clarke & Braun, 2013). The researcher followed the model of Lincoln & Guba (1985), to ensure the trustworthiness of this study. These included: credibility, dependability, confirmability and transferability.

Prior to commencing the study, ethical clearance was obtained from the Human Research Ethics Committee of the University of the Witwatersrand (**Appendix I)**. Approval to conduct the study

was obtained from the Research and Postgraduate Committee of the School of Therapeutic Sciences (**Appendix K**). Permission to conduct the study was obtained from the institution (**Appendix J**).

5.3 SUMMARY OF THE MAIN FINDINGS

This study examined the experiences of ICU nurses regarding the withdrawal of treatment and end-of-life care. This study was carried out in an academic hospital in the Gauteng province. Three major themes with thirteen subthemes emerged during data analysis.

Following a comprehensive thematic analysis of the qualitative interviews, the following themes emerged: *obstacles to withdrawal of treatment and EOLC, emotional burden and coping mechanisms.*

These experiences revealed that EOLC is a very emotional process, very difficult to manage with limited resources and policies to follow and many obstacles present. The participants in this study expressed many obstacles that hindered withdrawal of treatment and EOLC as a process. These included: psychological support, spiritual support, policies and protocols, lack of resources, education and training, involvement in decision making and environmental factors.

The EOLC process is an emotionally burdening process substantiating the need for psychological support and counselling which according to participants of this study is an area that is lacking or not accessible. Psychological support was seen either as non-existent, not accessible or not important. This finding is consistent with the Australian studies by Halcomb *et al.* (2004) and Ranse *et al*. (2012) and a South African study by Van Rooyen *et al*. (2005).

Although the process of treatment withdrawal created emotional distress. Thompson *et al*. (2012) and Halcomb *et al.* (2004) reported that nurses found it difficult to display their emotions, and as a result suffered alone, while the emotional impact lingered for a considerable time following the death of the patient. Debriefing following the death of a patient was considered beneficial but lack of time due to institutional demands, such as bed filling and paperwork, meant that nurses had to carry on without debriefing and moved on to the care of the next patient quickly after the preceding death (Halcomb *et al.*, 2004; Thompson *et al*., 2012).

Spiritual support is a fundamental factor to help, comfort and bring peace to the family, patient and nurse during this very distressing time Participants mentioned that this support during EOLC and the withdrawal of treatment process is unavailable.

The above can be confirmed by findings in a study by Kisorio and Langley (2016) which mentions that it was sometimes difficult to get the needed spiritual support when needed during EOLC and the withdrawal of treatment. Gonzalez-Rincon *et al.* (2018) further mention and supports the need for spiritual support during EOLC and the withdrawal of treatment and bring to the fore the findings that tending to spiritual needs was important to ensure a peaceful death.

Policies and protocols make provision for guidance on how to manage the tasks of withdrawal of treatment and EOLC. The lack thereof often results in ineffective end-of-life care. This in turn causes inconsistencies, conflicting feelings, moral dilemmas and delays in terms of decision making and carrying out of proposed management.

Lack of policies and protocols during the EOLC and withdrawal process are a common

occurrence according to participants in this study. Ranse *et al*. (2012) raised a concern that there were no policies or protocols available to guide end-of-life care and that this led to uncertainty and ambiguity regarding the prognosis of the patient and EOLC decision making. The current guidelines and recommendations on EOLC in the ICU have not entirely addressed the issues associated with the provision of EOLC, especially in low- and middle-income countries where non-western cultures exist (Downar *et al.,* 2016; Truog *et al*., 2008; Sprung *et al*., 2014). The multi-cultural and diversified societies and differences in EOLC practices globally warrant contextual adaptation of the EOLC guidelines.

Lack of resources was also mentioned by participants to be a huge factor that influenced EOLC negatively. Resources such as beds in the ICU setting are never enough for the patients at hand and so these beds and resources needed to treat such ill patients are allocated based on who has a better prognosis of survival.

Another form of lack of resources not mentioned by any participants in the study is the shortage of staff. The participants in the study by Beckstrand *et. al*. (2006), reported that shortage of staff caused lack of time to nurse and care for the dying patient and the family.

Inadequate nurses' knowledge and education on EOLC was perceived as a hindrance to effective EOLC. This study's findings highlighted that there is limited knowledge and provision regarding how to carry this out efficiently enough to meet the needs of the patient and family. This challenge concern was first reported more than three decades ago (Thomson, 1988). There have been improvements in adding EOLC content in textbooks and publishing guidelines on EOLC (Downar *et al.,* 2016; Truog *et al*., 2008; Sprung *et al*., 2014) and yet literature reports that the knowledge gap and insufficient preparedness of ICU nurses persist (Carlet *et al.,* 2003; Beckstrand *et al.,* 2006; Van Rooyen *et al.,* 2005; Crump *et al*., 2010; Attia *et al*., 2012; Holms

et al., 2014; Naidoo & Sibiya, 2014).

Decision-making should be a team effort to offer a holistic informed decision that will benefit all parties regarding the withdrawal of treatment and EOLC. Most nurses that partook in this study expressed concern about being excluded from decision making. They described their relationship with the doctors as authoritative because they were just "simply carrying out orders" even though they spend more time with the patient and have valid input that may benefit the EOLC process.

Several studies support the perceived lack of collaboration between doctors and nurses during decision-making with physicians described as quite authoritative (Halcomb *et al*., 2004; Fridh *et al*., 2009; Van Rooyen *et al.*, 2005; Jones & FitzGerald, 1998). They felt very strongly about being undervalued and undervaluing nursing as a profession.

In a study by Langley *et al.* (2013) only 35% of nurses stated that they were actively involved in EOL discussions with physicians. Carlet *et al.* (2003) also mentioned nurses' dissatisfaction with not being involved in decision-making. Latour *et al*. (2009) emphasised that the inconsistent inclusion of nurses in the EOLC discussion leads to lack of uniformity and ambiguity for nurses. McAndrew *et al*. (2015) reported that nurses experienced moral distress related to the inability to influence end-of-life decisions.

Environmental factors play a huge part in the delivery of efficient EOLC during a very distressing time. It creates peace calm and comfort for everyone involved in the process. Covid 19 and its negative repercussions such as isolation, social distancing and the family not being allowed to visit the dying patient as well as catering to the needs and likes of the dying as well as a need for privacy and to create an environment of peace and comfort free from noise were uncovered from participants. Participants in a study by Holms *et al*. (2014) mentioned lack of peace privacy and

space. However, some participants contradicted these findings mentioning that they were privileged to be able to give one-on-one nursing care during EOLC and the withdrawal of treatment. Kisorio and Langley (2016) reported that a huge flaw found was that noise had become normal in the ICU setting and needed to be rectified according to participants. Gonzalez-Rincon *et al*. (2018) emphasises the importance of the patient not dying alone to make sure for a peaceful death.

Negative emotions and feelings are rife during the EOLC process, the negative emotions and feelings of nurses who witness and are part of the process of patients dying are observed to be intense in this study resulting in emotional burdens on the nurse.

These emotions range from being scared and feeling guilty, sad and depressed and within the midst of a moral dilemma that affects the nurse holistically to much more intense change in attitudes such as becoming emotionally blunt and not being scared of death. The following studies reiterated that the withdrawal of treatment and EOLC process is rife with emotions and causes emotional burdens on the nurse (Halcomb *et al*., 2004; Van Rooyen *et al*., 2005; Mcmillen, 2007; Kisorio & Langley, 2016; Holms *et al*., 2014).

While patients are central to the experience of withdrawal of treatment in ICU, families and family presence comprises an overwhelming part of intensive care nurses' narratives. The families of the dying patients observed by participants who partook in this study have been portrayed as individuals that cannot accept that their loved one is dying, denial, and blaming healthcare professionals for the deaths were reported. Families have described making end-of-life decisions as being surreal, overwhelming and devastating (Thelen, 2005). The current study findings are

supported by Stokes *et al.* (2019). The nurses in this study expressed that being there for the dying patients and their families was meaningful and part of providing a good death. They emphasized that nobody should die alone and that family presence at the bedside was extremely vital.

Dying patients have a lot to deal with mentally, emotionally, spiritually and physically. The nurses in this study added that their observations were that most of the dying patients had mixed feelings, which included sadness, aggression, giving up and being helpless. Nurses have a responsibility to support the patient and the family during withdrawal of treatment and EOLC as well as to carry out their professional obligations to their profession and their employer, the hospital (Halcomb *et al.*, 2004).

Coping mechanisms are strategies utilized to reduce unpleasant emotions, which are often, experienced during end-of-life care they can be conscious or subconscious, however, they may - be negative or positive to one's being, overall growth and progress holistically. Negative coping mechanisms can be harmful. Participants that partook in this study mentioned negative coping mechanisms that can affect them badly in the long run.

Some of the coping mechanisms that were mentioned were the consumption of alcohol, ignoring, blocking out or avoiding the situation of EOLC and becoming emotionally blunt. Van Rooyen *et al*. (2005) reported that at times nurses withdrew from patients emotionally by creating distance or avoiding being involved.

Positive coping mechanisms are a necessity to maintain good overall well-being, especially during an intense emotional process such as EOLC. Participants in this study mentioned sharing,

talking, debriefing as well as praying and partaking in activities that they like which bring about relief and happiness. Some of the participants mentioned ignoring their own psychological needs. Naidoo and Sibiya (2014) emphasised that nurses need to have support networks in place not only to assist in providing care but also for their emotional support and well-being. Van Rooyen *et al*. (2005) reported that some of the nurses coped by turning to a colleague who had been through similar situations for comfort and empathy.

5.4 LIMITATIONS OF THE STUDY

This study had several limitations:

- This study was conducted at a single South African public academic hospital and therefore the results cannot be generalised to other private and public hospitals, only to the specific ICUs in which the study was conducted.
- This study was conducted in an academic hospital that has a high grade of technology as well as skilled nurses and more resources. This may not be the case for other smaller hospitals with less technology, resources and less skilled nurses. Hence, the findings may not reflect the experiences of ICU nurses in other settings.

- The interviews were conducted in English language since this is the medium of communication in the ICU unit. This could affect the responses of the nurses, as they may not have been able to express themselves fully even though the interview was conducted in simple English.

- The sample size for this study was small which may prevent the findings from being extrapolated.

- Purposive sampling technique was utilised to choose nurses for this study, hence nurses that volunteered may have specific perspectives on this topic and this may have influenced their responses.

5.5 RECOMMENDATIONS OF THE STUDY

This study examined the experiences of ICU nurses regarding end-of-life care and the withdrawal of treatment in an academic hospital in Gauteng. Based on these findings, the following recommendations can be made.

5.5.1 Recommendations for Nursing Practice

Insufficient or lack of psychological and organisational support may influence the care provided to patients and their families, and nurses' end-of-life care experiences, and coping. It is recommended that formalized support structures made up of the members of the multidisciplinary are implemented. Mentoring and coaching for new and junior staff and regular debriefing and critical reflection sessions facilitated by a social worker or psychologist be readily available and advocated for, by all ICU staff members. Orientation for all new staff members and in-service training for all staff members is crucial.

Although EOLC policies and guidelines exist, the participants in this study were not aware of any organisational or unit-specific policies to guide EOLC. Therefore, the development of contextual

guidelines and protocols specific to the intensive care may also assist nurses in the provision of EOLC and minimize inconsistencies. It is recommended that ICU nurses should be involved in the development and implementation of the protocols on EOLC.

It was evident from literature and the current study findings that lack of involvement in decision-making during EOLC hinders efficient EOLC and withdrawal of treatment. Collaborative decision-making should be implemented in all ICU settings. Nurses are primary caregivers in ICU and can add valuable contributions during decision-making.

5.5.2 Recommendations for Nursing Education

Withdrawal of treatment and EOLC has been mentioned to not be sufficiently covered in education and training.

Education in EOLC must be mandatory in all nursing education curriculum (undergraduate and postgraduate) at all levels. Levy (2005) agrees that training to deal efficiently with EOLC is not routinely given and most nurses learn on the job from other nurses and experience. Areas that need more nursing education include making decisions, handling one's emotions and feelings, how to manage and care for the patient and the family during EOLC and withdrawal of treatment holistically

5.5.3 Recommendations for Future Research

In this study, it was only the experiences of the Intensive Care nurses regarding EOLC and the withdrawal of treatment in an academic hospital in Gauteng that was explored. Further studies that would create a broader understanding with more results could include conducting research in

private hospitals as well as other academic and non-academic hospitals both locally and internationally.

5.6 CONCLUSIONS OF THE STUDY

The objectives of the study were met. It was evident from literature as well as from this study's findings that for more than three decades several obstacles concerning withdrawal of treatment and EOLC exist. These concerns are related to inadequate training for nurses, lack or inadequate support systems for nurses, the unfavourable nature of the ICU, nurses' lack of or inconsistent involvement in decision-making, lack of communication and teamwork among the ICU team members.

Despite the multi-cultural and diversified societies, differences in disease profiles and differences in EOLC practices globally, all ICU nurses experience similar barriers and perceive withdrawal of treatment and EOLC as a very difficult, emotional process.

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APPENDIX A: INTERVIEW GUIDE

Opening Question:

Tell me about your experiences regarding withdrawal of treatment and EOLC in ICU.

INFORMATION TO BE ELICITED

- Relate your experiences of caring for patients during EOLC where artificial life support is not initiated or is being stopped.
- Tell me about your experiences regarding initiating or stopping artificial life support on patients with poor prognosis in ICU.
- What is your opinion about how the process of not initiating or stopping artificial life support affected you, the patient and the family?
- What did you experience physically, mentally (thoughts), emotionally (feelings) or behaviourally (that is, your actions) which you consider due to the effects of this experience?

- How did you manage the feelings or thoughts in order to reassure/ soothe yourself or regain your composure?
- Is there anything else you would like to talk about?

THANK YOU FOR TAKING PART IN THIS STUDY.

APPENDIX B: DEMOGRAPHIC DATA

1. What is your gender?

Male	Female	Other

2. How old are you?

20-29	
30-39	
40-49	
50-59	
60-65	
>65	

3. What is your highest Nursing qualification?

Advanced Nursing Diploma	Masters	Doctorate

4. How many years have you worked in the ICU setting?

1 to 5 years	
6 to 10 years	

› 11 years to 15 years	
› 16 to 20 years	
› 21 years	

5. How many hours do you work per week on average in the ICU ……...hours?

6. Which of the following best describes your current position?

Professional Nurse	
ICU or Trauma trained Professional Nurse	
Shift Leader	
Charge Nurse	
Nurse Manager	
Clinical Educator	

THANK YOU FOR TAKING PART IN THIS STUDY.

APPENDIX C: PARTICIPANTS INFORMATION LETTER

Dear Colleague

My name is Shenaz Hussein. I am a student at the University of the Witwatersrand I study at the Department of Nursing and am currently obtaining my Master of Science degree in (Trauma and Emergency) nursing. I hope to conduct a research project and would therefore like to invite you to consent to me including you in my sample of nurses that I hope to study in the intensive care units. The aim of the study is to explore and describe the experiences of intensive care unit nurses with regards to withdrawal of treatment in order to gain a better understanding of the nurses' experiences in order to make recommendation that would improve the experience and process and after effects of the withdrawal of treatment and end of life care.

Should you agree to participate in this study you will be asked to sign a consent form to confirm your willingness to participate in the study and for the interview to be recorded. I will then make an appointment with you suitable to your needs to conduct an individual interview asking you to respond to questions related to ICU nurses' feelings towards the withdrawal of treatment. I anticipate that this should take no more than one hour of your time. Participation in the study is entirely voluntary and you may choose to not participate or to withdraw from the study at any time which will not affect you in any way. Anonymity and confidentiality will be ensured by using a code number instead of your name. No personal information will be mentioned in the study. No foreseen risk will be associated to the study. There will be no direct benefit to you from this study However, the study will benefit nurses and the nursing profession in terms of deriving nurses' feelings and challenges and suggesting better approaches in optimising the withdrawal of treatment in ICUs and its outcomes.

Since the nature of this study is sensitive and may result in you experiencing some distress. As a result, a support person is available to you at no cost. Her contact details are as follows:

Name: Professor Shelley Schmollgruber

Contact details: shelley.schmollgruber@wits.ac.za; 064 751 3214.

The findings of the study will be available upon request. The appropriate people and research committees of The University of Witwatersrand and Gauteng Department of Health and Charlotte Maxeke Johannesburg Academic Hospital have approved the study and its procedures.

Thank you for taking the time to read this information letter. I have applied to the Faculty of Health Sciences, School of Therapeutics Postgraduate Research Committee and the Ethics Committee of the University of the Witwatersrand to conduct the study. I have also applied to the management of the Charlotte Maxeke Johannesburg Hospital for permission to conduct the study. Should you require additional information about this study and its procedures rights you are free to contact me in the Department of Nursing or by telephone on 0813456334 or email 1508403@students.wits.ac.za. Professor Clem Penny, the chairperson can be contacted at 011 717 2301 email: clem.penny@wits.ac.za or the secretary of the committee, Mrs Zanele Ndlovu can be contacted at 011 717 1234 email: zanele.ndlovu@wits.ac.za .

Yours Sincerely

Mrs S Hussein (MSc Nursing student)
Supervisor: Dr Ntombifikile Klaas, email: fikile.klaas@wits.ac.za

APPENDIX D: PARTICIPANTS CONSENT FORM

I, …….. (Name and surname) give permission to be included in the research study.

I have read with understanding the content of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to me being included in the study.

I hereby declare my voluntary participation in the study.

Date …… Signature ……

APPENDIX E: CONSENT FOR AUDIO TAPE RECORDING

I ……. (Name of participant) having been informed on the purpose of audio-taping this interview, hereby give consent to have the interview audio-taped for the study entitled "Intensive Care Unit nurses experiences towards withdrawal of treatment and end of life care".

Date: ……... Signature ……...

APPENDIX F: INSTITUTIONAL APPROVAL



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
12 November 2019

Mrs. Shenaz Hussein
Department of Nursing Education
University of Witwatersrand
Faculty of Health Science
NHRD REF: GP_201909_033

Dear. Shenaz Hussein

RE: **"Intensive Care Unit Nurses experiences regarding the withdrawal of treatment and end of life care"**

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~~
Pule
Ms. M.M Pule
Nursing Director
Date: 12/11/2019

Approved / not approved
Bogoshi
Ms. G. Bogoshi
Chief Executive Officer
12.11.2019

APPENDIX G: ETHICAL CLEARANCE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mrs Shenaz Hussein

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M190640 MED19-06-065

NAME: (Principal Investigator)	Mrs Shenaz Hussein
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Intensive care unit nurses' experiences regarding the withdrawal of treatment and end of life care
DATE CONSIDERED:	28/06/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Ntombifikile Klaas

UNIVERSITY OF THE WITWATERSRAND
OFFICE OF THE DEPUTY VICE CHANCELLOR RESEARCH
25 NOV 2019
RESEARCH OFFICE
JOHANNESBURG

APPROVED BY: Dr C Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 17/10/2019

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 June and will therefore be due in the month of June each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

25/11/19.
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX H: TITLE APPROVAL LETTER

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

14 November 2019
Person No: 1508403
PAG

Mrs S Hussein
76a
Lettie Street
Montclare
2092
South Africa

Dear Mrs Shenaz Hussein

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Intensive care unit nurses experiences regarding the withdrawal of treatment and end of life care* 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