DEVELOPMENT OF AN INSTRUMENT TO MEASURE THE QUALITY OF CARE AFTER THE WITHDRAWAL OF LIFE-SUSTAINING TREATMENT IN THE ADULT INTENSIVE CARE UNIT

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of
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DECLARATION

I, Emmanuel Kwame Korsah, declare that this thesis, which is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg, is my own work. It has not previously been submitted for any degree or examination at any other university.

Signature:

Date: 25th September 2023

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DEDICATION

I dedicate this work to my wonderful family, friends and mentors for their prayers, guidance and support throughout the journey

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ABSTRACT

Background: The majority of deaths in the intensive care unit occur after the withdrawal of life-sustaining treatment. Most patients often die within 24 hours after treatment has been withdrawn. The short time interval between treatment withdrawal and death has highlighted the urgent need to prioritize the quality of care provided for patients and their families during this period. In South Africa, the quality of care provided for patients after treatment withdrawal has been plagued with cultural differences, challenges, and ethical dilemmas. Currently, no instrument exists to measure the quality of care provided for patients at the end of life and their families after treatment is withdrawn in the adult ICU. Existing measuring instruments have been developed for western countries with no consideration for the South African context. Hence, using these measuring instruments, especially in a country where non-western cultures exist, may be inappropriate, unrealistic, and liable to fail, necessitating revision.

Purpose: To develop an instrument to measure the quality of care provided for patients after the withdrawal of life-sustaining treatment and their family members in the adult intensive care unit.

Methodology: An exploratory sequential mixed-methods research design was used. The study was conducted in two phases, namely: domain identification and item generation; and instrument development and validation. In Phase 1, a summary of findings from a scoping review of the literature and qualitative interviews with nurses, doctors, and family members were used to generate relevant content domains and items. Relevant items generated were synthesised and reduced to develop the first version of the measuring instrument in Phase 2. The instrument underwent further expert panel review for relevance and clarity. A content validity index and modified Kappa statistic were performed. Comments and feedback from the panel of nine experts were also used to assess the face validity of the instrument.

Results: The instrument development and validation process yielded a final instrument that consisted of 64 items across 7 domains. From an initial set of 143 items, the content validity process found seven domains and 64 items. These included patient- and family-centered decision making (9 items), communication among the ICU team and with patients and

families (12 items), continuity of care (3 items), emotional and practical support for patients and families (12 items), symptom management and comfort (7 items), spiritual care (5 items), and modifying the ICU environment (12 items). A study of content validity revealed that this instrument recorded an appropriate level of content validity. The overall content validity index of the instrument was high (S-CVI/Ave = 0.97) when using the average approach and moderate (S-CVI/UA = 0.77) when using the universal agreement approach. The moderate value of the S-CVI/UA can be advocated with respect to the high number of content experts that make consensus difficult. The instrument items also obtained excellent kappa values that ranged from 0.89 to 1.00.

Conclusion: The researcher developed and validated the content of an instrument to measure the quality of care provided for patients and their families after the withdrawal of life-sustaining treatments in the adult ICU. This instrument will support the provision of care for patients and their families following treatment withdrawal and the training and education of healthcare providers in end-of-life care. It will also aid future research in the care of critically ill and dying patients in the ICU. Future research should conduct more assessments and pilot test the instrument.

Keywords: Instrument development, End-of-life care, withdrawal of treatment, intensive care unit, quality of care

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
CODE	Care of the Dying Evaluation
COVID	Coronavirus Disease
CVI	Content Validity Index
EOL	End of life
EOLD-SWC	End-of-life in Dementia Satisfaction with Care
FATE-S	Family Assessment of Treatment at the End-of-life Short Version
FPPFC	Family Perception of Physician-Family Caregiver Communication
HIV	Human Immunodeficiency Virus
HPCSA	Health Professional Council South Africa
HREC	Human Research Ethics Committee
HSB	Health-seeking behaviour
ICU	Intensive Care Unit
I-CVI	Item Content Validity Index
IOM	Institute of Medicine
IPFCC	Institute for Patient- and Family-Centred Care
LST	Life-sustaining treatment
LTC	Long-term care
NCI	National Cancer Institute
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QOC	Quality of Care
QOD	Quality of dying
ScR	Scoping Review
S-CVI	Scale Content Validity Index
TIME	Toolkit of Instruments to Measure End-of-life Care
UA	Universal Average
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

CHAPTER ONE

ORIENTATION TO THE STUDY

1.0 INTRODUCTION

The quality of care provided for patients at the end of life and their families in the intensive care unit (ICU) has gained attention across critical care communities across the globe, but not necessarily from developing and underdeveloped countries' perspectives. It could be argued that international literature, existing instruments, and guidelines can inform the care healthcare professionals provide for patients at the end of their lives and their families. South Africa has its own unique culture, disease profile, life expectancy, religious and societal differences, and intensive care practices that differ significantly from western culture. Healthcare professionals working in the ICUs and patients' families also come from diverse cultural backgrounds and have different perceptions and beliefs regarding death and dying. They also have diverse views on how to care for patients and their families after treatment withdrawal. Therefore, the development of a context-based intervention that is unique to the needs of such a population will be needed. The study focuses on developing an instrument to measure the quality of care provided for patients and their families in the adult ICU in the South African context. The emphasis is on the care rendered to patients and family members after the withdrawal of life-sustaining treatment (LST). The chapter presents an overview of the entire study. It focuses on the background of the study, the problem statement, the research question, the study objective, the purpose of the study, and the significance of the study. The chapter also presents an overview of the research methodology used and finally ends with the layout of the thesis.

1.1 BACKGROUND

Globally, the intensive care unit (ICU) has seen tremendous change in technology, therapeutic interventions, and intensive care over the past decade. Medical and surgical patients who would not have survived some years ago can now be managed and maintained on life support with the hope of recovery. The setting has been shown to benefit unstable and critically ill patients who present with chronic and life-threatening illnesses (Marshall *et al.*, 2017). Despite these continuing technological and medical advancements, mortality following intensive care admission is approximately 20%, with 60%-80% of these deaths

occurring after the decision to withdraw LST (Capuzzo *et al*., 2014; Sprung *et al*., 2019). While some patients survive and are discharged, others often fail to respond to the therapeutic intervention offered. Under such circumstances, the withdrawal of LST is inevitable (Myburgh *et al.*, 2016). This has therefore highlighted the need to pay particular attention to the care given to not only patients that will survive but also those that will have treatment withdrawn and die in the ICU.

Over the past few years, the care provided for patients at the end of their lives and their families has become a relevant public health concern for discussion and research across the various international critical care communities (Myburgh *et al*., 2016; Sprung *et al*., 2014). This is timely due to the increased ICU admission, demand, and usage, the growing ageing population characterized by chronic illnesses and life-threatening diseases, and the increase in the ICU mortality rate nowadays. The ICU's modern equipment has also prolonged the dying process after the onset of chronic illness compared to some decades ago. There are also noticeable variations and differences in end-of-life (EOL) care practices, multi-cultural societies, disease profiles, and different life expectancies (Mark *et al*., 2015) that further place a huge demand on the quality of care provided for patients at the end of life and their families in various healthcare settings.

End-of-life (EOL) care refers to the holistic and supportive care rendered to patients with chronic, life-threatening illnesses and advanced diseases and their families as curative therapies become physiologically inappropriate, typically in the last few weeks or months before death. The emphasis is on relieving suffering, promoting comfort, and ensuring a dignified death (Badir *et al*., 2016; Mistry *et al*., 2015). This form of care begins when a patient is at high risk of dying and fails to recover despite the medical interventions given. It also encompasses multi-disciplinary team discussions on patients' health, a decision to limit LSTs, the possible withdrawal and withholding of LSTs, nursing care for the dying patient and family, and care for the family after the patient dies and the body is laid to rest (Braganza, Glossop & Vora, 2017).

In the ICU, death frequently occurs, and most of these deaths occur after the withdrawal of LSTs (Connolly *et al*., 2016). The literature defines "withdrawal of life-sustaining treatment" as the "*decision to actively stop a life-sustaining intervention presently being given"* (Sprung *et al.*, 2014:860). It refers to an end to medical therapies such as antibiotics,

artificial mechanical ventilation, and vasoactive drugs, with no intention to continue or choose another substitute. For instance, if a treatment such as mechanical ventilation is already offered to a critically ill patient and will offer no clinical improvement but is considered burdensome and will prolong suffering, then the already ongoing treatment is stopped (Connolly *et al*., 2016). The reasons for withdrawing life-sustaining interventions include the worsening of patients' conditions (e.g., persistent multiple organ dysfunction) despite continued optimal treatment, an extremely poor functional outcome that results in severe functional disability (e.g., brain damage), and coexisting severe systemic diseases such as metastatic malignancy that make survival unlikely (Braganza, Glossop & Vora, 2017). Once a decision is made to withdraw treatment by the multidisciplinary team after obtaining agreement from the patient, if able, and/or the family, then there is a transition from curative to comfort and end-of-life care (Sprung *et al*., 2014). In most cases, the sequence of treatments discontinued varies; however, mechanical ventilation is the last aggressive therapy stopped (Cooke *et al*., 2010). The other treatments include blood products, antibiotics, vasopressors, oxygenation, renal replacement therapy, intravenous fluids, and feeding (Lesieur *et al.*, 2015).

Research evidence from a systematic review report that the mean prevalence of withdrawal of LST for adult patients who died in the ICU ranged from 0 to 84% (Mark *et al.*, 2015). In Tunisia, the United Kingdom, and France, the total ICU deaths that occurred following the withdrawal of LST were 8.9% (Quanes *et al*., 2012), 31.8% (Wunsch *et al*., 2005), and 71% (Lesieur *et al*., 2015), respectively. Another large-scale study conducted by Azoulay *et al.* (2009) in 282 ICUs across Europe, Australia, the United States of America, and some Mediterranean countries found that, out of the reviewed data on 14,488 patients, hospital mortality was 21%. Among these deaths, 1,105 (36.2%) occurred after decisions to forgo LSTs; seventeen percent (17%) of those were preceded by a decision to withdraw LSTs. These statistics confirm that death following the withdrawal of LST is common in our current ICU setting and varies significantly. Sprung, Rusinova, and Ranzani (2015) and Mark *et al.* (2015) attribute these variations in forgoing LST to cultural differences, religion, geography, institutional policies, legal factors, individual patients' characteristics, triggers to withdraw treatment, and the attitudes of healthcare professionals. These differences and variations, according to the literature (Avidan *et al*., 2021; Myburgh *et al*., 2016), also support the uniqueness of individual cultures, societies, and religious beliefs and preferences. These further provide additional evidence in support of the claim that no single

statement, guideline, policy, or instrument can be regarded as a standard criterion applicable to all societies and countries.

In the ICU setting, the time to death after the withdrawal of LST is considerably short, however, varies. The majority of patients die within 24 hours after treatment has been withdrawn (Cooke *et al*., 2010). For instance, Wunsch *et al*. (2005) found that in the UK, only 25% of ICU patients who had treatment withdrawn survived longer than 7 hours, and only 8% of such patients survived longer than 24 hours. Lesieur *et al.* (2015) also reported that the majority of deaths that occurred after withdrawal of LST occurred between 0 and 3 days, a median time of 24 hours in French ICUs. In South Africa, the reported median time was also 11.4 hours (Turner *et al*., 1996, cited in Mark *et al*., 2015). The provision of optimum care for the dying patient, family members, and even healthcare providers is crucial given the short time between the withdrawal of LST and death in the ICU. The quality of care provided for patients and their families in the ICU will consequently be impacted by the average time of 24 hours. Therefore, any intervention tailored toward improving the quality of care for patients and their families, especially after the withdrawal of LST, will help shape the current EOL care practice.

Recent research findings highlight concerns that have been raised about the quality of care critically ill patients at the end of life and their families receive in our current health care and intensive care settings. These concerns are related to ethical dilemmas in the withdrawal of treatment, poor interdisciplinary communication and conflict (Braganza, Glossop, & Vora, 2017; Brooks *et al*., 2017), healthcare professionals' and families' attitudes toward end-of-life care and treatment withdrawal (Beckstrand *et al*., 2021; Beckstrand *et al*., 2017), inadequate supportive structures for the ICU team (Flannery *et al*., 2016), the unfavourable nature of the intensive care setting for EOL care (Attia *et al*., 2013; Brooks *et al*., 2017), and the lack of appropriate context-based guidelines and instruments to measure care at the EOL (Myburgh *et al*., 2016). These challenges hamper the provision of quality EOL care to both patients and their families in the ICU.

It is also evident in the literature that nurses, the principal providers of EOL care, continue to face challenges within the working environment while providing care for patients and family members. These challenges include a lack of autonomy, a low level of nurse-physician collaboration, physician dominance in the ICU setting, and high levels of

complexity and conflict regarding treatment withdrawal (Efstathiou & Walker, 2014; Kisorio & Langley, 2016b; Vanderspank-Wright *et al.*, 2018). Hence, nurses express diverse emotions relating to EOL care and the withdrawal of LSTs, which leads to moral distress and compassion fatigue (Mani, 2016; Vanderspank-Wright *et al*., 2018). Similarly, family members of patients receiving EOL care have also expressed their dissatisfaction in diverse ways with the quality of care rendered to their relatives at the end of life (Chen *et al*., 2020; Kisorio & Langley, 2016a). The sense of neglect, little involvement in the patient's plan of care, emotional disturbances, and a lack of communication characterize their experiences. These concerns further intensify the need for quality care and also bring to mind the growing interest in the quality of care at the end of life among consumers of healthcare services and other healthcare providers.

In an attempt to improve and measure the quality of care desired in the current intensive care setting, several research groups and critical care communities have, over the years, developed and published guidelines (Downar *et al*., 2016), instruments (Clarke *et al*., 2003; Kupeli *et al*., 2019; van Soest-Poortvliet *et al*., 2013), recommendations, and statements (Myburgh *et al*., 2016; Sprung *et al*., 2014; Truog *et al*., 2008) to help guide the provision of EOL care in the ICU. Downar *et al.* (2016) recently developed a guideline for quality EOL care during treatment withdrawal. These guidelines, although intended to guide the provision of high-quality care, were based on literature that consisted only of expert opinions and an expert group from only one western country. Therefore, its application to other regions, especially Sub-Saharan Africa, that have different disease profiles and cultural differences will be difficult. Truog *et al.* (2008) also developed recommendations to improve care during the dying process in the ICU. Although the recommendations are vital in EOL care, they are based only on ethical and legal principles that were not derived from empirically based evidence. Therefore, only these guidelines and recommendations are not enough to address the current challenges and shape the desired quality of care at the end of life globally.

Van Soest-Poortvliet *et al.* (2011) also conducted a qualitative content analysis to evaluate the existing measurement instruments used to assess the quality of life and care when dying in long-term care settings. Although several instruments were found to assess the quality of life and care, most of them were developed and validated using long-term facilities in the United States of America. The "ICU Palliative Care Quality Assessment Tool" has also been

developed to measure the quality of palliative care in the ICU. The tool was developed using the seven domains of quality care developed by the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Work Group (Clarke *et al*., 2003). The tool has since been adapted and validated across several studies (Ho *et al*., 2011; Sepelete, 2019). Further validation of the tool is recommended, especially in developing and underdeveloped countries.

Considering the multi-cultural and diversified societies and differences in EOL care practices globally, using these existing measuring instruments, especially in low- and middle-income countries where non-western cultures exist, may be inappropriate, unrealistic, and liable to fail. They can, however, be adapted and need further revision. This is due to the disease profile, the epidemiological context of death, life expectancies, and cultural and religious differences. The World Federation of Societies of Intensive and Critical Care Medicine in their statement also emphasized the need to develop national interventions that are specific to EOL care needs and the population in the ICU within each country (Myburgh *et al*., 2016). Therefore, context-specific guidelines and measuring instruments are appropriate and needed.

In South Africa, admissions to the ICU have increased tremendously over the years. This is attributed to the high prevalence of HIV disease, trauma (gunshots, stabbings, and motor vehicle accidents), and non-communicable diseases. A multicentre study described the 30-day mortality of patients admitted to 11 ICUs in 6 different hospitals in KwaZulu-Natal, South Africa (De Vasconcellos *et al.*, 2017). The authors found that a higher percentage of ICU admissions (73.7%) occurred on an emergency basis. Almost half of the admissions were for non-communicable diseases (49.6%), followed by trauma (29.0%) and infectious diseases (21.5%). The median age of the adult patients admitted to the ICU was 38.0 years (IQR 28.5–58.0 years) with an ICU mortality rate of 19.7%. Similarly, Schmollgruber's (2015) findings on the clinical profile of patients admitted to 4 ICUs in one academic hospital in Johannesburg showed that the mean age of the patients admitted to these ICUs was 48.2 years. The majority of the patient's admission was for surgical reasons, and more than half of the patients (59.7%) had a pre-existing co-morbid illness. The observed mortality rate for adult ICU admissions was also 20%. These profiles and figures show that death frequently occurs in South African ICU settings, and most of these deaths are preceded by a decision to withdraw LST (Seligman *et al*., 2020).

Currently, healthcare providers continue to struggle when it comes to EOL care and treatment withdrawal in the ICU, especially after the withdrawal of LST. Nurses' and family members' involvement in EOL care discussions and decisions, for instance, continues to be infrequent despite the definite views about the process and participation in care delivery (Jordan *et al*., 2017; Kisorio & Langley, 2016b; Langley *et al.,* 2014). Most nurses have also expressed differences in attitudes and beliefs regarding death and dying rituals (Langley *et al.*, 2014). They are frequently confronted with challenges associated with the withdrawal of treatment (Jordan *et al.,* 2017). There are inadequately established support systems and supportive strategies in place for nurses. Several research studies conducted in South Africa (Jordan *et al.,* 2017; Kisorio & Langley, 2016a) recommend robust interventions like those reported in the international literature. Amongst them are robust interventions capable of supporting the provision of quality EOL care, being sensitive to the diverse cultures, focusing on the disease profile, attending to the needs of patients and their families, and strengthening healthcare providers' capacity to deliver quality EOL care.

Various ICUs in most South African tertiary hospitals have developed protocols for the care of terminally ill patients in the ICU. The Health Professions Council of South Africa (HPCSA) has also published a document on guidelines for the withholding and withdrawal of treatment to assist healthcare professionals (HPCSA, 2016). Several initiatives have been undertaken to develop best practice guidelines to assist healthcare providers in providing EOL care in the adult ICU. These interventions provide an ethical framework for good practice for healthcare providers regarding EOL care and making decisions to withdraw or withhold LST. However, they do not attempt to address the desired quality of care provided to the patient and their families after the withdrawal of LST. They are not robust enough considering the cultural diversities and different beliefs around caring for the dying in the ICU. One important way to improve on the already existing care provided is to have the ability to assess the current quality of care. Currently, no instrument exists to measure the quality of care provided to patients at the end of life and their families after treatment is withdrawn in the adult ICU.

South Africa represents a pluralistic country with its unique patient and disease profiles and diversified religious beliefs and attitudes. The country's population presents with both first- and third-world health conditions (Brysiewicz & Bhengu, 2010; Langley *et al*., 2014). The number of patients admitted into the various ICUs is gradually increasing, owing to the

HIV/AIDS epidemic and the high prevalence of multiple trauma resulting from motor vehicle accidents and high levels of violence. This profile profoundly impacts intensive care usage, the need for EOL care, and decisions to withdraw LST. Likewise, physicians, nurses, and family members will have many challenges to deal with when it comes to EOL care and the withdrawal of treatment. A study focused on assessing and improving the quality of care after treatment withdrawal in the ICU in the South African context will be a starting point to influence change in EOL care practice. The quality of care can be measured, monitored, and improved. The development of an instrument to measure the quality of care after the withdrawal of LST in the adult ICU will be needed and essential to ensure a good death.

1.2 PROBLEM STATEMENT

The demand for quality EOL care in South African adult ICUs has increased over the past few years. This is due to the increasing numbers of ICU admissions and usage due to the HIV/AIDS epidemic, the high levels of multiple trauma resulting from motor vehicle accidents and gunshots, and the high levels of violence. It is also estimated that one in five patients succumbs to their illnesses following ICU admission. Most of the deaths are preceded by a decision to withdraw life-sustaining treatments. Due to these, healthcare providers and patients' family members have become mindful of the quality of care patients receive during EOL care and after the withdrawal of treatment. Unfortunately, the quality of care provided for patients and their families after the withdrawal of treatment has been plagued with inconsistencies, ethical dilemmas, and challenges. The focus has been on who, when, and how decisions on treatment withdrawal are made instead of the quality of care rendered to patients and their families after the withdrawal of treatment. The ICU team, including nurses and physicians, still struggles to deal with the care of critically ill and dying patients in the ICU. Family members are also not satisfied with the current quality of care they personally received and provided for their relatives in the ICU. There are persistent gaps and challenges in the provision of EOL care across diverse racial and cultural groups, especially the care given to patients after treatment is withdrawn. Several efforts to improve the quality of care have intensified over the years. However, there is a lack of a well-defined, reliable, and valid method for measuring the quality of EOL care patients received and rendered to them and their families after the withdrawal of LST in the adult ICU. No instrument currently exists within the South African context to measure the quality of care provided for patients and their families after the withdrawal of treatment.

Several validated instruments, however, are available across the globe to measure the quality of care at the end of life in the ICU. These instruments, however, have been developed for western countries with no consideration for the African context. Therefore, using these measuring instruments, especially in South Africa, where non-western cultures are prevalent, will be inappropriate, unrealistic, and liable to fail. Comprehensive quality measurement requires multiple perspectives, including those of nurses and doctors, the principal caregivers of EOL care in the ICU, and patients and family members. The development of a context-based instrument will help understand South African perspectives on the quality of care expected for patients and their families after the withdrawal of treatment.

1.3 RESEARCH QUESTION

How can the quality of care provided for patients and family members after withdrawal of life-sustaining treatment best be measured in the adult ICU?

1.4 PURPOSE OF THE STUDY

The study seeks to develop an instrument to measure the quality of care provided for patients and families after the withdrawal of LST in the adult intensive care unit.

1.5 OBJECTIVES OF THE STUDY

The research study addressed seven objectives in two phases as indicated below:

1.5.1 Phase One: Domain identification and Item Generation

- To identify and synthesise the perspectives of patients, family members and healthcare providers on providing quality care for patients at the end of life and their families through a scoping review.
- To explore the experiences of intensive care nurses providing care to patients and their families after treatment withdrawal.
- To explore physicians' experiences of making end-of-life decisions to withdraw treatment and providing care after treatment withdrawal in the intensive care unit.

- To explore the experiences of families who have been a relative of a patient with treatment withdrawn in the intensive care unit.

1.5.2 Phase Two: Instrument Development and validation

- To develop a provisional instrument through content analysis of the literature and qualitative studies from phase one.
- To assess the content validity of the instrument.
- To assess the face validity of the instrument.

1.6 SIGNIFICANCE OF THE STUDY

South Africa has a unique disease profile and many different cultures. Healthcare professionals working in intensive care units and patients' families also come from diverse cultural backgrounds with different views on caring for patients and their family members at the end of life. These groups have different perceptions and beliefs regarding death and dying and how to care for patients after treatment withdrawal. Healthcare professionals are expected to provide the best nursing, medical, and curative care and, at the same time, provide quality comfort care for dying patients and their families. They are also expected to provide care sensitive to the socio-cultural diversities among the population. The development of a context-based instrument will help understand the desired quality of care for patients and their families after the withdrawal of active treatment in the ICU. This instrument will also inform future educational interventions and measures tailored toward improving the provision of EOL care in the ICU. The development of the instrument will provide a measurement tool to monitor the quality of care against the agreed-upon standards. Areas for possible future research will also be highlighted and serve as a starting point to assist healthcare providers in providing care to dying patients based on their voices and tailoring interventions to assist them.

1.7 PARADIGMATIC ASSUMPTIONS OF THE STUDY

A paradigm, according to Polit and Beck (2017:11), is a worldview, thus a set of beliefs, values, and attitudes that guide and influence human actions, thoughts, and behaviors. It

encompasses a collection of philosophical assumptions and guides an individual's approach to inquiry. An assumption is a basic principle that is believed to be true without proof or evidence; as a result, it is true even though it has no scientific proof or verification (Polit & Beck, 2017:12). All research studies need to be grounded in and situated within a philosophical framework, paradigm, or set of assumptions, as this directs the researcher's thoughts, provides the study with a logical and deliberate structure, and enhances the study's quality. The meta-theoretical, theoretical, and methodological assumptions, which are covered in the sections below, are among the paradigmatic assumptions of this study.

1.7.1 Meta-theoretical Assumptions

Meta-theoretical assumptions, also known as meta-paradigms, are statements or groups of statements not intended to be tested but to spell out the phenomena of interest in a most global manner. They are assumptions behind theoretical, empirical, and practical work. In the field of nursing science, meta-paradigms are the philosophical views that underpin nursing practice, inform the nursing profession, and are essential when providing patient care (Branch *et al*., 2016; Nikfarid *et al*., 2018). Four main nursing meta-paradigms have been developed and are fundamental to nursing theories. Almost all the nursing theorists built their theories and models on these four meta-theoretical assumptions. Fawcett (1984) and later in 1999 developed the four nursing meta-paradigms, which include person, environment, health, and nursing (Fawcett, 1984; Fawcett, 1999). These nursing meta-paradigms provide the basis for nursing practice, how nurses think and play a key role in the nursing process. These four main philosophical meta-paradigms in nursing were applied in the study as follows.

1.7.1.1 Person

The meta-paradigm "person", also referred to as "client" or "human beings" in the philosophy of nursing, is described as the recipient of care. In nursing practice, the recipient of care encompasses the individual, the individual's culture, spirituality, and his or her families and friends (Branch *et al*., 2016). Henderson identifies the "person" meta-paradigm as an individual that has basic health needs and requires assistance in order to achieve health and independence or a peaceful death (Ganzalo, 2023). In the context of the ICU, "person" encompasses the critically ill and dying patients and their families. The critically ill and

dying patients have an equal right to holistic intensive care regardless of their chronic, life-threatening illness or imminent death. They need to enjoy a peaceful and dignified death free from suffering and pain. Likewise, patients' families need to be supported physically, emotionally, and spiritually. Both patients and families are seen as a unit of care; therefore, in the event of the cessation of life-sustaining interventions and the transition to end-of-life care, they should be offered the best of care.

1.7.1.2 Environment

The environment refers to a "place" or "community" where care is given (Fawcett, 1999). It comprises the internal and external surroundings that affect the individual receiving care. Florence Nightingale divides the environment meta-paradigm into internal and external environments in her environmental theory (Nursing Theory, 2023). Maintaining a balance between these two environments is essential for the restoration of patients' health. According to Nightingale, external factors associated with a patient's surroundings affect his biologic and physiologic processes and development. Environmental factors such as ventilation, temperature, water, bed and bedding, light, nutrition, and noise level affect the well-being of the individual. A noise-free and warm environment that attends to the needs of the patient has a great effect on him or her. In this case, the environment encompasses the ICU and patient bedside, where patients are admitted, receive intensive care, and their families are permitted to visit. For the critically ill and patients nearing the end of their lives, it is imperative to create a serene and conducive environment to support the transition to EOL, accommodate patients' families' presence, and promote privacy. Healthcare providers need to create enough space within the environment to accommodate patients' families following the transition from curative care to EOL care. A noise-free environment where alarms from monitors and other equipment are minimized supports the care of dying patients and their families. In such an environment, adequate special rooms are created to nurse the dying patient, with plenty of chairs for family members.

1.7.1.3 Health

The metaparadigm "health" refers to the quality and degree of wellness or well-being of an individual or patient (Branch *et al*., 2016). This includes patients' access to healthcare. In the context of intensive care, the broad goal is to ensure that patients survive and return to

an acceptable functional state without any further physiologic deterioration (Marshall *et al*., 2017). In most cases, death is inevitable despite the array of technologies that support the heart, lungs, and kidneys. Most of these deaths in the ICU are preceded by the withdrawal of LST. Based on the peaceful end-of-life theory, Ruland and Moore (1998) emphasize that the dying patient deserves frequent access to peaceful end-of-life care that promotes comfort and a dignified death. The patient needs to enjoy a pain-free death, enjoy family closeness, and experience dignity and respect. Watson (2009) also explains health as unity and harmony within the mind, body, and soul and further indicates that total health goes beyond curative factors but encompasses caring, or carative factors. Apart from physical and physiological well-being, the mental and spiritual health and wellness of a person are also important.

Based on these theories, the researcher argues that patient care in the ICU goes beyond just curative care and includes mental and spiritual wellness. In instances where curative care is physiologically futile and inappropriate and withdrawal of treatment is inevitable, the patient deserves peaceful EOL care. It is prudent for healthcare providers, including doctors and nurses in the ICU, to manage common symptoms such as pain, agitation, and anxiety associated with death and dying. This promotes comfort and ensures a peaceful death. The nature of care should also focus on the emotional and spiritual well-being of the patient.

1.7.1.4 Nursing

Virginia Henderson defines the paradigm "nursing" as "the unique function of a nurse to assist the individual sick or well in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge, and to do this in such a way to help him gain independence as rapidly as possible" (Ganzalo, 2023). In her nursing need theory, she emphasizes patients' basic needs and how nurses can assist in meeting those needs. In the context of intensive care and the care for patients after the withdrawal of LST in the ICU, the focus of the healthcare team is to ensure a peaceful death. The quality of care provided for patients after the withdrawal of LST is achieved by adopting a multidisciplinary approach where patients' families and/or patients and the healthcare team work together to meet the basic needs of patients nearing the end of their lives. The major basic needs of the critically ill and dying patients, as summarized in Henderson's Need Theory, include: physical needs (bathing, grooming, and clothing); physiological needs (elimination, breathing, and eating); emotional

needs (expression of opinions and fears); a need for information (open communication); spiritual needs (worship according to one's faith); and safety needs (avoiding dangers in the environment). These needs are essential in the care of critically ill and dying patients, especially in the ICU. It is important for the ICU team to plan care activities that take these needs into consideration. An aspect of achieving quality care for patients and their families after the withdrawal of LST centers on meeting these basic needs.

The peaceful end-of-life theory, as developed by Ruland and Moore (1998), explicitly states that nursing care is crucial for creating a peaceful EOL experience. The goal of EOL care is to make judicious use of technology and comfort measures to improve quality of life and achieve a peaceful death (Ruland & Moore, 1998). It also encompasses the monitoring and administration of pain relief, promoting comfort through pharmacological and non-pharmacological interventions, providing emotional support, facilitating the participation of families in patient care, and promoting death with dignity and respect.

1.7.2 Theoretical Assumptions

Theoretical assumptions are inclusive of theories, models, and concepts used as a point of departure in the study.

The theoretical assumptions for the study are selected from the Comfort Theory developed by Katherine Kolcaba in 1990 and published in 1994. The emphasis of this middle-range theory is that comfort is the product of holistic nursing and an immediate desirable outcome of nursing care (Kolcaba, 1994). Kolcaba (1991) defined comfort as satisfying basic human needs. The theory best fitted the study because EOL care encompasses this fundamental need for comfort. Thus, following the transition from curative care to EOL care and the withdrawal of LST, the fundamental need for both dying patients and their families is comfort. The primary goal for the dying patient is comfort, which can be an outcome for the family if the patient is unable to express their needs. The care the nurses provide to the dying patient should be based on the identified needs, and the care should be holistic with outcomes that can be measured and that are nurse drivers (Kolcaba 1994).

According to the theory, comfort exists in three forms: relief, ease, and transcendence. Relief is the experience of having a specific comfort need met. Thus, if the specific comfort needs

of a patient are met, the patient experiences comfort in the sense of relief. Ease is the experience of care that promotes calm and/or contentment (Kolcaba, 1991). Transcendence is described as a state of comfort in which patients are able to rise above their challenges or pain. Patient comfort, which exists in three forms (relief, ease, and transcendence), occurs and can be met in four different contexts of human experience. These contexts are physical, psychospiritual, environmental, and sociocultural. The physical context pertains to bodily sensations and functions. The psychospiritual context also refers to internal awareness of self, which includes self-concept, life meaning, and relationship to a higher power. Sociocultural context includes one's social (e.g., family and friends), interpersonal, and cultural relationships. Environmental context pertains to the external world, like nature, or any aspect of the patient's, family's, or institution's surroundings that can be manipulated in order to enhance comfort (e.g., noise, light, temperature, and colour) (Kolcaba, 1991; Kolcaba, 1994).

In ensuring a peaceful death, comfort is essential, as the dying person requires psychic strength for acceptance and release (Kolcaba, 1994). Clear communication addressing expectations and comfort helps improve the dying experience at the end of life (Ranse *et al*., 2012; Taylor *et al*., 2020). When the nurse has clear communication, this will help meet the patient's physical, psychosocial, environmental, and social needs. Physical needs are related to the symptoms of illness and sensations during the dying phase. The psychosocial component is what is going on inside the patient and their awareness. A pleasant environment, which includes a quiet room, dim lights, and a comfortable temperature, is also needed (Taylor *et al*., 2020). The social needs of the patient are to have the family present with supportive relationships (Stokes *et al*., 2019). Through an understanding of Kolcaba's theory of comfort, nurses can provide EOL care to meet the multiple needs of the dying patient. Kolcaba's theory of comfort provided the framework necessary to guide this project, promoting staff knowledge and confidence in providing symptom management for the dying patient. When nurses can recognize and treat end-of-life symptoms, they are providing comfort to both the patient and the family (Efstathiou & Walker, 2014).

1.8 THEORETICAL AND CONCEPTUAL DEFINITIONS

The definitions below indicate how the following terms are used in the context of the study.

- **End-of-life care**

End-of-life care encompasses the total and supportive care healthcare providers' offer to dying patients and their families when curative therapy becomes physiologically inappropriate, typically in the last few weeks or months before death; with emphasis on relieving suffering, promoting comfort, and ensuring a dignified death (Badir *et al*., 2016; Mistry *et al*., 2015). For this study, end-of-life care includes the care and support rendered to the patients who are at risk of dying and are near the end of life, and their families.

- **Life-sustaining treatment (LST)**

Life-sustaining treatment, also known as life-sustaining therapy encompasses all treatments, procedures and healthcare interventions that have the potential to increase patient's life span or postpone the patient's death and sustain life without necessarily reversing the underlining condition. This includes mechanical ventilation, vasoactive agents, dialysis, IV fluids, nutrition, blood or bold replacement products, anti-arrhythmic or any other supportive therapy (Lesieur *et al*., 2015)

- **Withdrawal of life-sustaining treatment (WLST)**

This refers to the termination of all life-sustaining therapies given to dying and critically ill patients as it will not benefit the patient and prevent death (Sprung *et al*., 2014). In this study, withdrawal of life-sustaining treatment will be termination of all treatments that have the potential to postpone the patient's death, however, will not prevent death. Treatments such as mechanical ventilation, vasopressors and specialised treatment for particular conditions such as dialysis.

- **Intensive care unit (ICU)**

Intensive care unit is a special area within the hospital setting staffed with specifically trained healthcare providers and offers specialised and intensive nursing and medical care services to critically ill patients who are seriously injured or ill and demand continuous monitoring and interventions (Marshall *et al*., 2017).

- **Critical / Intensive Care nurse**

This refers to a specially trained nurse working in the ICU who provides care to critically ill patients. They have undergone additional specialised nursing education and training in intensive care nursing and are registered with a recognised Nursing Professional Council.

- **Quality of care**

Quality of care, according to the Institute of Medicine, (IOM 1999:1) refers to *"the degree to which health services for individuals and population increase the likelihood of desired health outcomes and are consistent with current professional knowledge".* For this study, Quality of care refers to the array of services that affect the health of individuals or populations intended for the care, has the potential to provide more benefit than harm and provide care that responds to the individual needs, values and preferences. In the care of the critically ill and dying patient and their families in the ICU, quality of care encompasses services that affects their health, and has the potential to promote meaningful EOL care and support the family members.

- **Family**

For the purposes of this study, the term family refers to persons plays significant role in the life of the patient. This may any person that relate legally or biologically to the person and this includes spouse, parents, friends, next of Kin and significant others. The term is used interchangeably with and synonymous to "family member"

- **Instrument**

Instrument refers to any form of measure that includes scales, tools, questionnaires and surveys used to measure a construct and collect data on a research area of interest.

1.9 OVERVIEW OF THE RESEARCH METHODOLOGY

A research methodology refers to the overall strategy that involves a collection of research methods used by the researcher to systematically address a research problem scientifically and logically (Polit & Beck, 2017:730). This study, an intervention study, was conducted using a mixed-methods research approach. The researcher used this research design to develop an instrument to measure the quality of care provided for patients and their families after the withdrawal of treatment in the adult ICU.

Mixed-methods research is a type of research design that involves the use of more than one research approach or method of design, data collection, or data analysis within a single study, with the integration of the different approaches or methods occurring during the study and not just as its concluding point (Johnson, Onwuegbuzie, & Turner 2007). An exploratory sequential mixed method research design guided the researcher to develop the instrument (intervention). The mixed-method methodology has been well-described as an intuitive and practical way to understand and solve complex research problems by drawing on the individual strengths of both the traditional qualitative and quantitative methodologies. One of the rationales for using a mixed methodology in instrument development is that qualitative inquiry strengthens the development of quantitative instruments (Onwuegbuzie, Bustamante, & Nelson, 2010). This further enhances the description and understanding of the construct and assures instrument fidelity (Johnson, Onwuegbuzie, & Turner, 2007). A sequential mixed methods design is typically used to develop quantitative instruments, whereby data is collected in the first phase to inform subsequent phases (Ostlund *et al*., 2011).

The study was organized into two phases: domain identification and item generation, and instrument development and validation. The two-phase exploratory sequential mixed methods were structured under the five-step instrument development process as outlined by Lynn (1986) and Zamanzadeh *et al*. (2015) and addressed six objectives. T**able 1.1** presents the summary of the phases, steps, and research methods as applied in the study.

Table 1.1: Summary of the research methods applied in this study

Phase		Objective (s)	Research design	Sample/Sampling	Data collection	Data analysis
Phase One: Domain identification and item generation	**Step 1**: to determine the content domain of the construct that the instrument intends to measure and sample items from the literature	**Objective 1**- To identify and synthesise the perspectives of patients, family members and healthcare providers on providing quality care for patients at the end of life and their families	Scoping review using the Joanna Briggs guidelines (Peters *et al*., 2020) and reported according to the PRISMA-ScR checklist (Tricco *et al*., 2018)	Peer-reviewed published between 1999 – 2020 Limits: English, Empirical and theoretical literature	A literature search from databases: SCOPUS, PubMed, CINAHL, MEDLINE and SCIENCE DIRECT	Braun and Clarke Thematic analysis approach
	Step 2: To sample and generate items from qualitative interviews	**Objective 2**- To explore and describe the experiences of intensive care nurses providing care to patients and their families after treatment withdrawal	Qualitative exploratory descriptive design	Purposive sampling - (n=16) nurses	Individual in-depth interview	Braun and Clarke (2006) Thematic analysis approach and MAXQDA Plus 2020 software
		Objective 3- To explore physicians' experiences of making end-of-life decisions to withdraw treatment and providing care after treatment withdrawal in the intensive care unit	Qualitative exploratory design	Purposive sampling (sample size: saturation)	Semi-structured interview	Braun and Clarke (2006) Thematic analysis approach and MAXQDA Plus 2020 software
		Objective 4 -To explore the experiences of families who have been a relative of a patient with treatment withdrawn in the intensive care unit	Qualitative exploratory design	Purposive sampling (n=7) bereaved family members	Semi-structured interview	Braun and Clarke (2006) Thematic analysis approach and MAXQDA Plus 2020 software

Phase two: Instrument Development and Validation Phase	**Step 3:** To assimilate the domains and items into a useable form	***Objective 5***: To develop a tentative instrument	Integration, synthesis and triangulation of the Content analysis of the scoping review and qualitative interviews	Potential items generated from content analysis of the scoping review and qualitative studies	Item pooling from the analysis from phase 1	Content analysis (inductive and deductive coding)
	Step 4: To quantify the content validity of the instrument (content validity of the items through a Delphi study)	***Objective 6***: To determine the content validity of the tentative instrument through expert analysis	Methodological research design Expert analysis (Two-round Delphi Survey)	Purposively selected 9 experts (Expert group)	Delphi technique approach using a 4-point scale to assess relevance and clarity	Content Validity Index (I-CVI) for each item and the instrument. Determine the comprehensive of the instrument
	Step 5*:* Determine the face validity of the instrument	***Objective 7***: To determine the face validity of the tentative instrument	Methodological research design Expert analysis (Two-round Delphi Survey)	Purposively selected 9 experts (Expert group)	Delphi technique approach using a 4-point scale to assess relevance and clarity	Assess the clarity and wording of items and the instrument

1.10 RESEARCH SETTING

The study was conducted in a specialized unit in one of the tertiary academic hospitals. The academic hospital is situated in Johannesburg, Gauteng Province, South Africa. The Gauteng Province is the smallest, but fastest-growing, province out of the nine provinces. It is bordered by the provinces of Mpumalanga on the east, North West on the west, Limpopo on the north, and Free State on the south. The provincial capital, Johannesburg, is considered the country's financial and industrial metropolis. The city of Johannesburg has 3/4 of its population black, 1/5 white, and the rest are colored, Asian, and Indian.

The study was conducted in the ICUs of an academic Hospital in Johannesburg. The hospital is classified as a level 4, central, and specialized hospital according to the levels of the healthcare system in South Africa. It is located in Parktown, a city in the Johannesburg Metropolitan Municipality. It has approximately 1088 beds and over 4000 staff members. The hospital consists of highly specialized referral units and departments that provide specialized services to the province and neighboring provinces (Parliament Research Unit, 2022). The study setting is also one of the teaching facilities for the Faculty of Health Sciences at a number of universities in the province. The hospital offers a full range of quaternary, tertiary, secondary, and highly specialized services. Additionally, the facility serves as a referral hospital for several lower-level health care facilities in the province and beyond.

The hospital has over six ICUs with over 100 beds, namely, multidisciplinary, trauma, coronary, cardiothoracic, and neurological ICUs. There is also a private ICU attached. All these ICUs are managed by well-trained and qualified staff and provide a wide range of intensive care services to critically ill patients.

1.11 ORGANISATION OF THE THESIS

The theses is organised into nine chapters.

- Chapter One: Orientation to the study
- Chapter Two: Literature review and conceptual framework
- Chapter Three: Research methodology

- Chapter Four: Phase One- Domain Identification and item generation: Scoping Review
- Chapter Five: Phase One: Domain Identification and item generation: Results of qualitative studies
- Chapter Six: Phase two: Instrument development and validation – Instrument Development
- Chapter Seven: Phase two: Instrument development and validation – Instrument validation
- Chapter Eight: Discussions of study findings
- Chapter Nine: Justification, strengths, limitations, recommendations and conclusion of the study

1.12 SUMMARY

In Chapter One, the reader was introduced to the study, which included an overview of the background to the study, the problem statement, the research question, the aim of the study, and the objectives of the study. The chapter also presented the justification for the significance of the study, theoretical and conceptual definitions of terms used in the study, and an overview of the research methods used to achieve the study's aim and objectives. The chapter ends with the outline of the study as organized according to the chapters. Chapter Two presents the literature review for the study and the study conceptual framework.

CHAPTER TWO
LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

2.1 INTRODUCTION

The chapter presents a review of existing literature to help the reader understand EOL care and withdrawal of treatment in the ICU. The chapter begins with a brief history and overview of critical care, followed by a discussion of EOL care in the ICU and the withdrawal of life-sustaining treatment in the ICU. The chapter also presents information on the quality of care, measuring the quality of care, and instruments for measuring quality care at the EOL. The chapter also presents a description of the Comfort Theory as the framework for this study.

2.2 A BRIEF HISTORY AND OVERVIEW OF CRITICAL CARE

Intensive care, also known as critical care, refers to "a multidisciplinary and inter-professional speciality dedicated to the comprehensive management of patients having, or at risk of developing, acute, life-threatening organ dysfunction" (Marshall *et al*., 2017:272). It is a clinical specialty and a system of care that uses a variety of technologies to support failing organ systems like the cardiovascular system, kidneys, and lungs. The skilled inter-professional team delivering the care includes nurses, physicians, physiotherapists, and many others, using an array of technologies that provide support to organ systems such as the lungs that are failing. The ultimate goal is to treat the underlying disease while preventing further physiologic deterioration (Marshall *et al*., 2017). The provision of intensive care to critically ill patients take place in a defined geographic area within the hospital setting known as the intensive care unit (ICU).

Florence Nightingale is frequently credited with founding the intensive care unit (ICU) that exists today (Weil & Tang, 2011). She and a group of nurses established a location within a military field hospital during the Crimean War in the 1850s to closely monitor and provide more intensive nursing care for the most seriously injured soldiers. This development is regarded as the start of intensive care. In the late 19th and early 20th centuries, their actions led to an early understanding of the significance of a separate geographic area for the management of critically ill patients. A few decades later, Dr. Walter Dandy opened a

neurosurgical postoperative care unit at Johns Hopkins in Baltimore to treat critically ill postoperative neurosurgical patients, setting the precedent for postoperative recovery. These seriously ill patients were frequently being treated by professional nurses on call, who were overseen by neurosurgeons (Weil & Tang, 2011). In the surgical ward at the University of Tubingen in Germany, another postoperative recovery and intensive care ward was created in 1930, furthering the idea of specialized sites for the care of the critically ill (Vincent, 2013).

The model of intensive care for creating postoperative and postanesthesia sites was continued even during the Second World War, when specialized shock units were also established to provide efficient resuscitation for large numbers of severely injured soldiers. The primary emphasis was on providing lifesaving interventions based on vital signs, primarily by specially trained nurses (Weil & Tang, 2011). Additionally, respiratory units for patients who required mechanical ventilation were established as a result of the polio epidemics in the 1950s, notably in Copenhagen. With time, more sophisticated respiratory and hemodynamic monitoring methods were also introduced. These included quantitative measurements of circulation, metabolism, and ventilation (Ristagno & Weil, 2009).

The modern ICU evolved in the late 1950s. Training and recruitment of nursing and medical expertise followed to increase the capabilities of these professionals after the introduction of monitors and life-support interventions (Ristagno & Weil, 2009). Following these actions and increasing awareness of critical care, several units, such as shock wards and multidisciplinary ICUs, were opened across the USA and in Toronto in the late 1950s as special areas within the hospital to provide continuous monitoring for critically ill patients using medical technologies for organ support. In the 1960s, other surgical units followed these examples, such that almost all hospitals had a recovery unit attached to their operating rooms (Vincent, 2013). Over the next two decades, the ICU became an essential element of hospital-based health care, and intensive care emerged as a distinct medical subspecialty. Intensive care units began to be created in hospitals across Europe, the USA, Australia, and China (Vincent et al., 2010).

In the 1970s and early 1980s, the use of intensive care units (ICUs) increased dramatically in developed countries. Most of the established ICUs have since made major advances in medical resources, technology, and the management of critically ill patients (Ristagno &

Weil, 2009). In South Africa, Critical care medicine evolved gradually over the years. The development of critical care as a specialty began in the late 1960s and early 1970s (Mathivha, 2002). It was initiated by individuals with a background in anesthesiology who were passionate about the field. Beginning in the 1980s, a more formal strategy was adopted. The Critical Care Society of South Africa marked the beginning of this movement. This organization consisted of medical and nursing care professionals. The society was instrumental in establishing the World Federation of Societies of Intensive and Critical Care Medicine and establishing guidelines for the development of ICUs for the treatment of critically ill patients (Mathivha, 2002).

With the advancement of technology, more sophisticated life-support and invasive techniques became available over time. The present ICU is quite different compared to that of several decades ago in terms of physical space, support and monitoring technology, human resources, critical care services provided, and research, education, and quality improvement (Marshall *et al*., 2017). High-tech machines such as mechanical ventilators are now mobile, user-friendly, and smaller. Oxygen administration, blood transfusion, fluid administration, and the use of vasopressors are widely used and often supported by sound clinical evidence. The ICU team now consists of specially trained and qualified nurses, physicians, respiratory therapists, physiotherapists, dieticians, pharmacists, etc. There are multidisciplinary rounds on a daily basis and as and when needed based on patient acuity and complexity (Marshall *et al*., 2017).

2.3 END-OF-LIFE CARE IN THE INTENSIVE CARE UNIT

The intensive care discipline has evolved and broadened over the years. There is now a dedicated space to provide care to critically ill patients with organ dysfunction for an extended period by a skilled team of healthcare providers. Additionally, the intensive care setting has also seen tremendous improvement in terms of physical space, support and monitoring technology, human resources, critical care services provided, research, education, and quality improvement (Marshall *et al*., 2017). The ICU has also been classified into levels based on skilled personnel availability, specialists, patient monitoring capacity, organ support resources, and physical space. These changes have increased patients survival chances and their quick return to an acceptable functional state following ICU admission (Myburgh *et al*., 2016).

Even though the ICU has gotten better over the years in terms of technology, some patients still die there from their illnesses. The reported mortality rates in the ICU are still high, ranging from 9% to 61% (Endeshaw *et al*., 2022; Vincent *et al*., 2009), depending on the region and its ICU resources. In Africa, studies conducted in Kenya, Nigeria, and South Africa reported an ICU mortality rate of 53.6% (Lalani *et al*., 2018), 34.6% (Onyekwulu & Anya, 2015), and 19.7% (De Vasconcellos *et al*., 2017), respectively. A recent systematic review conducted by Endeshaw et al. (2022) also reported a high mortality rate in the adult ICUs in Ethiopia. Elsewhere across Europe, Capuzzo et al. (2014), in a multicenter cohort study, also found a 19.1% mortality rate in the ICU. Also according to United States of America Critical Care Statistics, the mortality rates in the adult ICU range from 10% to 29% (Society of Critical Care Medicine, 2023). These figures demonstrate that the high rate of ICU mortality is a major public health issue worldwide and that patients, especially at the end of life, and their families require extra attention.

Death and discussion about EOL care have become common in our recent ICU setting. Yet these conversations are often difficult to initiate due to the ICU's life-saving ethos and orientation. Hence, acknowledging that death is approaching may be difficult in the ICU. Nevertheless, various critical societies and communities have realized that not all patients will survive despite intensive care. End-of-life (EOL) care refers to the care given to a critically ill patient within the period when death is inevitable (Razmaria, 2016). This type of care shifts the focus of care from treatments aimed to cure or prolong life to comfort, symptom management, dignity, and reducing suffering for patients (Stokes *et al*., 2019; Taylor *et al*., 2020) and supporting their family members (Wiegand, 2016). End-of-life care encompasses withholding life-sustaining treatment, the withdrawal of LST, and a do not resuscitate (DNR) order, all of which are performed after consultations and discussions with the ICU team and agreement from the patient (if able) and family members (Divatia, 2020).

The section below discusses the withdrawal of life-sustaining treatment:

2.3.1 Withdrawal of life-sustaining Treatment in the Intensive Care Unit

Withdrawal of life-sustaining treatment is defined as “a decision to actively stop a life-sustaining intervention being given” (Sprung *et al.*, 2014:860). Decisions made on treatment withdrawal are described as an individualized approach and are made bearing in mind

patients' particular circumstances in the ICU (Cook & Rocker, 2014). However, the reasons behind treatment withdrawal fall into three broad categories (Halevy *et al*., 1996, cited in Braganza, Glossop, & Vora, 2017). First, it is based on the imminent death of the patient. Thus, patients who continue to deteriorate despite the most aggressive therapy, regardless of whether treatment is continued or stopped, are likely to die. The other reason is treatment withdrawal made on the presumed basis of an overwhelmingly poor neurological or functional outcome resulting in a continuing coma or severe neurological or functional disability, such as post-hypoxic brain injury. The last reason behind treatment withdrawal is based on lethal conditions: patients with coexisting severe systemic disease that makes prolonged survival after critical illness unlikely, such as metastatic malignancy (Halevy *et al*., 1996).

The decision to withdraw treatment and the overall EOL decision-making process are multidisciplinary in nature. Thus, all stakeholders involved in patient care discuss the plan of care and the decision to be taken (Flannery *et al*., 2016; Joynt *et al*., 2015). In most cases, the ICU consultant initiates the EOL discussions and is the decision-maker (Flannery *et al*., 2020). Following a multidisciplinary consensus, LST such as feeding, intravenous fluids, oxygenation, vasopressors, and mechanical ventilation are withdrawn in a gradual process and in no particular order. Mostly, mechanical ventilation is the last aggressive therapy discontinued (Cooke *et al*., 2010). According to Guidet *et al*. (2018) and Quill *et al*. (2014), factors such as the clinical frailty score, the admission SOFA score, the poor baseline functional status of the patient, and their higher age guide the withdrawal of LST. Once all curative interventions are discontinued in the process, the emphasis becomes centered on promoting comfort and ensuring a dignified death (Stokes *et al*., 2019; Vanderspank-Wright *et al*., 2018).

Most deaths in the ICU are preceded by a decision to discontinue already receiving treatment. It is estimated that over 80% of deaths that occur in the ICU are preceded by a decision to withdraw life-sustaining treatments (Sprung *et al*., 2019). This figure makes the withdrawal of treatment a common event in the ICU but an area that is subjected to inconsistencies and ethical issues owing to the ongoing and great variability between individual physicians, cultures, and geographical areas (Avidan *et al*., 2021; Mark *et al*., 2015). Inconsistent practices have been noted with regard to decisions to withdraw treatment. There are also differences in judgments about the appropriate level of care for

critically ill patients and diversity in the process of withdrawal, as well as in who is charged with withdrawing treatment (Benbenishty *et al*., 2022; Flannery *et al*., 2020).

Mark *et al*. (2015) reported that the mean prevalence of withdrawal of LST for adult patients who died in the adult ICU varied between 0% and 84%. In France, Lesieur *et al*. (2015) found that out of the total number of deaths that were recorded across the 43 ICUs following a decision to limit LST, 71% of the deaths occurred after treatment withdrawal. Guidet *et al*. (2018), also in Germany, found that among the older patients that died in the ICU, 12.2% of the total deaths were preceded by a decision to withdraw treatment. Quanes *et al*. (2012) found that 8.9% of ICU deaths in Tunisia occurred after withdrawal of LST in their prospective cohort study on the patterns of EOL decisions in two ICUs. Similar results were reported in the United Kingdom (UK), where Wunsch *et al*. (2005) revealed that the decision to discontinue all active treatment was responsible for 31.8% of all hospital deaths.

Azoulay *et al*. (2009) also reported the prevalence and characteristics of decisions to forego LST in 282 ICUs across Europe, Australia, America, and some Mediterranean nations. Hospital mortality was 3,050 out of 14,488 patients, or 21%, according to the reviewed data. A total of 1,105 (36.2%) of the deaths occurred as a result of decisions to forgo LSTs. A decision to withdraw LSTs was made prior to seventeen percent (17%) of the total deaths. These variations in the decision to forego LST are attributed by Sprung, Rusinova, and Ranzani (2015) and Mark *et al*. (2015) to cultural and religious differences, geographic location, institutional policies, legal considerations, specific patients' reasons for stopping treatment, and the attitudes of healthcare professionals. Literature (Avidan *et al*., 2021; Myburgh *et al*., 2016) asserts that these distinctions and variations also support the distinctiveness of various cultures, societies, and religious beliefs and preferences. These provide additional evidence in support of the claim that no single statement, guideline, policy, or instrument can be viewed as a universal standard that applies to all countries and societies.

2.4 CARE OF PATIENTS AND THEIR FAMILIES DURING END-OF-LIFE CARE AND AFTER TREATMENT WITHDRAWAL

In the ICU setting, the time to death after the withdrawal of LST is considerably short, however, and varies. Cooke *et al*. (2010) found that most patients die within 24 hours after

the withdrawal of treatment. In the UK, Wunsch *et al*. (2005) also reported that a quarter of patients survived longer than 7 hours, and only 8% of the patients who had treatment withdrawn survived longer than 24 hours. Lesieur et al. (2015) also reported that the majority of deaths that occurred after withdrawal of LST occurred between 0 and 3 days, a median time of 24 hours in French ICUs. In South Africa, the median time reported was also 11.4 hours (Turner *et al*., 1996, cited in Mark *et al*., 2015).

Due to the short time between stopping LST and dying in the ICU (Cooke *et al*., 2010), providing the best care is important for the dying patient, their family, and even the ICU team. The average time of 24 hours affects how well patients, and their families are cared for in the ICU. Concerns have been raised about the care that dying patients and their families get during EOL care and after treatment is stopped. In the ICU, there are challenges and barriers that make it difficult to give both patients and their families' good EOL care.

2.4.1 Barriers and Challenges during End-of-life Care and Treatment Withdrawal in the Intensive Care Unit

The section below discusses the challenges the hamper the provision of quality care during EOL care and treatment withdrawal in the ICU.

2.4.1.1 Inadequate interdisciplinary communication and involvement

In an ideal situation, decisions and discussions surrounding treatment withdrawal, transition to EOL care, and a plan of care should be made by a multidisciplinary team with the involvement of appropriate specialties, including nurses (Flannery *et al*., 2016; Joynt *et al*., 2015). Unfortunately, the extent of interdisciplinary communication and involvement is suboptimal in the ICU. Beckstrand *et al*. (2021) highlighted that EOL care in the ICU was ineffective when doctors failed to communicate among the other disciplines. The authors also explained that poor communication between attending physicians delayed EOL discussions across the ICU team, leading to late interventions. The inadequate physician communication among the ICU team was considered the largest obstacle to providing end-of-life care in the ICU. Another review conducted by Flannery *et al.* (2016) also attested to the finding that communication problems in end-of-life decisions were one of the most

significant challenges both nurses and physicians encountered during the end-of-life decision-making process.

A recent study by Flannery *et al*. (2020) also found that only doctors made decisions about care at the end of life. Even though nurses and other health care professionals play important roles in figuring out when treatments are no longer effective, only the patient's attending physician is responsible for the patient's treatment and end-of-life (EOL) decisions (Calvin et al., 2009; Jensen *et al*., 2013). Benbenishty *et al*. (2022) revealed that in some European countries, nurses' involvement in EOL care discussions is increasing. Elsewhere in South Africa, this is rare. Langley *et al*. (2014) reported that nurses' involvement in EOL care decisions and discussions is uncommon. Efforts tailored at improving interdisciplinary communication and involvement not only improve patient care and family satisfaction with EOL care; they also create a conducive working environment.

2.4.1.2 Inadequate end-of-life care education and training

It is apparent in the literature that most healthcare providers, especially the newer and less experienced ones, are uncomfortable talking about death and giving end-of-life care after stopping treatment. This is a result of the lack of adequate EOL training and education (Attia *et al*., 2013; Brooks *et al*., 2017; Ivany & Aitken, 2019). In Australia, Brooks *et al*. (2017) pointed out that nurses and doctors have few chances to learn about end-of-life (EOL) communication and care, especially during their medical training. It is important to have basic education and training on EOL care to give the best end-of-life care in the ICU. Hall (2020) further reiterates the inadequacies in EOL care preparation for critical care nurses. According to the author, adequate knowledge gained through education, personal and professional experiences, and support resources is imperative in the provision of quality EOL care in the ICU.

In Poland, Ozga *et al*. (2020) also revealed that hospital managers rarely support nurses when it comes to EOL care in the ICUs. There are also no institutional support systems set up to help this group of health care workers. Kirchhoff and Kowalkowski (2010) agree that nurses do not get enough formal training to prepare them for end-of-life care. The absence of formal training and education meant that most healthcare providers providing EOL care rely on their previous experiences to inform their care. This also implies that they learn on the job

instead of through formal education and training. Wiegand *et al*. (2019) also shared similar findings that most healthcare providers learn how to deal with the treatment withdrawal process through daily exposure and experiences instead of formal EOL care training and education.

2.4.1.3 The nature of the intensive care environment

Several studies (Almansour *et al*., 2019; Attia *et al*., 2013; Brooks *et al*., 2017; Ivany & Aitkens, 2019) describe the ICU environment as an unfavorable place to provide EOL care for patients and their families. This finding is due to the crowded conditions in the ICU, the noise levels from monitors and various emergencies, the multi-bed system, and the ICU workload. Ivany and Aitkens (2019) highlighted that the ICU design lacks private space to support both patients and their families during EOL care. The ICU design and space do not always allow family members to be physically close to their loved ones during the dying phase. Similarly, Brooks *et al*. (2017) also reported the lack of privacy to be a major barrier when initiating and delivering EOL in the ICU. The open-space type of ICU makes it difficult to discuss sensitive EOL issues due to the close proximity of other patients and their family members. The lack of private rooms, especially for patients at the end of their lives and their families, makes it difficult to provide a dignified death (Griffiths, 2019). Patients' family members are also unable to get the privacy needed to go through the grieving process (Almansour *et al*., 2019).

The majority of ICUs have a multi-bed system where more than one patient is nursed in one open ICU space. This layout further compromises patients and their families' privacy at the EOL (Fridh *et al*., 2009; Holms *et al*., 2014). Ozga *et al*. (2020) also reiterated in their qualitative study that the intensive care settings offer limited private rooms and waiting space for patients and their families during EOL care in the ICU. The absence of single rooms for patients and their families during the EOL care phase implies that quality EOL care will always be compromised. The atmosphere of the ICU and its waiting rooms profoundly affects family members' satisfaction with EOL care in the ICU (DeSanto-Madeya & Safizadeh, 2017).

The noise from monitors, ventilators, and medical emergencies is also said to be a problem when it comes to giving good end-of-life care. Brooks *et al*. (2017) reported that the noise

level in the ICU is a major environmental barrier to end-of-life care in the ICU. In an ideal situation, a serene and noise-free ICU environment would promote comfort, facilitate spiritual meditation, and foster connectedness to the spiritual being. Also, in Egypt, Attia *et al*. (2013) also pointed out that lack of time and heavy workload in a fast-paced ICU affected healthcare professionals' ability to deliver effective care. Nurses had to juggle between taking care of their critically ill patients, controlling monitors and machines, and dealing with colleagues and the patients family members. These concurrent activities limit the amount of time allowed to care for dying patients and their families. Zomorodi and Lynn (2010) also asserted that due to the heavy workload, healthcare professionals were often undecided between spending adequate time with the dying patient and family and assisting other emergency patients'.

2.4.1.4 Lack of context-based guidelines and instruments

The literature (Avidan *et al*., 2021; Mark *et al*., 2015) makes clear that EOL care practices and treatment withdrawal differ from country to country. These variations demonstrate how each nation is distinct in terms of its cultures, institutional policies, and healthcare providers' attitudes towards EOL care practices. Myburgh et al. (2016) agree that because EOL care practices vary from country to country and society to society, a single criterion might not work in all of them. Hence, the development of context-based guidelines will be helpful. Several publications (Attia *et al*., 2013; Zomorodi & Lynn, 2010) have also described the lack of EOL care guidelines as a significant barrier to the provision of effective EOL care in the ICU. The absence of guidelines implies that healthcare providers in the ICU are unsure whether decisions are made correctly, and they will harbor constant fears of legal suits regarding treatment withdrawal.

The infrequent involvement of nurses in EOL decisions and discussions can perhaps be attributed to their limited knowledge and training in EOL care. Langley *et al*. (2014) are of the view that the development and frequent use of EOL care and treatment withdrawal guidelines would not only increase nurses' involvement but also increase their confidence in participating in EOL care decisions. Unfortunately, not all regions and societies, especially in Africa, have EOL care and treatment withdrawal guidelines developed to assist healthcare providers with the provision of EOL care in the ICU. According to Downar *et al*. (2016), guidelines help clinicians provide quality EOL care in the ICU. Griffiths (2019) also

supports the development and implementation of guidelines as they promote quality and patient- and family-centered EOL care.

2.5 STRATEGIES TO ENHANCE END-OF-LIFE CARE AND TREATMENT WITHDRAWAL IN THE ADULT INTENSIVE CARE UNIT

2.5.1 Improved and Effective Communication

One of the most cited facilitators of EOL care and treatment withdrawal is communication. The centrality of open, clear, consistent, and honest communication among the ICU team and with patients (where appropriate) and their families has been repeatedly emphasized in the literature (Beckstrand *et al*., 2017; Brooks *et al*., 2017; Coventry *et al*., 2020). Effective EOL communication is an integral part of EOL care, especially when LSTs are withdrawn (Coventry *et al*., 2020). This type of communication is described as being clear, timely, open, and sensitive. It involves every single individual that matters as far as patient and family care at the EOL is concerned. Patients (if able), family members, nurses, attending physicians, and other healthcare providers are all involved in any communication pertaining to the care of the critically ill and dying patient. It is also important to have a timely conversation with family members about the prognosis of their loved ones. This approach psychologically prepares the patient's family ahead of time for the anticipated and inevitable death (Coventry *et al*., 2020). The foundation of readiness is effective communication, which is essential for facilitating family needs during EOL care in the ICU.

Interdisciplinary communication during treatment withdrawal and end-of-life (EOL) care in the ICU is a key approach to the success of care for patients and their families (Braganza *et al*., 2017). The approach ensures that patient and family care responsibilities are shared jointly among the attending physicians and other healthcare providers. This measure reduces conflicts and prevents inconsistencies in the information carried across the team and patients families. The lack of interdisciplinary communication and involvement result in fragmentation of care (Zomorodi & Lynn, 2010), a feeling of not being involved, and neglect of opinion (Attia *et al*., 2013; Beckstrand *et al*., 2017).

The language and timing of communication are also important elements often overlooked but vital in improving the experiences of family members at the end of life (Ganz, 2019).

Ganz (2019) re-echoes that "good communication is based not only on what we say but how we say it". This implies that the atmosphere for communication and the timing of communication are as equally important as the message carried across. The kind of phrases used to describe a patient's prognosis to family members is an important part of effective communication. Beckstrand et al. (2021) describe physicians' behaviors such as giving false hope through the conversation with the family members as one of the largest obstacles to the provision of EOL care in the ICU. Brooks *et al*. (2017) stress honesty and openness in conversation as an important enabler of quality care at the EOL. It is important to be truthful in the plan of care and explain in clear terms to patients and their families the actual state of the patient's prognosis and the benefits of interventions provided. These findings point out the importance of clarifying the information communicated to avoid ambiguities.

2.5.2 Modification of the Physical Environment and Bedside Space

The unfavourable nature of the ICU environment has been well emphasized in the literature as a major barrier to the provision of EOL care (Almansour *et al*., 2019; Brooks et al., 2017; Ivany & Aitken, 2019). In this same setting, several modifications can be made to create a serene, non-technical, and peaceful environment for the provision of EOL care after the withdrawal of LST in the adult ICU. These changes include reducing noise levels from machines and monitors, creating a private space for intimacy and privacy, providing private rooms and extra facilities for waiting family members, and encouraging bedside presence through liberal visiting hours during EOL care (DeSanto-Madeya & Safizadeh, 2017; Jensen *et al*., 2020).

Due to ongoing alarms, therapeutic procedures, and emergencies, the ICU is expected to have a noisy environment. Numerous studies recommend keeping the ICU quiet and distraction-free while caring for dying patients and their families (Bratcher, 2010; Donnelly *et al*., 2018; Kisorio & Langley, 2016b). The reduction of noise from monitors and other equipment creates a calm and quiet environment in which patients and their families can spend their final moments together. Taylor *et al*. (2020) suggested turning off machines early after a decision has been made to discontinue treatment. This measure allows family members the needed privacy and takes their minds off the dropping hemodynamic changes shown on the monitors.

Several studies (Jensen *et al*., 2020; Ranse *et al*., 2012; Taylor *et al*., 2020) have shown that making space for intimacy and privacy after treatment withdrawal is an important facilitator of EOL care in the ICU. Patients' bedsides space in the ICU are often cluttered with machines, infusion pumps, and syringes, which limits family access to the patient. These equipment take up a lot of space and make the ICU surrounding more technical for the family members'. At the end of life, it is vital to remove all these unnecessary clinical equipment from patients' rooms to create enough bedside space for patients' families during visiting hours (Ranse *et al*., 2012). Additionally, flexible, and unrestricted visiting hours for families during the EOL care phase should also be encouraged (Arbour & Wiegand, 2014; Jang *et al*., 2019). During unrestricted ICU visits, family members are able to spend enough time with their loved ones until the end.

During EOL care, it is necessary to create special rooms for patients and their families. Such an environment promotes privacy and gives the family enough access to their loved one during EOL care. There should be a designated area in the ICU where patients in the EOL phase can be transferred and cared for (Attia *et al*., 2013; Jensen *et al*., 2020). A single private room is more appropriate to maintain privacy compared to multi-bed patient rooms. Such facilities should have enough comfortable chairs for family members. Another important measure is the dimming of the lights, decorating the patient's room in lovely colors, and hanging pictures on the walls (Coombs, 2015; Ranse *et al*., 2012). This further creates a less intensive and friendly environment for patient care. A welcoming and comfortable ICU environment significantly affects family members' satisfaction with EOL care (DeSanto-Madeya & Safizadeh, 2017).

2.5.3 Adequate End-of-Life Care Education and Training

Another way to improve end-of-life care and treatment withdrawal in the ICU Setting is the establishment of systems and mechanisms to support healthcare providers. This can be achieved through constant EOL care education and training. Nurses and physicians often lack the proper training and support to provide good EOL care in the ICU (Hall, 2020; Wiegand *et al*., 2019). There is limited opportunity to learn about EOL care and communication during medical training. Hence, it becomes a challenge to provide adequate EOL care during ICU practice (Brooks *et al*., 2017). Most healthcare providers working in the ICU learn how to manage patients and their families at end-of-life through frequent

exposures and experiences as opposed to formal education and training (Wiegand *et al*., 2019). Flannery *et al*. (2016) stressed that due to the lack of formal EOL training, most less experienced physicians avoid EOL decisions and discussions and focus more on the disease process.

Hall (2020) emphasized that there should be a combination of knowledge acquired through education, personal and professional experiences, and support resources in order to adequately prepare for EOL care. This implies that formal EOL education and training are essential components of EOL practice. In Australia, Flannery *et al*. (2020) also alluded to the fact that EOL is complex and there are several inconsistencies in the decision-making process. Nurses and physicians had different perceptions of their roles during EOL care. While nurses perceived EOL discussions should be done in a meeting involving the family and nurses, doctors discussed before meeting the family. These findings reveal the diverse opinions in EOL care and suggest the importance of interprofessional EOL care training and education. These findings reveal the diverse opinions in EOL care and suggest the importance of interprofessional EOL care training and education.

Beckstrand *et al*. (2017) also placed a strong emphasis on increased EOL care education for the ICU team and family members in their advocacy for good death at the EOL. The family members can better understand the patients' diagnoses, life-sustaining interventions and what goes into extending lives by educating them. Both doctors and nurses are also prepared adequately to care for the dying patients through the increased EOL care education.

2.5.4 Patient- and -Family Centred Care

The Institute for Patient- and Family-Centred Care (IPFCC, 2023) defines patient- and family-centered care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families". Inherent in the definition is that healthcare providers, patients, and their families are essential allies in direct care interactions, collaborate for quality and safety, and participate in care and decision-making. The emphasis is on working with patients and their families rather than doing it to and for them. The main goal is to promote the health and well-being of patients and their family members.

In the provision of EOL care and care after the withdrawal of treatment in the ICU, it is important to establish a mutually beneficial partnership among the ICU team and with patients and their families (Mitchell *et al*., 2016). The key components of a patient- and family-centered care approach associated with quality EOL care include shared decision-making, physical comfort for patients, emotional support, dignity, and respect for patients during the dying process, coordinated care, and attending to the needs of patients families (Secunda & Kruser, 2022; Teno *et al*., 2001; Wiegand *et al*., 2013).

Shared decision-making represents a key component of promoting patient- and family-centered care in the ICU. Kon *et al*. (2016:2) define shared decision-making as "a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences". The definition implies that decision-making is a collaborative process, and patients, family members, and healthcare providers make decisions together. The approach also takes into consideration the values, goals, and preferences of patients and their families. During EOL care decisions and discussions, it is important to involve patients, if possible, and their families. In most patients are unable to make informed decision due to their disease process and medical intervention given. It is therefore vital for the ICU team to elicit and incorporate the needs, wishes, and preferences of patients' families (Joynt *et al*., 2015; Taylor *et al*., 2020). An important characteristic of a good death in the ICU is honoring and respecting patients and their families' wishes and preferences (Bratcher, 2010; Stokes *et al*., 2019). In situations where an advanced directive is in place, it must be respected and followed as indicated by the patients.

Another important aspect of patient-focused care during EOL is the provision of physical comfort. The provision of comfort care is fundamental to the success of EOL care in the ICU. At the EOL, patients often experience symptoms such as pain, agitation, shortness of breath, and nausea. It is important to focus on the patient and address these symptoms through both pharmacological and non-pharmacological interventions (Jensen *et al*., 2020; Vanderspank-Wright *et al*., 2018). Good symptom management is a significant facilitator of improving patients and their families' satisfaction and experiences at the end of life (DeSanto-Madeya & Safizadeh, 2017; Ganz, 2019).

2.6 QUALITY OF CARE

The World Health Organization defines quality of care as "the extent to which healthcare services provided to individuals and patient populations improved desired health outcomes" (WHO, 2023:1). Inherent in these definitions are services that affect health, are evidence-based, avoid harm to people for whom the care is intended, and provide care that responds to the individual's needs, values, and preferences. The nature of the health services should also be timely, equitable, integrated, and efficient. According to Brook *et al*. (2000), the definition of quality of care also includes two essential components. First, providing care of high technical quality implies that a patient receives only those services for which the desired health outcomes outweigh the health risks by a greater margin, and that each of these services is executed in a technically excellent manner. The second component of quality of care is that all patients are treated in a humane and culturally appropriate manner and have the opportunity to make an informed decision on their therapy (Brook *et al*., 2000).

2.6.1 Measuring Quality of Care

The Institute of Medicine (IOM) emphasizes that quality of care can be measured and is important to measure (IOM, 1999). Thus, it serves as a reference point to check the quality of care delivered to patients and their families in a healthcare setting. In the provision of healthcare, frequently assessing the quality of care is important to make changes, revise interventions, and make important additions to existing documents such as guidelines and policies (Mularski, 2006). There is no established standard for measuring the quality of care. However, the three categories of structure, process, and outcome are commonly used to evaluate the quality sectors of the Institute of Medicine. Donabedian (2005) states that quality comprises structure, process, and outcomes. These categories represent the types of data that can be collected to infer the quality of care in a given system. According to the model, information about the quality of care can be drawn from three categories: structure, process, and outcome.

When selecting measures to evaluate the quality of care, structural measures, process measures, and outcome measures can be helpful. However, it is not prudent to develop public information regarding the quality of care solely based on structural measures (Brook *et al*., 2000). Structures are not a reliable indicator of quality. Again, outcomes are inadequate

measures of care quality. Process measures are only as useful as the evidence linking them to improved results. Process evaluations produce the most difficult care quality judgments. Brook *et al*. (2000) argue that the process of care should be measured when evaluating the quality of care. Thus, modifying the manner in which care is provided will affect its outcome.

The three-part method for judging quality is only possible because a good structure makes a good process more likely, and a good process makes a good outcome more likely. Therefore, before a specific element of a structure, process, or result can be used to assess quality, a relationship of this kind must already exist (Donabedian, 1988).

2.6.1.1 Structure

Structure is used to describe the physical and organizational characteristics of the healthcare system under which care is delivered (Donabedian, 1988). It encompasses the attributes of the service, such as personnel (staff), equipment, facilities, financial resources, and service operating times. It also includes staff education, training, certification, and experience. These attributes are the fundamental components of an organization that determine its capacity to provide high-quality care. While not a guarantee, structural aspects of health care give people the chance to receive care. In general, structures are contingent and indirect influences on care, even though they have the potential to increase or decrease the likelihood of receiving high-quality care. Structure is not a part of care; rather, it is the means by which care is given and received. Hence, it is not a good measure of quality (Brook *et al*., 2000).

2.6.1.2 Process

Process refers to the interactions between patients and healthcare professionals during the course of providing care—what is done when providing and receiving care (Donabedian, 1988; Donabedian, 2005). The process variable shows the specific actions, such as clinical procedures, taken by the care delivery team to preserve or enhance patients' health (Mularski, 2006). It includes both the patient's activities in receiving and completing care as well as the practitioner's activities in diagnosing a condition and advising or carrying out a course of treatment. Process measures are reliable indicators of quality (Brook *et al*., 2000). In the evaluation of palliative and EOL care in the ICU, Clarke et al. (2003) and Mularski (2006) consider process quality indicators as the most useful and important quality themes.

2.6.1.3 Outcome

The results of care are outcomes. The term "outcomes" refers to the effects of care on the patients' and the population's level of health. Outcome is not a component of care but a consequence of care (Donabedian, 1988; Donabedian, 2005). Processes and structure both have the potential to directly or indirectly affect the result. Health status and user evaluation, which include both non-health-related and health-related outcomes, are the two main outcome domains that can be used to define the effectiveness of structures and processes (clinical and interpersonal). A broad definition of health status includes enhancements in patient knowledge, positive changes in patient behavior, and the level of patient satisfaction with care (Mularski, 2006). In the evaluation of EOL care, especially after treatment withdrawal in the ICU, outcome quality indicators will include family and healthcare satisfaction. Donabedian (2005) reports that, although it is a good measure, it can be difficult to measure.

2.6.2 Measuring Quality of Care at the End of Life in the Intensive Care Unit

Quality of care is a complex concept, particularly at the EOL following treatment withdrawal and in intensive care settings. However, measuring it is essential to improving the healthcare rendered and received (Mularski, 2006). As a result of the state-of-the-art medical equipment in our hospitals, people with life-threatening and chronic conditions now live longer than they did in the past. Thus, prolonging the dying process with additional suffering and burden, particularly placed on highly sophisticated machines, particularly in intensive care units. These changes have made the quality of care provided to terminally ill patients and their families an essential topic of discussion. In many countries, the rising demand for intensive care and variations in ICU practices have increased interest in measuring and enhancing healthcare quality (Avidan *et al*., 2021; Myburgh et al., 2016).

In the ICU, deaths frequently occur. The fact that not all patients will benefit from intensive care has been stressed time and again in the literature. Some patients will die in the ICU due to their life-threatening conditions. As a result, it is imperative to provide the critically ill and dying patients only with services that will benefit them. In this case, provide care that will ensure comfort and reduce support. It is also important to treat critically ill and dying patients in a humane and culturally appropriate manner and allow them, if able, to make

informed decisions about their therapy. These are the key components of providing quality care for patients at the end of their lives (Brook *et al*., 2000; Mularski, 2006). As a quality assurance measure, it is therefore important to measure the quality of care patients and their families receive at the end of life.

2.6.3 Instruments Measuring Quality of Care at the End of Life

It can be challenging to develop a research instrument that measures the quality of care at the end of life and in the ICU, especially after treatment has been discontinued. This is because patients' health gets worse as they get closer to the end of their lives, making it difficult to identify patients who might be in the last stages of life and also to ask family members to help judge the quality of care at this time. But it's important to have a validated instrument if you want to improve the care you give to patients and their families. Research instruments that measure the quality of care at the end of life include questions about the environment, communication with health and social care professionals, and nursing care (Kupeli *et al*., 2019).

In the evaluation of care, especially care provided at the end of life, van Soest-Poortvliet *et al*. (2011:853) attested that it is important to differentiate the constructs "quality of care" and ‘quality of dying," as these constructs differ greatly. The quality of care reflects "elements in the settings where death and dying take place," whereas the quality of dying includes ‘symptom burden and other resident experiences that can be influenced by care and various patient-related factors" (van Soest-Poortvliet *et al*., 2011:853). Again, the quality of care-related measures guides quality improvement and other intervention efforts, whereas the quality of dying-related measures can be used to evaluate the effectiveness of those efforts. Therefore, to guide quality improvement efforts, van Soest-Poortvliet *et al*. (2013) recommend that measurement instruments be selected to capture a single construct, grounded on a theoretical model and based on empirical evidence.

Van Soest-Poortvliet *et al*. (2011) evaluated the content of available measurement instruments used to assess the quality of dying and care when dying in long-term care (LTC) settings. The study used qualitative content analysis to categorize items as the structure of care, process of care, satisfaction with healthcare, quality of dying, or patient factors. Eleven (11) instruments were found that measure both QOC and QOD. Among these instruments,

only five (5) measured the construct ‘quality of care’ at the end of life, namely: Family Perception of Physician-Family Caregiver Communication (FPPFC); End-of-life in Dementia Satisfaction with Care (EOLD-SWC), Family Perception of Care Scale (FPCS); Toolkit of Instruments to Measure End-of-life Care (TIME) after-death bereaved family member interview; and Family Assessment of Treatment at the End-of-life Short Version (FATE-S). The majority (at least 90%) of items of these instruments measured a single construct, "quality of care’ (van Soest-Poortvliet et al., 2011). For instance, the FPPFC instrument is 100% comprised of process of care items, EOLD-SWC instrument is also 90% comprised of process of care items and 10% comprised of outcome of care items (satisfaction with health care); and the FPCS instrument is 60% process of care items, 20% structure of care items, and 20% outcome of care items (van Soest-Poortvliet *et al*., 2011).

The instrument, EOLD-SWC, was specifically developed and validated to assess quality of care among patients with dementia in long-term care settings. The instrument is therefore not suitable for measuring quality of care among patients without dementia, hence the need for revision of the instrument items (Munn *et al*., 2007; van Soest-Poortvliet *et al*., 2013). The other instruments (FATE-S, TIME, FPCS, and FPPFC) measure the quality of end-of-life care among the critically ill population and non-dementia patients. All the instruments (FATE-S, TIME, FPCS, and EOLD-SWC) were also developed and validated using LTC settings in the United States of America, the Netherlands, and Canada (van Soest-Poortvliet *et al*., 2011; van Soest-Poortvliet et al., 2013). Although these instruments have been validated and useful over the years, they were developed in settings considered different from the African context. It may be argued that these instruments could be adapted, but they will also need to be validated and revised to suit the African context.

A systematic review by Kupeli *et al*. (2019) evaluated the psychometric properties and the applicability of instruments measuring the quality of care at the end of life. Out of four instruments (EOLD-SWC, TIME, FPCS, and Care of the Dying Evaluation-CODE) that were appropriate to measure the quality of care at the end of life, only two (CODE and EOLD-SWC) had strong psychometric properties. The EOLD-SWC had strong evidence of positive internal consistency, with Cronbach’s alpha (α) ranging between 0.83 and 0.90. Despite the strong psychometric properties and extensive use in research, Kupeli *et al*. (2019) recommended further psychometric evaluation. The CODE also had promising psychometric properties, however, which needed further validation. Maryland et al. (2019)

further translated the CODE into other languages and pre-tested the instrument across seven different countries. On the international level, the instrument recorded good face and content validity. There were, however, individual culturally relevant variations noted across the participating countries. These findings highlight the significance of a culturally appropriate measuring instrument. A recent study on the validity and reliability of CODE (Maryland *et al*., 2022) further supported that it was an appropriate, valid, and reliable instrument to measure the quality of care provided to the dying patient in the last days of life and could be used at the international level.

In the ICU, the time to death after the withdrawal of LST varies, however, and is considerably short. The majority of patients die within 24 hours after the withdrawal of LST (Cooke *et al*., 2010; Lesieur *et al*., 2015), and some within days (Lesieur *et al*., 2015). These results show that the care given to patients and their families in the ICU during the last week of a patient's life after treatment is stopped is very important. Therefore, existing instruments measuring the quality of care in the last days of life can be adapted, revised, and validated. The instruments, CODE and TIME, assess the quality of care provided to patients in the last hours and days of their lives, respectively. These have also been validated in hospice and hospital settings (Maryland *et al.,* 2014; Teno *et al*., 2001). Other instruments (FPPF, FPCS, and FATE-S) also measure the quality of care at the end of life (van Soest-Poortvliet *et al*., 2011), but within the last four weeks to three months of the patient's life. Considering the short time between treatment withdrawal and death in the ICU, using these instruments will be too broad to capture the salient items within the first hours and days of a patient’s life. Hence, instruments that precisely measure the quality of care within the last hours and days will be appropriate.

The "ICU Palliative Care Quality Assessment Tool" has already been developed to help with the care of patients and their families in the ICU. It is used to measure the quality of palliative care in the ICU. The Critical Care End-of-Life Peer Work Group of the Robert Wood Johnson Foundation developed the seven domains of quality care, which were used in the development of the tool (Clarke *et al*., 2003). Since then, the tool has been modified and verified in numerous studies (Ho *et al*., 2011; Sepelete, 2019). It is advised that the tool be further validated, especially in developing and underdeveloped nations. Currently, in South Africa, no research instruments exist to measure the quality of care at the end of life in the ICU. Considering the unique disease profile, cultural and religious differences, and

increasing ICU usage, it will be important to develop a context-based instrument for the region. Avidan *et al*. (2021), in a prospective observational study, further highlighted the variations in limiting LST in the ICU. The authors recommended the recognition of these regional differences. Myburgh *et al*. (2016) also support the development of EOL care interventions within each country owing to the societal and regional differences in EOL care practices.

2.7 CONCEPTUAL FRAMEWORK

The study was based on Katherine Kolcaba's Comfort Theory, which was developed in the 1990s. According to the National Cancer Institute (NCI), the main goal of EOL care is comfort: ensuring that the patient is pain-free and controlling other symptoms (NCI, 2023). It also encompasses emotional, physical, spiritual, and social support for patients and their families. In the ICU, when curative care proves physiologically futile, the emphasis is on the transition to comfort care. At this stage, the focus is on relieving suffering, minimizing aggressive care, and promoting comfort through pharmacological and non-pharmacological interventions (Bratcher, 2010; Taylor *et al*., 2020).

2.7.1 Comfort Theory

The Comfort Theory was developed by Katherine Kolcaba in 1990 and published in 1994 (Kolcaba, 1991; Kolcaba, 1994). The Comfort Theory has been tested and supported in several patient populations, including psychometric and studies in persons nearing the end of life (Novak et al., 2001), cardiac patients (Krinsky, 2014), and EOL care in the neonatal intensive care unit (Marchuk, 2016). The emphasis of this middle-range theory is that comfort is the product of holistic nursing and an immediate desirable outcome of nursing care (Kolcaba, 1994).

Kolcaba (1991:239) defines comfort as "the state of having met basic needs for ease, relief, and transcendence addressed in four contexts of experience (physical, psychospiritual, sociocultural, and environmental)." According to the theory, comfort exists in three forms: relief, ease, and transcendence, and can be experienced in four contexts (physical, psychospiritual, environmental, and sociocultural). Relief is "the state of having a discomfort

mitigated or alleviated." (Dimarco &Kolcaba 2005:188). Thus, having specific basic human needs met. Ease is "the absence of specific discomforts", thus a state of calm or the absence of apparent discomfort (Dimarco & Kolcaba, 2005:188). Transcendence is the state of rising above discomforts that cannot be avoided or eradicated (Kolcaba, 1991; Dimarco & Kolcaba, 2005). While these forms are important in achieving comfort, it has to be experienced in four different contexts (physical, psychospiritual, environmental, and sociocultural).

The physical context to experience comfort concerns bodily sensations and homeostatic mechanisms; the sociocultural refers to family, interpersonal, and societal relationships; the psychospiritual pertains to the internal awareness of self, one's relationship to a higher being, and a sense of the meaning of one's life; and the environmental is one's external surroundings and conditions (e.g., noise, light, and temperature) (Kolcaba & Fisher, 1996; Kolcaba, 1994). The three forms in which comfort exists are juxtaposed with the four main contexts in which comfort can be experienced to form a taxonomic structure. This structure represents all relevant aspects that define comfort. The researcher also used this to develop a taxonomic structure (Table 2.1) for providing end-of-life care for patients and their families after treatment withdrawal in the adult ICU.

Table 2.1: Kolcaba's Taxonomy structure of Comfort Needs for patients and families after treatment withdrawal

Comfort form / Context	**Relief**	**Ease**	**Transcendence**
Physical	Pain, shortness of breath, agitation, nausea and vomiting	Pain medication, sedatives, positioning, attending to hygienic needs	Massage, music therapy, diversional therapy,
Psychospiritual	Anxiety, depression, spirituality, religion	Debriefing, counselling, prayer, pastoral care	Emotional support, reassurance, education, spiritual support, information sharing
Environmental	Noise ICU, bright light, technical equipment, lack of privacy	Dim light, switch of monitors, single rooms	Calm and serene environment, privacy

Sociocultural	Lack of social support, financial resources, Family not present, absence of traditions and cultural care	Social support systems, financial support,	Family presence, family culture and traditions, family relationships

From the comfort theory conceptual framework (**Fig. 2.1**), in achieving enhanced comfort for patients and families, it is important for healthcare providers to assess the healthcare needs of patients and their families. These healthcare needs refer to comfort needs in physical, psychospiritual, environmental, and sociocultural contexts. Following the identification of the comfort needs in these contexts, comforting interventions are rendered to alleviate the discomfort (relief), ensure a state of calmness in the absence of the discomfort (ease), and be able to rise above the discomfort when it cannot be avoided (transcendence) (**Table 2.1**). Intervening variables such as social support and financial resources are also vital to complement the comforting interventions and enhance comfort.

Following an effective comfort intervention, the recipients (patients and their family members) are strengthened to engage in health-seeking behaviors (HSBs) that further enhance comfort. The HSBs include internal behaviors, external behaviors, and a peaceful death. Internal HSBs occur at the cellular or organ level, such as healing, while external HSBs concern the outer world, such as self-care activities (Kolcaba, 2021). When HSBs are enhanced, the institution's integrity is also enhanced, and the desired outcomes at the institutional level, such as satisfaction with care services, successful discharges, a low readmission rate, improved family satisfaction, a short length of hospital stay, and financial stability, will be achieved. Kolcaba's (2021) conceptual framework (**Figure 2.1**) shows how comfort theory fits into the clinical practice setting.

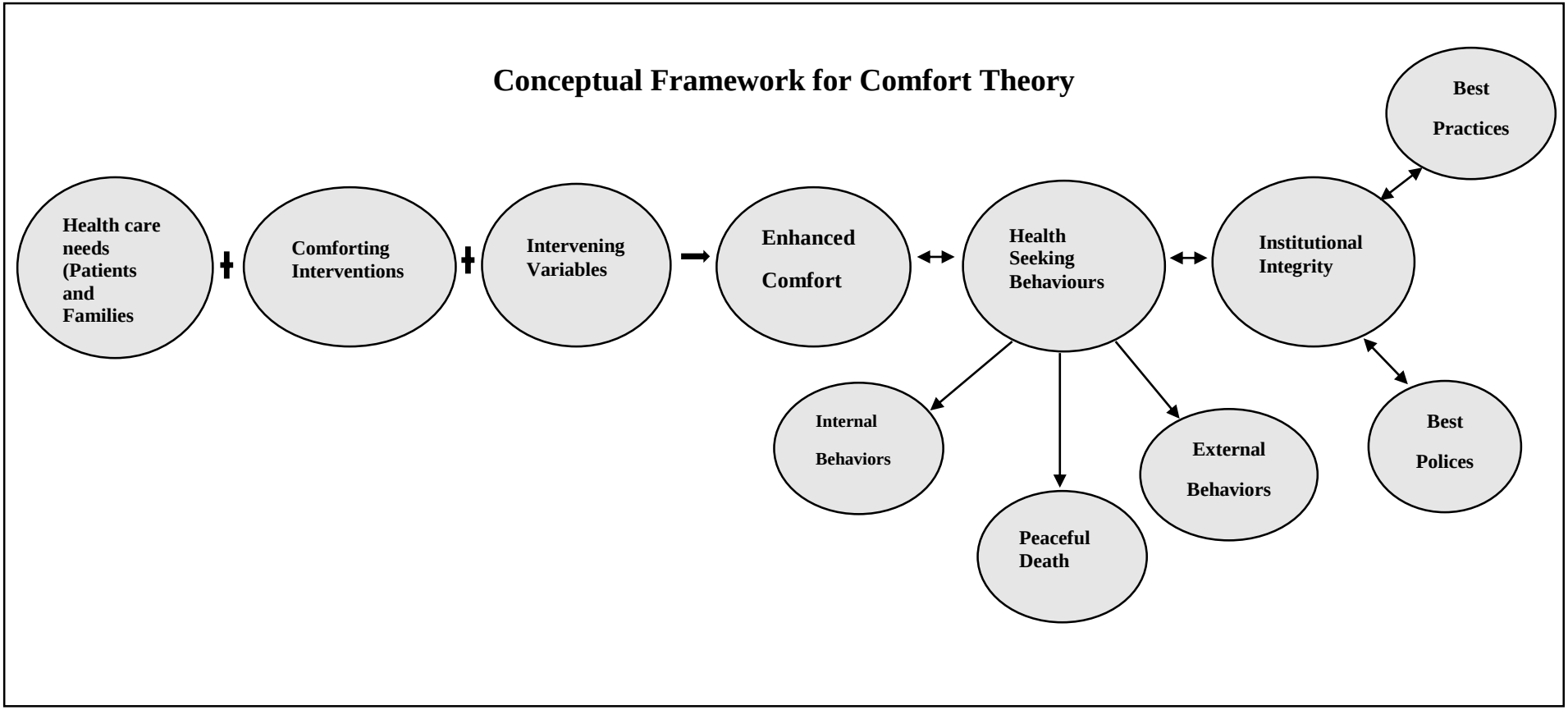

Figure 2.1: Conceptual Framework for Kolcaba's Comfort Theory (1994)

2.7.2 Application of the Comfort Theory to the End-Of-Life Care for Patients and Their Families after Treatment Withdrawal

Figure 2.1 is a diagram of the relationship between the important concepts in the Comfort Theory. Assessing the health care (comfort) needs of patients and their families, meeting those needs with comforting interventions, and taking care of things like social and financial support all lead to enhanced comfort. If the comfort level is enhanced, patients and their families engage fully in healthcare-seeking behaviors such as healing, self-care activities, and peaceful death. This further enhances the institution's integrity through patient and family satisfaction with healthcare services, successful discharges, and a short length of hospital stay.

The section below discusses the application of the comfort theory in relation to the care of patients and their families after their withdrawal from the ICU.

2.7.2.1 Health care needs and comforting intervention

The theory describes comfort needs in the context of physical, psychospiritual, environmental, and sociocultural. The comfort needs, when met, lead to enhanced comfort. In achieving enhanced comfort (relief, ease, and transcendence), comfort interventions are also implemented to address these comfort needs (physical, psychospiritual, environmental, and sociocultural).

- *Physical*

The *physical* context to experience comfort concerns bodily sensations and homeostatic mechanisms (Kolcaba & Fisher, 1996; Kolcaba, 1994). At the EOL and after treatment withdrawal, patients experience common symptoms such as pain, shortness of breath, agitation, nausea, and vomiting. These symptoms cause some form of physical discomfort. It is important to manage these symptoms through pharmacological and non-pharmacological means (Ranse *et al*., 2012; Wiegand, 2016). The administration of analgesics, sedatives, and antimucolytics are some of the pharmacological interventions used to manage and control most of the common symptoms patients' experience. Additionally, early withdrawal of interventions that are not beneficial and will not reverse death need to

be discontinued as early as possible (Coombs, 2015). These interventions promote physical comfort for the patients.

Another aspect of promoting comfort is through basic nursing care and non-pharmacological interventions. Measures such as positioning, body massage, music therapy, and distraction also promote comfort for the patient, although some may not necessarily alleviate the discomfort. These interventions will provide relief and ease the discomfort.

- *Psychospiritual*

The psychospiritual context to experience comfort pertains to the internal awareness of self, one's relationship to a higher being, and a sense of the meaning of one's life (Kolcaba & Fisher, 1996; Kolcaba, 1994). The EOL care trajectory is said to be an emotional phase for both patients and their families. Emotionally, it is a tough and difficult moment. Most families are not emotionally prepared for the loss; hence, assessing and addressing their emotional and psychological needs is paramount (Efstathiou & Walker, 2014; Taylor et al., 2020). In addressing the emotional needs of patients, it is vital to establish a relationship with patients and their families. This creates the opportunity to address the emotional concerns. Interventions such as debriefing sessions after treatment withdrawal, psychosocial counselling, reassurances from healthcare providers, and early referral to the psychologist are also integral to ensuring emotional comfort.

Additionally, there is huge emphasis placed on spirituality and accepting patients as spiritual beings during the dying process (Jang *et al*., 2019; Stokes *et al*., 2019). Spirituality encompasses connectedness to a spiritual being, and it is connected to religion. Hence, it is also important to address and meet the spiritual needs of patients and their families during EOL care. Interventions to address and meet the spiritual needs include the existence of good pastoral care, prayers, and allowing religious persons at the bedside during EOL care. These measures further enhance comfort.

- *Environmental*

The environmental context is one's external surroundings and conditions (e.g., noise, light, and temperature) (Kolcaba & Fisher, 1996; Kolcaba, 1994). The ICU environment poses several barriers to the provision of EOL care to patients and their families. The obstacles include the loud noises made by ventilators and monitors, the lack of privacy and space caused by ICU equipment, multi-bed rooms that can accommodate multiple patients, and bright lights. Making significant adjustments to the ICU setting and bedside area will be necessary to achieve this goal and promote environmental comfort. The adjustments and actions required to promote comfort include turning off machines, providing private rooms for patients and their families during the end of life, and removing unnecessary equipment from the patient's bedside to make space for family visits (Noome *et al*., 2016a; Stokes *et al*., 2019).

In order to create a calm and therapeutic environment for patients and their families, additional measures like drawing the curtains closer to ensure privacy, bringing in additional chairs for family visits, and dimming the room lights are also crucial. There should be quiet areas in the ICU for family gatherings, prayer, and meditation. The playing of soothing music during the dying process and ensuring that facilities such as beds, showers, and food are readily available to the family members are also other means to promote comfort within the external surroundings (Donnelly & Psirides, 2015; Ranse *et al*., 2012; Stokes *et al*., 2019).

- Sociocultural

The sociocultural context refers to family, interpersonal, and societal relationships (Kolcaba & Fisher, 1996; Kolcaba, 1994). This includes family customs and religious practices. These comfort needs are those for culturally sensitive reassurances, support, and caring. These needs are met through sending messages of assurance and encouragement, honoring the cultural traditions, and providing financial assistance if needed. At the EOL, cultural practices and customs considered important to patients and their families can be incorporated into patient care. Healthcare providers need to recognize and accommodate certain cultural beliefs so long as they are not endangering patients or the ICU. The cost of ICU care and

hospitalization can also be quite expensive. The organization of social support through financial assistance also relieves patients and their families of some discomfort.

2.7.2.2 Intervening variables

In reaching the expected level of comfort, several intervening variables are also considered. These include the extent of social support and financial resources, which are often not changed by attending healthcare providers (Kolcaba, 2003). However, they are essential in enhancing the comfort of patients and their families. Due to the cost of care in the ICU, avenues such as financial support, if they exist, relieve patients and their families of some form of discomfort. The existence of social support systems such as psychosocial counseling sessions, transportation, and resting and waiting facilities for families also brings some form of relief.

2.7.2.3 Health-seeking behaviours

Once the different forms and contexts of the comfort needs of patients and their families have been met in the ICU, they can fully take part in HSBs. In the ICU and after the withdrawal of treatment, the plausible HSB is peaceful death. Literature (Bratcher, 2010; Stanzl & Scammell, 2022) describes a good and peaceful death as one in which the patient is pain-free, does not die alone, and dies in an appropriate physical environment. It is also one in which the death is accepted by family members, and it accommodates and respects the wishes and preferences of patients and their families and is receptive to their cultural and spiritual needs.

2.7.2.4 Institutional integrity

At the institutional level, the desired outcome following meeting patients and their families comfort needs at the end of life is satisfaction with care services. DeSanto-Madeya and Safizadeh (2017) and Hinkle *et al*. (2015) found that factors such as effective communication, a favorable ICU environment, spiritual care, emotional support, support for shared decision-making, and patient symptom management strongly influenced family members' satisfaction or dissatisfaction with EOL care in the ICU. This implies that

addressing comfort needs in the context of physical, psychospiritual, environmental, and sociocultural aspects is necessary.

2.8 SUMMARY

This chapter presented a review of existing literature to help the reader understand EOL care and withdrawal of treatment in the ICU. In the chapter, there was also a brief history and overview of critical care, followed by a discussion of EOL care in the ICU and the withdrawal of life-sustaining treatment in the ICU. The chapter ended with a discussion of the Comfort Theory and how it was applied as the framework for the study.

The next chapter presents the research methodology used to address the research question and study objectives.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter presents the research methods that were used to answer the research question and meet the study's goals. The purpose of the study was to develop an instrument for measuring the quality of care provided to patients and their families after the withdrawal of treatment in the adult ICU. The chapter begins with a description of the research design used to achieve the study's aim. The chapter also presents detailed descriptions of the phases of the study and how each phase was achieved. The chapter ends with the ethical considerations applicable to this study and how these are managed, followed by a summary of the chapter.

3.2 RESEARCH DESIGN

A research methodology is “an overall plan that a researcher uses to approach a research problem in a scientific and logical way”. (Polit & Beck, 2017:730). This plan is made up of a collection of research methods. In this study, a mixed-methods design was selected for the development of the new instrument to measure the quality of care after the withdrawal of treatment in the adult ICU.

3.2.1 Mixed-Methods Research

Mixed-methods research has gained prominence over the years and complemented the existing traditional methodological approaches (quantitative and qualitative approaches) in various research studies. The approach is considered valuable in answering different research questions and meeting several objectives in different contexts (Johnson, Onwuegbuzie, & Turner 2007). Johnson *et al*. (2007) define mixed methods research as a type of research where a researcher uses the viewpoints of both quantitative and qualitative research approaches, data collection, and data analysis within a single study, with the integration of the different approaches or methods occurring during the study and not just as its concluding point. The rationale is to benefit from the strengths of both qualitative and quantitative approaches and have them complement each other when combined in a single study.

The mixed-methods research approach has been well-described as an intuitive and practical way to understand and solve complex research problems by drawing on the individual strengths of both traditional qualitative and quantitative methodologies (Ostlund *et al*., 2011). In the development of an instrument, the qualitative component of mixed methods strengthens the development of quantitative instruments (Onwuegbuzie, Bustamante, & Nelson, 2010). This further enhances the description and understanding of the construct and assures instrument fidelity (Johnson *et al*., 2007).

An exploratory sequential mixed method research design guided the researcher to develop the instrument. This study was organized using a two-phase sequential mixed methods design. A sequential mixed-methods design is typically used to develop quantitative instruments, whereby data is collected in the first phase to inform subsequent phases (Ostlund *et al*., 2011). A mixed-methods approach also provides a framework on which to develop the instrument, starting with conceptualizing the construct of interest (Onwuegbuzie *et al*., 2010). The two phases used to develop the instrument consisted of Phase 1: domain identification and item generation, and Phase 2: instrument development and validation. Conducting the study phases in a sequential manner provides a set of analytical approaches to confirm and validate findings generated from the preceding phase (Onwuegbuzie *et al*., 2010). In this study, the qualitative data collected in Phase 1 was used to inform the quantitative Phase 2. Phase one began the whole process of instrument development. This was followed by the development of the provisional instrument and validation in Phase 2. Phase 2 was also used to assess the content and face validity of the instrument.

The two-phase exploratory sequential mixed methods were structured under the five-step instrument development process as outlined by Lynn (1986) and Zamanzadeh *et al*. (2015) and addressed seven objectives of the study (refer to tables 1.1 and 3.1 for the details).

Table 3.1: Integration of the research structure, steps and objectives

Phase	Step	Study objective (s)
Phase One	**Step 1**:Content and domain identification To determine the content domain of the construct that the instrument intends to measure and sample items from the literature	1- To identify and synthesise the perspectives of patients, family members and healthcare providers on providing quality care for patients at the end of life and their families through a scoping review
	Step 2: Item generation To sample and generate items from qualitative interviews	2- To explore the experiences of intensive care nurses providing care to patients and their families after treatment withdrawal
		3- To explore physicians' experiences of making end-of-life decisions to withdraw treatment and providing care after treatment withdrawal in the intensive care unit
		4- To explore the experiences of families who have been a relative of a patient with treatment withdrawn in the intensive care unit
Phase two	**Step 3:** Instrument construction To develop the instrument into a usable format (assimilate the domains and items into a useable form)	5- To develop a provisional instrument through content analysis of the literature and qualitative studies from phase one
	Step 4: Judgement To quantify the content validity of the instrument (content validity of the items through a Delphi study)	6- To assess the content validity of the instrument
	Step 5*:* Determine the face validity of the instrument	7- To assess the face validity of the instrument

A detailed description of the phases, their steps and methods used to achieve the objectives are discussed in the next section 3.3.

3.3 PHASE ONE: DOMAIN IDENTIFICATION AND ITEM GENERATION

In the development of a new instrument, Boateng *et al*. (2018) recommend to researchers that they identify and define appropriate domains beforehand. A domain refers to a concept, attribute, or unobserved behavior that is the target of the research study (Haynes, Richard,

& Kubany, 1995). A well-defined domain guides the item generation process at some stages of the instrument development process and content validation. Domain identification and item generation are achieved through a thorough literature review and qualitative interviews (Boateng *et al*., 2018). While the literature review provides the theoretical basis for defining the domain, the use of qualitative data moves the domain from an abstract point to the identification of its manifest forms. Boateng *et al*. (2018) also consider it a best practice to combine both inductive and deductive methods to define the domains and identify items for the domains. Qualitative data obtained through exploratory research methodologies such as individual and group interviews can also be used to inductively identify domains and domain items (Morgado *et al*., 2018).

In phase one, a content analysis of existing peer-reviewed literature was conducted along with qualitative interviews with intensive care nurses, doctors, and bereaved family members to identify relevant content domains and generate items capable of measuring the quality of care provided for patients and their families after the withdrawal of LST in the ICU. According to Table 3.1, Phase 1 was conducted in two (2) steps consisting of four (4) objectives. This phase of the study addressed the first four objectives of the study, as indicated in Chapter 1. The outcome of this phase was to identify content domains and generate items for the development of an instrument to measure the quality of care after the withdrawal of LST in the adult ICU. Findings from this phase informed the development of the instrument in Phase 2.

In the sections below, the research designs and approaches used to meet the above objectives are explained in detail.

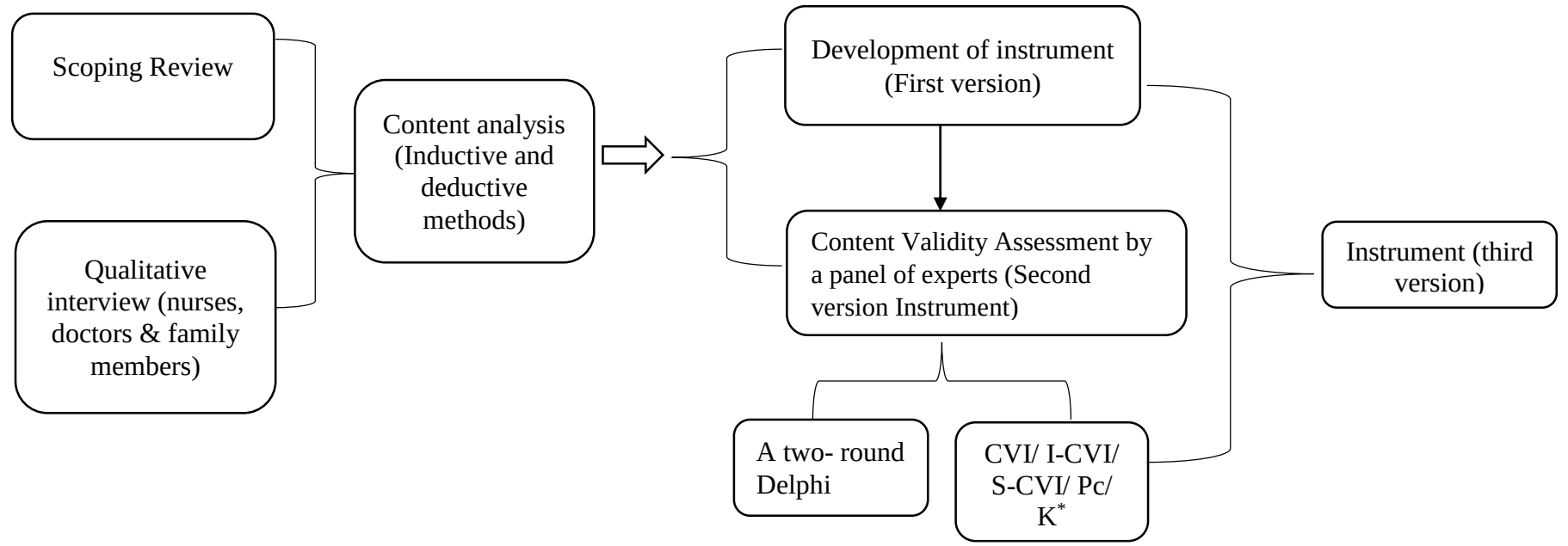

Figure 3.1: Instrument development using an exploratory sequential mixed method

3.3.1 Step 1: Objective One- Scoping Review

Step one of the study addresses objective one of phase one of the study, which seeks to identify and synthesize the perspectives of patients, family members, and healthcare providers on providing quality care for patients at the end of life and their families through a scoping review. This review was important to identify key domains and concepts for caring for patients at the end of life and their family members in the intensive care unit.

3.3.1.1 Research design

A scoping review approach was used. The scoping review followed the Joanna Briggs guidelines (Peters *et al*., 2020) framework and was reported according to the PRISMA-ScR checklist (Tricco *et al*., 2018). The headings used included: a specified research question; inclusion criteria; literature search/search strategy; selection of studies; data charting process; critical appraisal of individual sources; synthesis of results; and presentation of results, as described in detail in Chapter 4.

3.3.1.2 Review question

The following review question guided the view: *"What are the perspectives of patients, family members and healthcare professionals on providing quality care for patients at the end of life and their families in the ICU?"*

3.3.1.3 Inclusion and exclusion criteria

The review included only empirical studies published in English that focused on patients, family members, and healthcare professionals (nurses and doctors) and explored ways of improving end-of-life care. Grey literature, existing reviews, guidelines, documentaries, and expert opinions were excluded.

3.3.1.4 Literature search

The reviewers used the three-step search strategy recommended by the Joanna Briggs Institute (Peters *et al*., 2020). An initial search was conducted using databases (PubMed and

CINAHL) to identify mesh terms, subject headings, and index terms that were capable of conducting an exhaustive search in the other included databases. A second comprehensive computerized database search was conducted using the identified keywords and index terms across all five selected databases. Reference lists of the retrieved literature were then screened for possible articles for inclusion.

The electronic databases SCOPUS, PubMed, CINAHL, Science Direct, and MEDLINE were searched electronically to identify existing literature published in English since January 1999. The search terms and main concepts that guided the review were generated after thorough consultations with an experienced librarian. During the literature, the Boolean terms (AND, OR, and NOT) were used to combine the search terms.

3.3.1.5 Selection of study

Two reviewers, E.K. and S.S., independently looked at the abstracts and titles of the studies that were retrieved to see if they should be included in the study. First, the titles of the retrieved studies were read. The abstract of potential studies was read after the title. Possible articles were read in full and further examined for eligibility. A third independent reviewer was consulted at every point where there was disagreement. The detailed search outcome was described using the PRISMA flow diagram.

3.3.1.6 Data charting process

Upon achieving consensus, a standard data extraction developed by the reviewers was used to extract essential items from each included article. Data from the individual studies were extracted according to the headings: author(s), year, setting of publication, study objective, research methodology, population and sampling approach, and key findings.

3.3.1.7 Synthesis and analysis of results

Results obtained from the included sources, such as study population, study design, and country of origin, were descriptively mapped using simple frequency counts. Key individual study findings from each study were brought together, compared, and contrasted to identify recurring and prominent themes. Results were reported as a narrative summary with

consideration for the objective that guided the review. A thematic analysis approach was also used to summarize key findings under themes.

The results of the scoping review are presented and discussed in Chapter four.

3.3.2 Step 2: Objective 2- In-Depth Qualitative Study with Intensive Care Nurses

Step two of phase one sought to answer objective 2 of the study, which was to explore the experiences of nurses providing care to patients and their families after the withdrawal of treatment in the adult ICU. The summary of potential items and themes drawn from the interview findings informed the development of the instrument in Phase 2. Detailed findings from the interviews are presented and discussed in Chapter 5.

3.3.2.1 Research design

The study used the exploratory, descriptive, qualitative design.

3.3.2.2 Study population and sample

The study population comprised nurses working in the adult ICU at the study setting. A non-probability sampling method, namely purposive sampling, was used to sample participants from the selected ICUs as they had a wide range of experiences managing critically ill and dying patients in the ICU. Participants were selected on the basis that they were working in the ICU at the time of the study, willing to share their views on the topic under study, and also met the inclusion criteria. The inclusion criteria are summarized as follows:

- Registered practicing nurse with an additional clinical qualification in intensive care nursing or equivalent medical and surgical nursing in the subcategory of critical care
- More than 5 years of intensive care experience
- Provided end of life care to patient and family
- Witnessed treatment withdrawal in the intensive care unit
- Working in the adult ICU at the time of the study

Some intensive care nurses had a lot more experience than others in the ICUs, so that's why these criteria were set. Preference was also given to certain participants on the basis of their positions and their end-of-life care experience. The number of individual interviews conducted depended on the saturation of information, which was reached when themes and categories in the data became repetitive or redundant, such that no new information was collected (Polit & Beck, 2017:743).

3.3.2.3 Data collection method and procedures

Interviews are the predominant mode of data collection in qualitative studies. In this study, information from participants was gathered through individual interviews. After obtaining written permission and ethical clearance from relevant authorities (**Appendices AA, AB, and AC**), the researcher also sought verbal permission from the ICU unit manager. The purpose of the study was thoroughly explained to the nurse unit manager prior to obtaining her verbal permission to conduct the interviews. The unit manager offered the researcher the opportunity to explain the purpose and procedures of the study to all the nurses on duty during their tea break and invited them to participate in the study.

The researcher also approached some experienced nurses on different days during their ICU shifts. Copies of the study information letter that thoroughly explained the objective of the interview, information on confidentiality, and the benefits and risks of participation were given to each nurse (**Appendix A**). Participants who showed interest and were willing to participate in the study were requested to sign the consent form (**Appendices B & C**) to serve as proof of consent to participate in the study before being interviewed. Appropriate arrangements were made with interested participants for their preferred time of convenience and venue for the interview. A quiet room close to the ICU and an office in the Wits Nursing Department were agreed upon by the researcher and participants to be used for the interviews. The majority of participants preferred to undertake the interview during their ICU shift.

A day before each interview, the respective participant was reminded via a telephone call. The space dedicated for the interview in the study setting was also arranged, and the researcher followed the COVID-19 protocols at all times, both prior to and during the interviews. On the day of the interview, the researcher reiterated the purpose and procedures

of the study. Participants were once again assured that their identities would be protected by using alphabets and numbers. A notice was placed outside the interview room to indicate that the interview was in progress. Each participant was required to sign an additional consent for voice recording for the interview (**Appendix C**) and also complete some demographic data (**Appendix E**). An interview guide (**Appendix D**) prepared by the researcher was used to organize the interview session. The interview began with one broad question and was followed by probes to keep the interview focused. Both the researcher and interviewee encouraged each other to speak louder due to the face mask.

The interview session lasted for between 30 and 45 minutes. Interviews were conducted until no new information emerged, indicating data saturation (Polit & Beck, 2017). The researcher also took field notes to further enhance the meaning of the information gathered. During and at the end of each interview, the researcher frequently repeated and summarized the participant's words to ensure that the data captured was a true reflection of what the participant intended to say. Again, at the end of each interview, the researcher thanked the participant for their participation in the study. Participants were also informed that the transcribed interviews would be kept on a password-protected computer and that the interviews would be brought back for validation.

- Pilot testing

Two weeks prior to the actual data collection, a pilot test was conducted to identify potential pitfalls and avoid poor interviewing techniques and inappropriate interaction. Two participants were chosen to conduct pilot testing, which included piloting the main question as well as some probing questions. The transcripts and audio tape were critically reviewed by a colleague with interviewing experience. The intention was to ascertain if major changes were necessary for subsequent interviews, and should this be so, the data from the first initial interview would be discounted. A minimal amount of change was required, therefore the data was analyzed as part of the study.

3.3.2.4 Data analysis

The researcher analyzed the qualitative data concurrently with ongoing interviews. This was done to enable the researcher to recognize the point at which data becomes redundant in the

absence of new information. MAXQDA Plus 2020 data analysis software aided in data analysis. All the interviews were transcribed verbatim. The researcher read the interview transcriptions several times to obtain a full understanding of the participants' accounts. Field notes obtained during the interviews were also added to enhance the meaning of the information gathered. Braun and Clarke's thematic analysis method was used to provide a systematic procedure for the data analysis (Braun & Clarke, 2006). The six phases of the thematic analysis approach included familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

The researcher read the interview transcripts over and over again to fully understand the data. Data meanings, patterns, and ideas for coding were written down on a piece of paper during the reading. The approach helped the researcher familiarize himself with the depth and breadth of the content. The interview transcripts were then imported into the MAXQDA software. The imported transcripts were further read once again prior to coding. The meanings, patterns, and text extracts identified during the repeated readings were assigned as initial codes generated from the data. Important sections of the text were assigned labels to describe or represent that particular text in the transcript. The generation of initial codes was done for all the interview transcripts, giving equal attention to each transcript. The procedure was repeated for each transcript and for the entire set of interview transcripts. Individual codes or labels generated from the interview transcripts were then grouped according to how they related. Coded data were then reviewed to identify areas of similarity and overlap. Those that were similar and described the same activity were clustered under one umbrella to reflect a coherent pattern in the data and were noted as a "theme." The supporting coded areas that further explained the theme were also noted as "sub-themes." The potential themes were further reviewed in relation to the individual transcripts. Also, the collated extracts were cross-checked against the themes generated. The themes generated were further defined and possibly renamed following a review of the interview transcripts.

An experienced qualitative researcher also independently coded the same interview transcripts. Following the coding process, a meeting was held to compare results and discuss the codes, sub-themes, and themes that emerged from the data analysis. The agreed-upon themes and sub-themes were then organized into a table format, which contained the study's

findings and served as the foundation for the discussion. Individual interview findings are presented in detail in Chapter 5.

3.3.3 Step 2: Objective 3- Individual Interview with ICU physicians

This step addressed the objective 3 of the study that was to explore physicians' experiences on providing care for patients after treatment withdrawal in the ICU. The summary of potential items and themes drawn from the interview findings informed the development of the instrument in Phase 2. Detailed findings from the interviews are presented and discussed in Chapter Five.

3.3.3.1 Research design

An exploratory, descriptive qualitative design was used.

3.3.3.2 Study population and sampling

The study population comprised qualified specialist doctors working in the adult ICUs at the study setting. A non-probability sampling, namely purposive sampling, was used to sample doctors from the selected ICUs. These physicians had a wide range of experiences of managing the critically ill and dying patients in the ICU and were involved in the EOL decision making process. Participants were selected on the basis they were working in the ICU at the time of the study, willing to share their views on the topic under study and also met the inclusion criteria. The inclusion criteria are summarised as:

- A registered physician with more than 5 years of clinical experience
- Provided end of life care to patient and family
- Witnessed treatment withdrawal in the intensive care unit
- Have made a decision to withdraw treatment or been a part of a team that made the decision to withdraw treatment in the ICU
- Working in the adult ICU at the time of the study

Sample size: The number of individual interviews conducted depended on the saturation of information which was reached when themes and categories in the data become repetitive or redundant, such that no new information was collected (Polit & Beck, 2017:743).

3.3.3.3 Data collection method and procedures

In this study, information from participants was gathered through individual interviews. After obtaining written permission and ethical clearance from relevant authorities (**Appendices AA, AB & AC**), the researcher also sought verbal permission from the ICU consultant and unit manager. The purpose and procedures of the study were explained in detail to the ICU consultant prior to obtaining verbal permission to conduct the interviews. During one of their routine morning ward rounds, the ICU consultant offered the researcher the opportunity to explain the purpose and procedures of the study to the attending physicians on duty and invited them to participate in the study.

The researcher also approached some experienced physicians during their routine case reviews and ward rounds to further invite them to participate in the study. After each interaction, copies of the study information letter were given to each physician (A**ppendix F**). Participants who showed interest and were willing to participate in the study were requested to sign the consent form (**Appendices G & H**) to serve as proof of consent to participate in the study before being interviewed. They were also requested to provide their contact details for follow-up on the venue and time for the interview. Appropriate arrangements were made with interested participants for their preferred time of convenience and venue for the interview. A quiet doctors' rest room close to the ICU was agreed upon between the researcher and participants to be used for the interviews. All the participants preferred to undertake the interview during their ICU shift.

A day before each interview, the respective participant was reminded via a telephone call. The space dedicated for the interview in the study setting was also arranged prior to the interview. At all times, the researcher followed the COVID-19 protocol prior to and during the interviews. On the day of the interview, the researcher reminded participants of the purpose and procedures of the study. Each participant was assured that their names would not be used during the findings presentation. Instead, alphabets and numbers will be used to protect their identities. At every interview session, a notice was posted on the door to indicate

that an interview was in progress. Each participant was required to sign an additional consent for voice-recording the interview (**Appendix H**) and also complete some demographic data (**Appendix J**). The researcher used a self-prepared interview guide (**Appendix I**) to guide the interview session. The interview began with one broad question and was followed by probes to keep the interview focused. Both the researcher and interviewee encouraged each other to speak louder due to the face mask.

The interview session lasted for between 25 and 40 minutes. Interviews were conducted until no new information emerged, indicating data saturation level (Polit & Beck, 2017). The researcher also took field notes to further enhance the meaning of the information gathered. During and at the end of each interview, the researcher frequently repeated and summarized the participant's words to ensure that the data captured was a true reflection of what the participant intended to say. Again, at the end of each interview, the researcher thanked the participant for their participation in the study. Participants were also informed that the transcribed interviews would be kept on a password-protected computer and that the interviews would be brought back for validation.

- Pilot study

A pilot test was conducted a week before the actual data collection to identify potential pitfalls, avoid poor interviewing techniques, and prevent inappropriate interaction. One individual was selected to conduct pilot testing, which included piloting the main question as well as some probing questions. A colleague with experience conducting interviews evaluated the transcripts and audio recording. The objective was to determine if significant changes were required for subsequent interviews, and if so, the data from the initial interview would be discarded. As only minor adjustments were necessary, the data were analyzed as part of the study.

3.3.3.4 Data analysis

The data analysis software MAXQDA Plus 2020 was used, as well as Braun and Clarke's (2006) thematic analysis. All of the interviews were transcribed verbatim. The researcher read the interview transcripts several times to fully comprehend the participants' accounts. Field notes taken during the interviews were also added to help make the information

gathered more meaningful. Thematic analysis by Braun and Clarke was used to provide a systematic procedure for data analysis (Braun & Clarke, 2006). To fully immerse himself in the data, the researcher read the interview transcripts thoroughly and repeatedly. During the reading, data meanings, patterns, and coding ideas were scribbled on a piece of paper. The method assisted the researcher in becoming acquainted with the breadth and depth of the content.

The interview transcripts were then imported into the MAXQDA software. The imported transcripts were further read once again prior to coding. The meanings, patterns, and text extracts identified during the repeated readings were assigned as initial codes generated from the data. Important sections of the text were assigned labels to describe or represent that particular text in the transcript. The generation of initial codes was done for all the interview transcripts, giving equal attention to each transcript. The procedure was repeated for each transcript and for the entire set of interview transcripts. Individual codes or labels generated from the interview transcripts were then grouped according to how they related. Coded data were then reviewed to identify areas of similarity and overlap. Those that were similar and described the same activity were clustered under one umbrella to reflect a coherent pattern in the data and were noted as a "theme." The supporting coded areas that further explained the theme were also noted as "sub-themes." The potential themes were further reviewed in relation to the individual transcripts. Also, the collated extracts were cross-checked against the themes generated. The themes generated were further defined and possibly renamed following a review of the interview transcripts.

An experienced qualitative researcher also independently coded the same interview transcripts. Following the coding process, a meeting was held to compare results and discuss the codes, sub-themes, and themes that emerged from the data analysis. The agreed-upon themes and sub-themes were then organized into a table format, which contained the study's findings and served as the foundation for the discussion. Individual interview findings are presented in detail in Chapter 5.

3.3.5 Step 2: Objective 4- Semi-Structured Interviews with Family Members

This section of phase one of the study focuses on the step 2 of the instrument development and validation process and addresses objective 4 of the study. The interview sought to

explore the experiences of families who have been a relative of a patient with treatment withdrawn in the ICU. Individual interviews were carried out with seven (n=7) bereaved family members who had their relatives receiving end-of-life care in the adult ICU.

3.3.5.1 Research design

An exploratory, descriptive qualitative design was used.

3.3.5.2 Study population and sampling

The study population consisted of all family members who had relative admitted in the adult ICU, visited their relative more than once and had been bereaved in the last 6 months to 1 year. A purposive sampling approach was used to select potential participants based on a set inclusion criteria. Participants were selected on the basis that they were willing to share their experiences on the topic under study and also met the inclusion criteria. The inclusion criteria are summarised as:

- Had a relative of an admitted patient in the ICU, had treatment withdrawn and died in the ICU
- Bereaved in the last 6 months or more
- Adult relative (parent, sibling, spouse) above 18 years
- Fluent in English
- Willing to share his or her experience

Sample size: The number of individual interviews conducted depended on the saturation of information which was reached when themes and categories in the data become repetitive or redundant, such that no new information was collected (Polit & Beck, 2017:743).

3.3.5.3 Data collection method and procedures

The data was collected through individual interviews. Following ethics approval and written permission to conduct the study from the relevant authorities (**Appendices AA, AB, and AC**), the researcher had a thorough discussion with the ICU manager on the purpose and procedures of the study. A verbal permission was obtained from the unit manager and shift

leader to access the ward register of patients admitted to the ICU, the patients' ICU chart, and other admission notes, as well as speak to the patients' families.

The researcher, who is also an ICU-trained nurse, routinely joined the ICU ward rounds. During the ward rounds, patients with a poor prognosis, an increased risk of death, and information on their ICU chat such as "patient not for further escalation, family counseled, and futility of care" were identified. The researcher further contacted the attending physician to confirm the plan and expressed interest in being part of the team that routinely counseled the family together with the attending physician. The attending physicians on duty on those days were always briefed on the purpose and procedure of the study. Patient particulars, together with the name and contact details of regular visiting family members, were taken with permission from the unit manager and attending ICU physician. During the counseling session with the patients' families, the researcher, with the assistance of the attending physician, explained the purpose and procedures of the study to them and sought verbal permission if they wanted to be followed up and be part of the study after 6 months or more. Family members that agreed to be contacted after 6 months were noted. An information sheet that explained the purpose and procedures of the study was also given to them (**Appendix K**). A reliable contact details and email address of an identified and preferred family member, as agreed by the family members, was obtained. Family members' recruitment for the study took place between October 8 and December 10, 2021.

The researcher routinely worked in the ICU during the data collection period and constantly checked on the patients and their families. With the assistance of the attending physicians and unit managers, counseling sessions were frequently arranged for the families to help them cope with the situation. The researcher was often present to speak to them and create further therapeutic relationships with the families until the end of their relatives' lives. This made it easy to follow up with the families after the death of their relatives in the ICU. The researcher constantly checked up on the family members via phone calls following the deaths of their relatives.

In the first week of June 2022, the researcher called the families who had agreed to take part in the study to remind them about it. Again, the information sheet was handed out to those that were close and within Johannesburg, and the others were shared via their emails (**Appendix K**). Family members who agreed and were willing to share their experiences

were followed up with in the second week of June 2022 to make further arrangements for the interviews. Family members that were close to the hospital agreed to be interviewed in their homes or at an arranged place that was favorable to them. Alternatively, others indicated that an online session worked best for them due to the COVID-19 pandemic. The majority of family members preferred the online platform due to the COVID-19 resurgence and its related restrictions and precautions.

A day before each interview, the respective participant was reminded via a telephone call. The researcher also shared the information sheet (**Appendix K**), demographic data form (**Appendix O**), and informed consent sheet (**Appendix L**) with participants via email to complete. A Microsoft Teams link with family members' preferred schedule times was also sent to participants. The Ms Teams was the university's official online platform that was well-protected with double encryption. Hence, participants' information was kept confidential. Due to the sensitive and emotional nature of the interview, a qualified psychologist was involved, and appropriate referrals were made prior to the interview. Participants were informed that the psychologist was always ready and willing to provide support should the need arise.

On the day of the interview, the researcher reminded participants of the purpose and procedures of the study. A verbal consent to proceed with the interview and to record the session was obtained before the online interview as a proof of consent to participate in the study before being interviewed. Each participant was assured that their names would not be used during the findings presentation. Instead, alphabets and numbers will be used to protect their identities. Each participant was also required to sign an additional consent for voice-recording the interview (**Appendices L & M**) and complete some demographic data (**Appendix O**). The researcher used a self-prepared interview guide (**Appendix N)** to guide the interview session. The interview began with one broad question and was followed by probes to keep the interview focused. Both the researcher and interviewee encouraged each other to speak louder due to the online recording. Participants were encouraged to feel free to pause for a moment and continue at any time. An experienced psychologist joined the sessions to provide support for the participants.

The interview session lasted for between 25 and 35 minutes. Interviews were conducted until no new information emerged, indicating data saturation level (Polit & Beck, 2017). The

researcher also took field notes to further enhance the meaning of the information gathered. During and at the end of each interview, the researcher frequently repeated and summarized the participant's words to ensure that the data captured was a true reflection of what the participant intended to say. Again, at the end of each interview, the researcher thanked the participant for their participation in the study. Participants were also informed that the transcribed interviews would be kept on a password-protected computer and that the interviews would be brought back for validation.

3.3.5.4 Data analysis

The interviews were transcribed verbatim. The data were analyzed using Braun and Clarke's (2006) thematic analysis approach. The qualitative software MAXQDA Plus 2020 aided in the data analysis process. The procedure followed the procedures outlined in the preceding section (refer to Section 3.4.3.4 of Chapter 3).

The findings of the interviews are presented in Chapter Five.

3.3.6 Methodological Rigour of the Qualitative Study

Measures of trustworthiness are crucial aspects of the rigor of qualitative research. The four criteria for developing the trustworthiness of qualitative studies recommended by Lincoln and Guba (1985) were used in this study to ensure methodological rigor. Holloway and Wheeler (2010:302) explain trustworthiness in qualitative research as "methodological soundness and adequacy". The four aspects of trustworthiness are credibility, dependability, confirmability, and transferability.

3.3.6.1 Credibility

Credibility refers to the confidence in the truth of the study findings and how they are interpreted (Polit & Beck, 2017:559). It relates to the notion of internal validity. Polit and Beck (2017) and Holloway and Wheeler (2010) state that member checking, reflexivity, prolonged engagement, persistent observation, data triangulation, audiotaping, and verbatim transcription are measures used to ensure credible findings.

In this study, credibility was ensured by the research through prolonged engagement. The researcher spent enough time with participants in their natural setting to learn about the environment, establish rapport, and build a trusting relationship. The researcher also frequently summarized and repeated the participant's words to ensure that the interpretations were a true or false representation of their perspective. Audiotapes of each interview were listened to several times during data transcription and were transcribed verbatim. The field notes gathered were combined with the transcribed interviews during data analysis.

3.3.6.2 Dependability

Dependability, an alternative to reliability, refers to the stability of the data over time and under various conditions. If the findings of a qualitative study are to be dependable, they should be repeated if they were replicated with similar participants in a similar context (Holloway & Wheeler, 2010; Polit & Beck, 2017). Thus, the readers should be able to judge the adequacy of the analysis by following the researcher's decision-making processes. Holloway and Wheeler (2010) state that an audit trail is necessary to achieve dependable findings. Thick description as recommended by Polit and Beck (2017) is also linked to the audit trail. To ensure this, the researcher provided a detailed report of the processes involved in the study. This included a description of the research design used to achieve the study purpose, research questions, and objectives, a detailed explanation of the data collection procedures; and a thorough description of the study setting. Study participants were given the opportunity to go through the study information sheet and were required to sign the consent form to confirm their willingness to participate in the study. An experienced qualitative researcher and co-coder assisted during data analysis, and the emerging codes and themes were compared.

3.3.6.3 Confirmability

Confirmability refers to the objectivity of the data (Polit & Beck, 2017:560). This measure of trustworthiness guarantees that study findings represent a true reflection of the information provided by participants and that the data interpretations are not based on the researcher's preconceived assumptions and perspectives. Polit and Beck (2017) and Holloway and Wheeler (2010) state that audit trails and triangulation of methods are some of the strategies to ensure confirmability. To ensure this, the researcher kept an audit trail to

help readers trace the source of the data. Interviews were transcribed verbatim. The audio recordings were listened to several times and compared with the transcribed data to ensure that participants' voices were correctly captured. Field notes were also written after each interview. During and after each interview, the researcher presented a summary note to the participants to ensure that their information was captured correctly.

3.3.6.4 Transferability

Transferability refers to the extent to which findings can be transferred to similar situations or be applicable in other settings (Polit & Beck, 2017:560). For Holloway and Wheeler (2010:303), the knowledge acquired in one context should be relevant in another. This was achieved by providing a sufficient description of the study design, sampling methods, and inclusion criteria set by the researcher. A vivid description of the fieldwork, study setting, and study participants were provided in detail to enhance the applicability of the study.

3.4 PHASE TWO: INSRUMENT DEVELOPMENT AND VALIDATION

The outcome of phase two of the study was to develop a provisional measurement instrument informed by the findings from the review of literature and qualitative interviews of phase one and determine the content and face validity of the instrument. The five-step approach to instrument development and validation as outlined by Lynn (1986) and Zamanzadeh *et al*. (2015) was followed to develop the instrument and assess the content and face validity of the instrument. In phase 2, the researcher followed steps (3, 4, and 5) and addressed objectives 5, 6, and 7 of the study, as shown in **Table 3.1**.

3.4.1 Step 3: Objective 5 - Instrument Development

Following the identification of content domains of a construct and the generation of items from literature and qualitative interviews, the next step is to develop the instrument into a usable format (Lynn, 1986; Zamanzadeh *et al*., 2015). This part of Phase 2 addresses Objective 5 of the study, which seeks to develop a provisional instrument through the integration and synthesis of findings from the review of literature and qualitative interviews conducted in Phase 1. The sections below unfold how the instrument was constructed and developed into a usable form.

3.4.1.1 Provisional instrument construction

The findings from phase one (scoping review and qualitative interviews) informed the development of the provisional instrument. The domains identified and items generated through the scoping review and qualitative interviews with nurses, physicians, and families provided the blueprint for developing the instrument items. The summary of domains and potential items derived from the scoping review (**Table 4.6**), nurses interviews (**Table 5.3**), interviews with specialist physicians (**Table 5.5**), and family interviews (Table 5.8) were integrated (**Table 6.1**) for further content analysis. The total numbers of domains and items generated after the integration then underwent further refinement and reduction by a research team that consisted of the principal researcher, the supervisor, and an EOL content expert (AH). The instrument development guidelines highlighted by Boateng et al. (2018), Morgado *et al*. (2017), Kalkbrenner (2021), and Zamanzadeh *et al*. (2015) were applied to ensure the enhancement and quality of the new instrument.

3.4.1.2 Instrument construction, item reduction and refinement

A total of 143 items organized under different domains and sub-themes (**Table 6.1**) underwent further construction, reduction, and refinement. A research team that comprises the researcher, supervisor, and one content expert met to discuss and revise the list of items and domains generated in phase one. At the first meeting, the domains and sub-themes identified from the scoping review and the qualitative interviews were compared and contrasted to identify similarities and differences. Each team member independently reviewed the lists of domains, sub-themes, and items. The goal was to agree on the domains and subsequently arrange relevant items under each domain. Any disagreement was resolved following a thorough discussion and relevant information from the research literature. The team also placed emphasis on existing literature on quality indicators for EOL care in the ICU and treatment withdrawal guidelines and recommendations to validate the domain similarities in the literature. Following a series of reviews, the working domains were identified from the list of domains. The team further ranked the domains in order of priority according to how the treatment withdrawal process takes place in the adult ICU.

The next task of the team was to agree on 143 items from **table 6.1** that best fit under the domains agreed. Again, each team member (EK, SS, and AH) independently created their

own list of potential items. The research team edited and reduced the list by looking for repetitions, the wording of items, and overlapping. Another meeting was scheduled to review and discuss each team member's list of items and eventually come to consensus about the initial pool of items that will be sent to the expert reviewers.

Following further refinement, reduction, and item analysis, the first version of the new instrument (**Table 6.2**), which consisted of 65 items organized under 7 domains, underwent expert panel review via a Delphi study to assess the content and face validity (Chapter seven).

3.4.2 Step 4: Objective 6 - Instrument Validation: Content validity Testing

This part of phase two seeks to determine the content and face validity of the instrument. It follows steps 4 and 5 and addresses objectives 6 and 7, as shown in **Table 3.1**. Lynn (1986) and Polit, Beck, and Owen (2007) term this part as the judgment-quantification stage, where a group of experts is invited to determine the adequacy with which relevant content domains have been included in the instrument and the extent to which the instrument was developed to measure a particular concept of interest. Validity is commonly defined as the extent to which an instrument measures what it intends to measure (Harley *et al*., 2009). In the development and testing processes for any newly developed instrument, establishing content validity is extremely important. Content validity provides evidence about the degree to which an assessment instrument has appropriate elements and sample items that are relevant to and representative of the targeted construct of interest (Almanasreh, Moles & Chen, 2019; Polit, Beck & Owen, 2007). Content validity can be established using either qualitative or quantitative methods, or a combination of both (Zamanzadeh *et al*., 2015). Evidence supporting the content aspect of the validity of an instrument may be gathered using an expert review process. This involves collecting feedback from a panel of experts who are knowledgeable of either the construct of interest or the target population of the instrument. While a specific number of experts has not been established, prior research has recommended a range of five to ten experts as sufficient, particularly when aiming to quantify content validity (Lynn, 1986; Zamanzadeh *et al*., 2015).

3.4.2.1 Research design

A methodological research design guided the instrument validation part of Phase 2. Methodological designs involve "assessment of content validity, evaluation of the conceptual structure of a scale, construct validity, and assessment of reliability" (Grove, Burns & Gray, 2013:255). The instrument validation process was achieved using the Delphi technique. The Delphi technique has been described as a method for soliciting judgment or seeking consensus from experts in which they identify the nature and fundamental elements of the studied phenomenon (Polit & Beck, 2017: 222). A two-round Delphi was conducted using expert reviewers to assess the content validity of the instrument.

3.4.2.2 Content validity testing

Content validity refers to the degree to which an assessment instrument is relevant to and representative of the targeted construct it is designed to measure (Almanasreh, Moles & Chen, 2019; Polit, Beck & Owen, 2007). Content validity testing includes an assessment of the relevance, representativeness, and clarity of the items measuring a particular construct. In this study, the construct is the quality of care after the withdrawal of treatment in the adult intensive care unit.

- Population, sample and sample technique

The target population consisted of experts in the fields of critical care medicine and nursing. A purposive sampling technique was employed to invite experts in critical care practice who are knowledgeable about EOL care and have experience with treatment withdrawal in the adult ICU. In determining the content validity of an instrument, Lynn (1986) and Zamanzadeh *et al*. (2015) recommend between 5 and 10 experts. This number of experts is considered appropriate to control the probability of chance agreement; as the number of experts' increases, the probability of chance agreement decreases. In this study, nine (9) experts were used during the instrument validation process.

Inclusion criteria: In the recruitment of a panel of content experts to review and critique the content of an instrument, Grant and Davis (1997) recommend well-defined criteria such as qualifications, experience, clinical expertise, and relevant training of the content experts.

Onwuegbuzie, Bustamante, and Nelson (2010) also consider the use of local experts and key informants as an important part of the item-writing and validation processes to draft a culturally sensitive instrument. Additionally, the inclusion of experts from different geographical locations also increases the chance of identifying colloquial terms inappropriate for an instrument (Grant, Kinney, & Guzzetta, 1990). In this study, both local and international experts were included. The selection of expert panel members was based on the following criteria:

- A critical care nurse with at least a master's degree in critical care nursing
- A nurse with a critical care specialty working in an academic hospital
- A critical care lecturer at a University
- A critical care nurse practising in an adult ICU with more than 10 years of bedside experience and involved in the care of critically ill and dying patients
- A critical care nurse actively participating in end-of-life care research
- A specialist physician working in the ICU

Exclusion criteria: Experts who do not fall under the above criteria were excluded

3.4.2.3 Data collection and content validity procedure

Using the Delphi technique, consisting of two consecutive rounds, the content validity of the first version of the instrument was determined. Prior to the data collection and content validity processes, the researcher and supervisor decided on the list of potential experts that would be included in the validation process. The inclusion criteria guided the process. The emails and cell phone numbers of the respective content experts were obtained through the personal relationships the researcher and supervisor had with some of the experts.

Initially, an invitation letter was sent to all the potential content experts via their email addresses, requesting their participation as experts to review the first version of the instrument developed (**Appendix P**). An information sheet (**Appendix Q**) was also attached that explained the phases of the study, how the first version of the instrument was developed, and what is expected of the review experts. After a positive response from 10 experts to participate in the two-round Delphi study, the information kit, which included an information sheet (**Appendix Q**), an informed consent form (**Appendix R**), an expert demographic data

form (**Appendix S**), and a copy of the developed instrument (**Appendix T**), was sent via email to the panel of experts. The information sheet contained the purpose of the study, a brief description of the instrument, instructions and assessment criteria for completing the content validity assessment. Again, the conceptual and operational definitions of the instrument domains were provided to the panel of experts as a guide in their assessment.

The panel of experts was requested to assess the content validity of the instrument domains and items using a 4-point scale recommended by Lynn (1986). The rating criteria evaluate the instrument based on the clarity of the items measuring the construct and their relevance to measuring the construct the instrument intends to measure. The rating criteria attached to the information kit sent to the panel of experts is shown below.

The 4-point rating scale (Lynn, 1986)

Criteria for measuring the content validity (Relevance/ Clarity)	
Relevance	**Clarity**
1 [not relevant and should be deleted]	**1** [Not clear and should be deleted]
2 [Item needs major revision]	**2** [item needs some revision]
3 [Relevant but needs minor revision]	**3** [clear but needs minor revision]
4 [very relevant]	**4** [very clear and concise]

The expert panel review for the content validity assessment of the instrument was achieved using a two-round Delphi study.

- **Delphi round one: review of first version of the instrument**

In round one of the Delphi, the first version of the instrument (**Appendix T**), which consisted of 65 items organized under 7 content domains, was emailed to the panel of 9 experts that agreed to participate in the study. The information sheet package (**Appendix T**) included instructions for completing the instrument, criteria for rating items based on clarity and relevance, and conceptual and operational definitions of the domains. A panel of experts was required, based on their expertise, to assess the clarity and relevance of each item under the respective domains. A comment section was provided against each item for their suggested revisions and comments. An overall comment box was also provided for their final comments on the first version of the instrument as well as items not covered but relevant for

the study. The various comments and suggested revisions from the experts were used to refine the instrument.

- **Delphi round two: review of second version of the instrument based on comments from round one**

The first version of the instrument was changed after the panel of experts from round one sent back their ratings of domains and items and their comments. On clarity, the various suggested comments on the wording, technical errors, and arrangement of items were incorporated to eliminate ambiguous terms, complex items, and difficult items that may confuse target respondents. Items were revised or discarded based on the comments provided. The researcher and supervisor thoroughly discussed the comments to ensure the methodological rigor of the process. The experts' ratings on the clarity and relevance of the items were also used to guide the revision or rejection of the items.

For each item in the seven domains, the item content validity index (I-CVI) was calculated. The researcher computed the I-CVI of all 65 items using the experts' ratings of item relevance. To obtain the content validity index of each item (I-CVIs), the number of experts who rated the item as 3 or 4 was divided by the total number of experts. On the item relevance side, the I-CVIs were used to include, revise, and delete items. As proposed by Davis (1992) and Abdollahpour *et al*. (2010), the judgement on each item's content validity (I-CVI) was made as follows: if the I-CVI was higher than 0.79 or 79 percent (i.e., 80 percent agreement or higher), the item was considered relevant and clear. If the I-CVI was between 70 percent (0.70) and 79 percent (0.79), the item needs revision; if it was less than 70 percent (0.70), the item was eliminated.

The revisions, comments, and I-CVIs based on item clarity and relevance informed round two. In round two, all revised items that scored I-CVIs less than 0.80 were returned to the panel of experts for further rating using Lynn's (1986) relevance rating criteria (**Appendix V**). Items, including those that were revised and had I-CVIs of 0.80 or higher, were considered relevant. Additionally, new items suggested for inclusion by experts in round one were also returned to the panel of experts in round 2 for further assessment on clarity and relevance. The panel of experts was also requested to indicate the particular domain under

which the new items fall in addition to the ratings. Comment sections were also provided for any input.

Finally, in round two, the panel of experts was requested to indicate with a "yes" or "no" for each domain and the overall instrument the extent to which they agreed the domain and its items were complete and comprehensive for the domain and overall instrument (**Appendix V**). The comments, ratings, and responses on the comprehensive of the domain and items from round two of the Delphi were incorporated into the third and final version of the survey instrument.

Methodological rigor for the Delphi study: The developed instrument for the Delphi study (**Appendix W**) was informed by the findings from phase one of the study. The instrument was developed and reviewed by the researcher, supervisor, and an external content expert before being sent out for expert review. Thorough discussions and a series of meetings took place during the item pooling to ensure a good representation of each item under the respective domains.

During each round of the Delphi, the researcher and supervisor discussed the responses and made necessary changes according to the comments from the expert panel. If there were any discrepancies, a meeting was set with the expert to resolve them. An instrument development expert and an experienced statistician were consulted during the calculation of the I-CVIs to enhance the rigor of the study.

3.4.2.4 Data analysis

There is no one way to measure the content validity, nor is there a single statistical method. A number of quantitative indices for two or more rates have been suggested (Yaghmale, 2009). Amongst them are content validity-related estimates such as the content validity ratio, the content validity index (CVI), and the modified Kappa statistic. Although the content validity index (CVI) is the most widely used method of quantifying content validity for multi-item scales, it does not consider the possibility of inflated values because of chance agreement (Polit *et al*., 2007). In content validity quantification, Wynd *et al*. (2003) propose both a content validity index and a multi-rater kappa statistic. Unlike the CVI, the modified

kappa statistic provides information about the degree of agreement beyond chance (Polit *et al*., 2007). In this study, the content validity index (CVI) and modified Kappa statistics were performed.

- Content validity indexes (CVIs)

Item-level CVI (I-CVI) and scale-level CVI (S-CVI) were estimated. The item content validity index (I-CVI) expresses "the proportion of agreement on the relevancy of each item, which is between 0 and 1" (Lynn, 1986). The CVI for each item (I-CVI), average individual content validity index (I-CVI/Ave), scale level content validity index (S-CVI), and average scale content validity index (S-CVI/Ave) were estimated. To estimate the item content validity index (I-CVI), the number of experts who rated the item as 3 or 4 was divided by the total number of experts. In this study, nine experts were involved in the Delphi study. For example, if all nine experts rate an item as 3 or 4 using the rating scale, then the I-CVI for that item will be: 9/9 = 1.00. A content validity index of 0.80 or higher is considered good for new instruments (Davis, 1992). The average I-CVI for a domain was also estimated as the sum total of all the I-CVIs divided by the number of items under the domain.

Scale level CVI (S-CVI) refers to *"the proportion of items on an instrument that achieved a rating of 3 or 4 by the content experts"* (Beck & Gable, 2001) or "*the proportion of total items judged content valid*" (Lynn, 1986:383). The S-CVI calculates the content validity of the overall scale. It is calculated using two methods. One method requires universal agreement among experts (S-CVI/UA), and the other method averages the item-level CVIs (S-CVI/Ave). To calculate S-CVI/UA, the total number of I-CVIs equal to one (I-CVI=1) is divided by the total number of items on the scale. The S-CIV/Ave is also the sum of all the I-CVIs divided by the total number of items. A universal agreement among experts (S-CVI/UA) of 0.80 or higher and an average approach (S-CVI/Ave) of 0.9 or higher demonstrate excellent content validity.

- Modified kappa

Kappa provides a degree of agreement beyond chance (Polit *et al*., 2007). It is calculated as: K= (I-CVI - Pc)/ (1- Pc), where Pc = [N! /A! (N-A)!]* 0.5N (Zamanzadeh *et al*., 2015). In the formula, Pc = probability of chance agreement; N = number of experts; and A =

number of experts that agree the item is relevant. Kappa scores above 0.74 are considered excellent, 0.60 to 0.74 good, and 0.40 to 0.59 fair (Zamanzadeh *et al*., 2015).

3.4.3 Step 5: Objective 7- Instrument Validation: Face Validity Testing

Face validity is also a component of content validity. Haynes, Richard, and Kubany (1995) define face validity as the "degree that respondents or end users [or lay persons] judge that the items of an assessment instrument are appropriate to the targeted construct and assessment objectives". It is an empirical assessment that focuses on the appearance and attractiveness of an instrument in addition to the soundness of the construct (Almanasreh, Moles, & Chen, 2019; Zamanzadeh *et al*., 2015). It is neither quantifiable nor considered important in psychometric testing, but it contributes to the validation of an instrument. The face validity of the instrument was assessed by asking the panel of experts to comment on the content with regard to coverage of the domains of interest and to suggest the addition, deletion, and revision of the individual items (Grant & Davis, 1997; Lynn, 1986; Polit *et al*., 2007). The experts were also asked to provide feedback on the survey instrument's readability, style, formatting, and clarity of language.

The instrument validation was achieved via the use of a Delphi technique or study.

3.5 ETHICAL CONSIDERATIONS

The researcher took several steps to reduce the potential risk when dealing with human subjects. Ethical considerations are discussed under the following headings: Institutional permission, informed consent, and anonymity and confidentiality.

3.5.1 Institutional Permission

Before beginning the project, the postgraduate research committee reviewed the research study and title and approved them (**Appendix AC**). The Postgraduate and Human Research Ethics Committee (Medical) of the University of the Witwatersrand was also consulted for approval and permission to do the study from an ethical point of view (**Appendix AA; No. M210229**). The Chief Executive Officer of the place where the research was conducted was also asked for written permission and an ethical clearance (**Appendix AB, No.**

GP_202107_010). The researcher also got verbal permission from the ICU consultant, the managers of nursing services, and the unit managers of each ICU.

3.5.2 Informed Consent

The researcher obtained written informed consents from nurses (**Appendices B & C**), physicians (**Appendices G & H**) and family members (**Appendices L & M**) before the individual interviews and audio-recordings and also from the panel of experts (**Appendix R**). An information sheet that explained the purpose and procedures of the study was always provided prior to all participants signing the consent forms (**Appendices A, F, K & Q**). The researcher also obtained separate written informed consent from participants prior to audio-recording interviews (**Appendices C, H & M**). For the online interviews, verbal consent was obtained before the interview session. Letters of invitation were also sent to the respective experts that were included in the study (**Appendix P**).

3.5.3 Anonymity and Confidentiality

Interviews were conducted in a separate private room chosen by participants at their convenience. All participants were assured in writing of the study's confidentiality. No names or identifying characteristics were mentioned in the study, and care was taken to protect the anonymity of the participants. The qualitative results were reported using pseudonyms [N1–N16, D1–D9, and F1–F7] to maintain participants' anonymity (nurses, doctors, and family members). Participants were also assured of their unrestricted right to withdraw from the study at any time. The data were always kept under lock and key, with the intention of destroying them once the thesis was complete. As such, raw data will be locked up and stored with the research supervisor for a period of five years, after which it will be destroyed. The analyzed data will be stored in computer files that are password-protected and known only to the researcher.

3.6 SUMMARY

This chapter describes the research methodology used to answer the research question and meet the study objectives. The study's purpose was to develop an instrument for measuring the quality of care provided to patients and their families after the withdrawal of treatment

in the adult ICU. The chapter also presented detailed descriptions of the phases of the study and how each phase was achieved. The chapter ended with the ethical considerations applicable to this study and how these were managed.

In the next chapter, the researcher focuses on Phase 1 of the study and presents findings from the scoping review.

CHAPTER FOUR
PHASE 1: DOMAIN IDENTIFICATION AND ITEM GENERATION SCOPING REVIEW

4.1 INTRODUCTION

The chapter focuses on Phase one of the study and presents findings from the scoping review. The chapter begins with a brief description of the scoping review approach, followed by the outcome of the review and the review question that guided the scoping review. The chapter also presents the inclusion and exclusion criteria, information sources and search strategy, selection of study, data extraction, and synthesis of data. The chapter presents the findings that emerged from the scoping review. The chapter ends with a summary of the key findings that emerged from the review, discussions of the review findings, and a summary of the chapter.

4.2 SCOPING REVIEW

A scoping review is an approach used to identify, map, and summarize existing scientific evidence on a particular subject of interest in the literature. It is also used to clarify working definitions, note knowledge gaps, and identify characteristics related to a concept (Tricco *et al*., 2016). In instrument development, one of the suitable steps for domain identification and item generation is a thorough review of existing literature (Boateng *et al*., 2018). A scoping review was suitable to scope the extent of literature on the area of interest and identify characteristics related to the concept under study.

In improving the current intensive care experience, the perspectives of the providers (healthcare providers) and consumers of health care (patients and their families) are vital in shaping the quality of care desired (Latour *et al*., 2022). As part of domain identification and item generation, it was important to summarize the scope of scientific literature on the perspectives of patients, family members, and healthcare providers on providing quality care at the EOL through a scoping review. The review was guided by the Joanna Briggs Institute (JBI) methodological framework and reported according to the PRISMA-ScR guidelines (Peters *et al*., 2020; Tricco *et al*., 2018). The outcome of this review provides rich background information and a scientific foundation for the development of an appropriate

instrument to measure the quality of care after treatment withdrawal in the adult ICU in Phase two.

4.2.1 Review Objective and Question

The review's objective was to identify and synthesise the available evidence from the perspectives of patients, family members, and healthcare providers on providing quality care for patients at the EOL and their families in the intensive care unit. The following review question guided the review:

"What are the perspectives of patients, family members, and healthcare professionals on providing quality care for patients at the EOL and their families in the ICU?"

4.2.2 Inclusion and Exclusion Criteria

In the inclusion and exclusion criteria formulation, the PCC mnemonic (Peters *et al.*, 2020) guided the review. The PCC mnemonic refers to Population (participants), Concept and context.

Population (P): Patients, family members and healthcare professionals (nurses/physicians)

Concept (C): Perspectives on providing quality care and good death at the end-of-life

Context (C): International studies (Qualitative, quantitative and mixed-methods) conducted in the adult ICU or hospital that focused on care for patients at the end of life or the palliative care phase. Details of the inclusion and exclusion criteria shown in **table 4.1**.

Table 4.1: Eligibility criteria for scoping review

Inclusion	Exclusion
- Peer-reviewed published primary research - Studies published from 1999 - Studies published in English - Studies that focused on the care of patients in the palliative phase - Studies conducted in the Adult ICU - Studies conducted in the hospital that focused on patients at the end of life, palliative and end-of-life care	- Grey literature, Existing review studies, guidelines, commentaries, and expert opinions - Studies in other languages - Studies that focused on acute care - Studies conducted in paediatric and neonatal ICU - Studies conducted outside the hospital setting

4.2.3 Information Sources and Search Strategy

The reviewers used the three-step search strategy recommended by the Joanna Briggs Institute (Peters *et al*., 2020). Five electronic databases, namely SCOPUS, PubMed, CINAHL, SCIENCE DIRECT and MEDLINE, were searched electronically to identify existing literature published in English since January 1999. The rationale for choosing this date was because the concept "end-of-life care" and ways of improving the care have been extensively researched since the 1990s. The first study focused on patients' perspectives on what matters at the end of life and was published in 1999. At the time of data gathering, most of the grey literature relevant to the subject had been published; hence, only peer reviewed studies were included.

An initial search was conducted using databases: PubMed and CINAHL, using the JBI search strategy, to identify Mesh terms, subject headings and index terms capable of conducting an exhaustive search in the other included databases. A specialist librarian (DV) was consulted when developing the search strategy. A second comprehensive computerized database search was conducted using the identified keywords and index terms across all four selected databases. Reference lists of the retrieved literature were then screened for possible articles for inclusion. In this review, no particular author was contacted for specific studies. Data gathering started in July 2020 and ended in November 2020.

The search terms and main concepts that guided the review are displayed in the figure below. These were generated after thorough consultations with an experienced librarian. During the literature search, the Boolean terms (AND, OR, and NOT) were used to combine the search terms.

-End-of-life care / terminal care / palliative care / withdrawal of treatment
-Quality of care / Quality of health care / Good death
-Patients / family members / healthcare professionals / *nurses
-Perspectives / experiences
-Intensive care unit / hospital

Figure 4.1: Search terms combined in the literature search

4.2.4 Selection of Study

All identified articles were collated and uploaded onto the referencing tool (Endnote) to track the studies and remove duplicates. Two reviewers (E.K. and S.S.) independently examined the abstracts and titles of the retrieved studies for their inclusion in the study. First, the titles of the retrieved studies were read, followed by the abstracts. Sixty-eight (n = 68) potentially relevant articles were read in full by the two reviewers independently and further examined for eligibility. A third independent reviewer was consulted at every point where there was disagreement.

The detailed search outcome was described using the PRISMA flow diagram. Refer to figure 4.2.

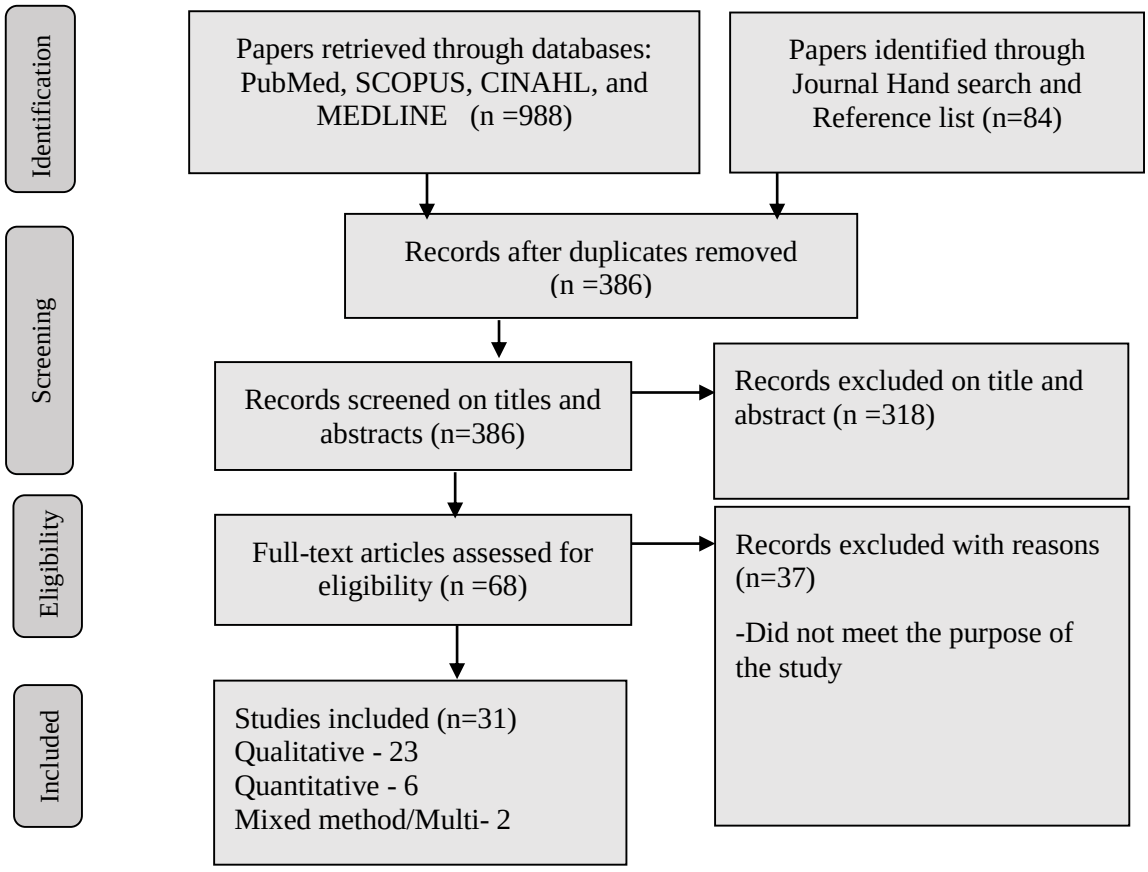

Figure 4.2: PRISMA diagram

4.2.5 Data Extraction

Upon achieving consensus, a standard data extraction developed by the reviewers was used to extract essential items from each included article. The data extraction tool was pilot-tested by reviewers before its use to ensure that it captured all the relevant information needed. Two reviewers independently extracted the data from each eligible article (n = 31). The results were discussed, compared, and constantly updated if there were any discrepancies. The data retrieved were summarized according to headings: author(s), year, setting of publication, study objective, research methodology, population and sampling approach, and key findings (**Table 4.2**).

4.2.6 Synthesis of Data

Results extracted from the included sources were descriptively mapped using simple frequency counts for headings such as study origin, study participants, and study design. These were presented using tables. The key findings sections extracted from each included article were brought together. The thematic analysis principles of Braun and Clarke (2006) were used to group the findings into codes, categories, and finally themes. Two reviewers independently read and re-read each study to become acquainted with its key findings. The themes generated were compared and contrasted and reported subsequently in a narrative format under each theme.

Table 4.2: Characteristics of included studies

	QUALIATIVE STUDIES			
	Author/Yr.	**Title / Objective**	**Research Design / Population/ Data collection**	**Key Findings/ providing quality care at the end of life**
1	Arbour & Wiegand (2014) USA	To understand nurses experiences and perceptions while caring for patients at end-of-life and their family and their roles during the transition from curative to comfort care	A descriptive phenomenological study Purposive sampling 19 Intensive Care nurses Interview	- Educate the family on the withdrawal of mechanical ventilator and vasoactive medications -Provide measures to ensure patients spiritual and physical comfort - Advocate for the patient, follow patient wishes, support their wishes and listen to patient -ensure that appropriate pain medication is given -Encourage and support family presence; have flexible and unrestricted visiting hours - manage symptoms -Protect the family and create positive memories; go beyond the call of duty (tender, love and care) - help the patient to look as comfortable and clean as possible while minimising technology
2	Bratcher (2010) USA	To explore the characteristics of a good death in the ICU as defined by nurses	Qualitative exploratory study (semi-structured interview – 15 ICU nurses)	**Characteristics of a good death** -ensure that Patient does not die alone - have the family or significant others around -Ensure that Patient does not suffer -provide adequate pain and symptom management -ensure that Patients is out of pain (analgesia) -Ensure that there are no unresolved issues between patient and loved ones -Have consensus with HCP about what was happening to patient -ensure Death with dignity, respect and peace -Meet the Religious and cultural needs of patients and their families: rituals -Honouring patients and family wishes -Facilitate a calm environment: music, a quiet environment, noise-free
3	Coombs (2015) United Kingdom	The needs of the family before and after treatment has been withdrawn in intensive care	Interpretive qualitative design (in-depth interviews)	Meeting family needs (events meaningful during and after treatment withdrawal) - achieve a painless and comfortable death; measure aimed at minimising suffering - Promote early treatment withdrawal

			Bereaved family members (21 family members)	- avoid unnecessary treatment - re-establishing the identity of the person (how the dying person will be remembered around the bedside during the final hours) - bringing in personal items that held particular memories or importance and were connected to the dying person - bring in pictures and religious artefacts holding significance or significant objects - talking about the person's hobbies and sings songs (being able to undertake such activities and remembering the person was important for family members) - reconnecting relationships with the person by looking for a sign that the person knew they were at the bedside (opening the eyes, speaking a few words, a squeeze of the hand, playing specific music) - being there for the person up to the point of death (being there to say goodbye
4	Donnelly and Psirides (2015) New Zealand	the experience of relatives and staff of patients dying in ICU	Qualitative study/ Grounded theory Relatives and staffs	Family members/ relatives - families have more frequent contact with the doctors - increase number of people/ family at patient's bedside - Frequent and accurate communication for the family - Availability of pastoral care: invite pastor/father to pray for the patient Nurses - Continuity of care: not abandoning the patient, the body or the family: presence - respect for the patient and the family - giving family time and allowing death as naturally as possible - creating a space of intimacy for the family - care of the body after death
5	Efstathiou & Walker (2014) USA	nurses' experiences of providing end-of-life care following treatment withdrawal	Descriptive exploratory Qualitative study semi-structured interviews 13 ICU Nurses	Facilitating a comfortable and dignified death" - Ensure a comfortable and dignified death through the provision of physical care and symptom management for the dying patient - Fulfil the basic standards of patient care such as bathing, pressure area care and administration of analgesics and sedatives - Develop an intimate relationship with the family, listen and provide information and offer reassurance - Provide and encourage family presence during the dying phase - Reconnecting the patient and family by allowing the time and space for intimacy - creating a less technical environment and reducing technical care

				- reducing distance between the patient and their family - increasing privacy and proximity
6	Fridh, Forsberg & Bergbom (2009) Sweden	Doing one's utmost: Nurses' descriptions of caring for dying patients in an intensive care environment	An exploratory qualitative study 9 nurses with 7-35 years of intensive care experience Interviews (Nurses)	- Patient must be made as comfortable as possible'' which implied no signs of pain or anxiety -Administer analgesic and sedative drugs - Provide these patients with the same warm and compassionate care as patients whose family members were present and to never leave them alone -Provide the family with the needed assurance that their loved one did not suffer -Inform them about the patient's condition -Promote family presence at the deathbed -Explaining the patient's medical condition, describing the ICU environment and medical devices in addition to promoting physical as well as psychological connection -Encourage the relative to touch and talk to the patient -Medical devices that were no longer required were removed and the patient was freed from unnecessary tubes and cables -follow-up visits by bereaved family members; opportunity for the family to meet the staff again and ask them questions in order to better understand what had happened to their loved one and why the intensive care was unsuccessful
7	Halcomb *et al* (2004) Australia	To explore the lived experience of nurses caring for clients in the ICU having treatment withdrawn or withheld	Qualitative study / Phenomenology 10 ICU Nurses	Important measure after treatment withdrawal -Minimise pain using pain medication -Promote dignity during the dying process -Ensure physical and psychological comfort for the family and significant other developing a good rapport with the patient and the family -Reduce the amount of unnecessary technical equipment in order to humanise the client -Discontinue burdensome active treatment that causes unnecessary suffering avoid the creation of false hopes -Have a good nurses-family relationship -Ensure the presence of close family -Involvement in the family in patient care
8	Hebert *et al* (2009)	To determine the factors that family caregivers consider important in preparing for the death	Focus groups and ethnographic interviews	-Have a clear, consistent and reliable communication among HCP, patient and family members

	USA	of their loved one and the subsequent bereavement	27 bereaved and 6 current family caregivers of terminally ill patients	-Cognitive and knowledge readiness (information on disease prognosis; how to access community resources; how to resolve family conflicts (psychosocial) and about the meanings of life (religious/spiritual); -Affective readiness (mentally or emotionally prepared for impending death)
9	Jang *et al* (2019) South Korea	how nurses working in an intensive care unit perceive their professional duties regarding end-of-life care based on their end-of-life care experience	Exploratory Qualitative research Focus group discussions 12 Nurses	How nurses managed EOL care -Letting the patient know that they are not alone -nurses to communicate warmth and tenderness when a dying patient is aware of and/or fears their death - Allow the patient to interact with their family as much as possible so that they don't feel they are alone - Fully explain the imminence of the patient's death and any accompanying medical treatment so that the family members can accept and prepare for the death of their loved one. -Providing time and space for the dying patient and family to say goodbye -Treating the patient as if they were conscious -Being together with the patient and the family during the painful process of transition (Nurses to listen to them, believe in them, and acknowledge them until the moment of their death) -Taking care of the patient's affairs; be honest and inform the dying patient that death is imminent, so that the patient has time to organise their affairs -Accepting a patient as a spiritual being accepting death
10	Kisorio and Langley (2016a) South Africa	To explore the experiences of family members regarding end-of-life care in the ICU	Descriptive exploratory Qualitative study using individual semi-structured interviews 17 family members ICU	-Communication and information sharing between nurses and the family -Provide family members with information on what is happening in the end-of-life process and about the patient -Provide emotional support for the family members -Involve the family members in the direct care of patients -Encourage family presence through liberal visiting hours during palliative care -Provide spiritual support: Allow the family to pray with their relative; allow their religious leader at the bedside to pray
11	Kisorio & Langley (2016b) South Africa	To explore the experiences of nurses regarding end-of-life care in the ICU	Descriptive exploratory Qualitative study	-Provide psychological support for the family -respect the ritual, cultural and beliefs of patients and their families -Allow family presence at patient's bedside -Promote family visitation and involvement

			24 nurses	-Minimise noise in the care environment -Promote patient's comfort
12	Lloyd-Williams, Morton and Peters (2009) UK / England	To explore the perceived palliative and supportive care needs for families of patients admitted with brain death who died in the ICU	Exploratory Qualitative study [29 family members]	1. Care for the patient and relatives -Provide basic nursing care to patient such mouth care -Being there for the patient -Provide information to the family -Allow the family to be at the bedside of the patient 2. Facilities [Environment] -Make rooms available where family members can stay; have tea and being able to get away from the ward [waiting area] -Hospital layout that promotes privacy, have enough chairs for the family 3. Communication -Provide information on patients conditions and impending death -Assist families to understand patient's condition, prognosis, interventions given and impending death 4. Bereavement -Support the family after patient's death -HCP pay attention to family needs after EOL decision has been made
13	Mistry *et al* (2015) Canada	To define what matter most in EOL care: the perspectives of community-based palliative care providers and administrators	Qualitative study (Phenomenological approach) Interviews (107 palliative care providers) Focus group of at least 8 members	1.Addressing the non-physical needs / aside pain -support the spiritual and emotional journey for the patient and caregivers -address the patient psychosocial issues -Being free of emotional and spiritual burden including fear of dying -treat the patient with respect, compassion and dignity -Value the patient, ensure patient is safe - align Care with patient and family religious and cultural beliefs 2.Healthcare teams nature of palliative care delivery -Being compassionate and have a healthcare team that functions as a unit -Ensure providers are on the same page about patient wishes and care needs -Effective communication among the healthcare team / Collaboration -Addressing patient needs on time / Adequate knowledge and skill -Teach caregivers and patient on what to expect at the EOL 3.Patient wishes are honoured

				-Provide the patient and family the option to choose how, when and where they want to be cared for -Help patient and family to understand the available care options and involved in decision making -patient have opinion on where to die; 4.Addressing the physical needs -Pain and symptom management 5.Supporting the family -Involving family in patient care and decision making -Meet the needs of family members
14	Nelson *et al* (2010) USA	To describe how patients and family members define high quality care in the ICU	A descriptive qualitative study using focus group (patients and family members)	Aspects of ICU palliative care that were most important to patients and families included 1. Communication (frequent and effective communication) -Being able to talk to the doctor and get information from there -Able to know what is happening daily; the condition of the patient and any changes -Communication with compassion -Having clarity in communication about burdens and benefits of critical care treatment -Consistent communication from one person (HCP); no break in the chain of communication -Discussion patients prognosis early to prepare the family -Keeping the family informed of the condition, any changes, interventions 2. Patient-focused decision making -Elicit patients and family values and treatment preferences early -If any advanced directives are made by patients, ICU need to know before any major decisions are made -Involve the families in the EOL decisions; focus on the patient interest as discussed earlier 3.Clinical care of patient [Comfort, Dignity, Personhood] - Ensure that patient is not in pain; relief of pain -Assess patients pain and give timely and effective analgesia -Treat patient with dignity and respect

				-Ensure that the patient body parts are not exposed; kept private from the public view - Treat the patient as a unique individual; has inherent value and worth respect and honor regardless of diseases -Treat the patient as a person even if he/she is hooked on machines and cables; not just a piece of meat or object -Have a team of HCPs around patient, treating patient with the same care as any other patient 4. Care of the family [Access and proximity; support including bereavement care] -Support patients relative / family -Providing emotional, practical and spiritual support for the family - Both patients and their families place high value on access and proximity to the patient - family presence at patient's bedside Family able to visit patient freely -Family access to patient to support patients, advocate for them and protect them -Have pastoral care available for patients and families who want it -Have someone to come by and offer prayers -Social workers available to patients and their families -Family receive support after the death of a loved one
15	Noome, Dijkstra, van Leeuwen and Vloet (2016a) Netherland	To examine the experiences of family with the nursing aspects of EOL care in the ICU after a decision to end life-sustaining treatment	A phenomenology qualitative study; interviews with 26 bereaved family members	1. Communication -Nurses available at any time and willing to answer questions from family members -Nurses being present during family visits to inform them about patient's condition status -Frequent meeting with the family members; nurses available to answer questions and update family about symptoms during the dying process 2. Nursing care for ICU patients -Show respect to the patient and care for patient as a whole person -Reducing any burdensome process during the dying process; promote comfort 3. Nursing care for family of ICU patients -Family able to stay with patient or at the bedside during the dying process

				-Family able to perform their own rituals during the dying process -Family members have enough time to say goodbye to loved ones -Providing bereavement care to the family members; receiving condolences messages 4. Preconditions -Ensuring privacy; patient nurses in a single room at the time of death -Open and unrestricted visiting hours for family members
16	Pattison, Carr, Turnock and Dolan (2013) UK	To explore the meaning of end-of-life care for critically ill patient, families and Healthcare professionals in the ICU	A phenomenology / Qualitative study 37 participants (7 patients/ 12 bereaved families and 18 healthcare providers – 7critical care consultant; 7 critical care nurses; 2 oncologists; 2 palliative care consultants)	-Nurses have limited role in decision making despite being regarded as advocates -Nurses feel the need to be involved and participate in decision making, not only when or if, to move to EOL -Team work when it comes to making EOL decisions in the ICU -Nurses focus on patient and families and concentrate less on machines -for families, good death extended to letting them participate in care or contribute to care planning -Comfort care for patient: ensuring warmth, regular mouth, eye and skin care, meeting hygiene needs -Family unrestricted access to patients -Having a comfortable environment:
17	Ranse, Yates and Coyer (2012) Australia	To explore end-of-life care beliefs and practices in the ICU	A descriptive exploratory Qualitative study Nurses (5)	Facilitating end-of-life care -Providing comfort care such as the administration of analgesics, bathing, hair care, mouth care, pressure area care -C*reate and intimate and peaceful environment for patient and the family members such as* a single room for patient and separate room as visitors room - Allow visitors at patient's bedside - Removing clinical equipment, modifications such as dimming the lighting, replacing the hospital linen with coloured sheets and quilts, putting up photographs and playing music - Provide the family with needed information and answer their questions - Provided an opportunity for the family to talk about their relative and reflect on their lives together -Encouraging the family to sit, talk to and touch the patient

				-Assist in creating memories for the patient's family: memory making activities included taking the patient's hand prints and collecting a lock of the patient's hair and their identity bands for the family to keep
18	Singer, Martin and Kelner (1999) Canada	To identify and describe elements of quality end-of-life care from the patient's Perspective	Descriptive Qualitative study in-depth, open-ended, face-to-face interviews 126 Patients from 3 patient groups: dialysis patients (n = 48), people with HIV (n = 40), and residents of a long-term care facility (n = 38).	- Patient receive adequate pain and symptom management -Avoid Inappropriate Prolongation of Dying **(**Participants were afraid of "lingering" and "being kept alive" after they no longer could enjoy their lives) and reduce suffering - Achieve a sense of control (patient able to retain control of their end-of- life care decisions while they were capable of doing so, and that they wanted the proxy of their choice to retain control if they became incapable - Relieve burden for family members -Patient have decisions written in advance -Strengthening relationships with loved ones -Patients prefer the full involvement of loved ones in communication about their dying -communication with loved ones was of overwhelming importance
19	Steinhauser *et al* (2000a) USA	To describe the attributes of a ''good death'' from the point of view of patients, family members, and care providers	An exploratory qualitative study Focused group discussion (nurses-27, patients-14, bereaved family member-4, social workers-10, chaplains-6, hospice volunteer-8, physician-6)	The main components of a good death were -manage patients' pain and symptoms well and minimise aggressive care -Have open communication and clear decision making with attending physicians -family physical and psychological preparation for death; know what to expect, plan of events that follow death -Spending time with family and friends; have the opportunity to say goodbye -Place deep importance on spirituality or meaningfulness at the end-of-life -Able to perform rituals with emphasis on faith -Affirmation of the patient as a unique and whole person (good relationship and empathic healthcare providers
20	Stokes *et al* (2019) Canada	what nurses describe as meaningful within the context of providing EOLC in the ICU	Interpretive Qualitative study ; unstructured interview Nurses (6)	Efforts to contribute towards a good death for dying patients and their families in the ICU -Respect the patient wishes -Attend to their physical and emotional needs - Facilitating comfort through both pharmacological (analgesia) and non-pharmacological means such as repositioning, providing mouth care and bathing patients -Being there for the patient and family

				-Preserve human dignity and peacefulness. For some, spirituality and religion were connected to peacefulness -Connect the families and get to know them - Keep the family informed and involved in the patient's care - **C**reate an intimate and personalised space for families, family does what patient like e.g. favourite music or music instrument
21	Taylor *et al*. (2020) Norway	To explore the experiences of ICU nurses when participating in the process of WLST with ICU patients.	a descriptive and explorative qualitative design using semi-structured interviews ICU Nurses (9)	Elements to achieve a dignified treatment withdrawal process 1. A thorough plan for WDLS process - have a plan in place to ensure dignified death for patients and family members, and prepare the family members 2. communication with family -inform the patient and family about all the aspects of the WDLS process -Make sure the family understand the reason for the withdrawal of the treatment -Prepare the family early and help them to accept that their loved ones will not survive -involving them in the decision-making process -preparing them to accept death -attending to their wishes, -Offer them the opportunity to say goodbye to their loved ones -talk with family after the death of a relative 3. Administration of relief and an aesthetic death -manage the patients' comfort -administer necessary medications for pain relief -make the patient look clean and presentable to the family without too much evidence of equipment and technical devices connected to the patient 4. Creating a peaceful environment -Get the family attention away from the dropping vitals, equipment noises -turn of machines in time to avoid noise Others -Work together as an interdisciplinary team -Support and cooperate with one another -Have a debriefing session after the withdrawal of treatment
22	Vedel *et al* (2014) France	The views of different stakeholders(patients, families, HCP and	Qualitative study (Grounded theory)	1.Patient Care and support -Availability of healthcare professionals at patient's bedside -Both patient and family spend time together

		managers) on the key elements in the quality of palliative care (high-quality end-of-life care) and compare findings with NCP domains	Interviews (14 end-of-life patients, 6 family members and 41 healthcare professionals)	-Provide psychological support 2. Relief and management of patient's symptoms such as pain, agitation and breathlessness 3.Family involvement and support -Frequent presence at patient's bedside -Family ability to share opinions on patients decisions -involve family in the care process, care for patient and have voice in patient needs -Private rooms and accommodation for the family -Attending to the needs of the family 4. Care for dying patient -Family presence at the moment of death -Respect patient and family rituals surrounding death (Spiritual, religious and Cultural aspects of care)
23	Wiegand (2016) USA	Families experiences of withdrawal of life support in the ICU	Hermeneutic phenomenological study / Qualitative study 22 family members	1. Preparing for the dying process (prepare the family) -Preparing the family for the withdrawal of treatment (what will be done and how it will be done during the withdrawal of treatment process) -Arrangements such as Having clergy from the hospital to visit patient for final rituals, meeting with their personal pastor at church 2. The dying environment - Prepare the patient and the ICU room for the dying process (patients in a comfortable position / side rails on bed are lowered) - Have dimmed lights - Curtains and glass doors are pulled closed - Remove equipment that are not needed from the room - Bring in additional chairs brought into the patients room 3. Patients comfort -Patients are unable to verbalise if they were uncomfortable; so making patient as comfortable as possible was expressed by family members / have a pain-free death -Patient receive pain medication before life support is withdrawn 4. The death vigil -The provision of emotional / psychological support for the family during the dying process]

				- 5. Essential aspects of care -Families have consistent nurses at the time of patients death -Nurses being there for the family; nurses verbalising that they will be there at the time of treatment withdrawal meant so much for the patient's family -Healthcare providers demonstrating respect and genuine care for patient and for the family; addressing patient and family by name -HCP taking care of the patient's body after death meant so much for the family members 6. Support for the family -Have no restriction placed on visitation -Be able to freely visit patient and stay -Spend time with their loved ones

QUANTITATIVE STUDIES INCLUDED				
	Author/Yr./ setting	**Study Objective / focus**	**Research Design / Population**	**Key Findings**
1	Beckstrand *et al* (2006) USA	suggestions from critical care nurses for improving end-of-life care in intensive care units	Quantitative – Survey Questionnaire Nurses	Suggestions for providing a good death for dying patients are 1.Making Environmental Changes to Facilitate Dying With Dignity -Encourage family members to stay with the patient -Beds should be made available for family members and also food and showering facilities -Have soothing music -Quiet places for prayer and meditation and family gathering -Private rooms available -to have someone present with them at the moment of death—to touch them, speak to them, to let them know it's okay to go 2. Managing Pain and Discomfort -minimising patient suffering by administering adequate comfort measures 3. Knowing and Following Patients' Wishes for End- of-Life Care 4. Promoting Earlier Cessation of Treatments or Not Initiating Aggressive Treatments, Especially When Care Seems Futile -eliminate painful procedures -Learning to know when 'enough is enough' is the best place to start

				5. Communicating Effectively as a Healthcare Team - improved communication between physicians and nurses would ultimately facilitate a good death because everyone could work toward the same goal or plan of care
2	Heyland *et al* (2006) Canada	what seriously ill patients in hospital and their family members consider to be the key elements of quality end-of-life care	Cross-sectional Survey Critically ill Patients (440) and family members (160) Using 5 tertiary hospital	Important to patients - To have trust and confidence in the doctors looking after you - Not to be kept alive on life support when there is little hope for a meaningful recovery - That information about your disease be communicated to you by your doctor in an honest manner - To complete things, resolve conflicts, and say goodbye to your family Member - To not be a physical or emotional burden on your family Family members - To have trust and confidence in the doctors looking after the patient," - "to no have a family member kept alive on life support when there is little hope for a meaningful recovery - That information about your family member's disease be communicated to you by the doctor in an honest manner - That your family member has relief of physical symptoms such as pain, shortness of breath, nausea
3	Heyland *et al* (2010) Canada	To identify aspects of EOL care that are high in priority from patients and their families	A multi-centre, cross-sectional survey (363 patients and 193 family members) Using the CANHELP questionnaire	Patients perspective -The feeling of peace -Assessment and treatment of emotional problems -physician availability -satisfaction that the physician took a personal interest in them -consistent and clear communication Family perspective -timely information about patient's condition -discussions with the doctor
4	Jensen *et al* (2017) Denmark / Netherland	To examine assessment of satisfaction with care in a large cohort of family members	1077 family members (573 from Denmark and 504 from The Netherland) from 21 ICUs (11 from	Areas with the greatest endorsement by family members 1.Concern and caring toward patient 2.Symptom management such as pain, agitation and breathlessness 3.Making changes in the ICU atmosphere 4.Family involvement, beside presence and Family support -Adequate time with the patient

			Denmark, 10 from Netherland) Using the euroQ2 questionnaire	-Involved in the care of the patient -Emotional support and needs 5.Effective communication -Easy access to information about patient -Including family in the decision making process
5	Steinhauser *et al* (2000b) United State of America	What patients, family members, physicians and others consider to be important attributes at the end-of-life	Cross-sectional survey Population: seriously ill patient , bereaved family members, physicians, nurses and other caregivers (chaplains, social workers, hospice volunteers) Using a 44-items survey tool	Items rated very important to participants (strong agreement across the 4 groups) - Patient freedom from pain, anxiety, and shortness of breath -Patient being kept clean and have physical touch - Patient having financial affairs in order -Patient and family feeling prepared for one's death -Preparing the family for loved one's death -Assisting the family to know what to expect about one's physical condition -patient have the opportunity to say goodbye to important people, -Patient able to remember personal accomplishment, and resolve unfinished business -Patient having treatment preferences in writing and naming someone to make decisions in the event that one cannot -maintaining one's dignity and sense of humour -having a physician who knows one as a whole person, presence of close friends, -Patient not dying alone and having someone who will listen - Receiving care from one's personal physician, trusting one's physician and having a nurse whom one feels comfortable, -Knowing that one's physician is comfortable taking about death and dying, and having a physician with whom one can discuss fears.
6	Teno *et al* (2004) USA	Family members perspectives on the quality of care at the last place the patient spent at least 48 hours	A follow-back survey of family members	Family perception of Quality of care at the End-of-life 1.Promote physical comfort and symptom management 2.Promote shared decision making 3.Treating patient with respect at the EOL 4. Attend to family needs: emotional support and information on what to expect while patient was dying 5.Ensure coordinated care

MIXED / MULTI-METHOD STUDY INCLUDED				
	Author/Yr.	**Title / Objective**	**Research Design Approach / Population/ Data collection**	**Key Findings**
1	Donnelly *et al* (2018) Ireland	Voices that matter: end-of-life care in two acute hospitals from the perspective of bereaved relatives The EOL care experiences of bereaved relatives	A quantitative descriptive post-bereavement postal survey retrospective data from relatives or friends of patients who died, utilising an adapted version of the VOICES (Views of Informal Carers - Evaluation of Services) questionnaire. Population: Bereaved family members	1.Communication -Communication that involves the multi-disciplinary team, patients and family members -communication of information in a supportive, timely and regular manner 2.Meeting care needs -the provision of personal care to patients and family -Ensure pain and symptom management -Provide emotional, spiritual and psychological support -Promote access to specialist palliative care outside normal working hours and at weekends 3.Dignity and respect -treat patient and family with dignity and respect -kindness and compassion 4.Hospital environment -Promote privacy: Access to a single room -Level of noise reduced -Family rooms and adequate facilities in the room 5.Support for family members -Ensure unrestricted family visitation -Allow the family to spend precious time with sick relatives -Privacy and sensitivity (breaking bad news, very thoughtful support from staff) -Provide bereavement support such as Counselling sessions
2	Teno *et al* (2001) USA	To develop a conceptual model for a retrospective survey of bereaved family	Using multi-method (A qualitative literature review of guidelines of existing professional	Conceptual model: Good care at the end-of-life 1.Provide patient with the desired physical comfort and emotional support through pain / symptom management and physical comfort measures

		members that incorporates both professional and family perspectives on what constitutes good care at the end of life	guidelines and 6 focus groups with bereaved family members (42).	2.Promote shared medical decision-making -Adequately inform Patient and family members about the disease -Have an advance care planning -Ensure that family members have some control on the care decisions 3. Focus on the individual (patient) -treat patient with dignity, sensitivity, kindness -respect individual needs and preferences for medical and other form of care -Attend to patients' needs for closure of important relationships, spirituality and transcendence in a sensitive manner -Attend to patient basic needs 4.Attend to the needs of the family (Need for information (patient's condition, need for proximity (presence, involvement in care), assurance need, and support need (emotional support before and after the death of patient) 5.Ensure coordination of care and teamwork among different healthcare professionals and others involved in patient care

4.3 RESULTS

The systematic search initially identified 1072 records. After taking out the duplicates, 386 articles were identified. After screening the titles and abstracts, 318 were excluded, and 68 full texts were retrieved and assessed for further inclusion. A total of 37 were excluded as they did not meet the inclusion criteria. Thirty-one studies finally met the inclusion criteria **(Figure 4.2).**

4.3.1 Characteristics of the studies

Table 4.3: Summary of studies and their origin

Country of Origin	Frequency (n)	Percentage (%)
United State of America	11	35.5
Canada	5	16.1
United Kingdom	3	9.7
Australia	2	6.5
South Africa	2	6.5
France	1	3.2
Norway	1	3.2
New Zealand	1	3.2
Sweden	1	3.2
Ireland	1	3.2
Netherland	1	3.2
South Korea	1	3.2
Denmark/ Netherland (Joint study)	1	3.2
TOTAL	**31**	**100.0**

The review presented data from 31 empirical studies conducted in thirteen (13) different countries. From **table 4.3**, the majority of 16 (51.6%) were conducted in North America, followed by 9 (29.0%) across Europe. The Australian continent accounted for three (9.7%) of the included primary studies. Africa had only two primary studies, all from South Africa. From the studies conducted on the Asian continent, South Korea was the only country. No study came from South America. A variety of research designs were used across the review studies. Table 4.4 displays these results.

Table 4.4: Summary of research designs/methods from the review studies

Research design/ Method		**Frequency (n)**	**Percent (%)**
Qualitative	Descriptive / Exploratory	12	38.71
	Phenomenology	6	19.35
	Interpretive	2	6.45
	Grounded	2	6.45
	Ethnography	1	3.23
	TOTAL	**23**	**74.19**
Quantitative	Cross-sectional survey	5	16.13
	Cohort study	1	3.23
	TOTAL	**6**	**19.35**
Mixed-methods / Multi-method	Quan/Qual	1	3.23
	Qual/review/ Quan	1	3.23
	TOTAL	**2**	**6.45**
	Sum ΣN	**31**	99.99

According to **Table 4.4**, the majority of the studies (74.19%) used a qualitative design, with descriptive exploratory being the most commonly used method, followed by phenomenology. The least qualitative method used was the ethnographic approach. Additionally, quantitative research designs constituted about six (19%), with cross-sectional surveys mostly used across the studies. Mixed-methods and multi-methods were the least used research methodologies.

Table 4.5: Summary of participants/ respondents used in the studies included in the review

Participants/ respondents	**Frequency (n)**	**Percent (%)**
Healthcare professionals (nurses, doctors, palliative care team)	12	38.7
Bereaved family members	10	32.4
Patients (near dying patients)	1	3.2
Patients and family members	3	9.6
Family members and healthcare providers	1	3.2
Patients, family members and healthcare providers	4	12.9
TOTAL	31	100.0

Patients, bereaved family members and health care professionals (nurses, physicians, palliative care team) made up the study's participants and respondents. According to t**able 4.5**, the majority of studies 12 (38.7%) presented findings with only healthcare professionals (nurses, doctors and palliative care team) as participants or respondents. Just one study presented findings using only patients (near dying patients) as a sample, and only one (1) study also used both healthcare providers and family members as their sample.

The majority of the studies (19) were conducted in the ICU, and the rest (12) were conducted outside the ICU. All were focused on good death at EOL and providing high-quality palliative care for patients and their families. The review also gathered data from studies that focused on four different areas, namely; experiences regarding the provision of end-of-life care and care after treatment withdrawal (n=12); palliative care needs at the end of life (n=6); characteristics of a good death (n=3); and attributes of quality EOL care (n=10).

4.3.2 Themes Arising from the Data

Following a thematic analysis, the overarching theme, "Providing quality care at the end-of-life in the Intensive Care Unit," was grouped under seven key emergent themes. The themes included: 1) patient- and family-centered decision making; 2) symptom management and comfort; 3) communication among the healthcare team and with patients and families; 4) care with compassion, dignity, and respect; 5) spiritual care and cultural support; 6) emotional support for patients and families; and 7) modifying the ICU environment. Each theme is discussed below:

4.3.2.1 Patient and family centred decision making

Following the analysis of the literature, the theme "patient and family-centered decision-making" emerged as an essential component of providing quality end-of-life care in the ICU. Findings from ten (10) studies, representing 32.3% of the included studies, supported and discussed the theme. In the study findings, decision making was described as shared and patient-family focused. Thus, the decision-making process involves the ICU team, patients, and their family members and also focuses on the needs, preferences, and wishes of patients and their families.

The decision-making process, especially for patients at the end of their lives, is often complex and encompasses many aspects. In their respective studies, Nelson *et al*. (2010), Teno *et al*. (2004), and Teno *et al*. (2001) agree that shared and patient-family focused decision making is critical in achieving quality end-of-life care for patients and their families. In the USA, Nelson *et al*. (2010) conducted a descriptive qualitative study that focused on how patients and families define quality care at the end of life in the ICU. Using a focus group discussion, the authors found that participants saw decision-making as

complex with multiple components attached. However, according to them, it was necessary to first focus on patients and their families, make a conscious effort to elicit their wishes, values, and treatment preferences early, and incorporate them into the decision-making process.

Teno *et al*. (2004) and Teno *et al*. (2001) further highlighted the need to promote shared decision-making. Thus, the healthcare team, together with patients and their families, are all involved, briefed on the EOL decision-making process, and have the opportunity to share their opinions on EOL decisions. In the United Kingdom, Pattison *et al*. (2013) supported the idea that teamwork is imperative when it comes to EOL decision-making in the ICU. Physicians, nurses, and other members of the ICU team, together with patients, if able, and their families, have major roles in EOL decision-making. Hence, a collaborative approach is required. Similarly, in France, Vedel *et al*. (2014) conducted a grounded qualitative study on the views of patients, families, and healthcare providers on the key elements in achieving quality care at the end of life. Their results supported the notion that families play a major role in patient care and that their involvement in decision-making and ability to share their opinions on patients' decisions are also important. In Canada, Mistry *et al*. (2015) further reiterate in their phenomenological qualitative study on the perspectives of palliative care providers on what matters most in EOL care that families' involvement in decision-making is an essential part of EOL care. Steinhauser *et al.* (2000a) describe having a clear decision-making process that involves family members and attending physicians as an attribute of a good death.

In decision-making, Nelson *et al*. (2010), Taylor *et al*. (2020), and Teno *et al*. (2001) support that there should be a thorough plan in place for the treatment withdrawal process, attend to patients' and families' wishes, and ensure a dignified death. In the plan, Taylor *et al*. (2020), in their qualitative study conducted in Norway, emphasize the need for supportive means to prepare patients and their families before and after EOL decisions are made. Teno *et al*. (2001) further reiterate that having an advanced care plan in place constitutes good care at the end of life. Similarly, participants in Nelson *et al*.'s study expressed that if there were any advanced directives made by patients in the care plan, the ICU team needed to know beforehand before any major decisions were made (Nelson *et al*., 2010).

In making end-of-life decisions, it is vital to consider patients' and their families' wishes and preferences (Nelson *et al*., 2010). In Canada, Singer *et al*. (1999) conducted a qualitative study to identify and describe elements of quality EOL care from the patients' perspective. The study found that seriously ill patients prefer to take charge of their decisions and retain control of their end-of-life care decisions if they are able or have decisions written in advance before death approaches (Singer *et al*., 1999; Teno *et al*., 2001). Unfortunately, in most cases, the majority of patients are unable to make decisions on their own due to their life-threatening conditions and the modalities of care needed. While patients are incapable of making end-of-life care decisions, they wanted a proxy of their choice or surrogate to make decisions on their behalf (Singer *et al.*, 1999). Teno *et al*. (2001) also found that bereaved families regard having control over care decisions as an important part of EOL care. While they are able to share their opinions, preferences, and wishes, it is important to respect and honour them. Studies conducted by Bratcher (2010) and Stokes *et al*. (2019) in the USA and Canada, respectively, further support honouring and respecting the patients' and families' wishes and preferences as an important characteristic of a good death in the ICU. Nelson *et al*. (2010) also established that decision-making at the end of life in the ICU can be challenging; however, it is important to know patients' wishes and preferences, which is essential to providing high-quality care. In instances where any advanced directives had been made, they needed to be respected and followed as indicated by the patients (Nelson *et al*., 2010).

4.3.2.2 Symptom management and comfort

An important theme synthesised from the key findings of most of the included studies (n = 25) was symptom management and comfort for patients at the end of life. The theme "symptom management and comfort" was described under the following sub-themes: managing and controlling symptoms (e.g. pain, breathlessness, agitation, and anxiety); minimising aggressive care and reducing suffering; and promoting comfort as much as possible for the critically ill and dying patients through basic nursing care and non-pharmacological interventions.

At the end of life, patients experience common symptoms such as pain, breathlessness, agitations, vomiting, and diarrhoea (Arbour & Wiegand, 2014; Jensen *et al*., 2017; Steinhauser *et al*., 2000b). An important element of achieving a peaceful withdrawal of the

treatment process and end-of-life care in the ICU is managing these symptoms. Thus, ensure that patients die without experiencing common symptoms such as pain, dyspnoea, and discomfort. Key findings from most of the included studies (n=21) reported symptom management through pharmacological means as an important part of end-of-life care and providing quality care for patients at the end of life (Stokes *et al*., 2019; Taylor *et al*., 2020; Wiegand, 2016). Qualitative studies conducted in Sweden and Australia by Fridh *et al.* (2009) and Ranse *et al.* (2012), respectively, mentioned the administration of analgesics, sedatives, and antimucolytics as some of the pharmacological interventions to manage and control most of the common symptoms patients' experience. Nurses interviewed in these studies expressed that patients must be pain-free, not struggle to breathe, and show no signs of anxiety. In France, Vedel *et al*. (2014) explored the views of patients, families, and healthcare providers on the key elements in the provision of quality EOL care. The authors found the relief and management of patients' symptoms such as pain, agitation, and breathlessness to be an important element of quality EOL care based on the views expressed by patients, families, and healthcare providers. Similar findings were reported in studies conducted by Arbour and Wiegand (2014), Bratcher (2010), Coombs (2015), and Efstathiou and Walker (2014). Achieving a painless and comfortable death through the administration of analgesics and sedatives was a common finding across the studies.

In the USA, patients and families mentioned the assessment of patients' pain and the timely administration of pain relief as another measure to ensure quality EOL care in the ICU (Nelson *et al*., 2010). According to Nelson *et al*. (2010), patients and their family members in the ICU also describe the assurance that patients are pain-free as key to providing quality care. Similarly, Wiegand (2016), in a phenomenological study that explored families' experiences of the withdrawal of life support in the ICU, also shared that a pain-free death was a priority for patients' families. Most patients, due to their illness, are unable to verbalize if they are in pain or uncomfortable. Family members suggested that pain relief be administered early in the treatment withdrawal process to ensure the patient's comfort. In Norway, Taylor *et al*. (2020) also reported similar findings and added that it makes death pain-free and aesthetic. Findings from several studies (Teno *et al*., 2004; Singer *et al*., 1999; Steinhauser *et al*., 2000a) also supported the management of patients' symptoms (such as pain and agitation) through the administration of pain medications and other pharmacological interventions.

Another concern with the care of patients at the end of life is the continuation of active treatment that may cause unnecessary suffering. Several study findings support measures aimed at reducing aggressive care and relieving suffering for patients nearing the end of their lives (Bratcher, 2010; Coombs, 2015; Halcomb *et al*., 2004; Heyland *et al*., 2006). In Canada, Heyland *et al*. (2006), in a cross-sectional survey across five tertiary hospitals, studied what seriously ill patients and their family members consider key elements of quality EOL care. The authors found that both patients and family members prefer a loved one not to be kept alive on life support when there is little hope for a meaningful recovery. This finding explains that patients and their family members' place much emphasis on minimizing aggressive care and ensuring that the patient does not suffer at the end of life. Bratcher (2010) also reported reducing patients' suffering at the end of life as an important characteristic of a good death. In minimizing aggressive care and reducing suffering for patients at the end of life, Coombs (2015), in a study conducted in the UK, emphasized early treatment withdrawal. Thus, therapeutic interventions that are not beneficial for patient recovery should be avoided and discontinued as early as possible. In an Australian study, Halcomb *et al*. (2004) also reiterated the early discontinuation of burdensome active treatments that cause unnecessary suffering and create false hopes. Early and appropriate discontinuation of unnecessary active treatment promotes comfort for the patient and increases family satisfaction with care (Noome *et al*., 2016a).

Singer *et al*. (1999) and Steinhauser *et al*. (2000a) describe a natural death as one in which the patient is extubated from all technical equipment and tubes and made clean and presentable to family members. Thus, untoward suffering and distress for patients at the end of life are minimized, and non-beneficial treatments are immediately stopped and removed. Any delay prolongs untoward suffering and puts patients in pain. These measures are important attributes of a good death for patients at the end of life. Patients and family members are also against patients being kept alive artificially on machines when there is no hope for survival. It is important to be allowed to die naturally and in peace, with no form of suffering attached (Singer *et al*., 1999). Family members describe it as inhumane to let a patient suffer at the end of life (Nelson *et al*., 2010).

Another aspect of the theme deduced from the study findings was providing comfort through basic nursing care and non-pharmacological interventions (Lloyd-Williams *et al*., 2009; Pattison *et al*., 2013; Ranse *et al*., 2012; Stokes *et al*., 2019). Key findings from several

studies (Efstathiou & Walker, 2014; Ranse *et al*., 2012; Stokes *et al*., 2019; Pattison *et al*., 2013) describe the provision of comfort through non-pharmacological means as fulfilling the basic standards of patient care and meeting patients' hygienic needs such as bathing, mouth care, pressure area care, and hair care. These are measures that ensure that patients are clean, well-kempt, and comfortable in bed at the end of life. Stokes *et al*. (2019) also emphasize positioning as a non-pharmacological measure to facilitate comfort, aside from meeting the basic standards of patient care. Taylor *et al*. (2020) conducted an exploratory study in Norway that reinforces making patients at the end of life clean and presentable to family members as a good measure to ensure a comfortable and aesthetic death.

4.3.2.3 Communication among the healthcare team, and with patients and families

The theme "Communication among the healthcare team and with patients and families" also emerged following data analysis as a vital element in providing quality EOL care in the ICU. The theme was deduced from the key findings of twenty-four (24) of the review studies. The theme describes the exchange of information within the healthcare team as well as between patients and their families. It focuses on what information is communicated, how and when the information is communicated (Nelson *et al*., 2010; Noome *et al*., 2016a; Taylor *et al*., 2020).

Effective communication among the healthcare team and with patients and families ensures a peaceful treatment withdrawal process and EOL care (Beckstrand *et al*., 2006; Donnelly *et al*., 2018; Jensen *et al*., 2017; Steinhauser *et al*., 2000a). It is seen as a prerequisite to informing the patient and family about all aspects of the withdrawal process. Thus, it prepares the family early to accept the death of a loved one and also allows them to ask and get answers to their questions. In such a situation, family members feel empowered to be part of the process and be prepared for any situation that is ahead (Beckstrand *et al*., 2006; Taylor *et al*., 2020). Bratcher, (2010), and Donnelly *et al*. (2018), in their respective studies, agree that effective communication is achieved when the healthcare team, patients, and their family members collaborate, reach consensus on the plan of care, and discuss and clarify the goals of treatments. This measure creates the opportunity to address any disagreement among the team and with patients and their families. Stokes *et al*. (2019) also mention the importance of getting to know patients' families, creating a relationship with them, and

understanding their needs and preferences. It creates a platform to listen to the family and provide them with the needed information regarding the care of their loved one.

Another aspect of communication deduced from the study's key findings was access to information, clarity, consistency, and frequency of information shared among the healthcare team and with patients and their families (Donnelly & Psirides, 2015; Herbert *et al*., 2009; Jensen *et al*., 2017; Nelson *et al*., 2010). In the assessment of family satisfaction with care in the ICU, Jensen *et al*. (2017) found that family members place greater emphasis on easy access to information about their loved ones. Several studies (Efstathiou & Walker, 2014; Fridh *et al*., 2009; Jang *et al*., 2019; Kisorio & Langley, 2016a) also support the finding that patients and families need necessary information, especially at the end of life. In South Korea, during EOL care, nurses working in the ICU see it as their professional duty to explain in detail the imminence of a patient's death and accompanying treatment so as to prepare family members. Kisorio and Langley (2016a) also stated the importance of providing adequate information to family members on the patient's condition, prognosis, and interventions given. A similar finding is reported by Fridh *et al*. (2009), who found that it was necessary to also explain the patient's medical condition to the family and describe the ICU environment and the medical devices while the patient was at the end of life.

In studies conducted by Donnelly and Psirides (2015) and Herbert *et al*. (2009), bereaved family members and healthcare providers supported clear, consistent, and accurate communication among the healthcare team, patients, and family members as an important part of EOL care. Having open and accurate communication reduces the stress associated with the fear of pain and inadequate symptom management. Patients and family members are also informed on what to expect, what will be done, and how things will be done (Steinhauser *et al*., 2000b). This measure also facilitated the family experience (Fridh *et al*., 2009; Noome *et al*., 2016a; Ranse *et al*., 2012). Patients prefer the full involvement of their loved ones in communication about their dying moments. Singer *et al*. (1999) described frequent communication with patients' family members as a key element of quality end-of-life care. Strengthening relationships with patients' loved ones through clear communications relieved them of the burden of making treatment decisions alone. Similarly, Mistry *et al*. (2015) added that frequent and open communication ensured that patients and their families were not provided with conflicting information from different healthcare

providers. This makes sharing information an important part of caring for patients and their families.

In the USA, Nelson *et al*. (2010) studied how they defined high palliative care in the ICU. Frequent and effective communication was a common theme expressed by patients and bereaved families as an important part of high-quality palliative care in the ICU. One bereaved family member explained that it was important to be able to talk to the attending physician and get the needed information on the condition of the patient and what is happening on a daily basis. It was also highlighted that the use of medical terminologies confused bereaved family members. Thus, it was necessary to convey clear information in a language that patients and their families understood and in layman's terms (Nelson *et al*., 2010). Another source of confusion mentioned was having interactions with multiple caregivers from different specialties. This leads to conflicting information and a lack of coordination and leadership among the ICU team. It was, therefore, necessary to have clarity in communication among the ICU team and also ensure that the chain of communication was not broken (Nelson *et al*., 2010).

Lloyd-Williams *et al*. (2009) also emphasized the need to assist families in understanding a patient's condition, prognosis, interventions, and impending death. This gives the family time to make needed arrangements, ask mind-boggling questions, and get needed support for the process. Again, some bereaved family members and nurses stressed the importance of holding frequent meetings to answer family members' questions and keep them informed about all aspects of treatment withdrawal during the dying process (Noome *et al*., 2016a; Taylor *et al*., 2020). Also, seriously ill patients and their family members consider timely and honest communication of patients' diseases as an important element of quality end-of-life care (Heyland *et al*., 2006; Heyland *et al*., 2010).

4.3.2.4 Care with compassion, dignity and respect

Another area of importance when providing care for patients and family members at the end of life is the provision of compassionate care with an emphasis on dignity and respect for patients and their families. Of the included studies in this review, thirteen (n = 13) highlighted that providing care with compassion, dignity, and respect was an important aspect of caring for the patient and their families at the end of life. Providing care that treats

the critically ill and dying person with dignity and respect was vital for the patient and family to achieve the desired level of control over their functioning and daily activities (Steinhauser *et al*., 2000b; Teno *et al*., 2004).

In facilitating end-of-life care, nurses expressed high levels of concern for promoting dignity during the dying process (Donnelly *et al*., 2018; Halcomb *et al*., 2004). Teno *et al*. (2004) also highlighted that many patients die of unmet needs, including not being treated with respect. Therefore, dying with dignity and respect was mentioned as an important part of EOL care. The end-of-life care trajectory has many stages, and within each stage, there are many different care needs and challenges. Healthcare providers expressed the high importance of the value placed on the patient and treating the patient with respect, compassion, and dignity (Mistry *et al*., 2015). Another qualitative study conducted by Bratcher (2010) aimed at describing the characteristics of a good death in the ICU found that nurses place more importance on their patients dying with dignity and respect. They added that dignified death meant that the patient was made clean at the time of death, the body was not exposed, and it looked good. This form of care created satisfying and positive memories for patients' families and also ensured that patients appeared honored in front of their families before death.

The care of a patient's body after death was also mentioned by nurses as a way to show respect to the patient and the family (Donnelly and Psirides, 2015). According to the nurses, what was important to them was not to abandon the patient, to show respect for the patient and body, and to treat a patient with respect as if it were their own family. In Canada, nurses described preserving patients' dignity as an important aspect of providing a good death in the ICU (Stokes *et al*., 2019). One participant expressed that measures such as keeping the patient's body clean, combing their hair, and removing unnecessary equipment were efforts to preserve patients' dignity. The final hours of a patient's life are considered the most crucial (Jang *et al*., 2019); therefore, nurses consider it important to ensure that the patient's last moments are honoured and respected.

Another study conducted by Donnelly *et al*. (2018) also emphasized the need for patients and their relatives to be treated with dignity and respect. The majority of relatives in the study indicated that they and their loved ones experienced kindness and compassion. They were also treated with dignity and respect. These forms of care, according to these relatives,

had a positive impact on their overall hospital experience. Similarly, a cross-sectional survey conducted by Steinhauser *et al*. (2000b) on the factors considered important by seriously ill patients, family members, and healthcare providers also found that above 70% of the respondents rated maintaining patients' dignity as being important. The need to facilitate dying with dignity was also repeated by nurses in the study by Beckstrand, Callister, and Kirchhoff (2006). Making environmental changes, such as creating a quiet environment and providing opportunities for prayer and meditation, also promoted dying with dignity.

Nelson *et al*. (2010) also stressed the importance of maintaining patients' dignity and treating them with respect at the EOL. A similar finding was shared by Noome *et al*. (2016a), which supported showing respect to the patient and treating a patient as a whole person. Many family members were against exposing the patient's private areas of the body in an open ICU; therefore, it was important to provide privacy. Again, it was also emphasized that each patient was a unique individual that had inherent values and was therefore worthy of respect, irrespective of the life-threatening illness. It was necessary to treat the patient as a person (Nelson *et al*., 2010). Wiegand (2016) also mentioned the demonstration of respect and genuine care for the dying patient as an essential aspect of care deeply appreciated by families. Examples mentioned included nurses addressing the dying patient by name, talking to the family members, and holding the hands of the dead patient. These aspects of care touched the family and created positive memories for them.

4.3.2.5 Spiritual care and cultural support

Another important theme that emerged following a deductive content analysis of the literature was "spiritual care and cultural support". The theme that emerged from the key findings of 11 (35.5%) of the included studies was classified as a key component of quality care at the end of life in the ICU from the perspectives of patients, families, and healthcare providers. The ethos of providing holistic care for patients and their families not only focuses on the physical, physiological, and emotional needs but also the spiritual and cultural ones. The theme places emphasis on spirituality, rituals, and meaning at the end of life and supports the spiritual journey and cultural beliefs of both patients and families, as well as attending to these respective needs as they cope with life-threatening illnesses, pain, loss, and grief (Jang *et al*., 2019; Kisorio & Langley, 2016a; Nelson *et al*., 2010).

In South Korea, Jang *et al*. (2019) conducted a study on how nurses perceive their professional duties regarding EOL care. The study findings brought to light the fact that nurses place greater emphasis on spirituality and accept patients as spiritual beings; hence, they make conscious efforts to attend to patients' and their families' spiritual needs and provide the necessary spiritual supports as much as possible. The experienced participants highlighted that the death visions were unique experiences for any dying patient and, therefore, should not be neglected. In a study conducted in Canada, Stokes *et al*. (2019) emphasized that during EOL care, most participating nurses associated spirituality and religion with peace. Any attempt to preserve dignity and promote peacefulness was seen as a good measure to support patients and their families' spirituality. Steinhauser *et al*. (2000a), in their study findings, further reiterate that patients, families, and healthcare providers place deep importance on spirituality and meaningfulness at the end of life. Spirituality encompasses patients' and families' religion, beliefs, and rituals. Therefore, spiritual care seeks to attend to these needs while patients and families cope with life-threatening illnesses, suffering, pain, and loss.

Findings from several studies included in the study revealed that it is important to align patient care with patients' and families' religious and cultural beliefs (Mistry *et al*., 2015), provide spiritual support for patients and families (Donnelly & Psirides, 2015; Kisorio & Langley, 2016a), and meet the cultural and religious needs of patients and families (Bratcher, 2010; Kisorio & Langley, 2016b; Noome *et al*., 2016a; Steinhauser *et al*., 2000a; Vedel *et al*., 2014). In Canada, Mistry *et al*. (2015) reported supporting the spiritual journey of patients as one way of addressing their non-physical needs. In doing so, it was important to align the patient care plan with the religious and cultural beliefs of patients and their families. This ensures that patients' and families' spiritual and cultural needs are recognized, elicited, and met during patient care. In the attempt to provide spiritual support for patients and families, Kisorio and Langley (2016a) reported in a study conducted in South Africa on the experiences of family members regarding EOL care in the ICU that it was important to allow families and a religious leader of their choice at the patient's bedside to offer prayer for the dying patient. Despite their loved ones' poor prognosis, participating families saw this as a source of hope and encouragement. Similarly, Donnelly and Psirides (2015) found in a grounded theory qualitative study conducted in New Zealand that families described the availability of pastoral care as a positive experience when their relatives were admitted to the ICU. The existence of good pastoral care made it easy for families to deal with and

become familiar with dying and death. Instances such as inviting a religious leader into the hospital and saying a word of prayer with the patient and family were well appreciated by families.

Bratcher (2010), Kisorio and Langley (2016b), Steinhauser *et al*. (2000a), and Vedel *et al*. (2014), in their respective studies, emphasized that meeting the religious and cultural needs of patients and their families was essential at the end of life. Bratcher (2010) highlighted that it was important for healthcare providers to accept and allow families to perform their rituals related to the death and dying of their relatives. In South Africa, Kisorio and Langley (2016b) also brought to light in their qualitative study that some patients and families regarded certain rituals and cultural practices, such as bringing in their traditional leaders during the EOL, as important. Participating nurses agreed that it was important to allow and respect these rituals and cultural practices as long as they were not harmful to patients, staff, or the institution. Steinhauser *et al*. (2000a) also regard the finding that patients and families are able to perform their rituals with an emphasis on faith as a key attribute of a good death in their qualitative study conducted in the USA. Such a finding is also consistent with that of Vedel *et al*. (2014), who also mentioned that most patients and families had several rituals surrounding death, and it was important to respect and incorporate these spiritual, religious, and cultural aspects of care.

4.3.2.6 Emotional support for patients and families

Following a deductive analysis of the literature, key findings from nineteen (19) studies representing 61.3% supported the theme "emotional and practical support for patients and families" as a vital component when it comes to caring for patients at the end of life and their family members in the ICU. The theme, as explained, involves preparing both patients and families emotionally for treatment withdrawal and the eventual death of the patient and finding practical ways to support them along the EOL trajectory. This includes establishing rapport with the patient and their family, providing them the needed assurances, counselling, debriefing sessions, and bereavement care (Donnelly *et al*., 2018; Taylor *et al*., 2020; Stokes *et al*., 2019; Wiegand, 2016).

It has been established from the study findings that the withdrawal of treatment affects both patients and their family members. Emotionally, it is a tough, sad, and heart-breaking period

for most family members. Most family members find it difficult to come to terms with end-of-life care decisions and let go of loved ones. They are often not prepared mentally and emotionally to hear their relative will not make it, and a decision was made to withdraw active treatment (Efstathiou and Walker, 2014; Kisorio and Langley, 2016a; Lloyd-Williams *et al*., 2009). Often, they are hoping for a quick recovery for their loved ones, and therefore, any changes other than that become a source of distress. Key findings from the included studies recommend the need to address the psychosocial issues associated with treatment withdrawal and EOL care and provide necessary emotional support for dying patients and their family members (Fridh *et al*., 2009; Herbert *et al*., 2009; Kisorio and Langley, 2016a; Mistry *et al*., 2015; Taylor *et al*., 2020).

In the provision of psychological comfort and emotional support, Efstathiou and Walker (2014) and Halcomb *et al*. (2004) in their respective studies mentioned the establishment of a good rapport with patients, their families, and significant others as a good measure to emotionally support patients and their families. In Canada, findings from Singer *et al*. (1999) also support the strengthening of relationships among patients, families, and healthcare providers as an element of quality EOL care from the patients' perspective. This measure creates an effective and therapeutic relationship among healthcare providers, patients, and their families. In the USA, Herbert *et al*. (2009) explored the views of bereaved and family caregivers on the factors considered important in preparing for the death of a loved one and the subsequent bereavement. The study showed that affective readiness was an emotional supportive measure that bereaved family members considered very important. Thus, it was important to mentally or emotionally prepare them for the patient's impending death. Key findings from Wiegand's study also affirm the importance of preparing the family emotionally and psychologically before, during, and after the withdrawal of treatment processes (Wiegand, 2016). Kisorio and Langley (2016b) and Mistry *et al*. (2015) further emphasize the need to attend to the emotional needs of patients and their family members during the EOL trajectory.

The practical ways for providing emotional support for patients and their families include reassurance (Fridh *et al*., 2009; Teno *et al*., 2001); counselling sessions (Donnelly *et al*., 2018; Kisorio & Langley, 2016b); debriefing sessions after treatment withdrawal (Kisorio & Langley, 2016b; Taylor *et al*., 2020); and bereavement care (Donnelly *et al*., 2018; Lloyd-Williams *et al*., 2009; Nelson *et al*., 2010). In the provision of emotional support for patients

and their families, Fridh *et al*. (2009) mentioned the need to reassure family members that their loved ones would not suffer and allow them to talk to and touch the patient. In instances where family members were not present, the study emphasized the need for nurses to act as substitutes and assure the patient that he or she is not alone. Teno *et al*. (2001) also reiterate that attending to the assurance needs of patients and their families constitutes good care at the end of life.

Counselling and debriefing sessions emerged as another practical way to support patients and their family members at the EOL. Family members, in particular, are frequently unprepared and uninformed about the death process and how to deal with their emotions (Teno *et al*., 2004; Teno *et al*., 2001). An organised counselling and debriefing session prepares the family and supports them in dealing with treatment withdrawal and sudden patient loss. Kisorio and Langley (2016b) reiterate that counselling sessions reduce family members' level of stress associated with EOL care and the death of a loved one. According to the findings of a study conducted in Ireland by Donnelly *et al*. (2018), breaking bad news to patients' families is a sensitive subject. Therefore, healthcare providers ought to be thoughtful and make counselling sessions readily available for patients' families. Also, having a constant psychologist available was a measure to support patients and their families emotionally.

Another practical way to support patients' families was to provide bereavement care and support, especially after the death of a patient. Taylor *et al*.'s (2020) findings emphasize the need to keep talking to family members before and after the death of a relative. It was important for healthcare providers to be available and share the moment with the family members. Family members describe the death vigil as a difficult one, and not every family member can stay with the patient during the dying process (Wiegand, 2016). It was important to be there for the family members as they went through the dying process. Donnelly *et al*. (2018) in Ireland also studied the perspectives of bereaved relatives on what was considered an important component of quality care at the EOL. The study brought to light that providing bereavement support to the family through various counselling sessions was very helpful. Bereavement care and support, such as a follow-up contact from a counsellor, timely bereavement information, and the provision of a link to people who had experienced a similar bereavement, were also mentioned by several bereaved family members. In the Netherlands, Noome *et al*. (2016a) also emphasized the sending of condolence messages as

an approach to supporting bereaved family members emotionally. Lloyd-Williams *et al*. (2009) and Nelson *et al*. (2010), in their respective qualitative studies, also support the care for family members even after patients' deaths.

4.4.2.7 Modifying the ICU environment

Another key theme that emerged from the analysis was the modification of the ICU environment. The theme refers to making changes in the ICU environment to create a peaceful, non-technical, and friendly environment suitable to support patients at their end of life and their family members. Key findings from 23 of the review studies mentioned the modification of the ICU environment as a means to enhance the quality of care provided for patients and their families at the end of life. This includes an environment that permits unrestricted family visitation during the EOL care phase; noise levels are reduced; space is created for intimacy and privacy; and there are adequate private rooms to support patient care and family members at the end of life (Efstathiou and Walker, 2014; Ranse *et al*., 2012; Stokes *et al*., 2019; Taylor *et al*., 2020).

In the USA, Wiegand (2016) explored family members' experiences of the withdrawal of life support in the ICU. The majority of families stressed the need to prepare the ICU environment for the dying process after the withdrawal of life support. The preparation of the ICU environment included the removal of unnecessary equipment from the patient's bedside, pulling curtains closer to ensure privacy, and bringing in additional chairs for family visits. Some families also expressed the need to have dimmed lights in patients' rooms. In facilitating dying with dignity in the ICU, Beckstrand *et al*. (2006) also added that the ICU environment should have quiet places for prayer, meditation, and family gatherings. Again, have private rooms for patients, play soothing music during the dying process, and ensure that facilities such as beds, showers, and food are readily available to the family members. Some bereaved families also mentioned the need to ensure privacy, where dying patients and their families have access to a single room with adequate facilities (Donnelly *et al*., 2018; Lloyd-Williams *et al*., 2009).

In the ICU, noise levels are expected to be high due to ongoing alarms, therapeutic procedures, and emergencies. Several studies recommend a quiet and noise-free environment during the dying process in the ICU (Bratcher, 2010; Donnelly *et al*., 2018;

Kisorio and Langley, 2016b). A therapeutic environment that is noise-free with machines turned off timeously helps take family members' attention off dropping vitals that are displayed on the monitors (Taylor *et al*., 2020). Such an environment also offers family members the opportunity to say their last words to their loved ones. Efstathiou and Walker (2014) also added that creating a less technical environment and reducing technical care, reducing the distance between the patient and their family, and increasing privacy and proximity were regarded by nurses as an essential way of reconnecting the patient and their family in the care environment. In the ICU environment, for instance, the monitoring equipment and invasive lines restrict family members' access to patients. Therefore, reducing the technical nature of the care provided by removing clinical equipment and allowing the family time and space for intimacy helps reconnect the patient at the end of life with the family (Efstathiou and Walker, 2014; Ranse *et al*., 2012). A patient dying alone in the ICU is considered an undesirable death in the ICU. Nurses in Efstathiou and Walker's (2014) study indicated that the physical presence of the family during the dying phase of a patient was an essential part of end-of-life care. Again, Halcomb *et al*. (2004) also reported that reducing the amount of unnecessary technical equipment at patients' bedside in the ICU also helped to humanize the patient at the end of life.

In the ICU, both patients and families place great significance on family access and proximity to the patient (Nelson *et al*., 2010; Steinhauser *et al*., 2000a). A restricted visiting time allows patients to rest and also facilitates routine shift changes, reporting, and addressing emergencies. However, having maximum openness and flexibility for family visiting during the dying phase allows the family to support the patient emotionally, recognize and interpret information that might have been missed or misunderstood, participate in decision-making, convey needed information to the other families, and also assist in the patient's care (Nelson *et al*., 2010; Pattison *et al*., 2013; Wiegand, 2016). Again, family members described positive aspects of the dying environment. The positive aspect involved preparing the ICU room for the dying process. Such measures included removing equipment that was not needed from the room, bringing in additional chairs for the family visits, lowering side rails, having dim lights, and pulling curtains close to maintain privacy (Lloyd-Williams *et al*., 2009; Wiegand, 2016). Families described having available facilities such as rooms and waiting areas where they can stay, have tea, and stay away from the ward as an important palliative and supportive care need in the ICU (Lloyd-Williams *et al*., 2009).

Similar to ensuring privacy, Noome *et al*. (2016a) also added that it was necessary to have a single room for patients at the time of death. This measure was vital to allow family members to be at the patient's bedside and pay their last respects to their loved ones. There is a need to create space for intimacy in the family (Donnelly & Psirides, 2015; Ranse *et al*., 2012; Stokes *et al*., 2019). After the withdrawal of treatment, bereaved family members preferred bringing in patients' items such as pictures that held particular memories and were connected to the dying person (Coombs, 2015). An environment that allows family members to play their favourite patient's music or musical instrument made care provision more meaningful (Stokes *et al*., 2019). These measures are important to create lasting positive memories for the family. Kisorio and Langley (2016a) also emphasized the need to encourage family presence during the dying process through liberal visiting hours. Arbour and Wiegand (2014) and Pattison *et al*. (2013) also agreed that flexible and unrestricted visiting hours allowed families to spend quality time with patients and provide closure.

4.3.3 Summary of Key Findings from the Review

This section presents a summary of the findings that emerged from the review. These conclusions drawn from the review themes explain the areas that are vital when it comes to providing quality care for patients at the end of life and their families in the ICU and palliative care centres. These themes were considered as content domains that potentially formed the blueprint for the instrument to measure the quality of care provided for patients and their families after the withdrawal of treatment in the ICU. Below is a concise summary of the content domains. **Table 4.6** presents the potential domains and items derived from the review.

- **Patient- and family-centered decision-making:** This category refers to measures centred on decisions made for the dying patient, the decision-making process, and decisions taken after treatment withdrawal is made.

- Shared and patient- and family-focused decision making is critical in achieving quality EOL care for patients and their families. When making decisions, it's important to keep the patients and their families in mind, find out their wishes, values, and treatment preferences as soon as possible, and take them into account.
- The healthcare team, the patient, and the patient's family must all be involved in the decision-making process. They must also be told how decisions are made about end-of-life care (EOL) and be given the chance to say what they think about EOL decisions.

- Teamwork is imperative when it comes to EOL decision-making in the ICU. Physicians, nurses, and other members of the ICU team, together with patients, if able, and their families, have major roles in EOL decision-making.
- There should be a thorough plan in place for the treatment withdrawal process to ensure a dignified death. In the plan, supportive measures should be in place to prepare patients and their families before and after EOL decisions are made.
- It is important to know patients' and families' wishes and preferences, which are essential to providing high-quality care. In instances where any advanced directives had been made, they needed to be respected and followed as indicated by the patients.

- **Symptom management and comfort**: This theme refers to measures aimed at controlling symptoms (e.g., pain, restlessness, and breathlessness), providing comfort, minimising aggressive care, and reducing suffering while a patient is in the dying phase of life.
- At the end of life, patients experience common symptoms such as pain, breathlessness, agitation, vomiting, and diarrhoea. An important element of achieving a peaceful withdrawal of the treatment process and end-of-life care in the ICU is to manage these symptoms. Thus, ensure that patients die without experiencing common symptoms such as pain, dyspnoea, and discomfort.
- The administration of analgesics, sedatives, and antimucolytics are some of the pharmacological interventions used to manage and control most of the common symptoms patients' experience. Patients must be pain-free, not struggle to breathe, and show no signs of anxiety.
- Another way to make sure that patients in the ICU get good end-of-life care is to assess their pain and administer painkillers when they need them.
- Another concern with the care of patients at the end of life is the continuation of active treatment that may cause unnecessary suffering. Both patients and family members prefer a loved one not to be kept alive on life support when there is little hope for a meaningful recovery. There is a need to minimise aggressive care and ensure that the patient does not suffer at the end of life.
- The patient needs to be freed of all tubes and technical equipment and made clean and presentable for family members.
- Comfort can also be provided through basic nursing care and non-pharmacological interventions such as bathing, mouth care, pressure area care, and hair care.

- **Communication among the healthcare team and with patients and families:** This refers to the consistent and reliable exchange of information among healthcare providers, patients, and their family members. It also focuses on both verbal and non-verbal forms of communication.

- Effective communication among the healthcare team and with patients and families ensures a peaceful treatment withdrawal process and EOL care.
- Effective communication is achieved when the healthcare team, patients, and their family members collaborate, reach consensus on the plan of care, and discuss and clarify the goals of treatments. This creates the opportunity to address any disagreements among the team and with patients and their families.
- At the end of life, it is also critical to have easy access to information as well as clarity and consistency of information shared among the healthcare team and with patients and their families.
- It's important to give family members as much information as possible about a patient's impending death and the treatment that will come with it. This will help them get ready.
- Clear, consistent, and accurate communication among the healthcare team, patients, and family members is an important part of EOL care. Having open and accurate communication reduces the stress associated with the fear of pain and inadequate symptom management. Patients and family members are also informed on what to expect, what will be done, and how things will be done.
- The use of medical terminologies confuses bereaved family members. Thus, it is necessary to convey clear information in a language that patients and their families understand and in layman's terms.
- Hold meetings often to answer questions from family members and keep them up to date on all aspects of treatment withdrawal.

- **Care with compassion, dignity, and respect:** This theme focuses on measures that respect and preserves the dignity of the dying patient. The patient is treated humanely just like any other patient in the ICU.

- Healthcare providers expressed the high importance of the value placed on the patient and treating the patient with respect, compassion, and dignity.
- A dignified death means that the patient is made clean at the time of death, the body is not exposed, and look good. This form of care creates satisfying and positive

memories for patients' families and also ensures that patients are honoured in front of their families before death.

- **Spiritual care and cultural support:** This category refers to the recognition of patients' and their families' spiritual, cultural, and religious needs, placing emphasis on them, and attending to them.

- Spirituality must be prioritized, and patients must be accepted as spiritual beings.
- Make conscious efforts to attend to patients' and their families' spiritual needs and provide the necessary spiritual supports as much as possible.
- It is also important to align patient care with patients' and families' religious and cultural beliefs and provide spiritual support for patients and families.
- It is also important to allow families and a religious leader of their choice at the patient's bedside to offer prayer for the dying patient. This is seen as a source of hope and encouragement for the family members.

- **Emotional support for patients and families:** This means taking care of the patients' and their families' mental and emotional needs during end-of-life care.

- The withdrawal of treatment affects both patients and their family members. Emotionally, it is a tough, sad, and heart-breaking period for most family members. Most family members find it difficult to come to terms with end-of-life care decisions and let go of loved ones.
- It is important to address the psychosocial issues associated with treatment withdrawal and EOL care and provide the necessary emotional support for dying patients and their family members. This begins with the establishment of a good rapport with patients, their families, and significant others.
- Before, during, and after treatment withdrawal, it is very important for family members to be emotionally and mentally ready. It is also important to reassure family members that their loved ones will not suffer and to allow them to talk to and touch the patient.
- An organised counselling and debriefing session prepares the family and supports them in dealing with treatment withdrawal and sudden patient loss. This reduces family members' level of stress associated with EOL care and the death of a loved one.

- Healthcare providers ought to be thoughtful and make counselling sessions readily available for patients' families, as well as have a constant psychologist available, as a measure to support patients and their families emotionally.
- It is important to keep talking to family members before and after the death of a relative, to be available, and to share the moment with the family members.
- Bereavement care and support, such as a follow-up call from a counsellor, timely bereavement information, and the provision of a link to people who have experienced a similar bereavement, as well as the sending of condolence messages, are methods of emotionally supporting bereaved family members.

- **Modifying the ICU environment:** This refers to making necessary changes in the ICU environment to support patients and families during care at the end of life.

- It is important to create a peaceful, non-technical, and friendly environment suitable to support patients at their end of life and their family members. This includes unrestricted family visitation during the EOL care phase, noise levels reduced, and adequate private rooms to support patient care and family at the end of life.
- The preparation of the ICU environment also includes the removal of unnecessary equipment from the patient's bedside, pulling curtains closer to ensure privacy, and bringing in additional chairs for family visits.
- Also, the ICU environment should have quiet places for prayer, meditation, and family gatherings and be able to play soothing music during the dying process.
- Facilities such as beds, showers, waiting areas, and food should be readily available for the family members.
- Dim lights are also required in a single room for patients at the time of death.
- Bereaved family members prefer bringing in items from patients, such as pictures that held particular memories and were connected to the dying person.
- Allow family members the opportunity to play their favourite patient's music or musical instrument.

Table 4.6: Summary of content domains and potential items derived from the Scoping review

Scoping Review	
Content Domains/ Themes	items
Symptom management and comfort	1. Remove all technical and unnecessary devices connected to the patient 2. Assess patients pain 3. Administer necessary pain medications for pain relief **4.** Provide relief and manage patient's symptoms such as agitation, restlessness and shortness of breath 5. Use non-pharmacological means such as repositioning, providing mouth care and bathing patients to promote physical comfort 6. Provide physical care and fulfil the basic standards of patient care such as bathing, pressure area care , ensuring warmth, regular mouth, eye and skin care, and meeting hygiene needs
Dignity, respect and compassion care	1. Treat patient with dignity during the dying process 2. Treat patient with kindness, compassion and sensitivity 3. Ensure that the patient body parts are not exposed and kept it private from the public view 4. Treat the patient as a unique individual with inherent value, worth respect and honour regardless of the disease 5. Show respect to the patient and care for patient as a whole person at the end of life 6. Address patient by name and title
Communication	1. Develop a therapeutic relationship with the family and connect with them 2. Ensure cognitive and knowledge readiness before relaying information on the disease prognosis 3. Have a collaborative, partnered and effective communication among the healthcare team that involves the multi-disciplinary team, patients and family members 4. Reach consensus with HCP about what is happening to patient and the goals of care 5. Provide clarity in communication about burdens and benefits of critical care treatment 6. Have a consistent communication from one person (HCP) with no break in the chain of communication 7. Communicate all information in a clear, consistent, supportive, timely and regular manner 8. Communicate in an honest manner to the family and with compassion 9. Keep the family informed of patient's condition, any changes and interventions given. 10. Assist families to understand patient's condition, prognosis, interventions given and impending death 11. inform the patient and family about all the aspects of the WDLS process 12. Assist the family to know what to expect about the patient's physical condition 13. Have frequent meeting with the family members 14. Nurses/ HCP available at any time and willing to answer questions from family members

	15. Nurses being present during family visits to inform them about patient's condition 16. Make sure the family understand the reason for the withdrawal of the treatment
Patient-and family centred decision making	1. Promote shared decision making between the healthcare providers and family members 2. Help patient and family to understand the available care options and involved them in the decision making and care planning **3.** Ensure that family members have some control on the care decisions and are able to share opinions on patient's decisions 4. Elicit patients and family values and treatment preferences early and honour their wishes as discussed earlier 5. If any advanced directives are made by patients, ICU need to know before any major decisions are made and follow such directives accordingly 6. Allow patient's proxy of choice to make end of life decision on behalf of the patient 7. Advocate for the patient and family, follow and support their wishes
Spiritual care and cultural support	1. Assess and talk to patient and family about their religious or spiritual beliefs and cultural beliefs associated with death and dying **2.** Attend to patients' and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner 3. Align care to suit the spiritual and cultural beliefs of patients and their families 4. Respect and accommodate the patient and family rituals surrounding death and dying 5. Meet the Religious and cultural needs of patients and their families 6. Invite pastor/father or a religious leader at the bedside to offer religious support for the patient and family
Emotional support for patients and families	1. Prepare the family psychologically for patient's death and let them know what to expect and the plan of events that follow death 2. Prepare the family early and help them to accept that their loved ones will not survive 3. Provide the family with the needed assurance that their loved one will not suffer 4. Provide bereavement care to the family members after the death of patient and send messages of condolences 5. Have a debriefing session after the withdrawal of treatment 6. Make counselling sessions readily available for the family and caregivers 7. HCP be available / Be there after the withdrawal of treatment and talk to the family 8. Involve a psychologist in the care of the family 9. Allow the family to externalise their feeling and share the moment with them
Modifying the ICU environment	1. Have flexible and unrestricted visiting hours to reduce the distance between the patient and their family 2. Provide adequate time and space for the dying patient and family to say goodbye 3. Family able to stay with patient at the bedside during the dying process

	4. Have someone present with the patient at the moment of death—to touch them, speak to them, to let them know it's okay to go 5. Connect the patient and family by allowing the time and space for intimacy 6. Allow the family to bring in personal items that held particular memories and were connected to the dying person 7. Be able to talk about the person's hobbies and sings songs 8. Remove all unnecessary clinical equipment from patients room 9. turn of machines completely 10. Silence all alarms from monitors 11. Dim the room lighting 12. Replace the hospital linen with coloured sheets and beddings 13. Pull curtains in full and close doors to ensure privacy 14. Make rooms available where family members can stay; have tea and being able to get away from the ward [waiting area] 15. Bring in additional chairs into the patients room 16. Make available beds, food and showering facilities for family members 17. Patient and family have access to private and single room during the dying process 18. Have a quiet place for prayer, meditation and family gathering 19. Allow the family to play patient's favourite music or music instrument

4.4 SUMMARY

The chapter focused on Phase 1 of the study and presented findings that emerged from the scoping review. Seven key themes emerged that explain the perspectives of patients, family members, and healthcare professionals on providing quality care for patients and their families at the end of life in the ICU. The chapter ends with a summary of the key findings that emerged from the review, discussions of the review findings, and a summary of the chapter. The themes as explained in detail included: patient-and family-focused decision making; symptom management and comfort; communication among the healthcare team and with patients and families; care with compassion, dignity, and respect; spiritual care and cultural support; emotional support for patients and families; and modifying the ICU environment. The chapter ended with key findings from the scoping review.

CHAPTER FIVE
PHASE 1: DOMAIN IDENTIFICATION AND ITEM GENERATION RESULTS OF QUALITATIVE STUDIES

5.1 INTRODUCTION

This chapter forms part of Phase 1 and presents a detailed description of the findings from the interviews conducted in the ICU with intensive care nurses, physicians, and bereaved family members. The chapter also presents the background information of participating nurses, physicians, and family members. The themes and sub-themes that emerged following data analysis are also presented and supported with direct quotes from participants. The chapter ends with a summary of key findings that emerged from the interviews and also a summary of potential items derived from the various interviews. The chapter finally ends with a conclusion to the chapter. The summary of potential items derived from the various interviews was used as the blueprint and formed part of the evidence used in the development of the instrument in Phase 2.

5.2 INDIVIDUAL INTERVIEW WITH INTENSIVE CARE NURSES

This section presents the results from the interviews conducted with intensive care nurses. The detailed findings are presented in the sections below:

5.2.1 Background Information of Participating Nurses

Participants' demographic data comprised gender, age group, years of ICU experience, and the highest level of qualification. A purposive sample of sixteen (n=16) intensive care nurses participated in the interviews. All participants have managed patients at the end of life and have witnessed treatment withdrawal in the ICU over the years of practice. All participants were interviewed in English. Table 5.1 presents a summary of the biographic information of the nurses that participated in the interviews.

Table 5.1: Demographics of participating nurses

Demographic information	Frequency (%)
Gender	
Male	2 (12.50)
Female	14 (87.50)
Age group in years	
30 – 40	8 (50.00)
41 – 50	3 (18.75)
51 – 59	3 (18.75)
60 – 69	2 (12.50)
Years of ICU experience	
2 – 5	-
6 – 10	7 (43.75)
11 – 15	3 (18.75)
16 – 20	1 (6.25)
>21	5 (31.25)
Highest level of qualification	
Diploma in Critical care nursing	7 (43.75)
Advanced Diploma in Critical care nursing	1 (6.25)
Master's degree in Critical care nursing	6 (37.50)
Doctorate	2 (12.75)

From Table 5.1, the majority of participants (87.5%) were female, while the least (12.5%) were male. Half of all participants (50%) were between the ages of 30 and 40, with the youngest (12.5%) between the ages of 60 and 69. The majority of participants' (43.75%) ICU experiences ranged from 6 to 10 years, followed by participants with more than 21 years of ICU experience (31.25%). The least amount of ICU experience was between 16 and 20 years. Almost half of the participants (43.75%) had completed a diploma in critical care nursing, followed by a master's degree and a doctorate in critical care nursing.

5.2.2 Themes and Sub-Themes Emerging from Interviews

This section presents the themes and sub-themes that emerged after data analysis. The experience of nurses providing care for patients and their families after treatment withdrawal was described under three themes: nurses' emotions, challenges to overcome, and rendering excellent care. The findings are discussed in detail and supported by the verbatim statements of the nurses from the interviews. The main themes are discussed and supported by subthemes for clarity. Similar statements by more than one nurse were grouped together rather than reported individually. The participating nurse was coded as "N."

Table 5.2: Themes and sub-themes from the data with nurses

Themes	Sub-themes
5.2.3 Nurses' emotions	5.4.1.1 Experience emotional attachment
	5.4.1.2 Mixed emotions experienced regarding withdrawal of treatment
5.2.4 Challenges to overcome	5.4.2.1 Behaviours and reactions of family members
	5.4.2.2 The unfavourable nature of the ICU environment
	5.4.2.3 Behaviours and attitudes of attending physicians
	5.4.2.4 Nurses-related challenges
5.2.5 Rendering optimum care after treatment withdrawal	5.4.2.5 Focus on the patient
	5.4.3.2 Support and work with the family members
	5.4.3.3 Modify the intensive care environment
	5.4.3.4 Effective communication and teamwork

5.2.3 Theme One: Nurses Emotions

During the interviews, participants expressed their emotions about providing nursing care for patients during and after the withdrawal of treatment in the ICU. These emotions are derived from nurses' involvement in patient care and relationships with others. The theme "nurses' emotions" was discussed under two sub-themes (as displayed in Table 5.2): "experience emotional attachment" and "mixed emotions experienced regarding withdrawal of treatment."

5.2.3.1 Experience emotional attachment

Some participants became emotionally attached to and connected to patients and their families during their stay in the ICU. This level of emotional attachment was due to the therapeutic relationship created between nurses, their patients, and their families. The extent of the attachment and bond created made the journey emotionally stressful for nurses, especially when a decision was made to withdraw treatment.

"You become emotionally attached such that when she failed to recover at the end, and it becomes stressful and heartbreaking…for that particular patient, I cried, because I had bonded with the patient..." ***[N4; N9]***

"…some patients you get to connect to more than others, especially if you've nursed them for a couple of days or for a week, then, and then you sort of have a connection with them" ***[N10]***

The extent of emotional attachment and bonding made it difficult to detach oneself from the situation. The family members get to know the caregiver, exchange contacts for further communication, and even become part of the family. It takes some time for carers to detach themselves and forget those memories.

"Also detaching yourself from this, emotionally is the hardest, detaching yourself from this whole situation with the patient and the family is very difficult…It really hits me hard. It leaves me with the feeling of guilt. And sometimes it takes about weeks to get over, even when I go home, I still tend to carry such things home" ***[N6; N13]***

5.2.3.2 Mixed emotions experienced regarding withdrawal of treatment

Another sub-theme that emerged was "mixed emotions experienced regarding withdrawal of treatment." Mixed emotions, also known as mixed feelings, according to the Merriam-Webster dictionary (2021:1), refer to conflicting feelings or emotions. It also refers to two or more emotions elicited by the same event that differ in quality and action tendency. In this study, the majority of participants expressed mixed emotions after treatment withdrawal in the ICU. Several participants described it as a traumatic and difficult moment when dealing with critically ill patients who had their treatment withdrawn. It was an emotional phase for nurses, as indicated in the quotes below:

"It's a very emotional phase when it comes to stopping treatment…Emotionally, it was really traumatic … it is traumatising to see a patient suffering" ***[N9; N16]***

Similarly, other participants also expressed feelings of sadness while providing nursing care to the patient and the family after treatment withdrawal. Participants recalled that knowing that the patient would not survive, having not done much in life, and the family members being unprepared for the sudden loss made the situation a sad one for nurses.

"It is really sad, very sad that the patient is not going to make it…To see them deteriorate even after so many efforts is very heart-breaking…I feel heartbroken" ***[N3; N15]***

Other participants described their feelings of guilt and helplessness, especially when the patient did not make it despite their best efforts.

"Some of these patients as you take care of them you can see the way they're going, they are not going to make it. It hits me hard. It leaves me with the feeling of guilt" ***[N3]***

"I feel useless. I feel useless in the sense that I'm not doing anything for this patient" [N4]

On the other hand, the nursing care provided after treatment withdrawal was described as providing a feeling of relief. Three participants described how having the family members verbalise how pleased they were about the efforts made the care so pleasing for them. It was also rewarding to be able to have the opportunity to care for the patient from the beginning to the end of life and be able to leave good memories for the family to remember in the future.

"…because we did our best, we made sure that everything was done accordingly. Unfortunately, she did not make it. But it was so pleasing to hear the family verbalizing that they are so pleased with all our efforts" ***[N4]***

"It is rewarding to take care of that patient from beginning to the end of his life…t it can leave family or relatives a scar forever" ***[N12]***

The age of the patient during treatment withdrawal greatly affected most participants' emotions. It was discovered that dealing with older patients was easier emotionally than dealing with younger patients. The older patients were said to have lived their lives and died naturally.

"It easier for me with the older person… I always believe that God has decided, let's just let the person go in peace so it's easier to get over those emotions" ***[N4; N6]***

Providing nursing care for the young patient after treatment withdrawal was, on the other hand, difficult, painful, and traumatic. Some participants indicated:

"It is more traumatic with the younger patient… I feel like the young ones sometimes need to be given a chance honestly, as compared to the old ones…It is difficult to deal with younger people. It's very difficult to deal with children that are dying because we always feel that that goes against nature. Those young people shouldn't die" ***[N4; N12]***

5.2.4 Theme Two: Challenges to Overcome

The provision of end-of-life care after treatment withdrawal comes with several challenges. The challenges nurses need to overcome, according to the transcripts, are areas that make care difficult and pose challenges for nurses while providing care for patients and their families in the ICU and are related to the withdrawal of treatment. The theme "challenges to overcome" highlights the barriers and obstacles to providing optimum care after treatment

withdrawal. Four sub-themes describe the theme: behaviours and reactions of family members; the nature of the ICU environment; the behaviours and attitudes of attending physicians; and nurse-associated challenges.

5.2.4.1 Behaviours and reactions of family members

After treatment withdrawal in the ICU, participants indicated that you also had to deal with the patient's family members. Family members are often hopeful that their relative will make it out of the ICU. Anything other than recovery is always a concern and tough for the family to accept, especially when the patient will not make it and death is imminent.

*"…there's not a single family that I've ever come across that was calm and was content seeing the relative like that… You will never find them [family] to be calm" [**N2; N15**]*

*"It's so difficult even to talk to the family, you know, you are reassuring them, but you can see that they still have that hope that because he's lying in the hospital, one day, you'll come out of the hospital…The hardest thing I'd have to say is getting the family to accept it, you would get one who will accept in the family, but you'll get five others who cannot accept it" **[N3; N4]***

Some family members were reluctant and in disbelief that the patient was at the end of his life. The extent of family denial made it challenging to provide optimum nursing care after treatment withdrawal. Such concerns were expressed as:

*"... Some will say oh if they believe in their cultures and everything to say no… If they're even in the reluctance stage to say they don't believe that he is going to die. They think if they took this patient ventilated to the traditional healers, then everything will be okay". **[N3; N15]***

The strong cultural beliefs and differences of most family members also hampered the provision of optimum care after treatment withdrawal. One participant added:

*"Some will encourage you to say, we've brought some traditional medicine …Can't you give this medication, and we say, No…" **[N3]***

Family members' frequent requests for information and updates on their loved ones were also mentioned. As soon as the treatment is withdrawn, families want to see their loved ones.

".. you can have quite an extended family, and everyone's got to know what's happening and, and you have to keep them updated…And if you do not talk to the family, they are getting agitated, they getting anxious" [N4]

"…they're going to look for you, every beep of the monitor, every twitch of the finger, they will come to you and say, but I just saw my, my mom's finger twitch but sister I did" ***[N5]***

Some family members vent their frustrations on nurses, ask difficult questions, and even scream at them. Some participants expressed that:

"… Now we have to go and break it down for the family and explain to them and they got the questions to ask us. But Sister, why are you not doing this? Is there any other? Should we get a second opinion? Now?...I have worked with families that have screamed and performed and gone wild when they heard it…" ***[N4; N7]***

Most family members are not willing to leave the patient's bedside, especially during basic nursing procedures. They are afraid that patients will pass away while they are away. As indicated in the quotes below:

*"…They don't want to leave their patient, they feel like you're taking their time out, you're taking time away from them to spend time with the patient… relatives are afraid that the minute they are away from the bedside, the patient will pass on. There is that element" [***N9; N12]***

5.2.4.2 The unfavorable nature of the ICU environment

Another challenge nurses faced while providing care after treatment was stopped was the unfavorable nature of the ICU environment. Due to the crowded conditions in the ICU, most family members are left out and uncared for. They are consequently left in the waiting areas.

"… The family is not given adequate access, we isolate family members from the care of the family member…You will find out that most of the time the patient is going and most of the relatives sitting outside the waiting area" ***[N6; N8]***

"…you find out that the dialysis sister and the radiographer are coming in, they'll be asked to move out because the radiographer wants to do an x-ray on the other patients" ***[N13]***

The ICU can also be noisy. Noise from monitors and emergencies in the ICU were also mentioned.

"We can be very noisy, you know, alarms can ring forever, and we don't stop them on time, phones can be endless, the cleaner comes in with a mob hits it against the wheels of the bed

…Whiles you are taking care of this dying patient, you find out that another one is having an emergency on the on the other side" ***[N2; N8]***

The ICU environment is very crowded due to the numerous machines.

"Regarding critically ill patients, you've got to have a lot of machines….So it takes a lot of space, space-wise, it takes a lot of space in that environment" ***[N4]***

Some participants also raised the ICU's multi-bed system, in which two or more patients are cared for in the same cubicle. The absence of single cubicles makes it difficult to maintain privacy. Some participants disclosed:

"…there are four patients per cubicle or sometimes these two patients per cubicle. So when we call the family in to come and spend time with the patient, you know, and the other patients that are in the cubicle can see all that…we don't have single cubicles where other patients cannot see when we do other things to other patients" ***[N6; N14]***

Additionally, the workload in the ICU diverts nurses' attention from caring for the needs of the families. Two participants said the following:

"*…when the patient is deteriorating we call the family we give them exceptions, we allow them to come in. But the problem is that we don't attend to them…it's not the fault of the nurses is the workload" [**N13; N16]***

5.2.4.3 Behaviours and attitudes of attending physicians

Following the withdrawal of treatment in the ICU, nurses encountered difficulties while providing care due to the behaviours and attitudes of the attending physicians. Some participants disclosed that when speaking to patients and their families, attending physicians explained medical terms at their level. They often use vague, technical words that are confusing and difficult to comprehend.

"Sometimes they [family] ask to speak to the doctor of the patient. But because doctors explain it at their level… they [doctors] talk to the family in their medical languages that are sometimes vague to the family" ***[N1; N11]***

In the ICU, discussions about treatment withdrawal frequently only involve doctors, with no place for nurses. Nurses are not involved in the EOL decision-making process. Doctors fail to take into account that nurses are always present at the patient's bedside and, therefore,

have no meaningful contribution when it comes to providing care for the patient and family members.

"The doctors don't involve the nurses. They just discuss among themselves and make the decision, forgetting that the nurses are the ones who are always with the patients 24-7" ***[N16]***

"So we practically stop the treatment without being involved in the whole decision-making process…They don't involve us as nurses, they just tell us what to do. There will never be a time that the doctor will call the nurse in his office to discuss issues concerning withdrawal. They make the decision and leave the bedside" ***[N9; N11]***

Once more, some participants mentioned how challenging it was to get doctors to document an order to withdraw treatment. Participants explained that either the decision was made while they were away or they were unaware of it until they were asked.

"They [doctors] just say we are now not going to be commencing treatment anymore. You will get the difficult Doctor who doesn't want to say and doesn't want to have it written" [N4]

"I have seen senior doctors, they just walking into a unit and saying, oh, by the way, we've stopped treatment, we've decided to stop treatment. That nurse who is caring, or in partnership with the doctor was not present when the family was spoken to" ***[N11]***

As soon as the decision to withdraw treatment was made, some doctors leave. Nurses are always left behind to carry out the plan, console the family and answer their questions. One experienced ICU nurse also further stated that once the decision to discontinue treatment has been made, doctors only visit the patient's bedside to certify death.

"The doctors step away, they will say sorry sister, we've withdrawn all treatment, there is a DNR order, we do not need to resuscitate and there's nothing and they are gone… and we the nurses are left behind to deal with this" ***[N4; N5]***

"…once a doctor says not for escalation or not for resuscitation, they're not involved. They're not going to do anything, so the doctor only comes when the patient has demised and come and certify the dead, but they're not involved after the patient has been after we've withdrawn the treatment" ***[N9]***

Often, EOL decisions are made in an open ICU by doctors, especially during ward rounds. The patient's cubicle is abandoned and the decision to withdraw treatment is made open in the presence of the family members. One experienced participant explained:

Some doctors frequently make EOL decisions in an open ICU, particularly during ward rounds. The decision to discontinue treatment is made in front of the patient's family members, with the patient's cubicle being abandoned. One experienced participant clearly stated:

"The other thing is the doctors don't go to that cubicle. So when the big ward rounds take place the family members are familiar with the ICU routine. Now everybody walks past that bed, past that cubicle, the comments get made, oh no we've pulled out treatment here and the family hear that because they there" ***[N7]***

Making decisions about end-of-life care can be difficult for inexperienced doctors. They do not have the necessary experience to deal with treatment withdrawal in the ICU. One more experienced participant added:

"Your inexperienced doctors don't know how to deal with it. So they will say to the family, oh, there's nothing more we can do, we've decided to pull out treatment and they are gone, you know, so it's a traumatic situation" ***[N7]***

5.2.4.4 Nurses-associated challenges

Several participants mentioned difficulties specific to nurses. When life-saving treatments are stopped, nursing care abruptly ends. Once treatments are discontinued, most patients and their families are left alone and neglected.

"…when treatment is withdrawn on the patient, then nursing care also stops. The patient becomes neglected now because we know that in the next hour, the patient is going; now comfort is diminished" ***[N8]***

"…Now {nurses} they leave the family members to watch for a straight line on a cardiac monitor, which is also very traumatic…and ignore the families grieving over the patient by the bedside" ***[N7; N13]***

The provision of care for a patient at the EOL is a unique area of ICU practice. Most nurses are not trained to care for dying patients. One participant mentioned:

"An ICU nurse is not trained to care for dying patients. Nowhere in our curriculum, do we cover aspects of the dying patient. So this is a new concept ***[N7]***

Some nurses admitted that they felt uncomfortable discussing death in the intensive care unit. The moment the decision to stop treatment was made, family members were left alone with their loved ones. Most people avoid the situation because they are unfamiliar with such events.

"Some people are uncomfortable dealing with end of life patients, they may be uncomfortable to communicate to the family….Most nurses don't know what to do when a patient's family is grieving. We don't know how to talk to the family, about the situation so sometimes we just disappear from the scene. So we need to work on incorporating nurses more at this end of life period" ***[N12; N13]***

Several participants recalled the lack of support for nurses while providing care for patients after treatment withdrawal in the ICU. Nurses were not supported, however, continue to carry out their nursing roles. Some participants were unable to express their feelings due to the lack of emotional support. They suppress their emotions and later become blunt.

Several participants recalled the lack of support given to nurses while they were caring for the ICU patients after treatment withdrawal. Emotionally, there are no support systems in place. Some nurses clearly stated:

"And sometimes in ICU, we don't acknowledge those feelings… Before that patient is gone out, another patient is already waiting in the bed for me. So I haven't got time to grieve. So what happens with a lot of the older nurses it builds up and builds up and it builds up. And then we start becoming desensitized towards our feelings" ***[N7]***

"We not even given a chance as nurses to debrief or to have people that speak to us also give us emotional support we don't get that. But as broken as we are we have to also continue giving emotional support to the families, despite the fact that no one is giving us emotional support….And if you become emotionally traumatized for a prolonged period, you end up being numb, you end up being so numb, it is burnout on its own, you end up being numb, you end up being emotionally blunt" ***[N8; N9]***

5.2.5 Theme 3: Rendering optimum Care after Treatment Withdrawal

Another theme that emerged after the analysis was "rendering optimum care after treatment withdrawal." Participants described how they provided care to patients and families following treatment withdrawal. The theme also describes how participants explained excellent care after the patient's treatment was withdrawn in the ICU. Five sub-themes emerged from the main theme, namely: focus on the patient; support and work with the

family; Modify the intensive care environment; support for nurses; and effective communication and teamwork.

5.2.5.1 Focus on the patient

The sub-theme "focus on the patient" refers to paying attention to the patient's needs after treatment withdrawal and providing total care for the patient even at the end of life. The sub-theme "focus on the patient" included: keeping care at the same level, making the patient comfortable and pain-free, meeting the patient's wishes, meeting their spiritual and religious needs, advocating for the patient, being there for the patient, and maintaining dignity and respect for the patient.

- ***Attend to the basic needs of patients***

Although treatment has been discontinued, some participants still place a high priority on meeting patients' basic needs, like personal hygiene. The patient was supported even at the end of life by being kept clean in bed. Two participants stated the following:

"Even though the treatment has been taken off, the hygiene needs of the patient are important. You cannot leave the patient in the poo or you can't leave them in a wet, wet bed. So that also has to be taken care of, even though the patient is no longer on the ventilator or the patient is no longer on inotropes" ***[N13]***

"Doing patient mouth care. Those types of things must still be done, we shouldn't do nothing for the patient unless it's not allowed. So I think basic care we must still continue" ***[N10]***

The majority of participants emphasized the importance of continuing basic nursing care after treatment is stopped. Like with any other patient, it was necessary to maintain the same standard of care.

*"Take care of the patient, all the personnel needs, like clean the patient, suction the patient, bath the patient until that imminent moment comes…do your basic nursing care on that particular patient…the patient should look as the family know the patient, well kept, shaved and all of that I need to do" [**N3; N8**]*

"I will turn the patient whether 2 or 4 hourly, I will turn the patient and rub the back. Make sure the hygiene needs of the patient are met". ***[N13]***

- ***Keep patient comfortable and pain-free***

Many participants emphasized that patient suffering and pain were not desired outcomes, especially when a choice had been made to stop treatment. As a result, they always made sure the patient was at ease and not experiencing any unpleasant pain.

"It is about pain, to ease the pain…. it's very important to keep the patient pain-free and to maybe you know say for instance if this patient is on for 4-hourly morphine, that you will continue to give it the morphine 4-hourly" ***[N2; N3]***

"Our goal in ICU is for our patients not to die in pain but to be as comfortable. I still have to manage the pain…even though the treatment has been taken off, I cannot leave my patient in pain. The patient should not die in pain but have a peaceful" ***[N9; N13]***

- ***Treat the patient with dignity and respect***

Participants emphasized that since each patient was an individual, they should be treated with respect and dignity. Nurses had a responsibility to ensure a dignified death, respect privacy, and consider the whole person.

"You want to give them [patient] a dignified death, I like to give all my patients' dignity and no matter what their age. That dignity, respect, I give that patient because it's a human being, a human life [N4]

"When they at those moments, ensure the privacy, ensure the dignity throughout the whole process…that give them also inner strength that they're not on this journey alone". ***[N5; N14]***

- ***Provide spiritual support and cultural care for the patient***

Several participants also brought up the need for patients and their families to receive spiritual support. Prayers, acknowledging the patient's spirituality and offering support in that regard, and allowing a spiritual person to be by the patient's bedside were among the actions mentioned.

"Once the decision is made, and I do think that that spiritual person, so whether it's somebody who has a minister, or whether it's somebody who goes through a chief, or whatever it is, that person should be included ***[N1]***

"Prayer, I found that prayer really calms them down. Other religious beliefs, such as Muslims and all that, also have their way of doing things. So they will come, the priest will

come, they'll say their prayers, they will have oils and then they will do whatever they need to do and you always respect that and give them space" ***[N8]***

"And I[nurse] personally normally tell them to connect with whatever the spiritual being that they, they believe in. I tell them, if they believe in God, they need to pray to God, then they need to connect with God more in that whole process" ***[N9]***

- ***Advocate for the patient***

Most patients who are nearing the end of their lives are unable to decide on their own care. Some nurses agreed that it was their responsibility as the patient's primary carer to speak up for them, even when they were near death.

"We should be able to say this patient's care today dictates that the family visit. The patient's probably not going to live through the night. Yeah. So whoever the patient wants today, the patient should get. And we should be arranging that" ***[N1]***

"So talking to the doctor and asking them, you know, what, can we do weaning off this and we know there's nothing we can do, but can we maybe give this for pain...Nurses are advocates for their patients, it is important for the nurse to advocate for the patient, to speak her mind, her knowledge and her input" [N4; ***N11]***

- ***Be there for the patient***

Many participants emphasized the importance of staying with the patient after the ICU stops providing care. It has been said that letting families spend time alone with their loved ones is stressful and makes the family anxious. Participants acknowledged that in order to comfort the patient, allay their fears, and deliver the best care possible, they needed to be by their bedside.

"Remember even just seeing your relatives with all these tubes in all these gadgets is already so placing them in such anxiety. You will not just leave people to visit and leave them to themselves. So we had to be at the bedside of your assigned patient…We have a body system in the intensive care unit, where if I'm going to lunch, my body is standing in there to answer any questions. And that's very important" ***[N2; N4]***

"… Ensure that a patient will never be left alone. So, to be there, to comfort them and to just allay the fears and allay their anxieties". ***[N3; N5]***

- ***Talk to the patient and empathize with them***

Even though the patient was unconscious and near the end of their life, some participants felt the need to continue talking to them. Despite the patients' low GCS, the nurses felt it was crucial to explain every procedure to them. This strategy was considered to a means of facilitating a calm environment.

"I will talk and greet and say Mr. so and so, I'm sister K and I taking care of you today. So you just keep talking to them just to create that environment of calmness…keep on conversing with your patient, although you know there's not going to be a response back. Talk to the patient always whatever procedures that you do to the patient, conscious or unconscious, you need to explain the procedure" ***[N3; N8]***

Even though the patient was dying, two participants with more experience added that they still needed to have empathy for them and be as genuine as they could be.

"So I believe you must be so empathetic, you know if you show that empathy, you can place yourself in that person's shoe…You must remain and be as authentic and humane as possible because this is a life you are dealing with" ***[N2; N7]***

5.2.5.2 Support and Work with the family members

The subtheme "support and work with the family members" refers to providing the family members the right kind of support and collaborating with them following the withdrawal of treatment in the ICU. The following headings provide explanations of the sub-theme:

- ***Meet the needs of the family***

Even though it was thought that there wasn't much time between stopping therapy and passing away, some participants made the point that it was crucial to take care of the family members' needs and fulfil their wishes while there was still time. It was essential to give them the support they required so that they did not feel as though they had missed anything. Three participants said the following:

"I think it's important that we meet the relative's needs, not forever but for a very short period I think it is important that we give them the support that they need so that they don't

feel that they've missed anything or the relative has suffered any stage of that, end of life process so that they can also have closure and peace". ***[N12]***

*"We should be much more in tune with the patient and the family's needs than our needs**…**we need to give extra attention, or just have to show compassion towards the family during that time…I think it's very hard on them"* ***[N1; N10]***

Other participants also stressed the significance of comprehending and honoring the family members' wishes. The majority of families have specific preferences and wishes regarding patient care after treatment is stopped. During that time, it was necessary to fulfil those wishes, as the quotes below demonstrate:

"So for me, understanding my patient and the family members' wishes and wanting you to know from the family how they want to do this" ***[N7]***

"I think families are different, you know, you need to respect their desires…If they want to have the rabbi and the minister and the Catholic priest that should be allowed" ***[N1; N12]***

- ***Involve the family in the care of the patient***

Involving the family in the patient's care was another form of family support that the participants emphasized. Family members were encouraged to touch their loved ones because they were seen as an integral part of the care provided to them. Some participants even revealed that they were permitted to participate in routine care tasks like cleaning and rubbing the patient.

"I encourage the family to be part of what we do for the patient, and even encourage them to talk to the person, even tell them, whisper in their ear, say something 'mummy I am rubbing your feet, I am doing this but encourage patients to do that…And also, touching the patient and you can even encourage the family members, whilst they are with the patient to touch the patient and say what they want to say to the patient" ***[N2; N3]***

"I think we need to involve the family members in the care of a patient….You need to like, to be honest with the family members. And it is your responsibility to involve them in the care or to prepare for anything that might come" ***[N5; N6]***

- ***Allow the family members at the patient's bedside***

Another way to assist the patient's family members was to offer them access to the patient and allow them to be present in the ICU. Participants gave the family members unrestricted

access to the ICU and allowed them to be there. It gave the family the freedom to spend as much time as they wanted by the patient's bedside.

"And if they [family] want to have somebody sitting with that patient 24 hours out of 24 that should be allowed. That should be allowed" ***[N1]***

"It's very important for me to you know to call the family, to let them know that they can come in as often as they want to come in, spend time with the patient, register their presence at the bedside or spend the last time with that loved one before the person dies. It is still part of the caring for me" ***[N13]***

Flexible visiting hours were mentioned as a way to support the patient's family, particularly after the decision to discontinue treatment. One or more participants explained that in order to let the family members visit the ICU at any time, they had to violate the visiting hour regulations.

"Relatives are always allowed to be at the bedside, we don't follow visiting hours when it comes to that; they will come in anytime, anytime, for their patient" ***[N8]***

*"We ask for two visitors at a time in the intensive care unit. I'd like to break the rules sometimes because I think you know what allowing a few families in the last few hours of the patient dying…In terms of the family care, I think giving them time, giving them more visiting hours instead of restraining them from visiting their family member" [**N4; N6]***

- ***Keep the family informed and updated***

In the ICU, Family members are more worried about the recovery of their loved ones than anything else. Particularly when the choice is made to stop the course of treatment, they are curious to learn everything there is to know about the patient and the interventions that have been given to them. Several participants emphasized how important it was to inform the family members of any changes made at every stage of the patient's care.

Nurses [4, and 6] added:

"With the family, you got to be very open because we have different family members and with the critically ill compared to a ward patient, you're going to have a family that more concerned, a family that you have to keep on updating the family of how the progress is. Everyone's got to know what's happening, and you have to keep them updated" [N4]

"I think when it comes to situations like dropping in a BP you know, inform the family members 'this what is happening, this is what we are doing, the condition of the patient and things like that" ***[N6]***

Several participants acknowledged during the information-sharing phase that it was critical to maintain open lines of communication with the family and to tell them the truth. Additionally, it was important to be truthful when communicating with the family members and to make sure that everyone was on the same page and concurred with the medical professionals' decisions. The family feels included in the care process and that their suggestions are valued as a result of this. Nurses 3, 7, and 11 reported:

"You need to be honest with the family members….You need to be truthful…You must tell them the truth. If he's not doing well, tell them don't conclude, because you are not God" ***[N3]***

"A nurse explains things in simple ways. So being on the same page is what the family wants, it is important. Do they want to be at the bedside? Do they want to call other family members? Do they want priests present? Those things for me are very, very important. If they say to me, you know that will make sure me our loved one is pain-free, you know, we don't want them to suffer, that is fine for me, I will facilitate that" ***[N7]***

"We should allow them to read and get to a point whereby they also agree with us to say take it up. Not whereby we feel that we know everything and that at this stage, the patient cannot make it. And then we just say to the family that we are withdrawing treatment, let's give them [family] a chance" ***[N11]***

- ***Be [nurses] there for the family***

It was impossible to stay with the patient's family for a longer period of time in a busy setting like the ICU. However, a few participants mentioned that it was important to set aside some time and take advantage of the opportunity to be present when the patient's family visits. It was crucial that the nurse was present to provide them with emotional support, to explain some of the interventions that were given to them, and to respond to their questions. Some participants said:

"... just seeing your relatives with all these tubes in all these gadgets is already so placing them in such anxiety. You will not just leave people to visit and leave them to themselves. So we [nurses] had to be at the bedside of your assigned patient. And for me, it was so striking to see how grateful the families were for the time they take to talk to them because they have many questions" ***[N2]***

"I do talk with them, I do clarify some of the things to them, the things that they don't understand, I make sure that I avail myself to them so that if ever there's anything that they need to ask, they asked me and I give them answers" ***[N9]***

- ***Spiritual care and cultural support***

Respecting the family's religious and cultural practices was another aspect of supporting them. Most families would like to perform certain rituals and beliefs for their loved ones if it were possible. In this study, nurses talked about the importance of recognizing and accommodating the cultures and beliefs of the families, so long as doing so did not endanger patients or nurses. Two participants emphasized the need to inquire about the family's spiritual practices and preferred cultural activities for the patient. According to nurses 2 and 10:

"We must take cognizance of any cultural ritual or any act that needs to be performed on. So, we must make room for it… So, if it means wrapping up the person, if it means not washing the person, don't wash the person" ***[N2]***

"Yes, I think you need to, for me, personally, always I asked, what are the spiritual beliefs? Or do they have a specific prayer or interventions that I need to do beforehand? And then and then to allow them to do that because that is a belief; that is their culture. …because that is part of the closure is to, to do the final spiritual religious attributes towards the patient" ***[N10]***

The majority of families preferred specific cultural practices and rituals related to death and dying in the ICU because of the cultural differences. While some preferred driving the patient's spirit away, others preferred having a religious leader offer a prayer and carry the patient's body on the same day. Once the cultural and religious customs surrounding death and dying were made known to the healthcare professionals, it became necessary to respect and accommodate them. As shown in the quotes below, a number of participants stated that they allowed the family members to carry out their rituals, which served as a sort of closure for the family:

"Some cultures, they've got their own rituals and everything, and then they'll come in, you know, collect the corpse. Others it must be buried before sunset, we accommodate and allow that" ***[N3]***

"Well, I think if they [family] understand the process and just for them to be there. If they can be there with the patient and they can do their last cultural or religious contribution and

just to be there until the end, then that is sort of closure for them because then they've seen okay, but everything was done" ***[N10]***

After a patient passes away, a particular group of families frequently enter the room carrying tree branches. It was a method of summoning and removing the patient's spirit, in accordance with their culture. Quotes from some nurses [4 and 11] indicate that these procedures are always permitted:

"We get a lot of times where the patient dies, and the funeral palace taking the body and they [family] come, call the spirit and they come with the little branch. Then you got another patient coming into that bed. You know in the ICU, no bed is empty. So get the family coming to call the spirit, we allow that. So you get the family coming in to call the spirit. We allow that" ***[N4]***

"One thing that I've seen is that they come and say that they want to fetch the spirit of their relatives. So, once we do this after the person dies. …They are here to fetch the spirit. So it is a culture here that they do. So you the nurse, you just lead them to where their relative had his last breath and they have some leaves or something. They go and do their own thing" ***[N11]***

Additionally, according to two participants, some family members, particularly the traditional believers, always wanted their traditional leaders present so that they could carry out the rituals that their beliefs required. All of these cultural beliefs were acceptable so long as they had no negative effects on the patient. Two participants clearly stated:

"For some of the family members, they have sangomas and special cultural practices. Some want to apply some ointments on their relative with the believe that it will help them recover and all that. Allow them as long as it will not affect the patient" [N6]

"Yes, some of them, they would invite a Sangoma [traditional leader or ritualist] to come. It's just need to give them space for so long as they're not going to be lighting things that will cause smoke and all that, just give them space for them to perform that ritual without affecting the other patient" ***[N8]***

Every culture has its own way to offer its last respect to the dying patient in the ICU. For some, it is mandatory to allow the family to observe their last prayers. According to them, the soul of the patient is never at ease until such rites are performed. Some families, especially the Christians, also wanted their pastors around to offer prayer for the dying patient. Some nurses indicated that they offered the family that space to offer prayer for the patient. Nurses 4, 6, and 9 expressed that:

"We all have different cultures that we belong to, and we have in I would say, the Indian culture, they have a prayer, they have to do. And allowing that to take place… you got to

allow the last rites to be done because the soul is never at ease. So I, for me, as a nurse, I want to give them that to be able to do the last right" [N4]

"If they feel like bringing in the Pastor to pray with them, allow that. Give them that space, and let the pastor be there with the family. We need to allow them to practice their cultural beliefs" [N6]

"… most families when they come there, knowing that their patient, their family member is in the process of dying, they normally read the Bible, they normally pray. And I normally get involved as well during prayer, I normally pray with them. It's also a way of letting them see that they are not alone on that road; we are together with them" ***[N9]***

- ***Empathize with the family and advocate for them***

Losing a family member in the ICU is not an easy moment for the family especially after treatments have been withdrawn. Several participants explained that caregivers had to show some form of empathy towards the family.

"So I believe you must be so empathetic, you know, if you show that empathy, you can place yourself in that person's shoe, so think that this person can be my mother lying here that they are deciding the support and I think once you can place yourself into that then whatever will come with it will come will come out. You will be warm. You will take all that Questions… I put myself in the shoes and say you know what if it was my mom or dad and how would I feel? I want answers so you have to accommodate them" ***[N2; N4]***

The caregiver will be able to speak up for the patient and family once you become friendly with them. One participant raised the advocacy roles nurses played at the time.

"I supported the family against the team and until they were in full agreement. And for me that was my advocacy role that I had to stand up for my patient and the family that they against the team until they were satisfied, that was a great decision" ***[N7]***

- ***Provide emotional support for the family***

Taking care of the family's emotional needs and offering emotional support were also mentioned as ways to assist the family. It is emotionally draining and heartbreaking to watch a loved one be admitted to the ICU and then enter the palliative care stage. Consequently, it was essential to provide the family with emotional support. When the decision to stop treatment was made, two participants said it was crucial to give the family time and space to grieve.

"For the family, I always allow them to grieve. I always allow them to grieve to whatever point they want to. If they want to stay overnight, let them stay overnight. If they want to sing and pray, let them sing, whatever that's going to bring comfort and closure also to the family, let them do" ***[N8]***

"You must allow them to come, grieve and then until the patient goes. So I think it gives them some sort of closure rather than they will come and their relative is taken off" ***[N11]***

While the family grieves over the loss, some participants reported that regular counselling and debriefing sessions were necessary to help the family cope emotionally. Experienced psychologists were involved to speak to the family members on a daily basis. As indicated in the quotes below:

"I think we need to involve psychologists to speak to them [family members] on daily basis, you know like to try and help them understand the situation that they are going through…We should have psychologists or counsellors that can sit down with the family and counsel the family in a very professional way. Or even after, okay, they can counsel the family during the whole process of treatment withdrawal" [N6; ***N13]***

"And then I think afterwards, the debriefing is extremely important for the family members, whether it's with the immediate immediately afterwards, I think you do need to have a debriefing session and then allow them to come back to see the patient once all the tubes and pumps have been removed the and then to perhaps follow up to see if they're okay" [N7]

5.2.5.3 Modify the intensive care environment

The sub-theme describes the adjustments required to create a suitable setting for offering patients and their families the best care possible after treatment withdrawal. A therapeutic setting that provides the patient with the necessary privacy, is noise-free, and lessens the technical nature of the ICU is one of these changes. Many participants agreed that the ICU needs to have a special area set aside for patients receiving palliative care. Such places encourage privacy and give the family easy access.

"If we are treating that kind of patient and maybe there should be a certain area in every ICU, that those patients who are not for continued treatment should be placed so that their relatives can come and go" ***[N1]***

"If a doctor withdraws treatment, for me, I'd like the person or the doctor to move the patient maybe to a like a step-down or to move the patient to another ward. And I'd like to tell you, you know, one of the things that I'd like is to have for the dying, a therapeutic environment…I would love to have an isolation room and allowing everyone anyone to come and see that person ***[N4; N5]***

In the creation of a therapeutic environment, some participants emphasized the need to have a less technical and clinical atmosphere, however, and a more homely one that shifts the families' focus to comfort care. Some participants mentioned playing soft music, closing the patient's curtains, and bringing in the radio as interventions necessary to create a less intensive care environment for the family members, as indicated in the quotes below:

*"Always I'd like to create a therapeutic environment, meaning I'd like my music playing and I feel that they are so much more at ease that you know, someone knows that they've got this music" [**N4]***

*"... Creating that therapeutic environment by closing curtains, giving them the privacy and playing some music or whatever for them" **[N5]***

*"We all don't have that therapeutic environment. But I create always I create in the sense of closing the curtains, and allowing that music, you know, ask them to bring the radio, I would say you bring the radio, you know, we can play it softly to the patient. And we do that all the time is to play the soft music, that soothing music for that creating that environment" **[N11]***

Dimming the lights, decorating the patient's room in lovely colors, and hanging pictures on the walls were additional changes that could be made to the ICU environment to support the care of the dying. For patients who are nearing death, these interventions help to create a peaceful, siren and therapeutic environment. Nurses 3 and 4 stated the following:

"*... if possible, another unit, where all this patient who are on most approaching death that they can be transferred in and it must be in a cubicle for where the families can actually, if they want to enter, they can go in, you know, every time they want to, you know, maybe preferably lights can be dimmed off" **[N3]***

*"I will love if we have palliative care unit. Somewhere that is not an ICU environment. It's a peaceful, siren and therapeutic environment created with pictures on the wall. It must not be a big ward, a small ward that is painted with beautiful and lovely colors. You have frames put up there and you got music playing. That will be the ideal for me" **[N4]***

The majority of the participants acknowledged that ICU patients' bedsides were cluttered with machines, infusion pumps, and syringes, which limited family access to the patient. These things took up a lot of space and made the family members' surroundings more technological. Some participants claimed that:

"Regarding critically ill patients, you've got to have a lot of machines…So it takes a lot of space in that environment, so you know what, you try to move the patient as much as

possible… so you got you have space for the family to fit in. also trying to make sure it's safe, because families are not able trip on anything" ***[N14]***

"Make sure that there's no clutter around the bed, they must have a free movement around the bed. Ensure if there is foot stool that you're not using it to remove it so that the family can move" [N15]

"So make sure that if there is drip stand around, if you're not using it, remove it so that they can have free movement…" ***[N16]***

Several participants acknowledged that it was important to be aware of the level of noise in the ICU setting. Participants made conscious efforts to lower the level of noise from the monitoring machines and technical equipment in the final moments after treatment withdrawal to maintain a calm environment.

"We must take cognizance of the environment, lower the noise make it as you know as quiet as possible. If you feel that the environment is too noisy, ask and make even the suggestion that lets move the patient to a quieter cubicle….Keep the noise levels of the machines down, although we cannot switch off" ***[N2; N16]***

"I do draw the curtain halfway, I'd say because we also don't want the alarms ringing and especially at night, for us alarms going off, and we try to keep it as quiet as possible during the night with these alarms going off…I'm a strong believer that all the monitors should be switched. I don't believe that you should be sitting and listening to beep, beep in the cubicle and waiting for a straight line" ***[N4; N7]***

5.2.5.4 Effective communication and teamwork

Participants emphasized the significance of effective communication and teamwork between the ICU team and the patient's family as a way to provide a dignified death for both the patient and the family. They emphasized the importance of working together as a team, so there was a plan in place to improve the care for the patient and family, and doctors, nurses, and patients' families were all involved in the care.

Three nurses stated that:

"I think that communication between the team and the patient's family is very important…. I think within the team we continue to have that connectedness that we are all facing. We all want the same outcome for our patient" ***[N1; N2]***

"As a multidisciplinary team, we need to involve the patient and the family in the care. I think we should be able to communicate with the patient and family more. Working as a team will help improve the care for the patient and the family" ***[N6]***

Similar to this, other participants also mentioned that caring for the patient and family was made simpler by having a plan for what to do. The group can discuss options, raise concerns, and come to consensus on every plan. Nurses 7 and 9 added:

"I think it's if you have a process or standard or if one discusses it, it might make it easier working through. So the team, the communication with the team, and how we plan this and my involvement, the doctors' involvement still coming to see my patient is extremely important" ***[N7]***

"As a multi-disciplinary team, we should decide together, they should also hear our views as nurses. So it's a very therapeutic environment for proper communication with the bereaved family. So we communicate with them there with the doctors and the nurses and they comfortably ask whatever questions they want to ask without any disturbance what is" ***[N9]***

5.2.6 Summary of Key Findings from Nurses Interview

The section presents conclusions drawn from the interview findings regarding nurses' experiences providing care after treatment withdrawal in the ICU. The conclusion statements are reported under the main themes and are as follows:

Theme 1: Nurses emotions

- When nurses care for patients and their families in the ICU for a few days or weeks, they become emotionally connected to them and their families.
- The extent of attachment and bond created is due to the therapeutic relationship created while spending more hours at the patient's bedside, getting to know the patient, and providing continuous care to them. Because nurses care about their patients emotionally, it's hard and stressful for them when treatments are stopped when patients don't get better.
- The bond created with patients and their families makes it difficult for nurses to forget those memories and detach themselves from scenes relating to care after treatment withdrawal in the ICU. Emotionally, it is described as the most difficult aspect of the care, and it takes nurses weeks or months to overcome it.
- Providing nursing care, especially after treatment withdrawal, comes with mixed emotions. Nurses experience and express feelings of guilt, sadness, and relief while providing care for patients and their families.

- It is never easy to deal emotionally with a patient whose treatment has been discontinued. It is emotionally draining, heart-breaking, and traumatic for nurses.
- Nurses are relieved when family members verbalise how pleased they are with the nursing care provided for patients.
- The age of the patient affects nurses' emotions. Dealing with the older patients is easier and less traumatic than dealing with the younger patients, according to the attending nurses. The older patients are considered to have lived their lives and died a natural death; therefore, it is easy to get over those emotions.
- After treatment discontinuation, nurses find it more traumatic and difficult to care for the younger patients.

Theme 2: Challenges to overcome

- Certain behaviours and reactions of family members pose a challenge to the provision of nursing care to patients after treatment withdrawal. Nurses deal with family members who are upset because their loved one is nearing the end of his or her life, as most family members are hopeful that their loved one will be able to leave the ICU despite the transition to comfort care.
- It is often hard to get the family to accept that the patient will not make it out of the ICU. Most family members are in a state of denial, are reluctant to accept, and disbelieve that their loved one is at the end of life.
- The strong cultural beliefs and differences of family members also affect how nurses provide care for patients after treatment withdrawal. Some family members bring in certain traditional medicines that, according to them, are important and could help their loved ones.
- The continuous requests from family members to see their patients and get updates on their loved ones also become a challenge nurses have to overcome. As soon as treatment is withdrawn, all the family members want to see their loved ones and keep asking for updates.
- Some family members are not willing to leave the patients' bedside after treatment withdrawal due to the fear of losing them while they are away.
- The ICU setting has limited space to accommodate patients' family members. The setting is overcrowded with machines and activities that occupy the space for the family to be with their loved one during ICU care.

- The ICU environment was noisy. The unending noise from alarms, emergencies, and co-workers in the ICU makes it difficult to provide optimum care for patients and their families after treatment withdrawal.
- The absence of single cubicles makes it difficult to maintain privacy. The multi-bed approach makes it difficult to maintain privacy.
- The workload in the ICU takes nurses' attention away from attending to the needs of patients and their family members.
- Certain behaviours and attitudes of attending physicians also make the provision of nursing care for patients and their families after treatment withdrawal challenging. Physicians explain medical terms to family members at their level. These words are vague and technical, such that they are confusing and difficult for family members to understand. Treatment withdrawal discussions are frequently held among ICU doctors without the participation of nurses.
- It is difficult to get doctors to write down the order to withdraw treatment. Nurses are made aware only when they ask, and mostly treatments are withdrawn while nurses are away. Mostly, the decision to withdraw is made during ward rounds, with no form of privacy and sometimes in the presence of family members. As soon as the decision is made to withdraw treatment, the attending physicians step away. Nurses are then left behind to answer questions from families for which they have no answers. Physicians are not there to answer questions.
- Inexperienced physicians are uncomfortable making a decision to withdraw treatment. They do not know how to break the news. While they make the decision to withdraw treatment, they just inform the family, and they are gone.
- Nursing care suddenly changes and even stops when patients' treatments are withdrawn. The patient and family are often neglected and left alone during the period. The majority of nurses are not trained to provide care for dying patients; hence, they are not comfortable talking about death in the ICU.
- Nurses are not supported while providing care for patients and their family members after treatment withdrawal. They are unable to express their feelings and, therefore, suppress them after the emotional scenes they encounter.

Theme 3: Rendering excellent care after treatment withdrawal

- After the patient's treatment was withdrawn, nurses said it was important to focus on the patient, help and work with the family, change the ICU environment, and encourage good communication and teamwork.
- Focusing on the patient encompasses paying attention to the patient's basic needs and providing holistic care for the patient, even in the last moments after patients' treatments are withdrawn. These steps include taking care of the patient's basic hygiene needs, like keeping him or her clean and well-kept in bed; making sure the patient is comfortable and free of pain; treating the patient with respect and dignity; and meeting the patient's spiritual, cultural, and religious needs.
- Another way to facilitate and ensure excellent care after treatment withdrawal is to work with and support the family members. This includes attending to family needs such as information, comfort, proximity, the need for assurance, and spiritual and cultural support. Family members can also be helped by getting them involved in the patient's care, letting them spend a lot of time at the patient's bedside, and speaking up for them.
- Modifying the intensive care environment is also an important way to ensure excellent outcomes following treatment withdrawal in the ICU. Nurses indicated that it is important to make changes in the ICU setting to support the dying and also accommodate the family. These measures include: silencing alarms on all monitors and equipment to minimise noise levels in the ICU; moving patients to a special area after treatment withdrawal; adjusting lighting; and closing nearby curtains.
- Effective communication and teamwork were mentioned as important measures to facilitate care after treatment withdrawal. The nurses said that it was important to have a plan in place to make sure that patients and their families got the best care possible, that all healthcare providers, patients, and their families were involved in the care, that healthcare providers and the patient's family communicated well, and that everyone worked as a team.

5.2.7 Theoretical sampling

For the purposes of generating suitable items for the instrument's development, this section focuses on the quotes that were pulled from the transcripts and examined as potential items.

These potential items formed the blueprints for the instrument to measure the quality of care provided for patients and their families after treatment withdrawal in the ICU. They are derived from participants' interviews and are quotes that represent the viewpoint of nurses. This section forms part of the items used in the development of the provisional instrument in Phase 2. Table 5.3 presents a summary of the potential items pooled from the interviews.

Table 5.3: Summary of potential items derived from Nurses interviews

Theme / sub-theme	Category	Nurses quotes [source]	Potential items identified
Focus on the patient	Attend to the basic needs	*"Even though the treatment has been taken off, the hygiene needs of the patient are important…Take care of the patient, all the personnel needs, like clean the patient, suction the patient, bath the patient until that imminent moment comes… turn the patient whether 2 or 4 hourly, I will turn the patient and rub the back"[**N3; N13]***	1. Attend to the hygienic needs of the patient (keep patient clean, provide mouth care, turn patient regularly)
	Patient comfort/ symptom management	*"it's very important to keep the patient pain-free and to maybe you know say for instance if this patient is on for 4-hourly morphine" **[N2]***	2. Administer prescribed medication and keep patient pain-free
	Dignity and respect	*"I like to give all my patients' dignity and no matter what their age. That dignity, respect, I give that patient because it's a human being..."**[N4]*** "*…ensure the dignity throughout the whole process..." **[N5]***	3. Treat patient with dignity and respect
	Spiritual care and cultural support	*"Prayer, I found that prayer really calms them down. Other religious beliefs, such as Muslims and all that, also have their way of doing things. So they will come, the priest will come, they'll say their prayers, they will have oils and then they will do whatever they need to do and you always respect that and give them space" **[N8]*** *"And I[nurse] personally normally tell them to connect with whatever the spiritual being that they, they believe in. I tell them, if they believe in God, they need to pray to God, then they need to connect with God more in that whole process" **[N9]***	4. Attend to the spiritual, cultural and religious needs of the patient 5. Allow the patient to connect to whatever the spiritual person they believe in 6. Allow the priest or any spiritual person to offer prayer for the patient
	Advocacy role	*"...Nurses are advocates for their patients, it is important for the nurse to advocate for the patient, to speak her mind, her knowledge and her input" **[N4]*** *"We should be able to say this patient's care today dictates that the family visit. The patient's probably not going to live through the night.*	7. Nurses advocate for patients during the last moments 8. Arrange and have patient's wishes followed

		Yeah. So whoever the patient wants today, the patient should get. And we should be arranging that" ***[N1]***	
	Nurse presence	*"… Ensure that a patient will never be left alone. So, to be there, to comfort them and to just allay the fears and allay their anxieties".* ***[N3; N5]***	9. Be there at the patient's bedside to support the patient
	Talk to patient	*"I will talk and greet and say Mr. so and so, I'm sister K and I taking care of you today…. Talk to the patient always whatever procedures that you do to the patient, conscious or unconscious, you need to explain the procedure"* ***[N3; N8]***	10. Talk to the patient during procedures and address them by their titles
	Meet family needs and wishes	*"I think it's important that we meet the relative's needs, not forever but for a very short period…"*[***N12]*** *"So for me, understanding my patient and the family members' wishes and wanting you to know from the family how they want to do this"* ***[N7]*** *"…show compassion towards the family during that time…"* ***[N1]***	11. Attend to the needs and wishes of the family members 12. Show compassion towards the family during the end of life care
	Family involvement	*"I think we need to involve the family members in the care of a patient…. it is your responsibility to involve them in the care"* ***[N5; N6]*** *"I encourage the family to be part of what we do for the patient, and even encourage them to talk to the person, even tell them, whisper in their ear…."*[***N2]***	13. Involve the family members in the care of the patient 14. Encourage the family members to talk to the patient and touch the patient
	Family bedside presence	*"It's very important for me to you know to call the family, to let them know that they can come in as often as they want to come in, spend time with the patient, register their presence at the bedside or spend the last time with that loved one before the person dies. It is still part of the caring for me"* ***[N13]*** *"Relatives are always allowed to be at the bedside, we don't follow visiting hours when it comes to that; they will come in anytime, anytime, for their patient"* ***[N8]***	15. Allow the family to spend the last moment with their relative before the person dies 16. Have flexible visiting hours that allow the family to be at the patient's bedside
	Information sharing	*"I think when it comes to situations like dropping in a BP you know, inform the family members 'this what is happening, this is what we are doing, the condition of the patient and things like that" [N6]*	17. Keep the family informed of patient's condition, any changes and the treatment

Support and work with the family		*"You need to be honest with the family members….You need to be truthful…You must tell them the truth"* ***[N3]*** *"We should allow them to read and get to a point whereby they also agree with us to say take it up. Not whereby we feel that we know everything and that at this stage, the patient cannot make it. And then we just say to the family that we are withdrawing treatment, let's give them [family] a chance"* ***[N11]***	18. Communicate to the family in an honest manner and be truthful 19. Ensure that the family members understand the process and be there to answer their questions
	Nurse presence	*"…So we [nurses] had to be at the bedside of your assigned patient. And for me, it was so striking to see how grateful the families were for the time they take to talk to them because they have many questions"* ***[N2]***	20. Nurses stay with the patient's family to clarity and answer their questions
	Spiritual care and cultural support	*"Some cultures, they've got their own rituals and everything, and then they'll come in, you know, collect the corpse. Others it must be buried before sunset, we accommodate and allow that"* ***[N3]*** *"We must take cognizance of any cultural ritual or any act that needs to be performed on. So, we must make room for it… So, if it means wrapping up the person, if it means not washing the person, don't wash the person"* ***[N2]*** *"For some of the family members, they have sangomas and special cultural practices. Some want to apply some ointments on their relative with the believe that it will help them recover and all that. Allow them as long as it will not affect the patient"* ***[N6]***	21. Allow the family to practice and perform their last rituals 22. Take cognisance of any family cultural rituals that needs to be performed 23. Allow the family to bring in their preferred pastor or traditional leader to observe their last prayers and perform their rituals if not harmful to the patient, staff and institution
	Empathy	*"I believe you must be so empathetic, you know, if you show that empathy, you can place yourself in that person's shoe…"* ***[N2]***	24. Empathise with the family and be there for them
	Advocacy	*"And for me that was my advocacy role that I had to stand up for my patient and the family that they against the team until they were satisfied, that was a great decision"* ***[N7]***	25. Advocate for the patient and the family members

	Emotional support	*"For the family, I always allow them to grieve. I always allow them to grieve to whatever point they want to…"* ***[N8]***	26. Give the family time and space to grieve
		*"I think we need to involve psychologists to speak to them [family members] on daily basis…We should have psychologists or counsellors that can sit down with the family and counsel the family in a very professional way" [**N6; N13]***	27. Involve a psychologist to speak to the family on daily basis
		"I think afterwards, the debriefing is extremely important for the family members, whether it's with the immediate immediately afterwards, I think you do need to have a debriefing session" [N7]	28. Have a debriefing session with the family members after the withdrawal of treatment
Modify the ICU environment	*Modify the ICU environment*	*"If we are treating that kind of patient and maybe there should be a certain area in every ICU, that those patients who are not for continued treatment should be placed so that their relatives can come and go"* ***[N1]***	29. Have a designated area in the unit where the patient will be managed
		"I create always I create in the sense of closing the curtains, and allowing that music, you know, ask them to bring the radio, I would say you bring the radio, you know, we can play it softly to the patient. And we do that all the time is to play the soft music, that soothing music for that creating that environment" ***[N11]***	30. Close nearby curtains to provide privacy 31. Play soft music
		"…lower the noise, make it as you know as quiet as possible. ….Keep the noise levels of the machines down" ***[N2; N16]***	32. Lower the noise from monitors and other equipment
		"So make sure that if there is drip stand around, if you're not using it, remove it so that they can have free movement…" ***[N16]***	
		"It's a peaceful, siren and therapeutic environment created with pictures on the wall. It must not be a big ward, a small ward that is painted with beautiful and lovely colors. You have frames put up there and you got music playing. That will be the ideal for me" ***[N4]***	33. Decorate patient's room with lovely colours and pictures of choice on the walls 34. Dim room lights

		"*… if possible, another unit, where all this patient who are on most approaching death that they can be transferred in…maybe preferably lights can be dimmed off"* ***[N3]***	
Effective communication and teamwork	Communication	*"I think that communication between the team and the patient's family is very important…. I think within the team we continue to have that connectedness that we are all facing. We all want the same outcome for our patient"* ***[N1; N2]*** *"I think it's if you have a process or standard or if one discusses it, it might make it easier working through. So the team, the communication with the team, and how we plan this and my involvement, the doctors' involvement still coming to see my patient is extremely important"* ***[N7]***	35. Communicate effectively between the team and patients' family

5.3 INDIVIDUAL INTERVIEW WITH PHYSICIANS

This section presents the findings that emerged from the individual interviews with physicians working in the ICU. The detailed findings are presented in the sections below:

5.3.1 Background Information of Participating Physicians

Participants' demographic data comprised gender, age, years of practice as a qualified physician, years of ICU experience and area of specialisation. A purposive sample of nine (n=9) doctors participated in the interviews. Participants participated in the study on the basis that:

- Working in the adult ICU at the time of the study
- Have made a decision to withdraw treatment or being a part of a team that made the decision to withdraw treatment in the ICU
- A registered physician with more than 5 years of clinical experience

All the participants were registered practising physicians with years of clinical experience ranging from 6 to 15 years. Additionally, all of them had some form of ICU experience ranging from 6 months to 7 years at the time of the study. Two of the participants were consultants that made a decision to withdraw treatment, and the rest were part of the ICU team that made the decision. Three female doctors and six male doctors were interviewed. The ages of participants ranged from 30 - 41 years. All participants were interviewed in English. The letter "D" was used to represent a participating doctor.

5.3.2 Themes Emerging from Physicians Interviews

Following the analysis of the individual transcripts, five main themes emerged that explain the experiences of doctors participating in the withdrawal of treatment in the adult ICU. **Table 5.4** provides an overview of the themes and sub-themes that emerged from the interviews with the doctors. Similar quotes from two or more doctors will be grouped together.

Table 5.4: Themes and sub-themes from the data with individual doctor participants

Theme	Sub-theme
5.3.3 Making End-of-Life Decisions	5.3.3.1 How the end-of-life decision is made to withdraw treatment in the ICU 5.3.3.2 Factors considered when making EOL decisions to withdraw treatment 5.3.3.3 Who is involved in making EOL decision to withdraw treatment
5.3.4 Shared Feelings around Making EOL Decisions	5.3.4.1 At peace with the decision made 5.3.4.2 Mixed feelings following treatment withdrawal
5.3.5 Challenges encountered Making EOL Decisions	5.3.5.1 Challenges from the family 5.3.5.2 Disconnect between attending doctor and nurses 5.3.5.3 Attending physician uncomfortable making EOL decisions 5.3.5.4 Documentation challenges
5.3.6 Novice to expert	5.3.6.1 Learning on the job
5.3.7 Facilitating care after treatment withdrawal	5.3.7.1 Providing comfort care for the patient 5.3.7.2 Treat patient with dignity and respect 5.3.7.3 Inform the family and help them to understand the process 5.3.7.4 Provide emotional support for the family 5.3.7.5 Involve the family member in the process 5.3.7.6 Allow the family at patients beside 5.3.7.7 Provide religious and spiritual support 5.3.7.8 Assess and meet the needs of the family

5.3.3 Theme One: Making End-of-Life Decisions

The theme describes the EOL decision-making process before treatment is withdrawn in the ICU. In making EOL decisions to withdraw treatment, it was discussed under three sub-themes, namely: "*How the EOL decision is made to withdraw treatment"*; "*Factors considered* when *making EOL decisions to withdraw treatment"*; and "*Who is involved in EOL decision making process*." Similar quotes from two or more doctors will be grouped together.

5.3.3.1 How the end-of-life decision is made to withdraw treatment in the ICU

In this study, participating physicians described EOL decisions made to withdraw a patient's treatment as a process and is taken over time. Before the withdrawal of treatment, there are

a lot of discussions among the ICU team on the best way to approach the withdrawal process. Attending physicians normally consults their senior critical care consultants for their input. Their views are illustrated in the following extracts:

"Most of these decision not to escalate or to withdraw are taken over time… I would probably think about the decision. But before I actually execute to the decision, I'll have to discuss with the other senior colleagues and have the professors input to the decision and to actually say…and it is not a decision that you take over 20 minutes or that you take over a day. It is a process…" [***D5; D8***]

"…then what we'll say is we've offered seven days of very good antimicrobial therapy, very intense, you know, renal replacement therapy, we've, we've made sure this patient has got the best shot that they got, but they haven't improved. At that point, we then say, look, is dialysis or something like that still indicated? Probably not …And we'll see from there so that those decisions get made usually by the critical care consultants and sometimes the fellows" ***[D3]***

The decision made to withdraw treatment is often made on a case-by-case basis. Once the patient is not improving despite the best therapeutic interventions provided, the most senior consultant in the ICU team initiates discussions around treatment withdrawal. The discussions are centered on the clinical presentation of the patient, the disease process, the organs affected and how reversible they are. Once they arrive that there is nothing to be done for the patient and they are not going to prolong the life of any quality, then a decision is made to withdraw treatment. Some experienced consultants mentioned:

"Once it looks like things are not improving no matter all the organs that we are supporting, nothing is really showing improvement not the lungs not the kidneys. Then usually it comes from the senior, the most senior person in the team to say that at this point in time we capping therapy and we're pulling out at which points in time we do not go above a certain dose of adrenaline, no matter what happens. If he crashes, we're not going to jump on chest. Those kinds of things" ***[D5]***

"…so it depends on a particular case that would get in ICU to say okay, based on this and that clinical presentation of the patient, disease process of the patient, premorbid status of the patient and all other scoring and other organs failure and how reversible are they, then you make a decision. ***[D8]***

5.3.3.2 Factors considered when making EOL decisions to withdraw treatment

The sub-theme explains the factors participants take into consideration when deciding to withdraw a patient's treatment. The factors mentioned included futility of care, the

worsening condition of the patient, scientific data, and the patient's chances of survival. Some participants explained:

"...Futility of care, I think there's a main thing. ...where they feel like they don't have anything extra to offer the patient, that's where they come in to make the decisions of withdrawing or withholding care" ***[D1]***

"Someone has been on a ventilator, let's say for more than a month and their condition is not improving. Meaning that organ function is not improving. And no matter what you do, there is nothing; they won't improve further than they could" ***[D2]***

"If you're on a ventilator and still on max settings, despite being on it for weeks on end, you know, we're not able to wean you down. We try to wean you and then you just crash, your PaO2 and everything just go to the bottom of the Yeah, then. And those are the ones that we say okay, now we hit a rock and we must just pull out. So, those kind of parameters" ***[D5]***

There is no one-size-fit-all approach, it often depends on the patient. The use of scoring systems such as APACHE scores, SOFA scores; and scientific evidence were also mentioned as helpful factors considered to decide to withdraw treatment in the ICU. These scoring systems are used in addition to other parameters to withdraw treatment. Some experienced physicians highlighted:

"So the idea is to use scientific data to back up to say patient chance of survival is very small because of the following scientific reasons. It's not a subjective feeling, it is an objective scientific evidence based decision…we use scoring systems and so there are scoring systems that predict mortality in certain cases and based on these scoring systems, a high mortality, the chances of survival is very small, therefore, they are either capping treatment" ***[D4]***

"There is no one scoring system that you can say you base your decision on. Its multiple things that you base them on. So yes, all of the scoring systems can assist such as APACHE score, SOFA scores. There are so many scores that you can use to see premorbid status of the patient, current condition of the patient and outcomes of that particular disease" ***[D8]***

"So parameters we look at obviously, the patient's comorbidities, patient's age, what is the initial pathology, the initial problem, the diagnosis, the outcome, is it a poor diagnosis, is it a good diagnosis, has there been studies done that show that there is progress in this type of disease?" ***[D9]***

5.3.3.3 Who is involved in making the EOL decision to withdraw treatment

Another sub-theme was who is involved in making the EOL decision to withdraw to treatment in the ICU. Several participants indicated that it was a multidisciplinary sort of decision made to withdraw the patient's treatment in the ICU. The decision-making process

was not an individual one but a team decision that involves physicians, nurses and other healthcare professionals.

"It is a multidisciplinary sort of type of decision. You will need to involve the family. You need to involve your other colleagues, be it physios, dieticians, social workers, psychologists. It's a collective decision. It's not just an ICU doctor…It will be unfair not to involve the nurses because they're the one that spent the time most with the patient who is critically sick" ***[D2; D8]***

"Whenever that decision comes it's never an individual one in the ICU settings, it's always because it's the hierarchy. There are the consultants, and us junior consultants and then their registrar's and medical offices, so that that hierarchy forms part of the medical side of the team. That decision is never really made by one person… that is a decision taken with the family, in consultation with everyone involved on patients that have no prognosis" ***[D5; D6]***

It was also mentioned that nurses played vital roles in the EOL decision-making process. Nurses assisted physicians to make the right decisions owing to their constant bedside presence and relationships with their patients. However, several participants mentioned that they were not fully involved in the decision-making process. The ultimate decision was made by the attending consultant with no input from nurses.

"I think we involve the nurses more in a in a; look in a decision making process, they help us a lot. They are the ones that are obviously always with the patients. They are the ones that decide, you know, they can tell us they'll be like, look this person's renal function is worsening, they've got no urine, you know, that they pick up on these things…I think from a decision making process that aren't too involved" ***[D2; D3]***

"To honest with you not the ones that I have been involved. Not in the discussion to not escalate treatment. Part of the discussion yes, more what do you think about the patient's general conditioning today? Has anything changed, gotten worse and but not in the act of decision of withdrawing. No, what I've seen nurses are not are involved" ***[D4]***

5.3.4 Theme two: Shared Feelings around Making EOL Decisions

Another theme that emerged from the interview was "shared feelings around making EOL decisions to withdraw treatment". The theme describes how physicians felt while being part of a team or the one that made decisions to withdraw treatment in the ICU.

5.3.4.1 At peace with the decision made

The majority of participants see the decision made to withdraw treatment as a difficult part of ICU practice, however, it has to be done and their hands are tied. As uncomfortable as it is, most experienced physicians do not struggle with those decisions. The decision to withdraw treatment is often made and arrived at upon several consultations in tandem with other factors such as patients' prognosis, medical history and scoring systems. Therefore, most physicians are at peace with the decisions they make. Some physicians indicated that:

"I don't struggle with those decisions. So when they've said we're going to withdraw on this patient or withhold treatment, I haven't felt a particular emotional connection to be, you know, to where I felt it was unfair or that I felt particularly sad. I often see it in the benefit of the patient. So, I'm at peace with those decisions" ***[D1]***

"I felt comfortable, I didn't feel like it was the wrong decision to make at the time because it didn't feel like we could do anything beyond what we were doing…At that point in time I don't see it as a bad decision when we choose to withdraw and it's not an easy decision. Most of the time I find that I agree with the decision. I agree that there isn't much more to be done, medically speaking. Yeah, and I'm comfortable. I'm comfortable with it" ***[D5]***

"I don't find it an emotional decision to make…it's never easy to be the one coming with a decision to say we no longer going to continue treatment…But yes, indeed I'm comfortable making those decisions. Having all the information that I can plug in the positive and say definitely this patient is less likely to survive…I don't think I've got no regret that I've made a decision to say not escalate" ***[D7; D8]***

5.3.4.2 Mixed feelings following treatment withdrawal

The decision to withdraw treatment being given to the patient comes along with some form of mixed feelings. It was never easy to be the one making such decisions and informing the family. Some participants mentioned that they felt to never withdraw and give the patient a fair chance to survive. On the other side, it was also considered unjustified to allow the patient to go through any form of suffering. Several participants expressed that it was not easy for them to withdraw treatment as it comes with a great emotional toll on them.

"…that being said on the patients that we do offer care for, the decision is quite a difficult one and I think it comes with great toll on our on my colleagues…..it's not a very easy thing to just withdraw. It's never an easy thing to tell a family that we can't offer the family member further care" ***[D3]***

"It's not a single feeling that you feel, it's a mixed bag because, on the one side, you never want to withdraw treatment, you want to give everybody a fair chance. And instinctively, it's difficult to say we're not going to continue. So there is part of you that is sad about it…but the other part of you knows that the chance of the patient surviving is so small and subjecting him or her to all the things we do it's like really, really justified" ***[D4]***

"So I would not say there's a single case or a single way that I feel about all cases because it's very patient specific and condition specific…It does definitely makes me feel sad, but there is also a point of acceptance" ***[D6]***

"From what I feel for the type of decision it's always almost heart-breaking that we try to do our best to make a patient progress further, but if we've tried all our best, in terms of treatment, escalation and eventually there's no better outcome" ***[D9]***

5.3.5 Theme three: Challenges encountered in Making EOL Decisions

Physicians describe the moment of making EOL care decisions about treatment withdrawal in the ICU as one that comes along with some challenges. As they strive to do their best to support both patient and their family, they are also faced with several challenges. The challenges are seen as hurdles they encounter during the decision-making process and providing care after treatment withdrawal.

5.3.5.1 Challenges from the family

While it is important to involve the family members of the patient in the EOL care decision-making process, it also comes it some challenges. Sometimes, the family takes a lot of time to agree to the withdrawal of treatment which eventually delays the process causing more untoward suffering to the patient. Some are capable of changing their minds following the decision while others become very aggressive towards the healthcare team.

"… The family was involved. And I understand why it's good to do that. But in this particular case that I'm thinking about. It also causes a bit of a delay, which I was dissatisfied with, because for me, it should be the patient first" ***[D1]***

Other family members are capable of changing their minds.

"You will call the family and say your relative is not coping right, we need to ventilate your relative so that we help them breathe if they continue to breathe on their own they will tire. Then the familiar gives you permission and the patient also consent. Five minutes after intubation, the patient pass away. Now some family members will ask you, wouldn't it have

been better if you had left the patient to breathe on their own, you know. So it is a challenging situation" ***[D2]***

"Some you have seen in a situation that a family member will just come they're aggressive. You haven't done anything to the patient, already they're shouting at you, you know and then you ask yourself, why is this family shouting at me? It's not like I'm standing or whatever and if I'm standing he's not the one to be telling me that I'm standing I should be doing my job you know. So it becomes quite difficult to deal with the family that is not accepting" ***[D9]***

Another experienced physician also mentioned the absence of the family during the withdrawal process as another challenge they encounter in the ICU. In such situations, the family members are unable to understand fully the disease process, prognosis and ask questions for clarification.

"What I've seen so far often the family isn't necessarily here for the whole process or the patient's hospital stay. Often the family members especially COVID made particularly difficult but often the patient; even though you've explained to the family members telephonically or via people how severe the situation is I don't think they're fully grasp it. So by the time you ask them please come to the hospital. This important decision that needs to talk about that is definitely missed" ***[D4]***

Again, having different family members that constantly ask for updates distorts the flow of information given to the family. The information given is always interpreted and carried along differently.

"You're not always speaking to the same person. And when the relative phones you don't want to say I'm not going to speak to you so you do speak to them. But information gets different stories, the story changes" ***[D4]***

5.3.5.2 Disconnect between attending doctor and nurses

Another challenge mentioned was the level of disconnect between the attending doctor and the nurses. The break in communication between attending doctors and nurses meant that most nurses were not informed about treatment withdrawal until the patient begins to deteriorate.

"…there is a bit of a disconnect between a consultant telling the treating doctor, and the treating doctor and nurse is disconnected because often what will happen is when the patient starts to deteriorate, and the nurse says doctor the blood pressures are dropping. And that's the first time usually that the nurse gets told oh no we're withdrawing here, so you don't need to increase adrenaline" ***[D1]***

"And sometimes, from my experience, is because the nurses are there every day, often they will be the ones to tell you here I don't think there's a prognosis Doc, what are we actually doing. If you actually listen to the nursing sisters that they will tell you that. That speaks again to the disconnect between those making decisions and people are scared to make those decisions and uncomfortable" ***[D8]***

5.3.5.3 Attending physicians uncomfortable making EOL decisions

Some attending physicians are uncomfortable initiating and arriving at decisions to withdraw treatment. They are scared of taking a wrong decision:

"So I think where it comes from is a lot of doctors are uncomfortable making those decisions. So you'll find the places that you know they're being led by doctors who is uncomfortable that those are the things that will happen and won't be documented" ***[D1]***

"And so I think a lot of the problems we face in this sort of specific sort of area with regards to that is peoples are scared to make decisions on terminating or, you know, capping care, because they feel like, you know, this is not right, and you know, I should, we should continue until and then, you know, whatever happens, but I'm like, essentially, you need to also just be thinking about all your medical ethics principles" ***[D3]***

5.3.5.4 Documentation challenges

Documentation challenge was also emphasized by some participants. The inability to document an order to withdraw treatment in the ICU was also highlighted. Some physicians preferred not to be involved in any medico-legal issues surrounding patient care in the ICU, hence, fail to document the order.

"So documenting is one of the challenges that we need to improve as a profession as a whole be it nurses, doctors, social workers. The documentation, its ethic, its ethics, actually. So we need to try to be clear with documenting. Not just say patient no more ICU treatment, patient for rehab" ***[D2]***

"The difficulty comes with withdrawing care when you started offering care to then stop offering the care, there is a medical, legal and ethical, gray areas that we don't really want to involve ourselves in" ***[D3]***

5.3.6 Theme Four: Novice to Expert

Making decisions to withdraw treatment in the ICU is a practice that most physicians are uncomfortable with. The majority of physicians explained that it was a skill one cannot get used to but rather can be developed over time. Most physicians learn along with the process and become comfortable making EOL care decisions through continuous exposure to several situations.

"So I mean, yeah, again, you could get better at it… It can comes by experience, definitely, doing it over and over again. It's something that you develop over time with active effort, it's not just something that you can just pick up in one day" ***[D3]***

"I don't think the experience can be taught. We do get teaching in a little bit of teaching in how to deal cope with end of life decisions, but it's not something that I think you can be really prepared for. It's something that unfortunately you only get exposed to when you go through it" ***[D4]***

"We've had couple of experiences as doctors now, from a junior aspect to seniors. So I think as the time progresses, we actually try to build up more courage and more experience with regards to making the type of decision. It is mostly on the job that we learn. We see, we experience and we move forward, we take back from what we get and apply to our next patient. So mostly gain experience on the job" ***[D7]***

"Every patient is a learning experience for us. We gather information as we move along. But in the end, we learn on the daily basis, the patient comes in with A, B and C disease. A week later the same patient or different patient comes in with a different or similar disease. And we notice that this patient improved on certain treatment and we can try it moving forward" ***[D9]***

5.3.7 Theme Five: Facilitating Care after Treatment Withdrawal

Physicians described their commitment to providing care and supporting both the dying patient and family through the entire process, especially during the decision-making process, the withdrawal of treatment process and the dying process. Physicians had important responsibilities throughout the entire process. They facilitated end-of-life care by providing comfort care to the dying patient, preparing the family in advance for the process and supporting both patient and family throughout the process. The themes 'facilitating care after treatment withdrawal' is discussed under sub-themes: '*Providing comfort care for the patient'*, treat *patient with dignity and respect; inform the family about the process; provide*

emotional support; involve the family in the process; allow the family at patient's bedside. Provide religious and spiritual support; and *asses and meet the needs of the family.*

5.3.7.1 Providing comfort care for the patient

Participants continued to provide comfort care for the patient even after treatment withdrawal. Comfort care measures focused on symptom control, pain relief and physical comfort. Some participants indicated that the withdrawal of treatment was not equivalent to the withdrawal of comfort. Therefore, pain medications were given to make the patient pain-free. Such quotes included:

"We need to also look at him being comfortable…withdraw of care doesn't mean withdrawal comfort. So we remove Life-extending medications, which is all stopped that but will ensure the patient is sedated if they need to be particularly like in a patient with burns. They need to be well analgised if they have any pain" ***[D1]***

"It's just its basic care, so making sure that there is no pain. I'll give a person a full dose of morphine point one milligram per kg, four to six hourly. Make sure they are comfortable" ***[D7]***

"So for the patient, what we can do is we try not to make them suffer if we feel that the patient is in pain; we try to make the patient feel comfortable as much as they can before the whole total body organ system gives up. So we try not to make patients suffer as much" ***[D9]***

5.3.7.2 Treat patient with dignity and respect

Some participants emphasised the need to continue treating the patient just like any other patient admitted to the ICU. Hence, medical care should be provided humanely. Some recalled that you needed to treat a patient just like one will do for a sibling or a parent. Thus, respect their wishes and allow patients to die in dignity. Two experienced physicians mentioned that, as indicated in the quotes below:

"So I think one thing as a human, you must treat a patient as a human being. Treat them as a sister, as fathers, mother, think that they are all somebody's brother, sister so treat them in a humane manner in any way" ***[D5]***

"We all going to die irrespective. But all we want is to die in dignity. Have good care, pain-free when we are dying. So you have to die in comfort and dignity" ***[D8]***

5.3.7.3 Inform the family about the process

Physicians described the importance of preparing the family during the withdrawal of treatment process and the dying process. They highlighted that it was important to inform the family about the withdrawal process and help them to understand the process. This allows the family time to come to terms with the inevitable. Several participants explained that it was important to keep the family members constantly informed on what was happening, the patient's conditions, interventions given and the possible medical outcomes.

"You have to explain to them what is happening; where we are; what are the organs that are failing? Sometimes we do not understand why the organs are failing, okay. So we'll explain to them what has happened, why you are here; where we are with our care, what we are anticipating; what might happen" ***[D8]***

"Same thing with the family, you will update them on how's the patient doing right up until you reach that end to say, now we have done, all the team members they have done everything that we can offer right" ***[D2]***

"In terms of the family management, we ask the family to come in. We explain to them what the prognosis is, and that there's nothing further we can do from our side". ***[D9]***

Other participants also stated that it was important to help the family understand the patients' current situation, the possible outcomes and the reasons for deciding to withdraw treatment.

"... Make sure that they understand the current situation; what has been done if they are any options that are outstanding, and possible outcomes… It's important that families understand that, they get given the opportunity to ask questions. They need to understand where we are, why we're making that decision" ***[D6]***

"We do very often call them [families] in and we have discussions with them…make sure that the family understands that the patient for whatever reason is critical may not survive" ***[D3]***

Another experienced physician also emphasized the need to give the family some time to come to terms with the decision once it has been made.

"It's good we give the family time to come to terms with it ...we also need to understand that that patient forms part of a family, as well, so they [family] should be at least informed" ***[D1]***

5.3.7.4 Provide emotional support for the family

Physicians also considered emotional support as an essential component of medical care especially before deciding to withdraw treatment and after treatment withdrawal. The family forms part of patient care in the ICU, therefore, emotional well-being in such a delicate time was also important. Shifting the focus on the family, especially in the palliative phase and supporting them emotionally through counselling were mentioned by some participants.

"I will focus more on the family because the patient in palliation they will still have get counselling and all those but the family need to be prepared before, during the process and even after the process….For the family, I think that the family should receive more counselling" ***[D2; D4]***

"It's always been a lot of counselling of families. We want our families to understand the reasons. So I think proper counselling, buy in from the family, explaining and then allowing the grieving process to happen naturally" ***[D6]***

5.3.7.5 Involve the family member in the process

The involvement of the patient's family members in the care process was also indicated as an important part of the treatment withdrawal process. Some participants mentioned the need to get the family involved in the meetings and discussions.

"Getting family involved in meetings, discussing with the nurses and letting them know exactly at what point we are going to stop care like; where we not intervening and how we are not intervening" ***[D3]***

"So we called the family just before midnight to say that we've cap the adrenaline to two mg per kg per minute and he's on a ventilator maximum support but he wasn't responding. And the family came over, then they started to realize that the patient might die. So I think that sometimes helps them [family] a lot. And then I think also for us, we realize that this patient's not doing well, it gives you time to prepare for it" ***[D7]***

" I have found that when you involve the family and tell them early, where you are, what you are anticipating, when the outcome eventually comes, it is usually well received versus when you don't tell the family what you think and where you are in your care, and what is the most likely outcome and that outcome becomes death, they take it very bad ***[D8]***

5.3.7.6 Allow the family at patients beside

Most family members do not want their relatives to die alone. This makes family presence, especially at the end of life important. Several participants mentioned that it was necessary to allow the family members at their loved one's bedside.

"... just reaching out to the family and allowing them in. It allows them to see that what we're doing is the most that we can offer and therefore at the end, they know that look; I mean, there wasn't much more we could do you know" ***[D3]***

"So family, they should be called in; they should be given the opportunity to see the family member. I think it's very important that they need to see the person so that they can also understand the critical nature. It's difficult to explain that on phone or even face to face if they haven't seen someone attached to all the machines" ***[D6]***

"We allowed the family to be here at the bedside even a day or two before she demised. I think that's one thing that will change. Allowing family members to be there, and to see their loved ones. It definitely does make a difference" ***[D7]***

Family members were offered the opportunity to see their loved ones and spend the last moments with them.

"We offer them the opportunity to come in and see the patient before, you know, their last moments" ***[D5]***

"If there are some family members who still need to come and visit them before they die, we would do whatever we can to make them at least have the chance to spend the last few minutes or hours with their loved one…We always ask them if they need time to see the patient. If they are willing to come spend the last few hours with the patient or mother saw the patient they were welcome to" ***[D8; D9]***

5.3.7.7 Provide religious and spiritual support

Family members often hold and have some religious beliefs and expectations following the admission of their relative to the ICU and subsequent death. Some participants agreed that it was necessary to accommodate and respect their religious beliefs. First, it was necessary to enquire about family preference and wish regarding any specific ritual or spiritual practice that needed to be done. Two physicians recalled that:

"one thing we ask family you know, is there any specific ritual things that they would like to do or have a pastor there or spiritual leader or somebody I think can also help them just to support them in that sense" ***[D7]***

"We also asked the patient's family to pray for them. We always try to pray for the families themselves and the patient themselves" ***[D9]***

Certain family members prefer to perform some sort of spiritual practice at the patient's bedside during the dying process. Two experienced physicians admitted that it was allowed and their belief was respected; as seen in the quotes below:

"A sort of spiritual practice that I've seen a lot happens afterwards and that is to bring or a branch or some kind of to draw the spirit out. It seem to be quite a common practice there and none of the doctors are part of that same spiritual decision, but we respect that and there's no reason for us not to allow people to have that closure" ***[D6]***

"Regardless of a patient's religion, if they have someone that is considered a sort of holy figure for them or a holy leader should I say whether it's a priest or an Imam, or rabbi or regardless of what the religion is, I personally am quite happy for them to come here, ... We have to respect our other patients" ***[D8]***

5.3.7.8 Assess and meet the needs of the family

Some family members have specific needs and wish especially during the dying phase in the ICU. Several participants expressed that it was important to elicit what their family wanted before and after treatment has been withdrawn. Once the family members had expressed their needs, it was, therefore, necessary to attend to those needs. Two physicians said that:

"Whatever the patient's family needs, or if the patient had pre-expressed wishes, I am happy with that within reason" ***[D1]***

"For the family, I asked what they wanted us to do for them what. Do they want to be there when we de-escalate or do they not. Do they want us to let them know immediately? Do they want to go in and pray or have final words with a family member?...So, in particular, that family, most of the family didn't want to be around but the brother was and we allowed that. Closed the curtains, gave him privacy and I switched off all the machines and he was there for his sister's final breath" ***[D6]***

Patients suffering after treatment withdrawal are not an expected outcome, especially for the family members. Family members expect their loved ones to be free from any untoward suffering. Two other participants mentioned that it was necessary to know what the family want and how they wanted it, especially at the end of life. As indicated in the quotes below:

"No one wants to their family member to suffer. So I think the simple answer is that you need buy in from the family and you need to know what they want; how they wanted to it to end. I think it's incredibly important to ask the family what they want" ***[D9]***

"Some families in England, some families in wherever, across the globe. So if they are going to wait for a week for the whole family to come and pay their last respect, you can't say no. So you've got to respect the individual" ***[D8]***

5.3.8 Summary of Key Findings from the Physicians Interview

The section presents conclusions drawn from the interview findings regarding physicians' experiences making end-of-life decisions in the ICU. The conclusion statements are discussed under the main themes, and are as follows:

5.3.8.1 Making end-of-life decisions

- End-of-life decisions made to withdraw treatment is a process taken over time and often made on a case-by-case basis. Before the withdrawal of treatment, there are initial discussions among the ICU multidisciplinary team on the best way to approach the withdrawal process. These discussions are initiated and led by the senior attending ICU consultant with all other stakeholders involved in the patient care and treatment.
- The discussions are centered on the clinical presentation of the patient, the disease process, prognosis, organs affected and how reversible they are. Once physicians arrive that there is nothing to be done for the patient and they are not going to prolong the life of any quality, then a decision is made to withdraw treatment. Patients' age, comorbidities, scoring systems such as APACHE score, and SOFA score together with the best scientific evidence on patient's chances of survival are used to guide the withdrawal process in the ICU.
- Once a collective decision is made to withdraw treatment, the treatment that a patient is on is gradually withdrawn without withdrawing care.
- In the decision-making process, the attending physician holds the overall responsibility for the patient's treatment and is considered the most appropriate person to initiate and lead end-of-life decisions and discussions. Physicians admitted that it was unfair not to involve nurses as they assisted them to make the right decisions, however, they were not involved in the end-of-life decisions and discussions

- Nurses are not involved in the EOL decision-making process. The ultimate decision to withdraw treatment is made by the attending physician with no input from nurses.

5.3.8.2 Shared feelings around making EOL decisions

- The majority of physicians see the decision made to withdraw treatment as a challenging part of ICU practice. The most experienced physicians do not struggle to make those kinds of decisions as they decide after several consultations and make a judgement based on the patient's prognosis, medical history, the organs affected and the best evidence available. Therefore, they were at peace with the decisions made and felt no particular emotional connection while making EOL decisions.
- Making end-of-life decisions to withdraw treatment comes along with some form of mixed feelings. It is never easy to be the physician in charge to make such kind of decision and inform the family members. It is described as sad and heart-breaking especially when everything has been done for the patient but to no avail. There is the side where physicians do not want to withdraw treatment and allow the patient some chance to survive. On the other side, it is difficult to continue treatment when there is no evidence to support that patient will survive, however, only prolong the dying process.

5.3.8.3 Challenges encountered in making EOL decisions

- Patients' family members take a lot of time to agree to the decision to withdraw treatment which delays the process and causes untoward suffering to the patient. Some family members are also capable of changing their minds once a decision had been made to withdraw treatment and become aggressive towards the healthcare team.
- Family members are absent during the treatment withdrawal process. Thus, they are unable to fully understand the process, patients' prognosis and clarity or ask questions.
- Different family members constantly phone healthcare providers for patient updates which distort the flow of information given to the family as they are interpreted and carried along differently

- Another challenge is the level of disconnect between the attending physicians and nurses when EOL decisions are made. There is a break in communication when attending physicians initiate and decide to withdraw treatment.
- Attending physicians are uncomfortable making EOL decisions due to the level of inexperience and the attached ethical considerations. They are scared to make decisions on terminating treatment.
- Due to the medico-legal issues associated with patient care, especially at the end of life, some physicians are unwilling to document an order to withdraw treatment in the ICU.

5.3.8.4 Novice to expert

- Most physicians learn how to make EOL decisions to withdraw treatment over time. They developed their expertise through continuous exposure and involvement in EOL discussions and treatment withdrawal processes.
- Their ability to be comfortable with EOL decisions takes time and comes with frequent experience and exposure. Physicians gain experience on the job as opposed to classroom teaching.

5.3.8.5 Facilitating care after treatment withdrawal

Following the process of treatment withdrawal and subsequent withdrawal of treatment, physicians supported the patient and the family members throughout the period. Patients and their family members are supported through: Providing comfort care for the patient', treating patient with dignity and respect; informing the family about the process; providing emotional support; involving the family in the process; allowing the family at patient's bedside.; providing religious and spiritual support; and assessing and meeting the needs of the family. For the purposes of generating suitable items for the instrument development, this section focuses on the quotes that were pulled from the transcripts and examined as potential items. These potential items formed the blueprints for the instrument to measure the quality of care provided for patients and families after treatment withdrawal in the ICU. They are derived from participant' interviews and are quotes that represent the viewpoint of doctors on facilitating care after treatment withdrawal. This section form part of the items used in the development of the provisional instrument in Phase 2. Table **5.5** presents a summary of the potential items pooled from the interviews.

Table 5.5: Potential items derived from the doctors interviews

Theme	Doctors quotes [source]	Potential items
Providing comfort care for the patient	*"It's just its basic care, so making sure that there is no pain. I'll give a person a full dose of morphine point one milligram per kg, four to six hourly. Make sure they are comfortable"* ***[D7]*** *"So for the patient, what we can do is we try not to make them suffer if we feel that the patient is in pain; we try to make the patient feel comfortable as much as they can before the whole total body organ system gives up. So we try not to make patients suffer as much"* ***[D9]***	1. Administer analgesics when the patient is in pain 2. Ensure that patient do not suffer
Treat patient with dignity and respect	*"So I think one thing as a human, you must treat a patient as a human being. Treat them as a sister, as fathers, mother, think that they are all somebody's brother, sister so treat them in a humane manner in any way"* ***[D5]*** *"We all going to die irrespective. But all we want is to die in dignity. Have good care, pain-free when we are dying. So you have to die in comfort and dignity"* ***[D8]***	3. Treat the patient in a humane manner 4. Ensure that patient die in dignity
Inform the family about the process	*"You have to explain to them what is happening; where we are; what are the organs that are failing? …So we'll explain to them what has happened, why you are here; where we are with our care, what we are anticipating; what might happen"* ***[D8]*** *"In terms of the family management, we ask the family to come in. We explain to them what the prognosis is, and that there's nothing further we can do from our side".* ***[D9]*** *"… Make sure that they understand the current situation; what has been done if they are any options that are outstanding, and possible outcomes… It's important that families understand that, they get given the opportunity to ask questions. They need to understand where we are, why we're making that decision" [****D6]*** *"It's good we give the family time to come to terms with it …we also need to understand that that patient forms part of a family, as well, so they [family] should be at least informed" [****D1]***	5. Explain to the family what is happening and patients prognosis 6. Make sure the family understand the decisions made and possible outcomes 7. Give the family the opportunity to ask questions and answer them 8. Give the family time to come to terms with decision and the inevitable death

Provide emotional support for the family	*"I will focus more on the family because the patient in palliation they will still have get counselling and all those but the family need to be prepared before, during the process and even after the process….For the family, I think that the family should receive more counselling"* ***[D2; D4]*** *"It's always been a lot of counselling of families. We want our families to understand the reasons. So I think proper counselling, buy in from the family, explaining and then allowing the grieving process to happen naturally" [****D6****]*	9. Prepare the family psychologically for the death of the relative 10. -Have counselling sessions available to support the family
Involve the family members in the process	*"Getting family involved in meetings, discussing with the nurses and letting them know exactly at what point we are going to stop care like; where we not intervening and how we are not intervening" [****D3****]* *" I have found that when you involve the family and tell them early, where you are, what you are anticipating, when the outcome eventually comes, it is usually well received versus when you don't tell the family what you think and where you are in your care, and what is the most likely outcome and that outcome becomes death, they take it very bad* ***[D8]***	11. Get the family involved early in the meetings and discussions 12. Let the family know what is happening, what to expect and possible outcome
Allow the family at patient's bedside	*"… just reaching out to the family and allowing them in. It allows them to see that what we're doing is the most that we can offer and therefore at the end, they know that look; I mean, there wasn't much more we could do you know"* ***[D3]*** *"We allowed the family to be here at the bedside even a day or two before she demised. I think that's one thing that will change. Allowing family members to be there, and to see their loved ones. It definitely does make a difference"* ***[D7]***	13. Allow the family members see their loved one and to be at the bedside till the end
Provide religious and spiritual support	*"one thing we ask family you know, is there any specific ritual things that they would like to do or have a pastor there or spiritual leader or somebody I think can also help them just to support them in that sense"* ***[D7]*** *"Regardless of a patient's religion, if they have someone that is considered a sort of holy figure for them or a holy leader should I say whether it's a priest or an Imam, or rabbi or regardless of what the religion is, I personally am quite happy for them to come here, … We have to respect our other patients"* ***[D8]***	14. Enquire about the family preference and wish regarding any spiritual ritual of practice 15. Respect the spiritual and cultural rituals of the family 16. Allow the family to bring in their traditional or spiritual person to the patient's bedside 17. Allow the family to offer prayers and perform their last rituals

Assess and meet the needs of the family	*"Whatever the patient's family needs, or if the patient had pre-expressed wishes, I am happy with that within reason"* ***[D1]*** *"For the family, I asked what they wanted us to do for them what. Do they want to be there when we de-escalate or do they not. Do they want us to let them know immediately? Do they want to go in and pray or have final words with a family member"* ***[D6]***	18. Elicit the needs and wishes of the family members 19. Know what the patient and family want and respect their needs

5.4 INTERVIEWS WITH THE FAMILY MEMBERS

This section focuses on individual interviews with bereaved family members. An exploratory qualitative study design was used. A purposive sampling method was used to select a sample of seven (n = 7) family members who had relatives receiving end-of-life care in the adult ICU and had been bereaved in the previous 6–12 months. The detailed findings are presented in the sections below:

5.4.1 Biographic Information of Participating Family Members

Participants' demographic data comprised gender, age, the participant's relationship with the patient, and the patient's length of ICU stay. Table 5.6 presents the summary of biographic data for the family members that participated in the interview.

Table 5. 6: Biographic data of family members

Code	Gender	Age (Yrs.)	Relationship with patient	Patients' Length of ICU stay
F1	Female	57	Adult child	5 days
F2	Female	43	Sibling	14 days
F3	Female	61	Adult child	21 days
F4	Female	72	Spouse	39 days
F5	Male	31	Sibling	7 days
F6	Male	69	Parent (father)	4 days
F7	Female	74	Spouse	23 days

A total of seven (n = 7) bereaved family members were interviewed. Demographic information obtained indicated that the majority of the participants were females (71.4%; n = 5), whereas the minority were male participants (28.6%; n = 2). The participants' ages range from 31 to 74 years. The length of a patient's stay in the ICU before death also ranged from 4 days to 23 days. Participants' relationships with the patient were as follows: adult child (n = 2), sibling (n = 2), spouse (n = 2), and parent (father).

5.4.2 Themes and Sub-Themes

Two themes emerged after data analysis that described the lived experiences of bereaved family members: "distressing emotions" and "meeting the needs of the family members."

Table 5.7 presents the themes and sub-themes that emerged from the individual interviews with the bereaved family members. The themes and sub-themes are presented and supported by excerpts from the interviews.

Table 5.7: Themes and sub-themes from the data with family members

THEME	SUB-THEME
Distressing emotions	A big shock
	Took much to take in
Meeting the needs of the family	Family presence
	Family involvement in patient care
	Information sharing
	Nursing care for the patient
	Connect relationship with the dying patient
	Spiritual support
	Privacy

5.4.2.1 Distressing emotions

The theme "distressing emotions" explains how family members reacted and felt emotionally upon receiving the news that their loved one's condition was worsening despite treatments and that it was appropriate to limit the life-sustaining treatments. The theme is discussed under two sub-themes: "a big shock"; and "took much to take in."

- ***A big shock***

The majority of family members were in shock when they learned about the poor prognosis and quality of life of their loved ones and that it would be best to stop treatments. Most family members found it challenging to accept the fact that their loved ones were not improving after receiving the recommended treatments. The majority of family members were optimistic that their loved ones would survive the intensive care unit. As a result, the decision to turn off the machines came as a huge shock to some family members.

"Well, it was not like we weren't expecting it. The doctor did tell me what was happening. It was not like I did not know. But it was still a shock – I remember just standing there thinking but my brother is still there they have got it wrong. I do remember the doctor asking me if they can switch off the machines. I only remember saying I understand you said he is brain dead and there is nothing more you can do for him" ***[F2]***

"It was like a shock. They did everything they could for our son. I think there was so much to think about what happens next. I think it was a lot to take in and I don't think I would have been able to care for him. We just sat there and tried to be strong but we were crying like inside." ***[F6]***

"I must admit for a moment I froze. I had never seen my father in that situation so it was a bit of a shock. My father did not look like my father" ***[F7]***

Family members were also having a hard time and were under a lot of stress as they dealt with the loss. Two participants said:

"Man it was hectic. I don't know how to explain how I felt. It was like a big shock. I did find it hectic because my sister is my twin and we always do everything together. We don't have any parents they died a long time ago. My sister and I are always there for each other. So it was hectic and I think I was in shock" ***[F5]***

"It was hard for me but I had to be strong, it was even harder for my wife…She has a strong faith and she prayed for our son to get better. When the doctor told us there was nothing more they could do for our son. My wife did not accept. Yes she found it very difficult when we kept on telling her that it is true he is not going to make it and we must let him go. She thought he would get better because she prayed for him to get better" ***[F6]***

- ***Too much to take in***

Most family members were not prepared for the sudden change in the patient's condition, the possible withdrawal of treatment, or even the imminent death of their loved ones. The time between the withdrawal of treatment and death was short, and it happened so fast that there was no time for the family members to adjust. The moment was too much for the family members to handle.

"I think it all happened so fast he was gone in about 3 hours. I think it was a lot to take in. it was very emotional. I have never been in this situation before. It all happened so fast" ***[F2]***

"I think it was a lot to take in and I don't think I would have been able to care for him. We just sat there and tried to be strong but we were crying like inside" ***[F6]***

One family member was frightened upon hearing the news that her loved one's condition was not improving and it was necessary to withdraw treatment. She felt numb and helpless and didn't know whom to turn to for help. One participant expressed that:

"I was frightened what did that mean. This was my father how can I help him what must I do. After the doctor put the phone down I just sat there and cried. I felt totally numb and helpless…I don't think I have ever felt so frightened in my life. Completely out of control and I did not know who to turn to help me" **[F1]**

5.4.2.2 Meeting the needs of the family

The theme describes the areas of care that bereaved family members identified as critical when their relative's condition deteriorated and treatment withdrawal became necessary. According to most participants, when there was a transition from curative care to end-of-life care, it was important to meet the needs of the family members. These needs were discussed under the sub-themes below.

- **Family presence**

The majority of the family members preferred to be there for the patient during the palliative care phase. Being there till the end was stressed by most participants. It was important for the family to be close to their relative, express their love, and share the last moment.

"I would like to be near…I kept on thinking If only I could see my father if only I could hold him and tell him what was happening. He must be so frightened in the hospital all alone and I can't be with him" ***[F1]***

"I think me being there –just sitting there was enough for my brother to know how much I loved him…We did get to say goodbye after he passed the nurses tool the pipes out and let us come and be with him to say goodbye" ***[F2]***

"I just wanted to be there to see that my mother was looked after and comfortable. I had time and I tried to help as much as I could" ***[F3]***

Several family members attested that they were given enough time to be there for their loved ones. Some nurses accommodated family presence during the dying phase of patients and afforded them liberal visiting hours such that they could stay at the patient's bedside as time allowed them.

"Yes I was visiting in the ICU. The nurse told me not to go away because he was not doing so well. She did let me sit in his room until he started to deteriorate" ***[F4]***

"Yes I think the nurse let me stay with my sister in the ICU. They switched off the machines. They asked me if I wanted to stay and be with her until the end. They said it will take one or two hours. I stayed with my sister until the very end" ***[F5]***

They told us we could stay there for as long as it takes. I remember sitting at the side of his bed holding his hand in silence. My wife was with me and we sat at the bed and waited for our son to pass away…They did let us say goodbye after he passed and the pipes were removed. He looked so peaceful" ***[F6]***

"We were allowed to sit there at the bedside, we could talk to him and hold his hand and that was pretty much it" ***[F7]***

- ***Family involvement in patient care***

Most family members wanted to be directly involved in the patient's care if they were allowed. After a decision was made to withdraw treatment, most participants mentioned that they wanted to be around and be allowed to do simple things such as washing patients, changing their dressings, rubbing their dry bodies, and applying cream to them. While the nurses did the technical ones, the family members wanted to support them with the easy ones. Family members appreciated being involved because it made them feel like they were contributing to the care of their relatives at such a difficult time.

"I can change a bed I can bath my father and rub cream on his skin. I can hold his hand and tell him how much we love him. I can sit there and tell him what is happening at home and why he must' not worry about those things that would normally worry him…I mean the family can do those things…" ***[F1]***

"I noticed her skin was very dry so I asked if they would allow me to bring special cream for her. They did allow me to do that. So they allowed me to rub her full of cream after they had washed her. I enjoyed doing this because I felt it must make her feel relaxed and comfortable when her skin was not dry. I was very happy at doing the simple things like washing her, or brushing her, putting crème on her skin and her lips and even helping to feed her" ***[F3]***

"Well I can wash him, rub his hands and feet, talk to him or even read to him. I can do other things if the nurses show me how to do it…change the sheets or even turn him to rub his bum" ***[F4]***

- **Information Sharing**

Another need of the family before, during, and after the withdrawal of treatment was the sharing of information between healthcare providers and the family. The majority of family

members highlighted the frequent access to information on their loved ones during the period of ICU admission. Information sharing between the healthcare providers and the family was seen as an important part of the care rendered to the patient and family in the ICU. Most family members interviewed admitted that they were informed and updated on the patient's prognosis, treatments given, and any changes that occurred at any point in the patient's care.

"We knew everything exactly what was happening all the time. They told us about the treatment all the time and how he was holding up. They even told us what the blood results were and when they were changing the treatments and starting new things" ***[F2]***

"Yes, they kept us informed all the way. I felt we had a good understanding of when treatments were happening and what the effects were. I found the doctors were always available to discuss options with you. I also found the nursing staff were very kind and supportive when they were caring for my sister" ***[F5]***

Even at a point where the patient was not responding to treatment and treatment withdrawal was an option, the attending doctors explained to the family the decision that needed to be made and the reasons for making such a decision. Family members were given ample time to understand and agree to the decision. Several families appreciated the access to information on the process and the support from attending nurses and doctors.

"The doctor spoke to me and said they are doing everything possible to try and help him but they are not really winning because my husband it not responding to the treatment. They think he is deteriorating and developing renal failure and other complications….The doctor told me they have decided to stop treatment because my husband will not get better. He said something about poor quality of life and that it would be better to stop all treatment now rather than waiting until more complications and problems kick in. I agreed to what the doctor was telling me" ***[F4]***

"I thought the doctors and nurses were very kind and supportive. They talked to me and explained things before decisions were made to switch off the machines. I also thought it was nice that the doctors showed me the X'Rays even though I am not a medical person. I felt the nurses were very kind and also checked to see that I understood exactly what was going to happen next… I did understand what the doctor told me. There was also another doctor there who showed me the problems on the X-Ray. The nurse also stayed with me to see if I understood what the doctor had told me" ***[F5]***

"We did know what was happening in the ICU. I am not sure we always understood but doctor XXX did explain to us when he was not doing well and his condition was changing. The doctor asked us if we understood what was going to happen. He explained that they were going to stop treatment. He asked us if we understood that this was going to happen" ***[F6]***

- **Nursing care for the patient**

Some bereaved family members desired comfort care for their loved ones. Despite the withdrawal of life-sustaining treatments, they wanted the patients to be clean and comfortable. According to them, basic nursing care such as tidying the bed and having clean sheets and dressings assured them that their loved one was cared for. It was reassuring to see the patient on a clean sheet. Some participants said:

"I would like to see that he is clean and comfortable. I want to see that the sheets are clean that his dressings are clean. That he looks nice and comfortable. This will tell me that the nurses cared for him. This will reassure me" ***[F1]***

"I would have loved to see him comfortable. I mean at least looking comfortable and fresh. I don't think they shaved him…" ***[F7]***

- ***Connect relationship with the patient***

Family members appreciated moments that enabled them to connect with their loved ones even at the end of life. Moments such as talking to their loved ones and holding hands were mentioned by some participants.

"…the nurses told me always to talk to her and remind her who I was and to tell her that she was in hospital and why she was in ICU. I think just talking to her helped her to recognise my voice and know what I am here with her" ***[F3]***

"I still continued to talk to him like the nurse told me to do. I spoke to him about things that were happening outside of the hospital…Some nurses were nice and they would tell me I can hold his hand and talk to him. They said even if he was sleeping he could hear me. So I would talk to him" **[*F4]**

"I watched my dad change physically over that time. At first he would squeeze our hands when we talked to him. Sometimes he would even pull a funny face or tell us to go home waiving his hands" ***[F7]***

- **Spiritual support**

Some participants also placed high importance on their religion, spiritual beliefs, and prayers during their loved ones' critical illness. Despite the poor prognosis and withdrawal of treatment, some families had hopes that their prayers could change the patient's situation. Their constant prayers and their firm spiritual beliefs helped them cope during such

moments. Some participants preferred nurses because it allowed them to exercise their faith and get the needed spiritual support. They believed that it was not their decision but were hopeful that something could happen.

"I think it life we learn to respect what comes our way. I think this is our spiritual belief. Our maker will never give us more than what we can cope with. Also as long as there is life we must do everything we can to respect and support that life. Because at the end of the day it is not our decision of what our fate is. So I think believe our religious or spiritual beliefs help us to cope in these circumstances" ***[F3]***

"You know we are Christians and we go to church a lot. My wife prayed a lot and the people from the church were also praying for our son to get better. She has a strong faith and she prayed for our son to get better. When the doctor told us there was nothing more they could do for our son. My wife did not accept. Yes she found it very difficult when we kept on telling her that it is true he is not going to make it and we must let him go. She thought he would get better because she prayed for him to get better" ***[F6]***

"Well it was not like we weren't expecting it. We knew he was very bad but we also had hope that the doctor would make him better again. But we knew we are religious people and we knew whatever happens it will be His (pointing upwards to the sky) will" ***[F6]***

After the decision to withdraw treatment was made, the inclusion of a priest was also mentioned. Having a religious leader was a good way to help the grieving family members.

"Yes I am also thinking perhaps having a priest there would also be helpful. I think if our Priest had been called he would have come to be there with me to hear the sad news and also to support me. That would also be helpful" ***[F5]***

- ***Privacy***

The need for privacy during the dissemination of sensitive information on the patient's prognosis to the family was also highlighted. Discussing the patient's prognosis while other patients' families and other visitors were present was described as inappropriate and compromised patient and family privacy. There was a need to have a special room within the hospital for the family where such delicate information could be shared.

"I think it would be nice for families to have a special place where they can sit and wait to hear what is happening to the patient. I found the doctors came to speak to me in the visitor's room when all the other family members were there. It was not private and it also could make the other people anxious or worry about what was going to happen to their patients. I think a private room would be better to share bad news with family. Yes then you can express your emotions" ***[F5]***

5.4.3 Summary of Key Findings Drawn from the Family Interviews

This section summarises the key findings from the interviews. The key findings are presented under the main themes and are as follows:

5.4.3.1 Distressing emotions

- Family members experience shock when they are informed that their relatives were not responding to treatment and that it was best to withdraw treatment.
- The moment when treatments are withdrawn is a hectic and difficult moment for family members.
- Family members described their experiences as emotional and frightening. The moment of treatment withdrawal and death happens so fast, and it was a lot to take in.
- Family members feel numb and helpless after treatments were withdrawn.

5.4.3.2 Meeting the needs of the family

- After the decision to withdraw treatment was made and treatments were withdrawn, family members wanted their needs and wishes met.
- These needs and wishes included access to information, comfort care for the patient, family presence at the patient's bedside, family involvement in the patient's care, being able to connect with the patient, spiritual support, and maintaining privacy.

5.4.4 Theoretical sampling

For the purposes of generating suitable items for the instrument's development, this section focuses on the quotes that were pulled from the transcripts and examined as potential items. These potential items formed the blueprints for the instrument to measure the quality of care provided for patients and their families after treatment withdrawal in the ICU. They are derived from participants' interviews and are quotes that represent the viewpoint of family members. This section forms part of the items used in the development of the provisional instrument in Phase 2. Table 5.7 presents a summary of the potential items pooled from the interviews.

Table 5.8: Potential items drawn from family members' interviews

Theme	Sub-theme	Family members quotes [source]	Potential items identified
Meeting the needs of the family members	Family presence	*"I think me being there –just sitting there was enough for my brother to know how much I loved him…We did get to say goodbye after he passed the nurses took the pipes out and let us come and be with him to say goodbye"* **[F2]** *"I just wanted to be there to see that my mother was looked after and comfortable. I had time and I tried to help as much as I could*" **[F3]** *"Yes I was visiting in the ICU. The nurse told me not to go away because he was not doing so well. She did let me sit in his room until he started to deteriorate"* **[F4]**	1. Give family enough time to be there for the patient 2. Offer the family the opportunity to say goodbye to their loved one while taking their last breath 3. Allow the family to see their loved one in the last moment of life and be there until the end 4. Have unrestricted visiting hours for the family during the last moment of life
	Family involvement in patient care	*"I can change a bed I can bath my father and rub cream on his skin. I can hold his hand and tell him how much we love him. I can sit there and tell him what is happening at home and why he must' not worry about those things that would normally worry him…I mean the family can do those things…*" **[F1]** *"…they allowed me to rub her full of cream after they had washed her. I enjoyed doing this because I felt it must make her feel relaxed and comfortable when her skin was not dry. I was very happy at doing the simple things like washing her, or brushing her, putting crème on her skin and her lips and even helping to feed her"* **[F3]**	5. Involve family members in the care of their loved one 6. Allow the family to do basic things such as bathing the patient, applying cream

	Information sharing	*"Yes, they kept us informed all the way. I felt we had a good understanding of when treatments were happening and what the effects were. I found the doctors were always available to discuss options with you. I also found the nursing staff were very kind and supportive when they were caring for my sister"* [**F5**] *"We did know what was happening in the ICU. I am not sure we always understood but doctor XXX did explain to us when he was not doing well and his condition was changing. The doctor asked us if we understood what was going to happen. He explained that they were going to stop treatment. He asked us if we understood that this was going to happen"* ***[F6]*** *"The doctor spoke to me and said they are doing everything possible to try and help him but they are not really winning because my husband it not responding to the treatment. They think he is deteriorating and developing renal failure and other complications….The doctor told me they have decided to stop treatment because my husband will not get better… it would be better to stop all treatment now rather than waiting until more complications and problems kick in. I agreed to what the doctor was telling me"* **[F4]**	7. Keep the family informed and update on the patient's condition, treatment options and changes 8. Explain to the family what is happening, the decision to made and the reasons for making the decision 9. Give the family ample time to understand the information given and agree to the decision
	Nursing care for the patient	*"I would like to see that he is clean and comfortable. I want to see that the sheets are clean that his dressings are clean. That he looks nice and comfortable. This will tell me that the nurses cared for him. This will reassure me"* ***[F1]*** *"I would have loved to see him comfortable. I mean at least looking comfortable and fresh. I don't think they shaved him…"* ***[F7]***	10. Ensure the patient is clean and comfortable in bed 11. Place patient on a clean sheet 12. Provide basic care such as bathing and grooming

	Connect relationship with the patient	*"…the nurses told me always to talk to her and remind her who I was and to tell her that she was in hospital and why she was in ICU. I think just talking to her helped her to recognise my voice and know what I am here with her"* **[F3]** *"I still continued to talk to him like the nurse told me to do. I spoke to him about things that were happening outside of the hospital…Some nurses were nice and they would tell me I can hold his hand and talk to him. They said even if he was sleeping he could hear me. So I would talk to him"* **[F4]**	13. Encourage the family to talk to the patient and speak in a voice the patient can recognise 14. Allow family members to hold the patient hands at the last moment 15. Allow the family to speak to the patient about what is happening outside the hospital
	Spiritual support	*"…So I think believe our religious or spiritual beliefs help us to cope in these circumstances"* ***[F3]*** *"You know we are Christians and we go to church a lot. My wife prayed a lot and the people from the church were also praying for our son to get better…" [F6]* *"Yes I am also thinking perhaps having a priest there would also be helpful. I think if our Priest had been called he would have come to be there with me to hear the sad news and also to support me. That would also be helpful"* ***[F5]***	16. Pay attention to and respect families' religion and spiritual beliefs 17. Allow the family to exercise their faith 18. Allow the family the opportunity to pray 19. Include a religious person (priest) of choice in the care of the patient
	Privacy	*"I think it would be nice for families to have a special place where they can sit and wait to hear what is happening to the patient. I found the doctors came to speak to me in the visitor's room when all the other family members were there. It was not private and it also could make the other people anxious or worry about what was going to happen to their patients. I think a private room would be better to share bad news with family. Yes then you can express your emotions"* ***[F5]***	20. Have a special place where information about the patient will be shared with the family

5.5 SUMMARY

The chapter presented findings from the individual interviews with intensive care nurses, physicians and bereaved family members. The various background information of the participants were presented. Themes and sub-themes that emerged following a thematic analysis were also presented and supported with direct quotes from participants. Summary findings and potential items derived from the various interviews were also presented.

The next chapter presents the phase of the study, instrument development and validation phase and focuses on the development of the survey instrument.

CHAPTER SIX

PHASE TWO: INSTRUMENT DEVELOPMENT AND VALIDATION

INSTRUMENT DEVELOPMENT

6.1 INTRODUCTION

Phase two of the study represents the instrument development and validation phase. The outcome of phase two of the study was to develop a measurement instrument and assess the content and face validity of the instrument. This chapter focuses on the development of the survey instrument, which is informed by the findings from the scoping review and qualitative interviews of phase one. Outlined in the chapter is how domains and items identified in phase one were integrated, synthesized, reduced, and refined to develop a draft of the measurement instrument. The chapter ends with a summary and conclusion and introduces the next chapter.

6.2 INSTRUMENT DEVELOPMENT

The study followed the process of instrument development outlined by Lynn (1986) and Zamanzadeh *et al*. (2015). The intent of the development instrument is to measure the quality of care provided for patients and their families after the withdrawal of treatment in the adult intensive care unit. The first draft of the instrument was informed by the findings from the scoping review and the qualitative interview conducted in phase one.

6.2.1 Integration and Synthesis of Findings from Phase One (Instrument construction)

In phase one, content domains and items relevant to measuring the quality of care provided for patients and family members after the withdrawal of LST in the ICU were identified and generated through a scoping review and qualitative interviews (with nurses, physicians, and families). The summary of potential domains and items identified formed the blueprint for the development of the first draft of the instrument.

Results from the scoping review on the perspectives of patients, families and healthcare providers on providing quality care at the end of life in the ICU were used to identify seven (7) potential content domains and 69 items relevant for the measuring construct under study (refer to **Table 4.6**). These were statements and direct quotes that were derived from the findings of existing empirical studies that were included in the scoping review. The domains identified were: "Patient and family centred decision making"; "communication among the healthcare team and with patients and families"; "symptom management and comfort"; "care with compassion, dignity and respect"; "emotional support for patients and families"; "spiritual care and cultural support"; and "modifying the ICU environment".

The qualitative exploratory study with intensive care nurses on their experiences of treatment withdrawal and providing care for patients and families after treatment withdrawal in the ICU also yielded 35 items organized under four sub-themes, namely: *focus on the patient*; *support and work with the family*; *modify the ICU environment*; and *effective communication and teamwork* (detailed in Chapter 5 and **Table 5.3**). Findings from an exploratory qualitative study with specialist physicians working in the ICU also led to the generation of 19 items under several sub-themes (**Table 5.5**). A further 20 items were also generated from the individual interviews with bereaved families (**Table 5.8**). A total of 74 items organized under several sub-themes were derived from the qualitative interviews with nurses, specialist physicians, and bereaved family members in the ICU. Overall, in phase one, a total of 143 potential items were generated and organized under seven domains and other sub-themes.

A total of 143 items organised under different domains and sub-themes as shown in **Table 6.1** below underwent further construction, reduction, and refinement.

Table 6.1: Summary domains and items drawn from scoping review and interviews with nurses, physicians and bereaved family members

Summary of content domains and potential items derived from the Scoping review	Summary of potential items derived from Nurses interviews	Summary of potential items derived from the doctors interviews	Summary of potential items derived from the family members' interviews
• **Symptom management and comfort** 1. Remove all technical and unnecessary devices connected to the patient 2. Assess patients pain 3. Administer necessary pain medications for pain relief 4. Provide relief and manage patient's symptoms such as agitation, restlessness and shortness of breath 5. Use non-pharmacological means such as repositioning, providing mouth care and bathing patients to promote physical comfort 6. Provide physical care and fulfil the basic standards of patient care such as bathing, pressure area care , ensuring warmth, regular mouth, eye and skin care, and meeting hygiene needs • **Care with compassion, dignity and respect** 7. Treat patient with dignity during the dying process 8. Treat patient with kindness, compassion and sensitivity 9. Ensure that the patient body parts are not exposed and kept it private from the public view	**Focus on the patient**: • ***Attend to the basic needs of patient*** 1. Attend to the hygienic needs of the patient (keep patient clean, provide mouth care, turn patient regularly) • ***Patient comfort/ symptom management*** 2. Administer prescribed medication and keep patient pain-free • ***Dignity and respect*** 3. Treat patient with dignity and respect • ***Spiritual care and cultural support***	***Facilitating care after treatment withdrawal*** • **Provide comfort care for the patient** 1. Administer analgesics when the patient is in pain 2. Ensure that the patient do not suffer • **Treat the patient with dignity and respect** 3. Treat the patient in a humane manner 4. Ensure that patient dies in a dignity • **Inform the family about the process** 5. Explain to the family what is happening and patients prognosis 6. Make sure the family understand the decisions	**Meeting the needs of the family** • **Family presence** 1. Give family enough time to be there for the patient 2. Offer the family the opportunity to say goodbye to their loved one while taking their last breathe 3. Allow the family to see their loved one in the last moment of life and there until the end 4. Have unrestricted visiting hours for the family during the last moment of life • **Family involvement in patient care** 5. Involve the family in the care of their loved one

10. Treat the patient as a unique individual with inherent value, worth respect and honour regardless of the disease 11. Show respect to the patient and care for patient as a whole person at the end of life 12. Address patient by name and title • **Communication** 13. Develop a therapeutic relationship with the family and connect with them 14. Ensure cognitive and knowledge readiness before relaying information on the disease prognosis 15. Have a collaborative, partnered and effective communication among the healthcare team that involves the **m**ulti-disciplinary team, patients and family members 16. Reach consensus with HCP about what is happening to patient and the goals of care 17. Provide clarity in communication about burdens and benefits of critical care treatment 18. Have a consistent communication from one person (HCP) with no break in the chain of communication 19. Communicate all information in a clear, consistent, supportive, timely and regular manner 20. Communicate in an honest manner to the family and with compassion 21. Keep the family informed of patient's condition, any changes and interventions given. 22. Assist families to understand patient's condition, prognosis, interventions given and impending death	4. Attend to the spiritual, cultural and religious needs of the patient 5. Allow the patient to connect to whatever spiritual being they believe in 6. Allow the priest or any spiritual person to offer prayer for the patient • ***Advocate for the patient*** 7. Nurses advocate for patients during their last moments 8. Arrange and have patient's wish followed • ***Nurse presence*** 9. Be [nurses] there at the patient's bedside to support the patient 10. Talk to the patient during procedures and address them by their titles **<u>Support and work with the family</u>** : • ***Meet the needs of the family*** 11. Attend to the needs and wishes of the family members	made and possible outcomes 7. Give the family the opportunity to ask questions and answer them 8. Give the family time to come to terms with decision and the inevitable death • **Provide emotional support for the family** 9. Prepare the family psychologically for the death of patient 10. Have counselling sessions available to support the family • **Involve the family in the process** 11. Get the family involved early in meetings and discussions centred on the care of the patient 12. Let the family know what to expect and the possible outcome • **Allow the family at the patient's bedside**	6. Allow the family to do basic things such as bathing patient, applying cream • **Information sharing** 7. Keep the family informed and update on patient's condition, treatment options and changes 8. Explain to the family what is happening, the decision to made and the reasons for making the decision 9. Give the family ample time to understand information given and agree to the decision • **Nursing care for the patient** 10. Ensure that patient is clean and comfortable 11. Place patient on a clean sheet 12. Provide basic care such as bathing and grooming

23. inform the patient and family about all the aspects of the WDLS process 24. Assist the family to know what to expect about the patient's physical condition 25. Have frequent meeting with the family members 26. Nurses/ HCP available at any time and willing to answer questions from family members 27. Nurses being present during family visits to inform them about patient's condition 28. Make sure the family understand the reason for the withdrawal of the treatment • **Decision making** 29. Promote shared decision making between the healthcare providers and family members 30. Help patient and family to understand the available care options and involved them in the decision making and care planning 31. Ensure that family members have some control on the care decisions and are able to share opinions on patient's decisions 32. Elicit patients and family values and treatment preferences early and honour their wishes as discussed earlier 33. If any advanced directives are made by patients, ICU need to know before any major decisions are made and follow such directives accordingly 34. Allow patient's proxy of choice to make end of life decision on behalf of the patient 35. Advocate for the patient and family, follow and support their wishes	12. Show compassion towards the family during the end-of-life care • ***Involve the family in the care of the patient*** 13. Involve the family in the care of the patient 14. Encourage the family members to talk to the patient and touch the patient • ***Allow the family at the patient's bedside*** 15. Have flexible visiting hours that allow the family to be at the patient's bedside 16. Allow the family to spend the last moment with their relative before the person dies • ***Keep the family informed and updated*** 17. Keep the family informed of the patient's condition, any changes and the treatment given 18. Ensure that the family members understand the process and be there to answer all the questions they may have	13. Allow the family to see their family member • **Provide religious and spiritual support to the family** 14. Enquire about the family preference and wish regarding any specific ritual or spiritual practice 15. Respect the spiritual beliefs and cultural rituals of the family 16. Allow the family to bring in their traditional or spiritual person to the patient's bedside 17. Allow the family to offer prayers and perform their last rituals • **Assess and meet the needs of the family** 18. Elicit the needs and wishes of the patients and their family members 19. Know what the patient and family want and respect their needs	• **Reconnect family relationship** 13. Encourage the family to talk to patient and speak in a voice the patient can recognise 14. Allow the family to hold patients hands in the last moment 15. Allow the family to speak to the patient about what is happening outside the hospital • **Spiritual support** 16. Pay attention and respect families religion and spiritual beliefs 17. Allow the family to exercise their faith 18. Allow the family the opportunity to pray 19. Include a religious person (priest) of choice in the care of the patient • **Privacy**

• **Spiritual care and cultural support** 36. Assess and talk to patient and family about their religious or spiritual beliefs and cultural beliefs associated with death and dying 37. Attend to patients' and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner 38. Align care to suit the spiritual and cultural beliefs of patients and their families 39. Respect and accommodate the patient and family rituals surrounding death and dying 40. Meet the Religious and cultural needs of patients and their families 41. Invite pastor/father or a religious leader at the bedside to offer religious support for the patient and family • **Emotional support** 42. Prepare the family psychologically for patient's death and let them know what to expect and the plan of events that follow death 43. Prepare the family early and help them to accept that their loved ones will not survive 44. Provide the family with the needed assurance that their loved one will not suffer 45. Provide bereavement care to the family members after the death of patient and send messages of condolences 46. Have a debriefing session after the withdrawal of treatment 47. Make counselling sessions readily available for the family and caregivers	19. Communicate to the family in an honest manner and be truthful • ***Nurses presence*** 20. Nurses stay with the patient's family to clarify and answer their questions • ***Spiritual care and cultural support*** 21. Take cognisance of any cultural ritual the needs to be performed 22. Allow the family members to practice and perform their last rituals 23. Allow the family members to bring in their preferred pastor or traditional leader to observe their last prayers and perform their rituals if not harmful to the patient, staff and institution • ***Empathize with the family*** 24. Nurses empathise with the family and are there for them 25. Nurses advocate for their patients and the family		20. Have a special place where information will be shared to the family

48. HCP be available / Be there after the withdrawal of treatment and talk to the family 49. Involve a psychologist in the care of the family 50. Allow the family to externalise their feeling and share the moment with them • **Modifying the ICU environment** 51. Have flexible and unrestricted visiting hours to reduce the distance between the patient and their family 52. Provide adequate time and space for the dying patient and family to say goodbye 53. Family able to stay with patient at the bedside during the dying process 54. Have someone present with the patient at the moment of death—to touch them, speak to them, to let them know it's okay to go 55. Connect the patient and family by allowing the time and space for intimacy 56. Allow the family to bring in personal items that held particular memories and were connected to the dying person 57. Be able to talk about the person's hobbies and sings songs 58. Remove all unnecessary clinical equipment from patients room 59. turn of machines completely 60. Silence all alarms from monitors 61. Dim the room lighting 62. Replace the hospital linen with coloured sheets and beddings	• ***Emotional support for the family*** 26. Give the family time and space to grieve 27. Involve a psychologist to speak to the family on a daily basis 28. Have a debriefing session with the family members following the withdrawal of treatment **<u>Modify the intensive care environment</u>** 29. Have a designated area in the unit where the patient will be managed 30. Close nearby curtains to provide privacy 31. Play soft music 32. Lower the noise from monitors and other equipment 33. Decorate patient's room with lovely colours and pictures of choice on the walls 34. Dim room lights **<u>Effective communication and teamwork</u>** 35. Communicate effectively between the team and patients' family		

63. Pull curtains in full and close doors to ensure privacy 64. Make rooms available where family members can stay; have tea and being able to get away from the ward [waiting area] 65. Bring in additional chairs into the patients room 66. Make available beds, food and showering facilities for family members 67. Patient and family have access to private and single room during the dying process 68. Have a quiet place for prayer, meditation and family gathering 69. Allow the family to play patient's favourite music or music instrument			

6.2.2 Instrument construction, reduction and refinement

Kalkbrenner (2021) recommends an exhaustive list of items during the first round of item development; however, the author also emphasizes that the research team needs to reduce and refine the items by looking for redundancy. A series of meetings among the research team is advised to discuss the list of items and eventually come to consensus about the initial pool of items that will be sent to the panel of experts at the validation stage. The 143 items and their domains and sub-themes, as shown in **Table 6.1**, were reviewed by the researcher, supervisor, and one experienced content expert (AH). The core objectives for the meetings were to assemble the instrument, look out for repetitions, check the wording of items, and reduce and arrange domains by comparing across the various findings (scoping review and qualitative interviews). Various comments from the supervisor and content expert led to a revision of the initially generated domains and items. Any disagreements were resolved through a consensus approach.

6.2.2.1 Domains and items generated

The domains from the scoping reviews and sub-themes that emerged from the qualitative interviews were assessed and compared by the researcher, supervisor, and one content expert. Findings were mapped against each other and compared. Similar themes were grouped under one heading and classified as a domain. The domains: symptom management and comfort, patient and family-centered decision making, communication among the ICU team and with patients and families, emotional support for patients and families, spiritual care and cultural support, and modifying the ICU environment were agreed upon as key domains identified.

Upon further review by the research team, the domain of "care with compassion, dignity, and respect was however considered a basic part of the medical and nursing scope of practice. The team agreed that it was a duty for all healthcare professionals to provide care for patients and their families, show respect, and be compassionate. The items were added to the domain "emotional support for patients and families". Existing literature and palliative care guidelines were also reviewed. The final domains were achieved and done according to the dominance of the domains, and then the domains were compared across the literature. The new search indicated similarities across the literature. The similarities were noticed

across existing literature such as Clarke *et al*.'s (2003) quality indicators for EOL care in the ICU, Jensen *et al*.'s (2020) practice recommendation for EOL care in the ICU, and Downar *et al*.'s (2016) guideline.

The researcher, supervisor, and content expert are critical care trained nurses who have extensive ICU experience and know much about the treatment withdrawal process in the ICU. It was established that continuity of care was an important part of patients and families care in the ICU, especially for critically ill and dying patients. Due to the multidisciplinary approach in the ICU, continuity of care is an important driver of quality of care. Upon further review of the existing literature (Clarke *et al*., 2003; Downar *et al*., 2016; Jensen *et al*., 2020) and discussions, the domain 'continuity of care' was added. The team also discussed the items under the domain "emotional support for patients and families". It was agreed unanimously that items that reflect practical ways of supporting both patients and their families were appropriate. The domain was reconstructed as "Emotional and practical support for patients and families". Additionally, the domain "spiritual care and cultural support" was also reconstructed as "spiritual care". A final seven (7) domains were agreed on and identified as: "symptom management and comfort"; "communication among the ICU team and with patients and families"; "patient and family-centered decision making"; "emotional and practical support for patients and families"; "spiritual care"; "continuity of care"; and "modifying the ICU environment".

The domains identified were further ranked in order of priority by the researcher and supervisor. Due to the enormous ICU experience and EOL care research backgrounds and knowledge, the team had extensive knowledge on treatment withdrawal in the ICU. Hence, the domains were ranked with emphasis on how the withdrawal process takes place in the adult ICU; which included: patient- and family-centered care decision making; communication among the ICU team and with patients and families; continuity of care; emotional and practical support for patients and families; symptom management and comfort; spiritual care; and modifying the ICU environment.

With content domains identified, the 143 items were reduced by looking for repetitions, overlapping, and wording of items. After the reduction and refinement process, an initial 62 items were deduced from the pool of 143 items. A further 3 items were added under the domain "continuity of care" following the series of discussions among the research team

(EK, SS, and AH). Following an iterative process of instrument development, a first draft of the instrument consisting of 65 items organized under 7 content domains was developed. This is shown in **Table 6.2**. The process of developing the first instrument is illustrated in **Figure 6.1**.

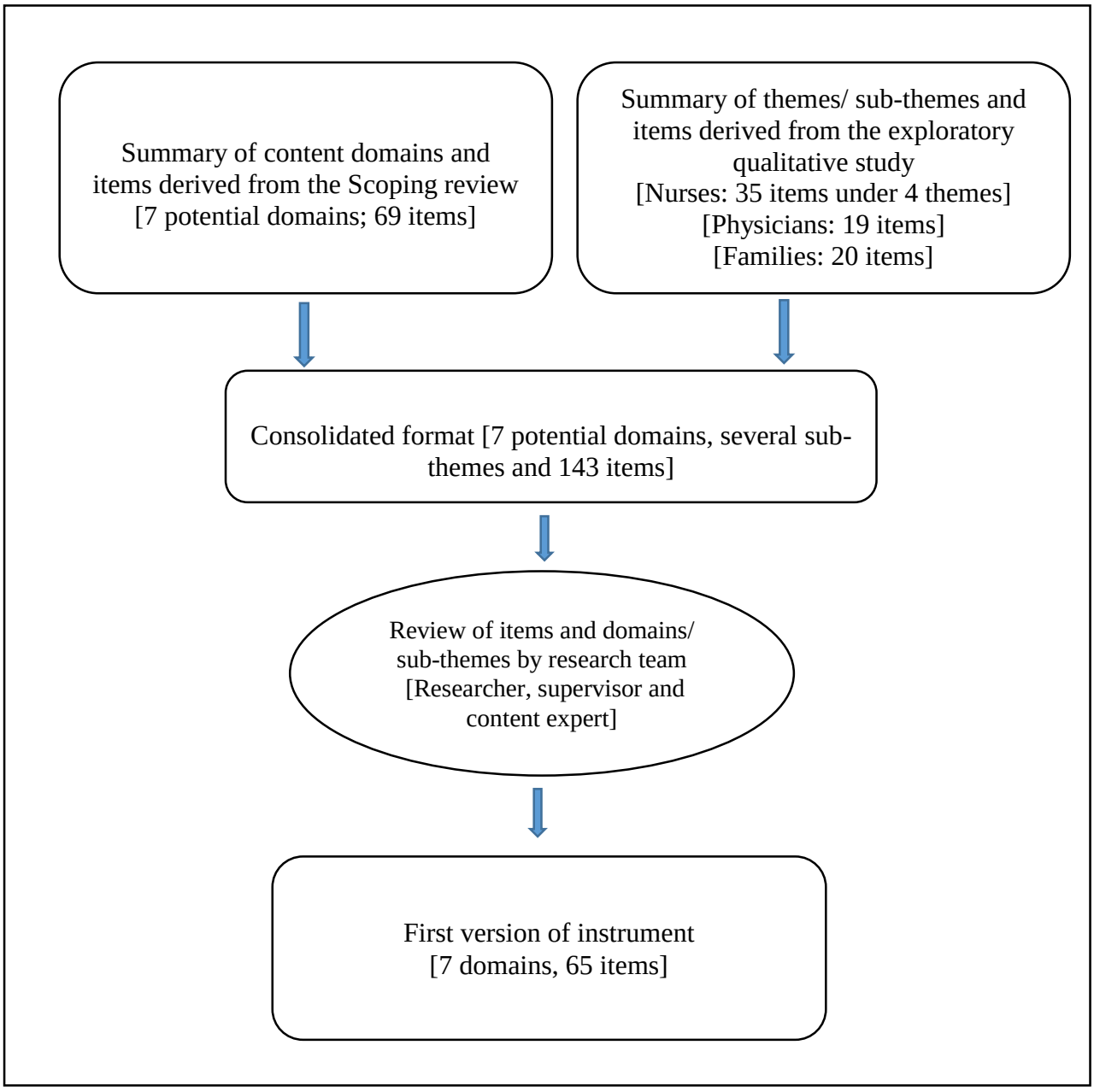

Figure 6.1: Domain identification and item generation process

Table 6.2: Domains and items identified following instrument construction, reduction and refinement [First version of the instrument]

Domain	Items
Patient and family centered decision making	1. Recognise the patient and family a unit of care 2. Assess the patient's and family's wishes and preferences, note and address any conflicts in decision making within the family 3. Share with the patient and family information about the options of treatments 4. Ask if the family want to be involved, their preferences of care and what the patient's wishes are and if there is any advanced directive in place 5. Engage the family in a meeting updating them on the process, current state and how it will unfold 6. Ask the family and identify the preferred choice to be the surrogate 7. Assure patients and family that their preferences will be incorporated in the decision making process
Communication with the ICU team and with patients and families	1. Meet as an interdisciplinary ICU team to discuss the patient's condition, clarify goals of treatment, and identify the patient's and family's needs and preferences 2. Address any disagreement among the ICU team before meeting the patient and family 3. Assess family readiness to receive before relaying information on the disease process 4. Reach consensus with the family about what is happening to patient and the goals of care 5. Provide clarity in communication about burdens and benefits of critical care treatment 6. Keep communication consistent with an identified family member to ensure no communication breakdown and misinformation 7. Communicate all information to the patient and family in a clear, sensitive, unhurried manner, and in an appropriate setting 8. Keep the family informed of patient's condition, any changes and interventions given 9. Assist family to understand patient's condition, prognosis, interventions given and impending death 10. Ensure the family have understanding the reason behind the withdrawing of the treatment 11. Meet the family on a regular basis to review patient's condition and answer their questions 12. Clarify family's understanding of patient's conditions and goals of care at the beginning and at the end of each meeting 13. Prepare the family for the dying process
Continuity of care	1. Handover the plan of care and family preference for the patient care to the oncoming ICU team 2. Liaise with other members of the ICU team to meet the identified needs of the patient and the family

	3. Introduce other members of the team that will provide services such palliative care, pastoral care and counselling to the ICU team, patient and family members
Emotional and practical support for patients and families	1. Elicit and attend to the emotional needs of the dying person and families 2. Provide the family with the needed assurance that their loved one will continue to receive good care 3. Healthcare provider available and have a debriefing session after the decision to withdrawal treatment 4. Make counselling sessions readily available as an option for the family and caregivers 5. Encourage the family to share their feelings in the moment 6. Ask them how they are coping 7. Facilitate strengthening patient-family relationship and communication 8. Value and support the patient's and family's cultural traditions 9. Arrange for social support for patients without family or friends 10. Give the family time and space and allow them to go through the grieving process 11. Encourage the family to talk to the patient and speak in a voice the patient can recognise 12. Allow family members to hold the patient hands at the last moment 13. Allow the family to speak to the patient about what is happening outside the hospital 14. Treat the patient and family with respect and protect their dignity 15. Talk to the patient and families during procedures 16. Provide bereavement care to the family members after the death of patient and send messages of condolences
Symptom management and comfort	1. Reduce the amount of unnecessary technical equipment in order to humanise patient care and promote comfort 2. Eliminate unnecessary tests and procedures such as routine vital signs 3. Assess patients pain and administer necessary pain medication for pain relief 4. Assess and manage patient's symptoms such as agitation, restlessness and shortness of breath using standardise best practice for symptom management 5. Attend to patient's appearance and hygiene needs by keeping the patient clean and well-kept in bed, providing mouth care and skin care 6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by patient and family 7. Minimize noxious stimuli such as monitors and strong lights 8. Ensure family's and healthcare providers presence so the patient is not dying alone

Spiritual care	1. Assess and talk to the patient and family about their religious beliefs and cultural beliefs associated with death and dying on regular basis 2. Attend to patients' and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner 3. Align care to suit the spiritual and cultural practices of patients and their families 4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed with/in the plan of care 5. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices 6. Show respect to the patient and care for patient as a whole person at the end of life
Modifying the ICU environment	1. Create a calm, peaceful environment 2. Silence alarms on all monitors and equipment 3. Turn off machines completely 4. Move the patient to a more private and quiet area in the ICU to create space for patient and family 5. Have flexible and unrestricted visiting hours to reduce the distance between the patient and family 6. Provide adequate time and space for the dying patient and family to say goodbye 7. allow the family to see their loved one in the last moment of life and be there until the end 8. Allow the family to bring in personal items that held particular memories or importance and were connected to the dying person 9. Draw nearby curtains to provide privacy for the patient and the family members 10. Allow the family to play patients favourite music or music instrument 11. Bring in additional chairs into the patients room to create space for the family 12. 12. Adjust (dim or turn off) the lighting around the patient's bed space

6.3 METHODOLOGICAL RIGOUR

The researcher followed several measures to ensure the study's rigour during the instrument development phase. To begin with, the researcher consulted end-of-life content and instrument development experts during the instrument construction, reduction, and refinement stages. Several meetings were held along the development process, and thorough discussions were used to resolve any disagreements that arose. Moreover, during the domain identification and item generation phases, the researcher stayed close to direct quotes from participants and literature. The findings from the scoping review and qualitative interviews informed the development of the provisional instrument.

6.4 SUMMARY

The chapter presents information on phase two of the study, instrument development, and validation. This chapter specifically focused on the development of the survey instrument, which was informed by the findings from the scoping review and qualitative interviews of phase one. Outlined in the chapter also was how domains and items identified in phase one were integrated, synthesized, reduced, and refined to develop a draft of the measurement instrument. An initial pool of 143 items organized under 7 domains and other sub-themes was generated from the findings from phase one. This was refined by a research team into a first draft instrument comprising 65 items and 7 domains.

The next chapter presents the instrument validation part of phase two and sets the stage for a Delphi study with a panel of expert reviewers.

CHAPTER SEVEN
PHASE TWO: INSTRUMENT DEVELOPMENT AND VALIDATION
INSTRUMENT VALIDATION

7.1 INTRODUCTION

The chapter focuses on the instrument validation part of phase two of the study. The outcome of phase two of the study was to develop an instrument and assess its content and face validity. This chapter discusses instrument validation, which includes evaluating the measurement instrument's content and face validity. Outlined in the chapter are the processes involved in assessing the validity of the instrument. The chapter begins with information on the composition of the expert panel involved in the two-round Delphi study, followed by the quantification of the content validity of the instrument based on an analysis of the ratings provided by the expert panel. A total of 65 items organized under 7 domains went for review by a panel of experts.

7.2 DEMOGRAPHIC DATA OF THE EXPERT PANEL

A panel of experts was constituted based on their academic qualifications, intensive care clinical experience and expertise, relevant training in critical care, instrument development experience, and EOL research involvement. A total of ten (n = 10) medical and nursing experts were invited to participate in the content validation assessment. All the experts responded to the invitation and agreed to be part of the two-round Delphi. One expert withdrew his participation due to workload and busy schedules. The final panel comprised nine participants.

Demographic data of the participating expert panel members is presented in **Table 7.1.**

Table 7.1: **Demographic characteristics of participating expert panel members**

#	Gender	Age /Yrs.	Academic qualification	Current Profession	Yrs. of experience	Current place of work	EOLC participation in ICU / Role
1	Female	52	MSc (Nursing)	Nurses educator / critical care nurse	30	Both academic/ clinical practice	Yes, as bedside nurse/
2	Female	37	Mmed (Internal Medicine)	Specialist physician/ Internal medicine	12	Both academic/ clinical practice	Yes, as a specialist physician
3	Female	55	PhD (Nursing)	Nurse educator/ Critical care	29	Academic setting	Yes, as a clinical and EOLC tutor
4	Female	37	MSc (Nursing)	Nurse educator/ Critical care	12	Both academic/ clinical practice	Yes, as a Nurse
5	Female	40	PhD (Nursing)	Critical care nurse	15	Clinical practice	Nurse/ EOLC researcher
6	Female	35	PhD (Nursing)	Nurse educator/ Critical care	16	Academic setting	Nurse
7	Female	48	MSc (Nursing)	Critical care nurse	22	Clinical practice	Bedside Nurse
8	Male	33	MSc (Nursing)	Critical care nurse	13	Clinical practice	Bedside nurse
9	Male	55	Mmed (Critical care)	Specialist physician/ Intensivist	30	Both academic/ clinical practice	Intensive care specialist

Note**:** *MSc=Master of Science degree; Mmed=Master of medicine degree; PhD= Doctor of Philosophy; EOLC= end-of-life care; ICU= intensive care unit*

Table 7.1 provides the demographic characteristics of the experts that participated in the two-round Delphi. As shown in the table, nine experts participated in the content validation assessment. The panel of experts comprises 7 females and 2 males, with their ages ranging from 33 to 55 years. All the experts had completed various postgraduate degrees within nursing and medicine; six of them had obtained their Masters academic qualifications, and three had their PhDs. All but two participants were nurse specialists with training as critical care nurses. The two were medical doctors with special training in internal medicine and critical care medicine. The cumulative years of experience in their respective professions ranged from 12 to 30 years. All experts had participated in EOL care in the ICU and played different roles, ranging from bedside nurses, nurse researchers, and nurse educators to specialist physicians.

7.3 DELPHI RESULTS

A two-round Delphi was undertaken during the content validity assessment of the instrument. A panel of nine experts was requested to assess the relevance and clarity of each of the 65 items organized under 7 domains using a rating scale informed by Lynn (1986). Comments, suggested revisions, and new items suggested guided the revision of the first version of the instrument. The results that emerged following the data analysis are presented and discussed in the sections below.

7.3.1 Delphi Round One

In the first round of the Delphi, the first version of the survey instrument (**Table 6.2 & Appendix T**) was sent to a panel of nine expert to specifically rate the 65 items organized under 7 domains according to their level of clarity and relevance to the domains and the overall survey instrument. The results from round one informed the development of the second version of the instrument. The sections below present the results from the feedback from the panel of experts during round one of the Delphi.

7.3.1.1 Delphi round one results

Assessment of content validity based on item level of clarity and relevance

Following the round one feedback from the panel of experts, their ratings under the options of clarity and relevance were used to compute the item content validity index (I-CVI). The item content validity index (I-CVI) guided the decision to accept, revise, or discard items. The item content validity (I-CVI) was calculated and presented for each domain and item, as shown on the tables below. Minor changes made to items level of clarity based on comments from the experts' panel are presented and shown in **Appendix U**.

Table 7.2: Calculation of I-CVI for relevance and clarity of each item under domain 1

Items	I-CVI Relevance	Interpretation	I-CVI Clarity	Interpretation
1.Recognise the patient and family as a unit of care	1.00	Relevant	1.00	Clear
2.Assess the patient's and family's wishes and preferences,	1.00	Relevant	1.00	Clear

note and address any conflicts in decision-making within the family				
3.Share with the patient and family information about the options of treatments	1.00	Relevant	1.00	Clear
4.Ask the family if they want to be involved, their preferences of care and what the patient's wishes are and if there is any advanced directive in place	1.00	Relevant	1.00	Clear
5.Engage the family in a meeting updating them on the process, current state and how it will unfold	1.00	Relevant	1.00	Clear
6.Ask the family and identify the preferred choice to be the surrogate	1.00	Relevant	0.89	Clear
7.Assure patients and families that their preferences will be incorporated into the decision-making process	0.89	Relevant	1.00	Clear

From **Table 7.2**, all seven items under the domain, patient and family-centered decision making, had a good content validity index regarding relevance (I-CVI of 0.89 to 1.00) with an average I-CVI of **0.98**. The item content validity indexes were considered relevant based on the set criteria [i.e., Abdollahpour *et al*. (2010) and Davis (1992)]. Regarding item level of clarity, all the items were rated as clear based on their I-CVIs (I-CVI of 0.89–1.00). However, minor grammar changes were suggested by some panel members.

Table 7.3: Calculation of I-CVI for relevance and clarity of each item under domain 2

Items	I-CVI Relevance	Interpretation	I-CVI (Clarity)	Interpretation
1.Meet as an interdisciplinary ICU team to discuss the patient's condition, clarify the goals of treatment, and identify the patient's and family's needs and preferences	1.00	Relevant	1.00	Clear
2.Address any disagreement among the ICU team before meeting the patient and family	1.00	Relevant	1.00	Clear
3.Assess family readiness to receive before relaying information on the disease process	0.89	Relevant	1.00	Clear
4.Reach a consensus with the family about what is happening to the patient and the goals of care	1.00	Relevant	0.89	Clear
5.Provide clarity in communication about the burdens and benefits of critical care treatment	1.00	Relevant	1.00	Clear

6.Keep communication consistent with an identified family member to ensure no communication breakdown and misinformation	1.00	Relevant	1.00	Clear
7.Communicate all information to the patient and family in a clear, sensitive, unhurried manner, and in an appropriate setting	1.00	Relevant	1.00	Clear
8. Keep the family informed of the patient's condition, any changes and interventions given	1.00	Relevant	1.00	Clear
9.Assist family to understand patient's condition, prognosis, interventions given and impending death	1.00	Relevant	1.00	Clear
10.Ensure the family has an understanding of the reason behind the withdrawing of the treatment	1.00	Relevant	1.00	Clear
11.Meet the family on a regular basis to review the patient's condition and answer their questions	1.00	Relevant	1.00	Clear
12.Clarify the family's understanding of the patient's conditions and goals of care at the beginning and at the end of each meeting	0.89	Relevant	0.89	Clear
13. Prepare the family for the dying process	**0.78**	**Need for revision**	1.00	Clear

From **Table 7.3**, in the domain "communication among the ICU team, with patients and families", the item content validity indexes (I-CVIs) for the items ranged from 0.78 to 1.00. The items had a good content validity index and were considered relevant based on the set criteria [i.e., Abdollahpour *et al*. (2010) and Davis (1992)] except for item 13, ***"Prepare the family for the dying process,"*** that recorded an I-CVI of 0.78 under relevance and needed further revision. One expert suggested that item 13 had already been repeated under domain 4 (emotional and practical support for patients and families) and needed to be removed **(Appendix U**).

Table 7.4: Calculation of I-CVI for relevance and clarity of each item - Domain 3

Items	I-CVI (Relevancy)	Interpretation	I-CVI (Clarity)	Interpretation
1.Handover the plan of care, patient and family preference for the patient care to the oncoming ICU team	1.00	Relevant	0.89	Clear
2.Liaise with other members of the ICU team to meet the identified needs of the patient and the family	0.89	Relevant	0.89	Clear

3.Introduce other members of the team that will provide services such as palliative	1.00	Relevant	1.00	Clear

Under the domain "Continuity of care", all three items had I-CVIs that ranged from 0.89 to 1.00 for relevance (**Table 7.4**). The average I-CVI was **0.96**. These values were considered to have good content validity and were appropriate based on the set criteria [i.e., Abdollahpour *et al*. (2010) and Davis (1992)]. Hence, no revision was needed based on item relevance. The panel of experts, based on their ratings on item level of clarity, rated all the items under the domain as clear with minor grammatical changes (I-CVI of 0.89–1.00).

Table 7.5: Calculation of I-CVI for relevancy and clarity of each item under Domain 4

Items	I-CVI (Relevance)	Interpretation	I-CVI (Clarity)	Interpretation
1. Elicit and attend to the emotional needs of the dying person and families	1.00	Relevant	0.89	Clear
2.Provide the family with the needed assurance that their loved one will continue to receive good care	1.00	Relevant	1.00	Clear
3.Healthcare provider available and have a debriefing session after the decision to withdraw treatment	**0.78**	**Need for revision**	**0.78**	**Need for revision**
4. Make counselling sessions readily available as an option for the family and caregivers	0.89	Relevant	1.00	Clear
5. Encourage the family to share their feelings in the moment	1.00	Relevant	1.00	Clear
6. Ask them how they are coping	0.89	Relevant	1.00	Clear
7.Facilitate strengthening patient-family relationships and communication	**0.78**	**Need for revision**	**0.78**	**Need for revision**
8.Value and support the patient's and family's cultural traditions provided	1.00	Relevant	1.00	Clear
9. Arrange for social support for patients without family or friends	0.89	Relevant	1.00	Clear
10. Give the family time and space and allow them to go through the grieving process	0.89	Relevant	1.00	Clear
11. Encourage the family to talk to the patient and speak in a voice the patient can recognise	1.00	Relevant	1.00	Clear

12. Allow family members to hold the patient hands at the last moment	1.00	Relevant	1.00	Clear
13. Allow the family to speak to the patient about what is happening outside the hospital	0.89	Relevant	1.00	Clear
14. Treat the patient and family with respect and protect their dignity	1.00	Relevant	1.00	Clear
15.Talk to the patient and families during procedures	1.00	Relevant	1.00	Clear
16. Provide bereavement care to the family members after the death of the patient and send messages of condolences	0.89	Relevant	1.00	Clear

From **Table 7.5**, the CVI for each item calculated from the level of clarity and relevance rating provided by the expert panel for domain 4 ranged from 0.78 to 1.00 (I-CVI of 0.78 – 1.00). Based on the set criteria proposed by Abdollahpour *et al*. (2010) and Davis (1992), I-CVIs below 0.80 needed revision. Items 3, "*Healthcare provider available and have a debriefing session after the decision to withdraw treatment"* and 7, "*Facilitate strengthening patient-family relationships and communication"* were modified based on the comments from the expert panel and sent for further rating based on the relevance at Round 2 of the Delphi. Two experts suggested that item 3 be revised to "*Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment"* and item 7 to *"Facilitate strengthening of patient-family relationships and communication"* (**Appendix U**).

Table 7.6: Calculation of I-CVI for relevancy and clarity of each item under **domain 5**

Items	I-CVI (relevance	Interpretation	I-CVI (Clarity)	Interpretation
1. Reduce the amount of unnecessary technical equipment to humanise patient care and promote comfort	1.00	Relevant	1.00	Clear
2. Eliminate unnecessary tests and procedures such as routine vital signs	0.89	Relevant	0.78	Need for revision
3. Assess the patient's pain and administer necessary pain medication for pain relief	1.00	Relevant	1.00	Clear
4. Assess and manage patient's symptoms such as agitation, restlessness and shortness of breath using standardise best practices for symptom management	1.00	Relevant	1.00	Clear
5. Attend to patient's appearance and hygiene needs by keeping the patient	1.00	Relevant	1.00	Clear

clean and well-kept in bed, providing mouth care and skin care				
6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by the patient and family	1.00	Relevant	1.00	Clear
7. Minimize noxious stimuli such as monitors and strong lights	1.00	Relevant	1.00	Clear
8. Ensure the family's and healthcare providers' presence so the patient is not dying alone	1.00	Relevant	1.00	Clear

From **Table 7.6**, the CVI for each item under the domain, symptom management and comfort, ranged from **0.78 to 1.00**. The CVIs of these items (I-CVIs of **0.89–1.00**) regarding item relevance were considered appropriate based on the set criteria [i.e., Abdollahpour *et al.* (2010) and Davis (1992)]. Hence, no further revision was needed based on item relevance. On the level of clarity, one expert suggested revision of Item 2 to "*Eliminate unnecessary tests and invasive procedures such as taking blood for arterial blood gas monitoring"* (**Appendix U**).

Table 7.7: Calculation of I-CVI for relevancy and clarity of each item under domain 6

Items	I-CVI Relevance	Interpretation	I-CVI Clarity	Interpretation
1. Assess and talk to patients and family about their religious or spiritual beliefs and cultural beliefs associated with death and dying on a regular basis	1.00	Relevant	1.00	Clear
2. Attend to patients and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner	1.00	Relevant	1.00	Clear
3. Align care to suit the spiritual and cultural beliefs of patients and their families	1.00	Relevant	1.00	Clear
4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed with/in the plan of care	1.00	Relevant	1.00	Clear
5. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	1.00	Relevant	1.00	Clear
6. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	1.00	Relevant	1.00	Clear

From **Table 7.7**, the CVI for each item calculated from the relevance rating provided by the expert panel for the domain, spiritual care, was **1.00**. The CVI of these items (I-CVIs) was considered appropriate based on the set criteria [i.e., Abdollahpour et al. (2010) and Davis (1992)]. Hence, no further revision was needed based on item clarity and relevance. Item 6, which was a repetition of item 5, was hence deleted (**Appendix U**).

Table 7.8: Calculation of I-CVI for relevancy and clarity of each item under domain seven

Items	I-CVIs Relevance	Interpretation	I-CVI Clarity	Interpretation
1. Create a calm, peaceful environment	1.00	Relevant	1.00	Clear
2. Silence alarms on all monitors and equipment	**0.78**	**Need for revision**	**0.78**	**Need for revision**
3. Turn off machines completely	**0.67**	**Need for revision**	**0.78**	**Need for revision**
4. Move the patient to a more private and quiet area in the ICU to create space for the patient and family	1.00	Relevant	0.89	Clear
5. Have flexible and unrestricted visiting hours to reduce the distance between the patient and family	0.89	Relevant	1.00	Clear
6. Provide adequate time and space for the dying patient and family to say goodbye	1.00	Relevant	1.00	Clear
7. Allow the family to see their loved one in the last moment of life and be there until the end	1.00	Relevant	1.00	Clear
8. Allow the family to bring in personal items that held particular memories or importance and were connected to the dying person	1.00	Relevant	1.00	Clear
9. Draw nearby curtains to provide privacy for the patient and the family members	1.00	Relevant	1.00	Clear
10. Allow the family to play the patient's favourite music or musical instrument	0.89	Relevant	1.00	Clear
11. Place additional chairs around the bed to create space for the family	1.00	Relevant	1.00	Clear
12. Adjust (dim or turn off) the lighting around the patient's bed space	1.00	Relevant	1.00	Clear

From **Table 7.8**, the CVI for each item calculated from the clarity relevance rating provided by the expert panel for domain 7, ranged from 0.67 to 1.00 (I-CVI of 0.67 – 1.00). Based on the set criteria proposed by Abdollahpour *et al*. (2010) and Davis (1992), I-CVIs below 0.80 needed revision. Items 2, "*Silence alarms on all monitors and equipment"* and 3, "*Turn off machines completely"* were modified based on the comments from the expert panel and sent

for further rating based on the relevance at the Round two of the Delphi. The other items [1, 4-12] were considered clear and relevant based on their I-CVIs, hence needed no revision based on their clarity and relevance to the domain and the overall instrument. Items 2 and 3 were modified to "*Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible"* and "*Turn off machines [such as ventilator/ dialysis/ monitors] completely" (***Appendix U***).* Even though item 3 had item content validity index (I-CVI of 0.67) regarding relevance, the item was not deleted. The item was considered important but needed further wording.

7.3.1.2 Items for revision and new items for survey instrument inclusion (Delphi Round one)

From the experts' feedback from the first Delphi round, items with I-CVIs below 0.80 needed further revision. Four new items were also suggested by the expert panel to be included in the survey instrument. **Table 7.9** displays the items that needed further revision due to their item content validity indexes (I-CVIs) lower than 0.80 (**I-CVI<0.80**) and **Table 7.10** also presents the new items suggested for inclusion in the survey instrument respectively. All these items were revised based on experts' comments on the level of clarity and sent back to them at round 2 of the Delphi for further rating on their relevance using the 4 point Likert scale.

Table 7.9: Items for further revision based on item content validity (I-CVI)

Domain	Items
Emotional and practical support for patients and families	*Item 3- Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment*
	Item 7 - Facilitate strengthening of patient-family relationships and communication
Modifying the environment	*Item 2- Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible*
	Item 3- Turn off machines [such as ventilator/ dialysis/ monitors] completely

***Note**: The underlined words are revisions done on the items level of clarity*

Table 7.10: New Items suggested for inclusion

New Items suggested
Discuss with patients and families who will take patients belonging or valuables, document and allow the families to sign
Speak to patients and families about organ donation, if there is one, and respect the wishes of patients and families
Discuss with patients and families the funeral parlour they intend to use
Encourage and allow families if they are comfortable to take part in the direct care of the patients under the supervision of healthcare workers

Table 7.10 shows the additional items the experts suggested for inclusion. Four new items were suggested to be included in the survey instrument. No specific domain was mentioned for any of the items.

7.3.2 Delphi Round Two

In round two of the Delphi, the second version of the developed instrument was sent to the nine expert panelist for their final comments and revisions. The changes made to the second version of the instrument were informed by the feedback and results from the first round of the Delphi. Information included in the package for the experts during the second round was the revised instrument based on experts comments from round one, item content validity indexes (I-CVIs), items that required further rating due to their I-CVIs below 0.80, and the new items suggested for inclusion under the various domains (**Appendix V**). Following the analysis of the round one feedback, four items needed further expert rating based on their I-CVIs (refer to **Table 7.9**). Four new items were also suggested by the panel of experts for consideration and inclusion (**Table 7.10**). A revised instrument consisting of 61 items organized under 7 domains, including those suggested for further rating, was sent out to the panel of experts in Round 2 (**Appendix V)**. The four new items were also added separately.

Further I-CVIs were calculated for the new items and those that went for further revision.

7.3.2.1 Assessment of content validity of revised items based on item level of clarity and relevance

This section presents the content validity indexes of items that were sent to the expert panel based on their lower I-CVIs and level of clarity. Table 7.11 shows the I-CVI as computed with the ratings from experts in the second round of the Delphi.

Table 7.11: Calculation of the I-CVI for relevance and clarity for each revised item - Round 2

Domain	Item	I-CVI Relevance	Interpretation	I-CVI Clarity	Interpretation
Emotional and practical support for patients and families	**Item 3**- Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment	1.00	Relevant	1.00	Clear
	Item 7 - Facilitate strengthening of patient-family relationships and communication	0.89	Relevant	1.00	Clear
Modifying the environment	**Item 2**- Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible	1.00	Relevant	1.00	Clear
	Item 3- Turn off machines [such as ventilator/ dialysis/ monitors] completely	1.00	Relevant	1.00	Clear

Table 7.11 shows that the revised items had a good content validity regarding relevance and clarity (I-CVI of 0.89 – 1.00). Based on their I-CVIs, the items were considered relevant and clear for inclusion under the various domains.

7.3.2.2 Domain allocation and assessment of content validity index of new items

The four new items suggested for inclusion (**Table 7.10**) were rated according to their level of relevance by the panel of experts at the second round of the Delphi. The various experts' comments were used to revise the items, as shown in **Table 7.12**.

Table 7.12: **Calculation of the I-CVI for relevance of new items**

Item	Domain suggested by the majority	I-CVI Relevance	Interpretation
Discuss with patients and families who will take patients belonging or valuables, document and allow the families to sign	Patient and family centred decision making	0.89	Relevant
Speak to patients and families about organ donation, if there is one, and respect the wishes of patients and families	Patient and family centred decision making	0.89	Relevant
Discuss with patients and families the funeral parlour they intend to use	Emotional and practical support for patients and families	**0.69**	Not relevant
Encourage and allow families if they are comfortable to take part in the direct care of the patients under the supervision of healthcare workers	Emotional and practical support for patients and families	1.00	Relevant

As shown in **Table 7.12**, all the items suggested for inclusion in the instrument were rated relevant by the panel of experts, except one. The CVI of each item suggested ranged from 0.69 to 1.00. Based on their I-CVIs, they were considered relevant to be included under the suggested domains as part of the instrument development, except for the item *"Discuss with patients and families the funeral parlour they intend to use"*. The item content validity (I-CVI - 0.69) was below 0.80, hence it was eliminated. The panel of experts, however, suggested revisions based on clarity. Item *"Discuss with patients and families who will take patients belonging or valuables, document and allow the families to sign"* was changed to *"Discuss with the family who will take patient's belongings, document and counter sign together with the family".* Item *"Speak to patients and families about organ donation, if there is one, and respect the wishes of patients and families"* was changed to *"Speak to the patient and/or family about organ donation where possible and respect their wishes".* Also, item *"Encourage and allow families if they are comfortable to take part in the direct care of the patients under the supervision of healthcare workers"* was changed to "*Encourage and allow the family (if they are comfortable) to take part in the direct care of the patient under the supervision of the healthcare workers*". The three items with I-CVI of 0.80 and above were added under the suggested domains as agreed by the expert panel. Refer to **Appendix W** for the final revised instrument and the I-CVIs.

7.3.2.3 Comprehensiveness of the overall instrument

The panel of experts responded using a "yes" or "no" to judge the extent to which they agreed that instrument domains and items were complete and comprehensive as far as theoretical definitions of domains and their dimensions were concerned. Table 7.13 displays the results as obtained from round 2 of the Delphi feedback.

Table 7.13: **Comprehensiveness of instrument domains and items**

Domains (D)	**Comprehensiveness of instrument domains, items and overall instrument**	
	Agree	**Proportion of consensus**
D1: Patient and family centred decision making	9	1.00
D2: Communication among the ICU team and with patients and families	9	1.00
D3: Continuity of Care	9	1.00
D4: Emotional and practical support for patients and families	9	1.00
D5: Symptom management and comfort	9	1.00
D6: Spiritual care	9	1.00
D7: Modifying the ICU environment	8	0.89
Comprehensive of the overall instrument	**9**	**1.00**

As shown in **Table 7.13**, almost all nine expert panel members agreed that the respective domains and their items were complete and comprehensive as far as the theoretical definitions of the domains and dimensions of the survey instrument were concerned. The proportion of consensus ranged from 0.89 to 1, indicating that 89 to 100% consensus was reached among the experts on the panel for all the domains and their items. Regarding the agreement on the total comprehensiveness of the overall instrument, all nine experts on the panel agreed that the overall instrument was comprehensive (n = 9). Hence, the proportion of consensus on the comprehensiveness of the entire instrument was equal to 1.

7.4 FINAL VERSION OF THE SURVEY INSTRUMENT

Following an iterative process for instrument development achieved in two phases and a two-round Delphi, a final version of the instrument that consisted of 64 items organised under 7 domains was developed (**Appendix W & Z**). The processes undertaken to arrive at

the final domains and items and the iterative summary of changes made to the survey instrument are shown in **Appendix Y**.

7.4.1 Item Content Validity Index (I-CVI) Results of the Final Version of Instrument

The item content validity index (I-CVI) calculation for the relevancy of each item under the seven domains is shown in **Appendices U** and **W**. Following a two-round Delphi, all 64 final items (100%) organised under 7 domains were marked as relevant, and the I-CIVs ranged from 0.89 to 1.00. Forty-nine items had an I-CVI of 1.00, and the rest (n = 15) had a score of 0.89. All the items obtained in the final version of the instrument were considered relevant (**Appendix W**).

7.4.2 Scale Content Validity Index (S-CVI) Results of the Final Version of Instrument

The computed universal agreement among experts (S-CVI/UA) was 0.77, and the S-CVI/Ave was also 0.97. Overall, the average approach shows a good scale content validity index (S-CVI of 0.9 or higher), while the universal agreement method demonstrates moderate content validity (S-CVI/UA lower than 0.80). The Universal agreement was computed by adding all I-CVIs equal to 1.00 (49 items) divided by 64, while the Average approach was the sum of all I-CVIs (62.35) divided by 64.

7.4.3 Modified Kappa

Kappa provides the degree of agreement beyond chance. The table below displays the kappa scores of instrument items as computed.

Table 7.14: Content validity Index and Kappa score for relevancy of each item (final version of instrument)

Domain/ item	I-CVI	Pc (probability of chance agreement)	Kappa (K*)	Interpretation
D1: Patient and family centred decision making				
D1-1	1.00	0.002	1.00	Excellent
D1-2	1.00	0.002	1.00	Excellent
D1-3	1.00	0.002	1.00	Excellent
D1-4	1.00	0.002	1.00	Excellent
D1-5	1.00	0.002	1.00	Excellent
D1-6	1.00	0.002	1.00	Excellent

D1-7	0.89	0.014	0.89	Excellent
D1-8	0.89	0.014	0.89	Excellent
D1-9	089	0.014	0.89	Excellent
D2: Communication among the ICU team and with patients and families				
D2-1	1.00	0.002	1.00	Excellent
D2-2	1.00	0.002	1.00	Excellent
D2-3	0.89	0.014	0.89	Excellent
D2-4	1.00	0.002	1.00	Excellent
D2-5	1.00	0.002	1.00	Excellent
D2-6	1.00	0.002	1.00	Excellent
D2-7	1.00	0.002	1.00	Excellent
D2-8	1.00	0.002	1.00	Excellent
D2-9	1.00	0.002	1.00	Excellent
D2-10	1.00	0.002	1.00	Excellent
D2-11	1.00	0.002	1.00	Excellent
D2-12	0.89	0.014	0.89	Excellent
D3: Continuity of care				
D3-1	1.00	0.002	1.00	Excellent
D3-2	0.89	0.014	0.89	Excellent
D3-3	1.00	0.002	1.00	Excellent
D4: Emotional and practical support for patients and families				
D4-1	1.00	0.002	1.00	Excellent
D4-2	1.00	0.002	1.00	Excellent
D4-3	1.00	0.002	1.00	Excellent
D4-4	1.00	0.002	1.00	Excellent
D4-5	0.89	0.014	0.89	Excellent
D4-6	0.89	0.014	0.89	Excellent
D4-7	1.00	0.002	1.00	Excellent
D4-8	0.89	0.014	0.89	Excellent
D4-9	0.89	0.014	0.89	Excellent
D4-10	1.00	0.002	1.00	Excellent
D4-11	1.00	0.002	1.00	Excellent
D4-12	0.89	0.014	0.89	Excellent
D4-13	1.00	0.002	1.00	Excellent
D4-14	1.00	0.002	1.00	Excellent
D4-15	0.89	0.014	0.89	Excellent
D4-16	1.00	0.002	1.00	Excellent
D5: Symptom management and comfort				
D5-1	1.00	0.002	1.00	Excellent
D5-2	0.89	0.014	0.89	Excellent
D5-3	1.00	0.002	1.00	Excellent
D5-4	1.00	0.002	1.00	Excellent
D5-5	1.00	0.002	1.00	Excellent
D5-6	1.00	0.002	1.00	Excellent
D5-7	1.00	0.002	1.00	Excellent
D6: Spiritual care				
D6-1	1.00	0.002	1.00	Excellent
D6-2	1.00	0.002	1.00	Excellent

D6-3	1.00	0.002	1.00	Excellent
D6-4	1.00	0.002	1.00	Excellent
D6-5	1.00	0.002	1.00	Excellent
D7: Modifying the ICU environment				
D7-1	1.00	0.002	1.00	Excellent
D7-2	1.00	0.002	1.00	Excellent
D7-3	1.00	0.002	1.00	Excellent
D7-4	1.00	0.002	1.00	Excellent
D7-5	0.89	0.014	0.89	Excellent
D7-6	1.00	0.002	1.00	Excellent
D7-7	1.00	0.002	1.00	Excellent
D7-8	1.00	0.002	1.00	Excellent
D7-9	1.00	0.002	1.00	Excellent
D7-10	0.89	0.014	0.89	Excellent
D7-11	1.00	0.002	1.00	Excellent
D7-12	1.00	0.002	1.00	Excellent

Note: D1-D7 represents the domains; (D1-1) also represents domain and item; I-CVI represents the item-level content validity index

As shown in table 7.14, items from the final version of the instrument recorded kappa values that ranged from 0.89 to 1.00. Based on the criteria, kappa score above 0.74 are considered excellent. All the items recorded excellent Kappa scores.

7.5 SUMMARY OF RESULTS FROM THE INSTRUMENT VALIDATION PHASE

The instrument validation phase represented the final part of phase two of the study. It followed steps 4 and 5 of the instrument development process and addressed objectives 6 and 7 of the study. The main findings from the instrument validation phase included the following:

- For the validation phase, nine experts with backgrounds in medicine and nursing who worked in both clinical and academic settings took part in a two-round Delphi.
- The mean age of the nine experts was 43.56 years. The minimum age was 33, and the maximum age was 55.
- The average number of years they had worked in their fields was 19.89, with the lowest being 12 years and the highest being 30 years.

- About 77.8% of the experts were nurse specialists with training in critical care, and 22.2% were medical doctors with special training in internal medicine and critical care.
- The two rounds of Delphi received a 100% response from experts. The panel of experts who took part in round one also responded to the Delphi in round 2.
- From a set of 143 items at the beginning of item generation, the instrument was reduced to 65 items organised under 7 domains. The first version comprised 65 items and 7 domains. The final version of the developed instrument included 7 domains and 64 items after an iterative and validation process. The content validity process identified seven domains, which included patient- and family-centered decision making (nine items); communication among the ICU team and with patients and families (12 items); continuity of care (three items); emotional and practical support for patients and families (12 items); symptom management and comfort (7 items); spiritual care (5 items); and modifying the ICU environment (12 items).
- Following the feedback from round one of the Delphi, version one of the instrument was further reduced to 61 items under 7 domains. Four new items were suggested for inclusion by the panel of experts.
- At the end of round 2, the final version of the instrument consisted of 64 items and 7 domains.
- At the end of the Delphi, the item content validity indexes (I-CVIs) ranged from 0.89 to 1.00: domain 1 (0.89–1.00, with an average I-CVI of 0.98); domain 2 (0.89–1.00, with an average I-CVI of 0.98); domain 3 (0.89–1.00, with an average I-CVI of 0.96); domain 4 (0.89–1.00, with an average I-CVI of 0.96); domain 5 (0.89–1.00, with an average I-CVI of 0.98); domain 6 (0.89–1.00, with an average I-CVI of 0.98); and domain 7 (0.89–1.00, with an average I-CVI of 0.98).
- The computed universal agreement among experts (S-CVI/UA) and the S-CVI/Ave for the final version of the instrument were **0.77** and **0.97**, respectively.
- The 64 items in 7 domains obtained excellent kappa values that ranged from **0.89 to 1.00**.

7.6 SUMMARY

The chapter focused on the instrument validation part of phase two of the study. The chapter presented on the validation of the instrument included an assessment of the content and face validity of the measurement instrument. Outlined in the chapter were the processes involved in assessing the validity of the instrument. The chapter began with information on the composition of the expert panel that was involved in the two-round Delphi study, followed by the quantification of the content validity of the instrument based on an analysis of the ratings provided by the expert panel. The chapter ended with a summary of the findings derived from the instrument validation phase. Overall, 7 domains and 64 items emerged as the final version of the survey instrument.

The next chapter, Chapter Eight, focuses on the discussion of study findings from phase one and two.

CHAPTER EIGHT
DISCUSSIONS OF STUDY FINDINGS [PHASE 1 AND 2]

8.1 INTRODUCTION

The chapter presents a comprehensive summary of the outcomes of the study as organized in each phase. The chapter also follows it up with the discussions and the interpretations of the findings. Findings from phase 1 were presented in detail in Chapters 4 and 5. In this chapter, the themes that emerged are stated. The outcomes of phase 2 are also presented, and the findings are discussed and their interpretations laid out in this chapter.

8.2 PHASE ONE OF THE STUDY

The outcome of phase one was to identify relevant content domains and generate items for the development of the instrument. This was achieved through a scoping review and qualitative interviews with nurses, physicians, and family members. Phase one followed steps 1 and 2 and met objectives 1, 2, 3, and 4 as outlined in Table 3.1 in Chapter 3.

The section below presents the main themes that emerged from the scoping review and qualitative interviews and also presents discussion and interpretation of the findings, as conducted in Phase 1.

8.2.1 Scoping Review

As part of the domain identification and item generation for the instrument development and affecting the quality of care desired at EOL, it was important to summarize the scope of scientific literature on the subject. Hence, the perspectives of patients, family members, and healthcare providers on providing quality care at the end of life through a scoping review were appropriate to deduce relevant domains and items for the instrument. The outcome of the review provided rich background information and a scientific foundation for the development of an appropriate instrument to measure the quality of care after treatment withdrawal in the adult ICU in Phase 2.

The objective of the review was to identify and synthesise the available evidence from the perspectives of patients, family members, and healthcare providers on providing quality care for patients at the end of life and their families in the intensive care unit. The perspectives of patients, family members, and healthcare providers were summarised under seven (n = 7) important themes, namely:

- Patient- and family-centered decision-making
- Communication among the ICU team and with patients and families
- Symptom management and comfort
- Care with compassion, dignity, and respect
- Emotional support for patients and families
- Spiritual support and cultural care
- Modifying the intensive care environment

8.2.1.1 Discussion of the scoping review findings

The results of the scoping review showed that there are seven key areas that are important for improving the quality of care in the ICU and palliative care centres for patients at the end of their lives and their families. The results were put together based on the perspectives of patients, family members, and healthcare providers about providing quality care for patients at the end of life and their families. Latour *et al*. (2022) agree that patients, family members, and healthcare providers are fundamentally key stakeholders in shaping the desired quality of care needed in the various healthcare settings. Thus, more research involving the key dimensions of stakeholders (patients, family members, and healthcare providers) is highly recommended. The results of the review also showed that Africa had the least amount of primary research. Most of the studies were done in Europe and North America. This means that more research needs to be done in Africa, where diseases, cultures, and religious beliefs are all different and unique. Most of the research designs that were used to find out what patients, their families, and healthcare providers thought were qualitative paradigms. Using quantitative, mixed-method, and multi-method approaches could also help us learn more about care at the EOL.

The perspectives of patients, family members, and healthcare providers were summarized under seven (n = 7) important areas, namely: patient- and family-centered decision making;

communication among the healthcare team and with patients and families; symptom management and comfort; care with compassion, dignity, and respect; emotional support for patients and families; spiritual support and cultural care; and modifying the intensive care environment. The section below presents discussion and interpretations of the findings that emerged from the scoping review.

- Symptom management and comfort

From the review, it was found that symptom management and comfort are key areas for providing quality care at the end of life. It was deduced from the review findings that therapeutic measures focused on managing symptoms (such as pain, shortness of breath, and agitation), minimizing aggressive care, reducing suffering, and providing comfort are fundamental to EOL care. It is important to ensure that patients die without experiencing common symptoms such as pain, agitation, and breathlessness. Early assessment and addressing of symptoms through both pharmacological (such as the administration of analgesics) and non-pharmacological interventions are important. A systematic review by Vanderspank-Wright *et al*. (2018) supports the need to focus on the patient during treatment withdrawal by alleviating patients' pain and promoting comfort through both pharmacological and non-pharmacological interventions. This implies that promoting patients' comfort through comfort measures is a major priority when life-sustaining treatments are withdrawn and EOL care becomes the main goal.

Jensen *et al*. (2020), in their review on practice recommendations for providing high-quality EOL care in the ICU, also alluded to the fact that symptoms such as pain, anxiety, thirst, agitation, breathlessness, and nausea are common patient symptoms at the end of life. Hence, appropriate measures are necessary to ensure patients' comfort, especially at the EOL. Ganz (2019) further agrees with the finding that good symptom management is a significant facilitator for improving family experiences at the end of a patient's life. These findings call for frequent patient symptom assessment and the provision of adequate interventions so as to manage patients' symptoms and promote comfort. Healthcare providers need to collaborate and work as a team, especially during EOL care, in order to meet patients' comfort needs.

It was also evident from the review findings that discontinuation of technical equipment, tubes, and non-beneficial treatments promoted patients' comfort and minimized suffering. Again, basic nursing care and non-pharmacological interventions such as bathing, mouth care, pressure area care, and hair care also promoted dignified death. The findings resonate with those of Efstathiou and Ives (2018), who reported that physical cleanliness and the removal of technical apparatus promoted dignified death after treatment withdrawal. The authors emphasize the need to remove all technical equipment, switch off monitors, and keep the patient clean through basic nursing care. The early discontinuation of technical equipment promoted suffering and less-medicalized deaths. The emotional stress that patients and their families experience along the EOL trajectory is also minimized. Findings from Downar *et al*. (2016) also agree with the discontinuation of non-beneficial treatments such as ventilation, hemodialysis, etc. This suggests that patient comfort is the ultimate goal when all curative interventions fail. This, however, calls for adequate EOL care training and education among the healthcare team. Also, there is the need to have effective, clear, and consistent communication among the healthcare team and with patients and their families. The development of practice guidelines for treatment withdrawal in the ICU, especially within the African context, will be needed. This is due to the unique disease profile, ICU usage, and variations in ICU practices.

- Care with compassion, dignity and respect

In the scoping review, the researcher found that the provision of care with compassion, dignity, and respect is a vital component of the care provided for patients at the EOL and their family members. This suggests that patients at the end of life are treated as unique human beings worthy of respect, dignity, and compassionate care. The review revealed that regardless of treatment withdrawal, patients and their families needed to be treated with respect and dignity. Su *et al*. (2018) support the finding and point out clearly that patients at the end of life in the ICU experienced a severe loss of dignity. Therefore, measures aimed at preserving patients' dignity are vital. The review finding is consistent with findings from Cook and Rocker (2014) that also supported the need to maintain and preserve patients' dignity during end-of-life care in the ICU. In maintaining a patient's dignity during the dying process, healthcare providers need to recognize the worth of their patients regardless of their imminent death, be sensitive to their suffering, and have the desire to relieve these sufferings. Similarly, Coventry *et al*. (2020) also support the finding and reiterate that the maintenance

of dignity and care with compassion is a key attribute of patient care most valued by families at the end of life. This perhaps implies that all patients, regardless of the nature of their illnesses, should be treated equally and accorded the needed respect.

- Communication among the healthcare team, and with patients and families

This review showed that communication between the healthcare team, the patient (if he or she is able), and family members is a key part of providing care at the end of life. The nature of communication was described as being open, effective, and consistent. The manner and language of communication were also mentioned as crucial aspects of communication. Healthcare providers have to engage patients and families in regular meetings, keep them informed about all aspects of the care process, and answer all questions. Information conveyed also needs to be open, clear, carried in an honest manner, and preferably in a language patients and their families understand. The findings resonate with those of Rhoads (2019), who highlighted regular communication with family members as a cornerstone of caring for patients at the end of life. The author also stressed the importance of valuing the comments from the family, listening to them, and allowing them to ask questions, especially during EOL care. DeSanto-Madeya and Safizadeh (2017) also reported communication as a key element to enhance family satisfaction with EOL care in the ICU. The authors emphasize the importance of involving patients' families in open and frequent communication throughout the patient's ICU stay. This implies that the healthcare team has important roles to play and is in a key position to initiate and promote EOL communication.

In support of the review finding, Brooks et al. (2019) also further emphasized the need to provide culturally sensitive communication at the EOL in the ICU. Thus, have clear and transparent communication with patients and their families while also being mindful of their cultural traditions, values, and preferences. Similarly, Coventry *et al*. (2020) reported timely provision of information in the ICU, especially during EOL care, as a basic need. These findings underline the relevance of effective communication during EOL care. This, however, calls for teamwork and collaboration among healthcare providers. It is important to acknowledge the comments made by the family and provide possible avenues to address their concerns. More research is required to identify appropriate strategies to facilitate effective communication among the healthcare team and with patients and their families.

- Patient- and family-centered decision-making

The review found that making decisions with the patient and family in mind is a key part of good end-of-life care for patients and their families. It was evident that decision-making forms a major component of EOL care. During the EOL decision-making process, it is important to involve the ICU team, patients, and their families and incorporate their needs, preferences, and wishes. Both patients, if able, and their families have the opportunity to share their opinions on EOL decisions. This finding agrees with that of Mitchell *et al*. (2016), who alluded to the fact that the patient admitted to the ICU is embedded in the family system; therefore, it is essential to include both the patient and family in patient care, including decision-making.

Joynt *et al*. (2015) also agreed with the finding and reiterated that when making end-of-life decisions in the ICU, the multidisciplinary team needs to talk and agree on what to do. This finding about how the ICU teams talk about end-of-life decisions is similar to what Flannery *et al*. (2016) found in an earlier review. Additionally, they stated in that review that end-of-life decisions ought to involve everyone who is involved in a patient's care rather than just one person. These findings underscore the importance of building a mutually trusted and beneficial partnership among healthcare providers, patients, and their families in the planning, delivery, and evaluation of health care (Institute for Patient and Family Centered Care, 2023). As explained, in patient and family-centered care (PFCC), both patients and families are recognized as essential allies in direct care interactions, collaborate with the healthcare providers for quality and safety, and participate in care and decision-making. This implies that patients and families collaborate with healthcare providers rather than healthcare providers simply caring for and providing care to patients and families. Although the literature suggests that physicians are the most appropriate people to initiate and lead EOL decisions (Baggs *et al*., 2012), it should be noted that other healthcare professionals, such as nurses, play an important role in EOL care (Bloomer *et al*., 2011; Jensen *et al*., 2013). This shows that teamwork and collaboration are integral to the provision of patient- and family-centered EOL care.

- Spiritual care and cultural support

Spiritual and cultural support was also named as an important part of giving good care to patients and their families in the ICU who are nearing the end of their lives. During EOL care, it is very important to pay attention to the spiritual, cultural, and religious needs of both the patient and their family. Willemse *et al*. (2020) agree that spiritual care is an essential part of improving the quality of care for ICU patients and their families. This means that a patient's and their family's spiritual health is just as important as their physical and emotional health. In practice, spiritual care is often overlooked, and healthcare providers fail to assess and address it, especially with critically ill and dying patients. In a narrative review, Ho *et al*. (2018) also revealed that meeting the spiritual needs of patients at the end of life improves the quality of care and improves family members' perceptions of care. It is important to tailor intensive care to suit individuals' spiritual or religious needs as they cope with suffering, loss, or pain.

Choi *et al*. (2019) agree with the finding and say it's important to meet religious and spiritual needs in the ICU. But the authors hinted that, in clinical practice, only a small number of health care providers actually meet these needs. This may be due to the limited amount of time, the workload in the ICU, and the demanding nature of care. These results show that there are still problems with how spiritual care is given to ICU patients and their families. From the patients', their families', and the healthcare providers' points of view, there needs to be more first-hand research on how spiritual care can be introduced at the end of life in the ICU. Swinton *et al*. (2017) further support the expression of spirituality during the dying process in the ICU. The authors stressed the need to solicit and realize patients' and their families' wishes at the end of life as far as spiritual care is concerned. These findings suggest the early integration of spiritual care in intensive care practice, especially during EOL care. Spiritual care education programs will be essential for the improvement of spiritual care delivery. Also, curriculum development targeted at identifying and addressing religious and spiritual care needs could have a profound impact on patient care (Ho *et al*., 2018). Comprehensive documentation of patients' and families' cultural wishes and preferences and proper handover sessions among the healthcare team will have a profound impact on EOL care. Hospital chaplain services will also be useful for providing spiritual assessment and care and bridging the gap between healthcare providers and patients and their families.

- Emotional support for patients and families

It is also evident from the review that emotional support for patients and families is integral to the provision of quality care at EOL. The review's finding shows that the withdrawal of treatment and EOL phase are emotional moments for both patients and their families. Dealing with a loss is a traumatic experience for family members. Therefore, it is important to address the emotional distress and stress that come along with EOL care. Avenues such as regular counseling, debriefing sessions, early referral to a psychologist, and bereavement care are some of the measures to support patients and their families. This resonates with findings from a metasynthesis conducted by Coventry *et al*. (2020) that reported support for family members and bereavement care as a key element of care when treatments are withdrawn in the ICU. The authors also highlighted the need to attend to the families' emotional needs while preparing them for the inevitable.

Kentish-Barnes *et al*. (2022) from a recent cluster-randomized controlled study echoed similar findings. The authors found that constant emotional support, such as regular meetings to prepare the family for a relative's impending death, regular visits, and the sending of condolence messages, cut down on long-term grief symptoms by a lot. These findings conclude the importance of emotional support for patients and their families. Families' members suffer high frequencies of post-traumatic stress disorder, depression, and complicated grief following the loss of a loved one in the ICU (Kentish-Barnes *et al*., 2015; Probst *et al*., 2016). The frequency of the reported emotional stressors highlights the need to support both patients and their families during EOL care. The early introduction of the palliative care team prior to treatment withdrawal will also be a good starting point. More primary research focusing on the coping strategies among bereaved families in the ICU will be needed. The findings will help tailor interventions to support family members and address their pertinent concerns.

- Modification of the ICU environment

The review also found that making changes to the ICU was an important part of providing quality care to patients at the end of their lives. The creation of a peaceful, non-technical, and friendly environment is critical. This includes creating space and adequate rooms for intimacy and privacy, permitting unrestricted family visitation, reducing noise levels,

playing music, and improving room lighting. According to the research literature, the ICU environment influences family satisfaction and also contributes to their dissatisfaction with EOL care in the ICU (DeSanto-Madeya & Safizadeh, 2017). Several environment limitations, such as lack of privacy in open ICUs, poor ICU layout, and constant noise from monitors, have been reported as major barriers to the provision of EOL care within the ICU (Attia *et al*., 2013; Brooks *et al*., 2017; Zomorodi & Lynn, 2010). These findings explain the importance of creating a serene environment to support dying patients in the ICU.

The ICU is not an appropriate setting to provide EOL care because of environmental limitations such as noise and lights (Brook *et al*., 2017). The results of the review show that making some changes in the ICU is important for providing the best care for EOL care. The changes include offering patients and their families separate and single rooms at the EOL, turning off alarms on monitors, turning down the lights in the rooms, and drawing the curtains closer to give people more privacy. Even in our busy ICUs, we can use these practical methods to improve family satisfaction with end-of-life care. This, however, necessitates collaboration among all parties involved in the patient's care, as well as open communication and teamwork. More research into strategies for creating a conducive environment for EOL care is required, particularly from the perspective of patients and family members. These groups are considered consumers of care, and their perspectives are essential in shaping the current quality of care provided at the EOL.

8.2.2 Qualitative Interview with Nurses

The objective was to explore the experiences of intensive care nurses providing care to patients and their families after treatment withdrawal in the adult ICU. A total of sixteen (n = 16) nurses, comprising 14 females and 2 males, were purposefully sampled and participated in the interviews. All participants had more than 5 years of ICU experience, managed patients at the end of life, and witnessed treatment withdrawal in the adult ICU over the years of practice.

Following a thematic analysis, three themes emerged that described nurses' experiences providing care for patients and their families after treatment withdrawal in the adult ICU. The themes, as explained in detail in chapter 5, included: "Nurses emotions", "challenges to overcome"; and "rendering optimum care after treatment withdrawal".

The key findings from the interview findings are summarised in Chapter 5.The section below presents the discussion and interpretations of the interview findings.

8.2.2.1 Discussions of the qualitative findings (nurses)

This section discusses the findings in relation to existing scientific literature.

- Nurses' emotions

It was evident from the interviews that the nurses' experienced mixed emotions during the provision of care to patients and their families after the withdrawal of treatment. The emotions experienced and expressed are a result of the emotional connection and bonding created with patients and their families along the EOL trajectory. These findings are consistent with earlier findings that described caring for patients at the end of life and their families in the ICU as a great source of emotional distress and psychological burden (Kisorio & Langley, 2016b; Rivera-Romero *et al*., 2019; Vandersprank-Wright *et al*., 2018). The experience can be traumatic, depressing, and draining. The study revealed that nurses expressed feelings of sadness, guilt, and helplessness during the care of patients and their families after the withdrawal of treatment. This finding resonates with that of Jordan *et al*. (2017), who also explored nurses' experiences of treatment withdrawal in the ICU. The authors also found that nurses experienced mixed emotions such as sadness, guilt, and relief when EOL decisions to withdraw treatments were made too early or prolonged.

The current study also showed that the age of the patients who were dying had an effect on how the nurses felt. It was discovered that dealing with the older patients was easier and less emotional compared to the younger patients. This is consistent with the report by Rafii *et al*. (2015), who reported that caring for younger patients was more painful compared to the older ones. Lack of support systems, poor communication, and not having a say in EOL decisions may be the cause of the emotional burden and a lot of emotional distress. This implies that the emotional and psychological well-being of nurses is important during EOL care and treatment withdrawal in the ICU. The findings suggest the creation of systems of emotional support, such as counseling and debriefing sessions, to be readily available for nurses during EOL care. Formal EOL care education and training for nurses will also be useful to equip them with the needed knowledge and skills. In assigning duties, it will also

be important to consider the nurse's level of EOL experience before assigning duties. The more experienced ones could also mentor the inexperienced ones, and they could be paired during EOL care.

The various coping mechanisms that nurses employ when providing care in the ICU following the termination of treatment should be the subject of further study. This will be especially useful from a qualitative approach as well as within the African context, where the majority of caregivers find it difficult to externalize their feelings.

- Challenges to Overcome

The results of this interview showed that nurses have to deal with a number of challenges in order to provide good care to ICU patients before, during, and after treatment is stopped. These challenges encountered are as a result of certain behaviors and reactions from family members, the poor nature of the ICU environment, the behaviors and attitudes of attending physicians, and nurse-associated challenges. In literature, the provision of EOL care in the ICU has been touted as a challenging practice for nurses (Vanderspank-Wright *et al*., 2018). While nurses provide care to patients at the end of life, they are also supposed to deal with family members, colleague physicians, and personal issues, as well as the busy nature of the ICU environment.

In the study, it was clear that nurses have to deal with family members who aren't calm, are in denial, have strong cultural beliefs about death, and ask for information all the time. These behaviors and reactions pose a challenge to the successful provision of care to patients following treatment withdrawal. There are instances where care is delayed or omitted due to family reactions. These findings are consistent with those of recent ones that reported certain behaviors and reactions of family members as current obstacles to providing EOL care in the ICU (Beckstrand *et al*., 2017; Beckstrand *et al*., 2018; Brooks *et al*., 2017). The authors (Beckstrand *et al*., 2017) reiterated that it is difficult to get family members to understand what lifesaving measures mean and to even accept a patient’s prognosis, especially at the EOL. Beckstrand *et al*. (2018) further revealed that the three most common obstacles were centered on family members' lack of EOL knowledge, lack of family participation, and lack of legal representation. Hence, family members are in constant denial and often go against patient wishes. Brooks *et al*. (2017) also identified the unrealistic family expectations and

difficulties in obtaining a family consensus about treatment options as a challenge during EOL care in the ICU. These findings suggest the need to thoroughly educate family members during EOL care. Effective communication among the ICU team and with patients and their families will also be useful to clarify the plan of care and answer important questions.

The study also found certain behaviors among physicians, such as documentation challenges, less bedside presence during EOL care, and a lack of communication, as obstacles to providing EOL care in the ICU. Beckstrand *et al*. (2021) support the finding that physician behaviors such as inadequate physician communication impede the success of EOL care in the ICU. The authors explain that inadequate physician communication meant that there was poor communication between attending physicians, EOL discussions were made too late, and communication across the ICU team was delayed. This finding, however, contradicts the findings of Flannery *et al*. (2016), who emphasized a multidisciplinary approach to EOL care over a unilateral approach. It is also evident from the current study that inexperienced doctors find it difficult to deal with EOL decisions and care. The findings suggest formal EOL care training and education for attending physicians. The involvement of other healthcare providers, such as nurses, will also have a profound impact on patient care, as literature describes them as principal caregivers during EOL care. The interdisciplinary team needs to collaborate and work together in order to achieve quality care at the EOL.

The unfavourable nature of the ICU environment was also reported in the current study as a challenge nurses face during the provision of care after treatment withdrawal in the ICU. This includes the crowded conditions in the ICU, the noise from monitors and various emergencies, the multi-bed system, and the ICU workload. This agrees with the findings of Ivany and Aitkens (2019) that the ICU design lacked private space to support both patients and their families during EOL care. Brooks *et al*. (2017) also reiterated that environmental limitations such as a lack of privacy, constant noise, and a lack of space made it difficult to accommodate family members, especially at the end of life. In Egypt, Attia *et al*. (2013) further support the finding that heavy workload and poor ICU design make the provision of EOL care challenging for nurses. The findings suggest that the ICU environment represents a crucial aspect of EOL care practice. Therefore, it is vital to make relevant changes and modifications in the setting to influence the desired quality of EOL care. This calls for a multidisciplinary approach to EOL care, collaboration with all relevant stakeholders, and interdisciplinary communication. Policies on liberal and unrestricted visiting hours for

family members could also be considered. The creation of separate waiting areas with adequate chairs, food, and bathing facilities will also have a profound effect on the care of the family members.

The current study also showed that nurses were not comfortable talking about death or helping patients and their families after they stopped treatment. When treatments are stopped, nursing care stops all of a sudden, and nurses usually try to avoid EOL care situations. This may be due to a lack of experience and formal EOL care training. This also points to the fact that EOL care is a unique area of ICU practice and that most nurses are not formally trained to deal with the dying in the ICU. Often, they learn on the job rather than through formal education and training. The finding also brings to light the minimum support nurses receive when it comes to providing care after treatment withdrawal. The finding is consistent with that of Kirchhoff and Kowalkowski (2010), who also revealed that nurses received limited formal training to prepare them for EOL care. There are no established institutional support systems in place to support this cadre of healthcare professionals. Several studies (Jang *et al*., 2019; Vandersprank-Wright *et al*., 2018) recommend innovative and formal EOL care education and training for the ICU team.

More research needs to be done to find and create context-based interventions that will help the nurses and the rest of the ICU team. Because there are so many different ways to provide end-of-life care, no single guideline, measurement tool, or policy can be used as a standard for all societies. Hence, more guidelines and measurement instruments from diverse regions and societies are recommended.

- Rendering optimum care after treatment withdrawal

The study showed that after treatment was stopped in the ICU, it was important to pay attention to the patient and help the family. As reported, putting the patient first means paying attention to the patient's basic needs and giving the patient care that takes into account the whole person, even in the patient's last moments after treatment is stopped. These include taking care of the patient's basic hygiene needs, making the patient comfortable and pain-free, treating the patient with respect and dignity, and meeting the patient's spiritual, cultural, and religious needs. The current study also found that it was important to help family members in order to make care easier after treatment withdrawal. As part of the support, the

family's needs, such as the need for information, comfort, closeness, reassurance, and spiritual and cultural support, need to be met. These findings resonate with those of Stokes *et al*. (2019), whose study revealed that in contributing to a good death in the ICU, it was important to support both patients and their families. The authors emphasized that the support included respecting patients' wishes, preserving patients' dignity, and creating space for families to be present in the ICU.

Coombs (2015) also said in their findings that it was important to meet the needs of the family members in order to give meaningful care during and after treatment withdrawal. Al-Mutair *et al*. (2013) reiterate that the only way to meet these needs is to help and involve the patient's family in their care. Noome *et al*. (2016b) also found, like this study, that quality end-of-life care was improved by taking care of both patients and their families through things like managing symptoms and giving emotional support. These reports indicate that both patients and families have special needs during EOL care. This calls for an interdisciplinary approach that includes both patients and their families during EOL care. Family involvement is crucial in the quest to enhance the quality of care provided for patients, especially after the withdrawal of treatment. Further studies will be needed to explore the factors that affect the involvement of family in the care of patients after the withdrawal of treatment, especially in a Sub-Saharan context. The findings will help develop interventions suitable to address the needs of families during the ICU admission of a loved one.

The study's results also showed that changing the ICU environment, having good communication, and working as a team were all important for giving the best care after treatment withdrawal. Beckstrand *et al*. (2021), Brooks *et al*. (2017), and Griffiths (2019) have all described how the layout and design of the ICU can serve as a barrier to good end-of-life care. This is due to environmental limitations such as a lack of single rooms, constant noise, and a lack of privacy. Nevertheless, according to the study findings, making relevant changes in the setting, such as creating special rooms for patients at the end of life, controlling the noise levels from machines, and creating space for family members during visits, will enhance EOL care. Research findings from Attia *et al*. (2013) agree that special rooms specifically designed for grieving families facilitate good EOL care and are extremely helpful for nurses, patients, and their families. Similarly, DeSanto-Madeya and Safizadeh (2017) also echoed in their review that the nature of the ICU environment had a greater

influence on family satisfaction with EOL care. Most family members prefer a clean, less-noisy place with adequate lighting for themselves and their relatives. This implies that the ICU environment can be favorable for not only curative care but also EOL and comfort care if adequate measures are put in place.

In this study, effective communication and working as a team were mentioned as important ways to make care easier after treatment withdrawal. Ganz (2019) agrees with these findings and says that effective communication is one of the things that are said to help with EOL care. Effective communication not only makes EOL care better for the family, but it also helps them make better decisions (Brooks *et al*., 2017).

8.2.3 Qualitative Interview with Physicians

The objective of the interview was to explore physicians' experiences of making EOL decisions and providing care for patients and their families after treatment withdrawal in the adult ICU. A total of nine (n = 9) doctors, comprising three females and six males, were purposively sampled and participated in the interviews. All participants were registered practising physicians with years of clinical experience ranging from 6 to 15 years. Additionally, all of them had some form of ICU experience ranging from 6 months to 7 years at the time of the study. The participants' ages ranged from 30 to 41 years.

Following a thematic analysis, five themes emerged that described physicians' experiences of making EOL decisions and providing care for patients and their families after treatment withdrawal in the adult ICU. The themes, as explained in detail in chapter 5, included: "Making end-of-life decisions to withdraw treatment in the ICU", "shared feelings around making EOL decision "; "challenges encountered making EOL decisions "; "Novice to expert"; and "facilitating care after treatment withdrawal". The key findings from the interviews are summarised in detail in Chapter 5. The section below presents the discussion and interpretations of the key interview findings.

8.2.3.1 Discussions of the qualitative findings (physicians)

- Making the EOL decisions

The results of the study showed that the decision to stop treatment is often made on a case-by-case basis and over time. Before the treatment is stopped, the ICU's multidisciplinary team talks about how to handle the withdrawal process in the best way. Usually, the senior attending ICU consultant on the team starts these discussions, which are then shared with the rest of the ICU team. The views of the majority of participants concur with those found in earlier literature. Baggs *et al*. (2012) argue that no two patients are the same, and a decision to withdraw treatments must take many individual factors into consideration and therefore can be done on a case-by-case basis. Cook and Rocker (2014) also acknowledged that the actual process of treatment withdrawal in the ICU is subject to great variability and that, therefore, no single, universally accepted approach exists. However, an individualized approach to the patient is required to provide the best possible care for patients.

The current study found that the attending physicians, particularly the ICU consultant, frequently start conversations about end-of-life issues. This finding agrees with what Flannery *et al*. (2020) found in a recent study. In that study, the authors said that doctors made decisions about EOL care. This, however, contradicts that of Joynt *et al*. (2015), who also emphasized that initial discussions among the multidisciplinary team are necessary during end-of-life decision-making and before any treatment withdrawal in the ICU. Therefore, there should be discussions with the relevant intensive care physicians, the family, and nurses. Flannery *et al*. (2016) also reiterated that EOL decisions should be discussed with all stakeholders involved in patient care as opposed to a unilateral kind of decision-making process.

In making EOL decisions, the current study findings revealed that there is no one-size-fits-all approach and that it depends on the patient. But the process was guided by things like the futility of care, the patient's chance of survival, the organs that were affected and helped, the possibility of reversing the affected organ scoring system (like SOFA scores), and scientific evidence. Once nothing could be done and interventions were not going to prolong life of any quality, a decision was made by the team to withdraw treatment. The sequence of the treatments withdrawn was also described as a "gradual" process. This confirms the results of a previous study (Guidet *et al*., 2018) that also indicated that factors such as the clinical frailty score, the admission SOFA score, and higher age guided the limitation of LST. Quill *et al*. (2014) emphasized the poor baseline functional status of a patient as a factor considered before the decision to forgo LST.

The study also revealed that most physicians admitted that the decision to withdraw treatment in the ICU was considered a multidisciplinary sort of decision. However, the nurses were not fully involved in the decision-making process and attending physician-led end-of-life decisions and discussions. Although some participants admitted that it was unfair not to involve nurses, the ultimate decision to withdraw treatment in the ICU was made by the attending consultant without input from nurses. These views shared by participants are also supported by Baggs *et al*. (2012), where ICU doctors and nurses agreed that the attending physician holds overall responsibility for the patients' treatment and is the most appropriate person to initiate and lead end-of-life decisions. An earlier study conducted in the US also concurred that an attending physician was the appropriate person to make end-of-life decisions; however, nurses were considered as being most likely to recognize the point where treatment becomes futile (Calvin, Lindy, & Clingon, 2009). This assertion also confirms the views expressed by some participants that nurses assisted and prompted attending physicians to make the right decisions, especially in instances where a patient was unresponsive to treatment already given and a shift to end-of-life care was appropriate. This also resonates with another study by Jensen *et al*. (2013), who surveyed 11 nurses and 10 doctors across Danish ICUs. These authors found that both doctors and nurses agreed that nurses recognized the point at which treatment was futile. Similarly, previous research by Bloomer, Lee, and O'Connor (2011) highlighted that the informal role of nurses in EOL decisions was to alert physicians at the point where end-of-life decisions were needed.

Despite the informal role of nurses in assisting and prompting doctors when end-of-life decisions were needed, some participants in this study mentioned that nurses were not involved in the decision-making process. Thus, their involvement was contingent on physicians' preferences, and the ultimate decision to withdraw treatment was made by the attending ICU consultant and physicians without input from bedside nurses. This is consistent with earlier findings by Latour, Fulbrook, and Albarran (2009). These authors, from a survey of I62 European ICU nurses, indicated that although 64% of nurses' recognized futility and thus initiated end-of-life discussions, only 48% were then included in the decision-making process by physicians. Another study conducted in the USA (Baggs *et al*., 2012) also attested to the finding that the participation of nurses in end-of-life decisions was commonly attributed to nurses' level of experience and physicians' reluctance to involve them.

Langley *et al*. (2014), who did research in South Africa, also found that critical care nurses rarely took part in discussions and decisions about end-of-life care, even though they were involved in giving care and had strong opinions about the process. Contrary to these findings, Benbenishty *et al*. (2022) revealed that in some European countries, significantly more physicians involved nurses in discussions and recorded a higher level of nurses' involvement, as expressed by fewer physicians recording a not applicable response. This implies that European physicians are increasingly involving nurses in EOL discussions. Although their findings contradict the current findings regarding nurses' involvement in EOL decision-making, they highlight the gradual recognition and acceptance that nurses play an important part in EOL decision-making and that their unique roles are vital to the success of the multidisciplinary team decision-making process.

- Sharing feelings around making EOL decisions

In this study, some physicians see the decision to withdraw treatment in the ICU as a difficult part of ICU practice. The most experienced doctors said that they didn't have trouble making EOL decisions and that they were at peace when they did. This was because they had talked to a lot of colleagues and thought about things like whether treatment was pointless, the patient's medical history, scoring systems, and the best scientific evidence of the patient's prognosis. So, it was thought to be a good decision when, from a medical point of view, all the necessary information had been gathered and a lot of talk had taken place, and the best option was to reduce pain and improve comfort care. The expressions of some participating physicians are consistent with the findings of Ledger *et al*. (2021). The authors found that doctors and consultants with more experience were less bothered by morally difficult situations that came up when making end-of-life decisions. This was because of how long they had worked in the ICU, how independent they were, and how much control they had over end-of-life decisions. Braganza *et al*. (2017) also agree that EOL decisions and plans must be evidence-based, taking into consideration patients' prognosis and best interests.

In the current study, it was also admitted that it was never easy to be the one making such decisions and informing the family of the decision made. This finding resonates with that of Ledger *et al*. (2021), who reported that physicians felt the burden of being the ones deciding to end treatment and, subsequently, life. The main goal of ICU care was to prolong life and give everyone a fair chance to survive; therefore, ending life comes with a great emotional

toll on some physicians. Some participants wished they had never stopped treatment and given patients a chance to live. However, it was also difficult to allow patients to suffer when there was no better outcome. It is hard and complicated to make decisions about the end of life, and this has been called a source of moral distress (Ledger *et al*., 2021). Thus, in making EOL decisions, physicians experience tensions between doing what is morally right and taking legally correct decisions. The idea of prolonging death rather than saving lives and the difficulty and complexity of making decisions at the EOL frequently lead to moral distress among doctors (Ledger *et al*., 2021).

- Challenges encountered in making EOL decision

The results of the study show that physicians have to deal with a number of problems when they decide to stop treatment in the ICU. Even though they do their best to help the patient and their family, they run into problems like dealing with the family, documentation challenges, and breaks in communication when making decisions and caring for the patient after treatment is stopped. This backs up earlier research (Attia *et al*., 2013; Brooks *et al*., 2017; Flannery *et al*., 2016) that said there are inherent challenges in initiating EOL care and making EOL decisions in the ICU setting.

Even though the family is an important part of taking care of the patient, they also slow down the withdrawal process. According to the current study, the patient's family members take a lot of time to agree to the withdrawal of treatment. Their constant changes of mind and aggressive behaviors, according to the participants, make the process challenging. Most family members are continuously absent during the end-of-life phase and withdrawal process. Thus, they are unable to be part of and engage in EOL discussions. The lack of understanding of the disease process and the constant seeking of updates by different family members were also mentioned as challenges. These situations, according to this current study, distort the flow of information and delay the transition to curative care. In a recent study, Beckstrand *et al*. (2017) attested to this finding that certain behaviors and reactions from patients' family members were obstacles to providing end-of-life care. The authors reported that behaviors such as family members' lack of knowledge regarding lifesaving measures, being in a state of denial, and not accepting the patients' poor prognosis made EOL decision-making challenging. Similarly, Beckstrand *et al*. (2018) also reiterated in their findings that the three prominent obstacles to providing end-of-life care to patients and

families were the lack of family participation, lack of knowledge, and lack of legal representation in the EOL decision-making process. Family members' refusal to accept patients' poor prognosis when there was a need to make a transition to EOL care and being in constant denial were also mentioned to support the current study finding. Previous studies by Attia *et al*. (2013) and Crump, Schaffer, and Schulte (2010) also concur with the finding that certain behaviors and reactions from family members served as barriers to the optimum provision of EOL care in the ICU.

Effective communication between doctors and other health care providers is thought to be important for giving the best care possible at the EOL. However, a lack of communication, especially between doctors and nurses at the bedside, can slow down the flow of information during end-of-life care. In this study, the lack of communication was mentioned as something that makes it hard to give the best care to patients at the end of their lives. Some physicians mentioned instances where a decision was made to withdraw treatment and the bedside nurse had no information. The extent of the disconnect between the attending physician and bedside nurses made end-of-life decision-making challenging. The study also highlighted that some attending physicians were uncomfortable arriving at a decision to withdraw treatment and subsequently relaying the information to the patient's nurses. This was a result of the level of inexperience and the attached ethical considerations, dilemmas, and principles. Brook *et al*. (2017) confirm that poor communication among the multidisciplinary team, physicians' inexperience in conducting difficult conversations, and a lack of collaboration are among the challenges most physicians encounter when initiating and delivering EOL care in the ICU.

Beckstrand *et al*.'s (2021) study on the obstacles with providing end-of-life care in the ICU also found that doctors' inability to communicate with nurses about end-of-life decisions was a problem. The inadequate physician communication among the ICU team was considered the largest obstacle to providing end-of-life care in the ICU. A recent review conducted by Flannery *et al*. (2016) also attested to the finding that communication problems in end-of-life decisions were one of the most significant challenges both nurses and physicians encountered during the EOL decision-making process. These findings suggest the importance of communication among the ICU team during EOL care. Effective communication enhances quality EOL care and promotes family satisfaction with EOL care (DeSanto-Madeya & Safizadeh, 2017).

Documentation issues were also reported in this study as a major challenge. Most physicians indicated their inability to document treatment withdrawal. The reason was the associated medico-legal issues surrounding patient care in the ICU. This finding resonates with previous research that revealed that comprehensive documentation on EOL care was lacking (Kirchhoff *et al*., 2004). The authors found few documentations on the date and timing of the initiation of treatment withdrawal. Similarly, Spronk *et al*. (2009) also highlighted the inconsistencies in the documentation of decisions regarding treatment withdrawal in the ICU. This may be due to the fact that ICU physicians were too busy with direct patient care and had less time to document all discussions. The issue of understaffing could also be a factor. These findings highlight the inconsistencies in EOL care documentation and further call for education and training of the ICU staff.

- Novice to expert

The current study revealed that the ability to make EOL decisions to withdraw treatment in the ICU is an expertise that most physicians get used to and learn over time. Physicians become accustomed to their constant exposure to various EOL and treatment withdrawal processes. The everyday experience gave them the ability to comfortably engage in other situations. This supports findings reported by other studies (Brooks *et al*., 2017; Wiegand *et al*., 2019) that expertise is developed through experience. As a result, less experienced providers observe and learn from more experienced providers. The experienced healthcare providers are regarded as mentors and supervise the younger and less experienced healthcare providers. Brook *et al*. (2017) also confirmed that most healthcare providers get better and more comfortable with EOL communication with experience. However, this can only happen when they are empowered and supported by others. This assertion highlights the need for the establishment of support systems to augment the education and training healthcare providers receive at the initial stages of practice. Similarly, participants in a recent qualitative study conducted by Wiegand *et al*. (2019) also described making EOL decisions, engaging in treatment withdrawal, and caring for patients and their families at the EOL as skills physicians learned and developed with time. This further highlights the need to empower healthcare providers, especially inexperienced physicians, through frequent end-of-life education and training and to also support them.

- Facilitating care after treatment withdrawal

From the results of the study, it was clear that doctors were committed to taking care of both patients and their families in the ICU during and after they stopped treatment. They helped with end-of-life care by giving patients comfort care, involving the family in the care of the patient, and giving both the patient and the family emotional and spiritual support. This finding concurs with that of Wiegand *et al*. (2019), where the authors found the care of both patients and their families to be a core duty of physicians during treatment withdrawal in the ICU. The authors emphasize the need to support patients and their families through the process. In facilitating care after treatment withdrawal, it was important to keep the family informed on any patient update, offer them time to understand and accept the inevitable, and support them accordingly. Similarly, Choi *et al*. (2022) reiterated in their study the importance of treating patients with respect and supporting their families to understand the dying process. These findings underscore the importance of patient- and family-centered care before and during the withdrawal of treatment in the ICU (Ranse *et al*., 2016). This also suggests that meeting patients and their families' needs is essential to facilitating care after treatment withdrawal in the ICU. This calls for a multidisciplinary approach to patient care, interdisciplinary communication, and teamwork.

8.2.4 Qualitative Interview with Family Members

The objective of the interview was to explore physicians' experiences of making EOL decisions and providing care for patients and their families after treatment withdrawal in the adult ICU. A total of seven (n = 7) bereaved family members, comprising five females and two males, were purposively sampled and participated in the interviews. The participants' ages range from 31 to 74. The length of a patient's stay in the ICU before death also ranged from 4 days to 23 days. Participants' relationships with the patient were as follows: adult child (n = 2), sibling (n = 2), spouse (n = 2), and parent (father). Following a thematic analysis, two themes emerged that described the experiences of bereaved family members. The themes, as explained in detail in Chapter 5, included "Distressing emotions" and "Meeting the needs of the family". The key findings from the interviews are summarised in detail in Chapter 5. The section below presents the discussion and interpretations of the interview findings.

8.2.4.1 Discussions of the qualitative findings (family members)

- Distressing emotions

In the qualitative interviews for the study, it was clear that the family felt sad after LST was taken away and end-of-life care started in the ICU. When family members heard that the patient would be getting end-of-life care and that treatment had to be stopped, they were shocked. The moment was described as emotional, frightening, and difficult to deal with. The study finding is consistent with that of a recent mixed-method review that evaluated family members' perspectives on end-of-life care in the ICU (Chen *et al*., 2020). The study found that family members experienced emotional distress during the transition phase in the ICU, especially when they were notified that death was imminent. Kisorio and Langley (2016a) also found that patients' family members experienced some form of distress following the transition to EOL care in the ICU. Following their loved ones' admission, most family members hoped they would recover and be discharged. Hence, the decision to transition to EOL care was unexpected, and family members were not ready or prepared for it. This finding also suggests the emotional distress family members experience following treatment withdrawal in the ICU. Similarly, in the USA, Wiegand (2016) also alluded to the fact that the death Virgil following the withdrawal of LST was a difficult experience for family members. Most family members could neither withstand the moment nor stay with their relatives throughout the dying process.

The emotional distress experienced by family members can be attributed to the unexpected loss of loved ones, inadequate attention and support, and updates from healthcare professionals (Coombs, 2015; Kisorio & Langley, 2016a). In this study, the extent of distressing emotions family members experienced was due to high expectations of patients' recovery, a lack of effective communication between healthcare providers and family members, and inadequate emotional support systems available in the ICUs. Patients' family members have several relational and existential needs during and after the withdrawal of LST in the ICU (Coombs, 2015). It is, therefore, important to take cognizance of their needs and provide effective support measures for the family members. The study findings suggest that healthcare providers in the ICU must make conscious efforts to support and work with family members throughout patients' ICU admission. This calls for a multidisciplinary approach to EOL care with great emphasis on family-centered care in the ICU. The early

introduction and referrals to psychologists and counseling sessions will also be beneficial in preparing family members before the unexpected happens. Personalized and frequent communication, compassionate care, and a family-friendly environment influence family members' satisfaction with EOL care in the ICU (DeSanto-Madeya & Safizadeh, 2017).

- Meeting the needs of the family

The current study revealed that following LST withdrawal and the transition to end-of-life care, family members wanted their needs and wishes met. These forms of need range from family presence at the bedside, access to information, family involvement in the patient's care, providing comfort care for the patient, being able to connect with the patient, spiritual support, and maintaining privacy. It is evident in previous literature that family members have needs during the EOL care in the ICU (Coombs, 2015). Addressing and meeting these needs affected families' satisfaction with the care provided for their loved ones during EOL care (DeSanto-Madeya & Safizadeh, 2017). The study findings are consistent with previous research that demonstrated that family members value close proximity to their loved ones during EOL care, the need for frequent communication, spiritual support, and a peaceful death (Al Mutair *et al*., 2020). In their study, Al Mutair *et al*. (2020) indicated that family members wanted more information on patients' prognosis even if they were approaching death and preferred to be welcomed at any time with no visitation restrictions.

Similarly, Choi *et al*. (2022) found that family members' presence at the moment of a patient's death was highly prioritized and valued. Most family members were satisfied and grateful to be with their loved one till the end. Ranse *et al*. (2016) also emphasized the sharing of information, especially information on patient comfort and emotional and spiritual support, as an important aspect of family-centered care during the provision of EOL care in the ICU. These findings imply that priority should be placed on supporting families and facilitating communication. Family should be prioritized as an extension of the care provided to patients during and after treatment withdrawal in the ICU.

8.3 PHASE TWO OF THE STUDY

The objective of phase two was to develop an instrument, assess its content, and determine its validity. The development of the instrument was informed by the findings from the scoping reviews and the qualitative interviews (with nurses, physicians, and family members). Phase two followed steps 3, 4, and 5 and met objectives 5, 6, and 7 as outlined in Table 3.1 in Chapter 3. The primary outcome was to develop an instrument and assess the validity of the instrument. The section below presents the findings that emerged from phase two and also presents discussion and interpretation of the findings, as conducted in Phase 2.

8.3.1 Instrument Development

The aim of the study was to develop an instrument to measure the quality of care provided to patients and their families after the withdrawal of treatment in the ICU. The first version of the instrument was informed by the findings from a scoping review and qualitative interviews with nurses, specialist doctors, and family members. The use of existing literature and subjective data from the providers (nurses, doctors) and consumers of care (family members) provided a solid foundation for the development of the instrument. The findings from a scoping review and the experiences of nurses, doctors, and family members on providing care after treatment withdrawal were consolidated, reduced, and synthesized into domains and items. According to Boateng *et al*. (2018), it is considered best practice to combine both a literature review and qualitative data in defining domains and items in instrument development. While the literature review provides the theoretical basis for defining the domain, the qualitative techniques identify items for the domain. Initially, the scoping review was conducted to identify content domains. The qualitative interviews were also to generate an exhaustive list of items for the development of the instrument.

Latour *et al*. (2022) also emphasized that improving the ICU experience necessitates the involvement of all stakeholders. This implies that the perspectives of patients, family members, and healthcare providers are essential to improving the care for ICU patients, increasing family satisfaction, and contributing to a dignified death. In this study, findings from the experiences of nurses, doctors, and family members on the provision of care after treatment withdrawal in the adult ICU contributed to the item generation phase of the instrument development. This reflects their unique perspectives and highlights the

genuineness of the instrument for the South African ICU setting and population. Myburgh *et al*. (2016) emphasized the development of context-specific interventions due to the uniqueness of cultures, societies, and individual ICUs, as a single criterion may not be applicable to all societies. Mark *et al*. (2015) further reiterate the differences in EOL care practices across regions and societies due to cultural differences, healthcare professionals' attributes, and institutional policies. This implies that the instrument will not only improve the care rendered to patients and their families in the ICU but will also represent the perspectives of the different stakeholders (nurses, doctors, and families) in the ICU.

The first version of the instrument consisted of seven domains and 64 items after an iterative instrument development process and a series of meetings. The domains included: "patient and family-centered decision making"; "communication among the ICU team and with patients and families"; "continuity of care"; "emotional and practical support for patients and families"; "symptom management and comfort"; "spiritual care"; and "modifying the ICU environment." These domains reflect areas that are vital to the provision of quality care for patients and their families after the withdrawal of treatment in the ICU.

8.3.2 Instrument Validation

The content and face validity of the instrument were assessed using a two-round Delphi. The approach allowed a panel of experts to comment on the relevance and clarity of the instrument domains and items. These comments and feedback aided in the refinement and judgment of the instrument. Content validity evidence is a key component in the instrument development and testing processes, as it is a requirement for evaluating other types of validity (Almanasreh *et al*., 2019). In this current study, the content validity assessment commenced early and relied on a panel of experts in a two-round Delphi. The two-round Delphi comprised participants with backgrounds in critical care, medicine, and nursing who were knowledgeable in the content area and involved in EOL care research. The mean age and average working experience were 43.56 years and 19.89 years, respectively. This represents a mature, knowledgeable, and experienced group. The inclusion of heterogeneous, mature, and experienced experts in the content validity testing has been widely reported in the literature to enhance the validity of the findings (Boateng *et al*., 2018; Kalkbrenner, 2021). Both local and international experts were included in the content validity testing phase. The inclusion of both local and international experts in the validation

processes enhances the development of culturally sensitive instruments and also increases the chance of identifying colloquial terms appropriate for an instrument (Grant *et al*., 1990; Onwuegbuzie *et al*., 2010).

A total of nine experts were involved in the instrument validation process. Research evidence recommends between five and ten experts in the content validation process. This number of experts is considered appropriate to control the probability of chance agreement and better inform instrument development (Almanasreh *et al*., 2019; Zamanzadeh *et al*., 2015). As part of the assessment of the face validity, comments from the panel of experts on the style, language clarity, formatting, and readability of the instrument were also used. This panel of experts, especially those in clinical practice, were also considered part of the target population; hence, their comments were useful and enhanced the revision of the instrument. The final version of the instrument consisted of 64 items organized under 7 domains.

Content validity testing is a crucial part of developing a new instrument. In quantifying the content validity of a multi-item scale, the content validity index is the most widely used method. The content validity indexes of the items and scale were examined. The item content validity (I-CVI) scores were 0.89–1.00, and the S-CVI/Ave score was 0.97, indicating excellent content validity for the instrument. The universal agreement among experts (S-CVI/UA) was also 0.77. The instrument showed high content validity for the individual items (I-CVI range: 0.89–1.00) and moderate to high content validity for the overall instrument (S-CVI/UA = 0.77; S-CVI/Ave = 0.97). This supports the conclusion that individual items were important and relevant to measure the quality of care provided for patients and their families after the withdrawal of treatment in the adult ICU. The universal agreement approach suggested the overall content validity of the instrument was moderate (S-CVI/UA = 0.77), while the average method suggested high content validity (S-CVI/Ave = 0.97). According to Polit *et al*. (2007), as the number of experts' increases, it becomes more difficult to obtain acceptable values for S-CVI/UA. This, perhaps, explains the study S-CVI/UA value of 0.77, which is below the acceptable range of 0.8 and above. On the contrary, the S-CVI/Ave is described as an acceptable method as it provides information about the performance of each item through the averaging feature. The S-CVI/Ave of the instrument (S-CVI/Ave = 0.97) indicates excellent content validity.

One limitation of CVI reported in the literature is the potential for inflation of agreement due to chance factors (Wynd *et al*., 2003). Boateng *et al*. (2018) and Wynd *et al*. (2003) recommended further estimation of kappa as it provides the degree of agreement beyond chance. The current study computed the kappa statistic, and the kappa values show excellent values (range: 0.89–1.00). This further strengthens the quantification of the content validity of the new instrument.

8.4 SUMMARY

The chapter presented a comprehensive summary of the outcomes of the study. The chapter also presented the discussions and the interpretations of the findings from all the two phases of the thesis.

The next chapter presents the justification, strengths, limitations, recommendations drawn from the study findings and conclusion.

CHAPTER NINE

EVALUATION, STRENGTHS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION OF THE STUDY

9.1 INTRODUCTION

The chapter presents the evaluation of the entire study, its strengths and limitations, recommendations drawn from the study findings, and the conclusion of the study. The chapter begins with the evaluation of the study, with specific emphasis on how the study objectives were met, followed by the specific contributions of the study. The chapter also elaborates on the study's strengths, limitations, and recommendations drawn from the study findings.

9.2 EVALUATION OF THE STUDY

The primary goal of the study was to develop an instrument to measure the quality of care provided for patients and their families after the withdrawal of LST in the adult ICU. The study's goal addressed seven specific objectives. A two-phase exploratory sequential mixed methods research design was adopted to accomplish the study's goal and set objectives. The five-step instrument development process as outlined by Lynn (1986) and Zamanzadeh *et al*. (2015) was also followed to address the study objectives (Table 3.1). Overall, the goal of the study was met; the instrument was developed and evaluated by a panel of experts. The study also met all the set objectives; hence, the study evaluation was achieved. The instrument development process was conducted in two phases: phase one, domain identification and item generation, and phase two, instrument development and validation.

The section below outlines the phases in line with the study objectives and how they were met.

9.2.1 Phase One: Domain Identification and Item Generation

The outcome of phase one was to identify relevant content domains and generate items for the development of the instrument in Phase two. This phase followed steps 1 and 2 and

fulfilled the first four objectives of the overall study (Table 3.1). The first objective was to identify and synthesize the perspectives of patients, family members, and healthcare providers on providing quality care for patients at the end of life and their families in the ICU. The results of the first objective are presented in Chapter Four. The objective was achieved through a scoping review that led to the identification of seven key emergent themes that described the desired quality of care provided for patients at the end of life and their families in the ICU. These themes potentially served as content domains that formed the blueprint for the development of the instrument. Additionally, 69 items were derived from the scoping review that also informed the development of the instrument (Table 4.6). The domains and items generated are elaborated on in detail in Chapter Four. The domains that were generated from the results of the first objective are as follows:

- Patient-and family centered decision making
- Symptom management and comfort
- Communication among the healthcare team, and with patients and families
- Care with compassion, dignity and respect
- Spiritual care and cultural support
- Emotional support for patients and families
- Modifying the ICU environment

The second objective was to explore the experiences of intensive care nurses providing care to patients and their families after the withdrawal of treatment in the ICU. The objective was achieved through an exploratory, descriptive qualitative study. A total of sixteen (n = 16) intensive care nurses were purposefully sampled and participated in the interviews. The individual interviews were audio-recorded, transcribed verbatim, and analyzed using the Braun and Clarke (2006) thematic analysis approach. The themes and sub-themes that emerged from the data analysis are also discussed and supported by verbatim quotes from the participants. A detailed report on the results of the second objective is presented in Chapter Five. The interviews with the nurses also led to the generation and identification of 35 items (Table 5.3) that were derived from the direct quotes from participants on the rendering of optimum care after treatment withdrawal. These items also informed the development of the instrument in Phase 2 of the study.

The third objective was to also explore physicians' experiences of making end-of-life decisions to withdraw treatment and providing care after the withdrawal of treatment in the ICU. This was achieved through an exploratory descriptive qualitative study using individual interviews. A purposive sample of nine (n = 9) physicians participated in the interviews. Individual interviews were audio-recorded, transcribed verbatim, and analyzed using Braun and Clarke (2006) thematic analysis and MAXQDA Plus 2020 analysis software. The theme and sub-themes that emerged from the interviews are presented and supported with participants direct quotes in Chapter Five. The theme "facilitating care after treatment withdrawal" led to the generation of 19 items that also formed blueprints for the development of the instrument in Phase 2 of the study (**Table 5.5**). These items were derived from the direct quotes of participants during the interviews.

The last objective of phase one, objective four, was to explore the experiences of families who have been relatives of a patient with treatment withdrawn in the ICU. An exploratory qualitative design was used to achieve the objective. A total of seven (n = 7) bereaved family members participated in the interviews. Participants' interviews were audio-recorded and transcribed verbatim. The Braun and Clarke (2006) thematic analysis in addition to the MAXQDA Plus 2020 software were used for data analysis. The theme and sub-themes that emerged following the data analysis are presented in detail and supported with participant-direct quotes in Chapter Five. The interviews with bereaved family members also led to the generation of an additional 20 items that were appropriate and also formed the blueprints for the development of the instrument (**Table 5.8**).

Overall, phase one objectives were met. A total of seven potential domains and 143 items were derived from the findings from the scoping review and qualitative interview with nurses, physicians, and family members. The development of the instrument in Phase 2 was informed by the domains and items generated in Phase 1.

9.2.2 Phase Two: Instrument Development and Validation

The outcome of phase two was to develop the instrument and assess its content and face validity. Phase two followed steps 3, 4, and 5 and fulfilled objectives 5, 6, and 7 of the overall study (**Table 3.1**). The fifth objective involved the development of a provisional instrument. This was achieved through the integration and synthesis of findings from the scoping review

and qualitative studies from phase one. The domains and items generated in phase one were integrated and synthesized (**Table 6.1**). This was achieved through a series of meetings to assemble the instrument items, check item wordings, reduce, and arrange domains. The researcher, together with the supervisor and content expert, undertook further instrument construction, reduction, and refinement. At the end of the instrument construction, reduction, and refinement process, a total of seven (7) domains were identified and 65 items were generated. This was considered the first draft of the instrument that measures the quality of care provided for patients and their families after the withdrawal of treatment in the adult ICU (**Table 6.2**). The domains and items generated as part of the first draft of the instrument included:

- Patient- and family centered decision making (7 items)
- Communication among the ICU team and with patients and families (13 items)
- Continuity of care (3 items)
- Emotional and practical support for patients and families (16 items)
- Symptom management and comfort (8 items)
- Spiritual care (6 items)
- Modifying the ICU environment (12 items)

At the end of meeting goal 5 of the study, a first draft of the instrument was made. A detailed results of objective five is presented in **Chapter Six**.

The sixth objective of the study involved the assessment of the content validity of the first version of the developed instrument. A methodological research design guided the instrument validation in Phase 2, and the objective was achieved using a two-round Delphi technique. A total of nine (n = 9) experts in critical care nursing, critical care medicine, EOL care research, and instrument development were recruited and involved in the two-round Delphi. A detailed presentation of results is presented in Chapter Seven. At the end of the two-round Delphi, the main findings drawn from the validation phase are presented as follows:

- The final version of the instrument was made up of 7 domains and 64 items. The content validity process identified seven domains and 64 items, which included patient- and family-centered decision making (9 items), communication among the ICU team and with patients and families (12 items), continuity of care (3 items),

emotional and practical support for patients and families (12 items), symptom management and comfort (7 items), spiritual care (5 items), and modifying the ICU environment (12 items).

- The item content validity indexes (I-CVIs) ranged from 0.89 to 1.00: domain 1 (0.89–1.00, with an average I-CVI of 0.98); domain 2 (0.89–1.00, with an average I-CVI of 0.98); domain 3 (0.89–1.00, with an average I-CVI of 0.96); domain 4 (0.89–1.00, with an average I-CVI of 0.96); domain 5 (0.89–1.00, with an average I-CVI of 0.98); domain 6 (0.89–1.00, with an average I-CVI of 0.98); and domain 7 (0.89–1.00, with an average I-CVI of 0.98).
- The overall scale content validity (S-CVI) using the computed universal agreement among experts (S-CVI/UA) was **0.77**, and the S-CVI/Ave was also **0.97**. Overall, the average approach showed a good scale content validity index (S-CVI of 0.9 or higher), while the universal agreement method demonstrated moderate content validity (S-CVI/UA lower than 0.80).
- The instrument items also recorded an excellent kappa values that ranged from **0.89** to **1.00**
- The proportion of consensus on the comprehensiveness of the instrument domains and items as far as the theoretical definitions of domains and dimensions were concerned ranged from 0.89 to 1. This means that indicating that 89 to 100% consensus was reached among the experts on the panel for all the domains and their items.
- All nine experts on the panel agreed that the overall instrument was comprehensive (n = 9) when it came to how well it covered all dimensions. So, the percentage of people who agreed that the whole instrument covered everything was 1, which means that everyone agreed.

The last goal of the study, goal number seven, was to assess the face validity of the instrument that was developed. This was also achieved via the use of the two-round Delphi. Comments from the panel of experts on the item clarity, formatting, language, and readability of the instrument were used to assess the face validity of the instrument. Chapter seven presents how changes were made to the instrument based on the suggestions and comments from the panel of experts.

Overall, the goal of the study was achieved. An instrument to measure the quality of care provided for patients and their families after the withdrawal of treatment in the adult ICU was developed. The researcher also conducted initial face and content validation of the instrument. This is unique considering the integration of findings from a scoping review and qualitative interviews (with nurses, physicians, and family members). This is the first instrument to be developed in South Africa for a tertiary-level hospital. Further instrument validation will be undertaken after the PhD degree.

9.3 SPECIFIC CONSTRIBUTION OF THIS STUDY

In Africa, there is no specific instrument to measure the quality of care at the end of life (EOL). In most cases, instruments used in most African studies are adapted and revised. The variations in EOL care and treatment withdrawal practices in the ICU are evident in the literature. Hence, one criterion may not be applicable to all due to the disease profiles and cultural and religious differences within the African context. At the time of executing this research, the researcher was unaware of any instrument developed for measuring the quality of care after treatment withdrawal in the adult ICUs in South Africa. The current study adds to the number of instruments developed to measure EOL care in the ICU. The developed instrument will be useful in providing quality care for patients and their families in the adult ICU, especially after the withdrawal of treatment. Additionally, it fills the research gap that has been indicated across the African literate concerning the lack of a standard instrument to measure quality of care after the withdrawal of treatment in the adult ICU.

Again, no existing instrument had triangulated, integrated, and synthesized data from existing literature, family members (consumers of healthcare), and healthcare providers (nurses and doctors) to develop an instrument. This is unique considering the disease profile and cultural differences across Africa and in South Africa compared to western countries. Previously, instruments developed in Western countries were adapted, modified, and used to conduct research within the African context, especially in South Africa. The perspectives of healthcare providers (nurses and doctors) working in the adult ICU have revealed the emotional distress healthcare providers encounter during treatment withdrawal in the ICU. Similarly, the study has also brought to light the views and standpoints of this cadre of healthcare professionals as far as facilitating care after treatment withdrawal and ensuring a good death in the ICU are concerned. Their suggested areas of challenge also present

important areas in patient care that need strengthening and maximum attention. The findings from the experiences of bereaved families on providing care after treatment withdrawal in the ICU also add to the existing body of scientific knowledge. Important aspects of patient and family care that are salient to family members were emphasized. These findings further amplify the existing areas to be strengthened in order to improve the quality of care in the ICU.

Lastly, the use of this instrument will improve the quality of care that clinicians give, make it easier for families to be involved in care and be happy with it, and improve the continuity of care. It will also offer important dimensions of care to focus on and attend to during the care of patients at the end of life and their families.

9.4 STRENGTHS OF THE STUDY

To reach the goal of the study, the exploratory sequential mixed method design made it possible to use more than one method in a single study. The strengths and weaknesses of both qualitative and quantitative research designs were complemented by the different points of view. In instrument development in particular, the qualitative interviews conducted in phase one strengthened the development of quantitative instruments in phase two. Additionally, the study applied and assiduously followed the five-step approach for instrument development as outlined by Lynn (1986) and Zamanzadeh *et al*. (2015). These steps helped in structuring and organizing the study flow and enhanced the rigor of the entire instrument development process.

Again, it was important to include all stakeholders as much as they thought they needed to in order to improve the quality of the work when developing an instrument to measure something as sensitive as treatment withdrawal. The researcher developed the instrument based on the synthesis of existing scientific literature and on the perspectives of family members, nurses, and doctors thought. This made sure that both people who provided and received end-of-life care were represented equally, and it also derive items and domains from what these people thought. Findings from the research that had already been done and interviews with nurses, doctors, and family members gave the instrument a strong scientific foundation.

In the validation of the instrument, nine experts with strong backgrounds and experiences in critical care, instrument development, and EOL care research were used. This also enhanced the content validity process. Both the CVIs of the individual items and the entire instrument were also calculated. The content validity index measures the agreement among experts regarding the relevance of items as opposed to the internal consistency between ratings provided (Polit *et al*., 2007). The most widely used approach in instrument quantification is computing the content validity index. According to Wynd *et al*. (2003), one threat for computing on CVI is the potential for inflation of agreement due to chance factors. The researcher further estimated the kappa values of the instrument items as they provided a degree of agreement beyond chance.

9.5 LIMITATIONS OF THE STUDY

Although the findings from this research will benefit the quality of care provided for patients and their families in the ICU, it was not without shortcomings. The study setting initially included ICUs in two academic hospitals. However, the study was conducted in only one general ICU. At the time the study began, the COVID-19 pandemic was at its peak; therefore, it was difficult to obtain institutional ethical clearance for all the included hospitals. Additionally, there was a fire outbreak in one of the proposed academic settings. This caused significant damage to the multidisciplinary, cardiothoracic, and coronary ICUs. This also further delayed the ethical clearance for data collection at the selected ICUs. Due to these limitations, only the multidisciplinary ICU in one of the academic hospitals was used. Perhaps the inclusion of other ICUs and hospitals could have enriched the findings.

The recruitment of participants (nurses, doctors, and family members) was also a major limitation of the study at the initial part of the data collection. After obtaining the ethical clearance, it was difficult to recruit participants. This limitation was due to the COVID-19 pandemic, ICU workload, and other ICU visiting restrictions. The researcher, who is also ICU-trained, was at the time assisting with patient care in the ICU; hence, it was manageable to some extent. However, it was difficult to recruit nurses and doctors due to the increasing number of COVID-19 cases. The researcher managed to recruit nurses and doctors as the COVID-19 pandemic subsided over time. Due to family visitation restrictions, recruiting family members was also difficult during the early stages of the COVID-19. Subsequently,

the ICU visiting policies were relaxed to accommodate families at the patients' bedside. This also delayed the data collection process.

The recruitment of family members in the ICU was also a major limitation of the study. It took the researcher several months to recruit participants. This was due to the COVID-19 pandemic and the loss of participants relatives in the ICU. The moment was an emotional one for family members, and it was not appropriate to interview participants' right after the loss. The researcher constantly followed up with participants six months after their loss. Due to the time interval, it was a challenge. Some participants were still in the grieving period; others had relocated, among others.

9.6 RECOMMENDATIONS

The study's recommendations are elaborated under the headings of recommendations for clinical practice, nursing and medical education, and further research.

9.6.1 Recommendations for Clinical Practice

From the interviews, it's clear that health care workers still face challenges in the adult ICU after treatment withdrawal. The instrument is expected to improve the quality of care given to patients and their families if it is used in clinical settings. It will help the healthcare team understand the desired quality of care for patients and their families following the cessation of ICU treatment. The instrument will be used to measure the quality of care and compare it to standards that have already been set.

The current study highlighted seven key domains that are vital to the provision of quality care after treatment withdrawal in the ICU. The study recommends the development of guidelines that address these key domains of care during and after the withdrawal of treatment. For example, in the domain of "symptom management and comfort", a guideline will raise awareness of the necessary interventions that could be implemented during and after treatment withdrawal. The less experienced healthcare team members could also benefit from it and it would assist them in providing comprehensive care to patients and their families.

Over the years, the palliative care approach used in oncology units has helped both patients and their families get physically, emotionally, and spiritually ready for the end of life. The study recommends the early introduction of the palliative care approach and team prior to an EOL decision to withdraw treatment in the adult ICU. The principles of palliative care will also enhance the care patients and their families receive during the dying phase.

In the ICU, making decisions about EOL care and providing care after treatment is withdrawn is said to be an emotional phase for both nurses and doctors. While they provide support for patients and their families emotionally, it is a draining and difficult moment for this cadre of healthcare professionals. The study recommends the constant availability of counseling sessions and facilities to support the healthcare team, especially after the withdrawal of treatment. The creation of easily accessible sessions for debriefing among the ICU team will again help them to externalize their feelings, discuss the plan of care, and prepare for subsequent EOL situations.

Finally, the study emphasizes the creation of a suitable bedside space and therapeutic environment as a key area vital to the provision of care after the withdrawal of treatment. Such an environment permits liberal family visitation and promotes patient privacy. The study recommends the creation of special and private rooms in the ICU for patients receiving end-of-life care and their families. Families are seen as an extension of the patient during ICU hospitalization; therefore, they need to be involved in the patient's care even until the very end. Also, hospital visiting hours should be unrestricted to allow family involvement in patient care and bedside presence in the last days of patients' lives.

9.6.2 Recommendations for Nursing and Medical Education

Nurses and doctors, especially ones with little experience, don't have the knowledge and skills they need to give care during and after treatment is stopped in the ICU. The identified domains of the instrument could be used as a scientific basis for the education and training of healthcare professionals like nurses and doctors. Therefore, the instrument's key dimensions should be incorporated into the EOL and palliative care curricula in order to train basic, post-basic, and specialist programs in intensive care. Additionally, undergraduate nursing and medical students should also have mandatory EOL care courses integrated into their education to prepare them for providing care for dying patients and their families.

The study further recommends the organization of frequent EOL and palliative care workshops in the form of compulsory continuous professional development (CPD) points for practicing healthcare professionals to facilitate EOL interest and augment the existing support for the ICU team. Frequent simulation exercises on the care of the dying patient are also recommended as a measure to boost the confidence of the ICU team during EOL care.

9.6.3 Recommendations for Further Research

The development of a measuring instrument will add to what is already known and address the lack of a suitable instrument to measure the quality after treatment withdrawal in the adult ICU. Although the study developed a survey instrument and conducted an initial assessment of the validity of the content by an expert panel, it did not pilot test the instrument. Usually, the next phase is the implementation of the outcome on a larger scale to determine the usefulness of what has been developed. This study suggests conducting more pilot tests of the instrument on a larger group of people to figure out how reliable it is. A pilot study would enhance the preliminary assessment of the psychometric properties of the instrument. The current study ended with the content validation of the instrument. Further assessment and validation, such as construct validation, will promote the accuracy and enhance the quality of the instrument.

Even though the literature talks about the nurses' unique roles, they rarely or never have a say in end-of-life (EOL) decisions in the ICU. In the future, research can be done to find out what nurses and doctors do during treatment withdrawal and care at the end of life in the ICU. This will show the different roles that each group of healthcare providers plays, point out any gaps, and make it easier for them to communicate, work together, and coordinate. Also, it's clear that stopping treatment and caring for the patient after stopping treatment are big sources of emotional stress for nurses, doctors, and family members who have lost a loved one. It is suggested that a study be conducted to identify the various coping strategies used by these individuals during and after the withdrawal of treatment in the adult ICU. This will be helpful for the development of organization-based emotional support systems for these groups prior to, during, and after treatment withdrawal in the ICU. Additionally, additional research is required to identify the specific barriers to the provision of care after the discontinuation of treatment in the ICU and to develop clinical guidelines for improved

patient care. This will, among other things, facilitate sustained communication and a collaborative relationship between the ICU healthcare team and patients and their families.

9.7 CONCLUSION

The study developed and conducted an initial content validation of an instrument to measure the quality of care provided for patients and their families after the withdrawal of life-sustaining treatments in the adult ICU. A two-phase exploratory sequential mixed methods approach was used to identify seven (n = 7) content domains and generate 64 items that are relevant to measure the quality of care after treatment withdrawal in the ICU. The development of the instrument was informed by findings from a scoping review and qualitative interviews with nurses, physicians, and family members. The findings were integrated, synthesized, and reduced to develop a preliminary version of the instrument. The instrument further underwent panel expert review to assess its face and content validity via a two-round Delphi study. The instrument showed high content validity for the individual items (I-CVI range of 0.89 to 1.00) and moderate to high content validity for the overall instrument (S-CVI/UA = 0.77; S-CVI/Ave = 0.97). This instrument will support the provision of care for patients and their families following treatment withdrawal and aid in the training and education of healthcare providers in EOL care. It will also facilitate future research in the care of critically ill and dying patients in the ICU. Future research should conduct more assessments and pilot test the instrument.

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APPENDIX A

INTENSIVE CARE NURSES' INFORMATION SHEET

Hello, my name is Emmanuel Kwame Korsah. I am currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for Doctor of Philosophy (PhD). I hope to conduct a research project to ***develop and test an instrument to measure the quality of care for patients and families after the withdrawal of treatment in the adult ICU.***

Why am I doing the study?

There is currently a strong push to provide excellent care at the end-of-life and improve the modern experience of death and dying in intensive care practice. The desired quality of care provided to critically ill patients after the withdrawal of active treatment in the intensive care unit, however, has been plagued with inconsistencies, challenges and ethical dilemmas. There is also persistent gaps and challenges in the provision of EOL care across diverse racial and cultural groups, especially the care given to patients after treatment is withdrawn. South Africa is a unique country with several cultural and religious differences. The disease profile and approaches to managing or caring for patients at the end-of-life also differ from the western culture approach. There are gaps and challenges in the provision of EOL care across diverse racial and cultural groups. Several efforts to improve the quality of care have been intensified over the years. These efforts, however, have been hindered by the lack of a well-defined, reliable and valid method for measuring the quality of care rendered to patients and their families after the withdrawal of treatment. Comprehensive quality measurement requires multiple perspectives, including nurses, the principal caregivers of EOL care in the ICU and patients and their family members, the recipients of the care rendered. No instrument currently exists within the South African context to measure the quality of care provided to patients and their families after the withdrawal of treatment in the adult ICU. The development of a context-based instrument will help understand South African intensive care perspectives of the expected quality of care for patients and their families after the withdrawal of treatment.

What am I asking you to do?

I would like to invite you to be part of the interview which will aim at eliciting your views and experience on the care rendered to patient at the end-of-life and their families and how best to improve the care rendered. There is no right or wrong answer. The interview will last approximately 45 minutes to one hour. Participation will be entirely voluntary. You are allowed to withdraw from the study at any time if you wish so without any penalty. If you consent to be part, a consent form will be signed by you to affirm your willingness to participate in the study.

How information you give will be kept from others?

The information you will give in the interview will be kept confidential. To ensure your anonymity, no identification of your personal information will be given in reporting on your opinions. With your permission, the discussion will be tape-recorded to ensure that all the information is recorded for transcription. An informed consent for audio-recording will be signed. All the tape-recorded information will be only available to me as the researcher. All the tapes will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data will be kept safe under a password-protected computer. Results of the study will be given to you on your request.

What about permission to conduct the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics Committee (Medical). [M210229]

Are there any benefits and risks of participation?

Participation in this study is voluntary. I appreciate that you will not derive any benefit from participation in this study. However, I hope that the results of the study will help clarify the approaches needed for the provision of quality comfort care in the ICU. Similarly, there will be no negative consequences for any individual who do not wish to participate.

Whom do you contact if you want more information?

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights as a study participant you are free to contact me on the following telephone number 0612920238 or email me using the following address: ekorsah8912@gmail.com Or my supervisor: Prof. Shelly Schmollgruber Tel. +27 114884270 Shelley.Schmollgruber@wits.ac.za. Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical): Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za Secretary: Zanele Ndlovu Tel: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za And Rhulani.Munkansi@wits.ac.za

Yours faithfully

Emmanuel Korsah (Researcher)

Prof. Shelley Schmollgruber (Supervisor)

APPENDIX B

INFORMED CONSENT FOR NURSES

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I have been given the information sheet, which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet, and all questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Name of participant: _____

Date: _____

Signature: _____

APPENDIX C

NURSES' INFORMED CONSENT FORM FOR AUDIO-RECORDING

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I have been given the information sheet, which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet, and all questions have been answered satisfactorily.

I understand that the voice recording will be secured on a password protected computer with restricted access to others but accessible to the researcher and the research supervisor. I understand that voice-recorded information will be transcribed and transcripts will be given a code, and any information that could identify me will be removed. I understand that the voice recordings will be destroyed two years after publications of the findings.

I understand that direct quotes from my interview, other than any information that could identify me, may be cited in the research report or other write-ups of the research.

I can also call to inquire anything concerning this study from Prof Penny, Chair of the Human Research Ethics Committee (HREC), the University of the Witwatersrand at Email: Clement.Penny@wits.ac.za.

I hereby consent to audio-recording of the interview.

Name of participant: _____

Date: _____

Signature: _____

APPENDIX D

INTERVIEW GUIDE FOR NURSES

Can you share with me your experience with caring for critically ill and dying patient and their family in the ICU?

- Can you tell me about your experience with caring for critically ill and dying patient and their family in the ICU; especially when patient's treatment is withdrawn?
- How do you feel caring for patient and family after patient's treatment is withdrawn?
- What are the areas of concerns managing and caring for patient with treatment withdrawn?
- What matters most to you when caring for patient with treatment withdrawn?
- Based on your experience, tell me what you think can be done to improve care for patient and their family after withdrawal of treatment?

THANK YOU FOR TAKING PART IN THIS STUDY

APPENDIX E

DEMOGRAPHIC DATA (NURSES)

1. Gender

Male	
Female	

2. How old are you?

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

3. Race

Black	White	Coloured	Indian

4. Years of ICU experience

<5 years	
6-10 years	
11-20 years	
>20 years	

5. What is your highest level of qualification

diploma	
Advanced diploma	
Masters	
Doctorate	

6. Are you ICU trained?

Yes	No

7. If yes, which of the following best describes your current position?

Clinical facilitator	
Nurse manager	
Charge nurse	
ICU lecturer / clinical researcher	

APPENDIX F

PHYSICIANS' INFORMATION SHEET

DEVELOPMENT OF AN INSTRUMENT TO MEASURE THE QUALITY OF CARE AFTER THE WITHDRAWAL OF LIFE-SUSTAINING TREATMENT IN THE ADULT ICU

Hello, my name is Emmanuel Kwame Korsah. I am currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for Doctor of Philosophy (PhD). I hope to conduct a research project to ***develop and test an instrument to measure the quality of care for patients and families after the withdrawal of treatment in the adult ICU.***

Why am I doing the study?

There is currently a strong push to provide excellent care at the end-of-life and improve the modern experience of death and dying in intensive care practice. The desired quality of care provided to critically ill patients especially after the withdrawal of active treatment in the intensive care unit, however, has been plagued with inconsistencies, challenges and ethical dilemmas. There is also persistent gaps and challenges in the provision of EOL care across diverse racial and cultural groups, especially the care given to patients after treatment is withdrawn. South Africa is a unique country with several cultural and religious differences. The disease profile and approaches to managing or caring for patients at the end-of-life also differ significantly from the western culture approach. Several efforts to improve the quality of care have been intensified over the years. These efforts, however, have been hindered by the lack of a well-defined, reliable and valid method for measuring the quality of care rendered to patients and their families after the withdrawal of treatment. Comprehensive quality measurement requires multiple perspectives, including physicians and nurses, the principal caregivers of EOL care in the ICU and patients and their family members, the recipients of the care rendered. No instrument currently exists within the South African context to measure the quality of care provided to patients and their families after the withdrawal of treatment in the adult ICU. The development of a context-based instrument will help understand South African intensive care perspectives of the expected quality of care for patients and their families after the withdrawal of treatment.

What am I asking you to do?

I would like to invite you to be part of the interview which seeks to explore and describe your experiences participating in the process of withdrawal of life-sustaining treatments for patient at the end-of-life in the ICU. There is no right or wrong answer. The interview will last approximately 30- 45 minutes. Participation will be entirely voluntary. You are allowed to withdraw from the study at any time if you wish so without any penalty. If you consent to be part, a consent form will be signed by you to affirm your willingness to participate in the study. In any case of emotional distress, a qualified counsellor will be available on phone or in person to offer counselling or further assistance.

How information you give will be kept from others?

The information you will give in the interview will be kept confidential. To ensure your anonymity, no identification of your personal information will be given in reporting on your opinions. With your permission, the discussion will be tape-recorded to ensure that all the information is recorded for transcription. An informed consent for audio-recording will be signed. All the tape-recorded information will be only available to me as the researcher. All the tapes will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data will be kept safe under a password-protected computer. Results of the study will be given to you on your request.

What about permission to conduct the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics Committee (Medical). [M210229] and the CEO of the Charlotte Maxeke academic hospital.

Are there any benefits and risks of participation?

Participation in this study is voluntary. I appreciate that you will not derive any benefit from participation in this study. However, I hope that the results of the study will help clarify the approaches needed for the provision of quality comfort care in the ICU. Similarly, there will be no negative consequences for any individual who do not wish to participate.

Whom do you contact if you want more information?

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights as a study participant you are free to contact me on the following telephone number 0612920238 or email me using the following address: ekorsah8912@gmail.com Or my supervisor: Prof. Shelly Schmollgruber Tel. +27 114884270 Shelley.Schmollgruber@wits.ac.za. Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical): Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za Secretary: Zanele Ndlovu Tel: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za And Rhulani.Munkansi@wits.ac.za

Yours faithfully

Emmanuel Korsah
(Researcher)

Prof. Shelley Schmollgruber
(Supervisor)

APPENDIX G

INFORMED CONSENT FOR PHYSICIANS

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I have been given the information sheet, which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet, and all questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Name of participant: _____

Date: _____

Signature: _____

APPENDIX H

PHYSICIANS' INFORMED CONSENT FORM FOR AUDIO-RECORDING

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I have been given the information sheet, which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet, and all questions have been answered satisfactorily.

I understand that the voice recording will be secured on a password protected computer with restricted access to others but accessible to the researcher and the research supervisor. I understand that voice-recorded information will be transcribed and transcripts will be given a code, and any information that could identify me will be removed. I understand that the voice recordings will be destroyed two years after publications of the findings.

I understand that direct quotes from my interview, other than any information that could identify me, may be cited in the research report or other write-ups of the research.

I can also call to inquire anything concerning this study from Prof Penny, Chair of the Human Research Ethics Committee (HREC), the University of the Witwatersrand at Email: Clement.Penny@wits.ac.za.

I hereby consent to audio-recording of the interview.

Name of participant: _____

Date: _____

Signature: _____

APPENDIX I

INTERVIEW GUIDE FOR PHYSICIANS

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

Question: Can you share with me your experiences you have had been part of a team that needed to make a decision about withholding or withdrawal of active treatment for a patient at the end of life?

Probes:

- Have did you feel having to make a decision? Did you feel comfortable?
- How was the decision made? The timing of the decision
- Do you see a place for the nurse, patient and family members in the team when making the decision? Did you include the nurse in the decision making?
- After the decision was made, what the plan for the patient and the family?
- Is there anything you wished had happened that didn't in order to improve the care given to patient and the family after treatment withdrawal?
- Were you prepared for the experience? What would have prepared you for the experience?
- What would you have changed or added to improve the care given to patient and the family after treatment withdrawal?
- What do you recommend should be done to improve the care and that of other patient and family in similar situation?

THANK YOU FOR TAKING PART IN THIS STUDY

APPENDIX J

DEMOGRAPHIC DATA (PHYSICIANS)

1. Gender

Male	
Female	

2. How old are you?

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

3. Years of ICU experience ……year(s)……months

4. Years of practice as a physician

1-5 years	
6-10 years	
11-20 years	
Above 20 years	

5. Area of specialty…….

APPENDIX K

INFORMATION SHEET: FAMILY MEMBERS

DEVELOPMENT OF AN INSTRUMENT TO MEASURE THE QUALITY OF CARE AFTER THE WITHDRAWAL OF LIFE-SUSTAINING TREATMENT IN THE ADULT ICU

Dear Colleague,

Hello, my name is Emmanuel Kwame Korsah. I am currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am hoping to conduct a research project to ***develop and test an instrument to measure the quality of care for patients and families after the withdrawal of treatment in the adult ICU.***

Why am I doing the study?

There is currently a strong push to provide excellent care at the end-of-life and improve the modern experience of death and dying in intensive care practice. The desired quality of care provided to critically ill patients and family members especially after the withdrawal of active treatment in the intensive care unit, however, has been plagued with inconsistencies, challenges and ethical dilemmas. There is also persistent gaps and challenges in the provision of EOL care across diverse racial and cultural groups, especially the care given to patients after treatment is withdrawn. South Africa is a unique country with several cultural and religious differences. The disease profile and approaches to managing or caring for patients at the end-of-life also differ significantly from the western culture approach. Several efforts to improve the quality of care have been intensified over the years. These efforts, however, have been hindered by the lack of a well-defined, reliable and valid method for measuring the quality of care patient rendered to patients and their families after the withdrawal of treatment. Comprehensive quality measurement requires multiple perspectives, including nurses, the principal caregivers of EOL care in the ICU and patients and their family members, the recipients of the care rendered. No instrument currently exists within the South African context to measure the quality of care provided to patients and their families after the withdrawal of treatment in the adult ICU. The development of a context-based instrument will help understand South African intensive care perspectives of the expected quality of care for patients and their families after the withdrawal of treatment.

What am I asking you to do?

I would like to invite you to be part of the interview which will aim at sharing your experience of having a family member critically ill and consequently there is a palliative management in the ICU. There is no right or wrong answer. The interview will last approximately 25-40 minutes to one hour.

Participation will be entirely voluntary. You are allowed to withdraw from the study at any time if you wish so without any penalty. If you consent to be part, a consent form will be signed by you to affirm your willingness to participate in the study. Interview will be held at your own time of convenience and a quiet place.

How do you know that the information you give to kept from others?

The information you will give in the interview will be kept confidential. To ensure your anonymity, no identification of your personal information will be given in reporting on your opinions. With your permission, the discussion will be tape recorded to ensure that all the information is recorded for transcription. An informed consent for audio-recording will be signed. All the tape recorded information will be only available to me as the researcher. All the tapes will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data will be kept safe under password protected computer. Results of the study will be given to you on your request.

What about permission to conduct the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics Committee (Medical) [M210229] and from CEO of Charlotte Maxeke Academic Hospital [GP_202107_010]

Are there any benefits and risks of participation?

Participation in this study is voluntary. I appreciate that you will not derive any benefit from participation in this study. However, I hope that the results of the study will help clarify the approaches needed for the provision of quality comfort care in the ICU. Similarly, there will be no negative consequences for any individual who do not wish to participate.

Whom do you contact if you want more information?

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights as a study participant you are free to contact me on the following telephone number 0612920238 or email me using the following address: ekorsah8912@gmail.com Or my supervisor: Prof. Shelly Schmollgruber Tel. +27 114884270 Shelley.Schmollgruber@wits.ac.za. Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical): Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za And Rhulani.Munkansi@wits.ac.za

Yours faithfully
Emmanuel Korsah
(Researcher)

Prof. Shelley Schmollgruber
(Supervisor)

APPENDIX L

INFORMED CONSENT FOR FAMILY MEMBER

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I have been given the information sheet which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet and all questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Name of participant: _____

Date: _____

Signature: _____

Witness_ Name…….. Signature……

APPENDIX M

INFORMED CONSENT FORM FOR AUDIO-RECORDING (FAMILY MEMBERS)

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I have been given the information sheet which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet and all questions have been answered satisfactorily.

I understand that the voice recording will be secured on a password protected computer with restricted access others but accessible to the researcher and the research supervisor. I understand that voice-recorded information will be transcribed and transcripts will be given a code and any information that could identify me will be removed. I understand that the voice recordings will be destroyed two years after publications of the findings.

I understand that direct quotes from my interview, other than any information that could identify me, may be cited in the research report or other write-ups of the research.

I can also call to inquire anything concerning this study from Prof Penny, Chair of the Human Research Ethics Committee (HREC), the University of the Witwatersrand at Email: Clement.Penny@wits.ac.za.

I hereby consent to audio-recording of the interview.

Name of participant: _____

Date: _____

Signature: _____

APPENDIX N

INTERVIEW GUIDE FOR FAMILY MEMBERS

Can you share with me your experience of having a family member critically ill and subsequently admitted in the intensive care unit?

Probes

- How did you feel when you were informed that there had been a change to palliative management and end of life care?
- Did you feel part of the decision making process? What do you think about your direct involvement in direct care of your family member?
- How do you describe the care that was given to you and your family member in his /her final hours of life?
- What would you have changed or added to improve the care given to you and your family member?
- Do you have any suggestions on how to make the care provided better in the ICU?
- What do you recommend should be done to improve your care and that of other families and patient in your situation?

APPENDIX O

DEMOGRAPHIC DATA (FAMILY MEMBERS)

1. Gender

Male	
Female	

2. How old are you? …….years old

3. Race

Black	White	Coloured	Indian

4. Relationship to patient

Parent	
Spouse	
Adult child	
Sibling	
Other, specify	

APPENDIX P

INVITATION LETTER TO EXPERTS (INSTRUMENT VALIDATION) – DELPHI STUDY

Department of Nursing Education
Faculty of Health Science
University of the Witwatersrand
7 York Road, Parktown
Johannesburg

Dear Expert,

INVITATION TO PARTICIPATE IN THE STUDY AS A CLINICAL EXPERT IN AN EXPERT REVIEW

My name is Emmanuel Kwame Korsah. I am registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am conducting a research project that seeks to develop and validate an instrument that measures the quality of care provided for patients and families after the withdrawal of treatment in the adult intensive care unit. This study is under the supervision of Professor Shelley Schmollgruber.

The instrument development process is being conducted in 2 phases. In Phase 1, the content domains and items that best describe the desired quality of care at the end of life and after the withdrawal of treatment in the intensive care unit were synthesised through a scoping review and qualitative interviews with intensive care nurses, specialist doctors and bereaved family members. In Phase two, the domains and items identified and generated from the review and individual qualitative interviews were compared, contrasted and reduced to develop a provisional and concise list of domains and their items. The researcher, supervisor and other four content experts were also involved in the item reduction. This stage of Phase 2 seeks to determine the content validity of the instrument through a Delphi study.

I am inviting you to take part in this two-round Delphi study that seeks to determine the content and face validity of the provisional instrument developed. Your content expertise (care of the dying patient in the ICU, palliative care, instrument development and end-of-life care) will be valuable to the development of a psychometrically sound and relevant measuring instrument. The instrument will ultimately be used to improve the quality of care

provided to patients and their family members in the ICU. There is no right or wrong answer as I am interested in your input on the subject.

In round one of the Delphi, you will be requested to use a 4-point rating scale recommended by Lynn (1986) to rate separately the relevance and clarity of each item under each domain. The various comments and suggestions from you as an expert at each session will be used to refine the provisional instrument. A comment section is provided for your input, suggested item revision and any additional items not covered, however, relevant to the domain and the study. In round two, the researcher will revise the provisional instrument based on your comments and revisions. The revised instrument will be sent to you again for another round of ratings using the same scale. This time, your rating will be used to calculate the content validity index of the individual items and the overall scales.

Thank you in advance for your input and participation.

Yours faithfully,

Emmanuel Kwame Korsah
(Researcher)

Prof Shelley Schmollgruber
Supervisor

APPENDIX Q

INFORMATION SHEET FOR EXPERTS - DELPHI STUDY

Project title: Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU

Hello

My name is Emmanuel Kwame Korsah. I am registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am conducting a research project that seeks to develop and validate an instrument to measure the quality of care provided for patients and families after the withdrawal of treatment in the adult intensive care unit. This study is under the supervision of Professor Shelley Schmollgruber.

Why am I doing the study?

There is currently a strong push to provide excellent care at the end of life and improve the modern experience of death and dying in intensive care practice. In the ICU, the time between treatment withdrawal and death is relatively short. A higher majority of patients die within 24 hours after the withdrawal of life-sustaining treatment. The desired quality of care provided to critically ill patients after the withdrawal of active treatment in the intensive care unit has been plagued with inconsistencies, challenges and ethical dilemmas. There are also persistent gaps and challenges in the provision of EOL care across diverse racial and cultural groups, especially the care given to patients after treatment is withdrawn. Several efforts to improve the quality of care have been intensified over the years. These efforts, however, have been hindered by the lack of a well-defined, reliable and valid method for measuring the quality of care patients rendered to patients and their families after the withdrawal of treatment. Comprehensive quality measurement requires multiple perspectives, including nurses, the principal caregivers of EOL care in the ICU and patients and their family members, the recipients of the care rendered. No instrument currently exists within the South African context to measure the quality of care provided to patients and their families after the withdrawal of treatment in the adult ICU. The development of a context-based instrument will help in understanding South African intensive care perspectives of the expected quality of care for patients and their families after the withdrawal of treatment.

How was the provisional instrument developed?

The instrument development process is being conducted in 2 phases. In Phase 1, the content domains and items that describe the desired quality of care at the end of life and after the withdrawal of treatment in the intensive care unit were synthesised through a scoping review and qualitative interviews with intensive care nurses, specialist doctors and bereaved family members. In Phase two, the domains and items identified and generated from the review and individual qualitative interviews were compared and contrasted to develop a provisional and concise list of domains and their items. The researcher, supervisor and other four content experts were also involved in the item reduction. This stage of Phase 2 seeks to determine the content and face validity of the instrument through a Delphi study.

What am I asking you to do?

I am inviting you to take part in this phase (Phase 2) of the study that seeks to assess the content validity of the provisional instrument developed. Your content expertise (care of the dying patient in the ICU, palliative care, instrument development and end-of-life care) will be valuable to the development of a psychometrically sound and relevant measuring instrument. The instrument will ultimately be used to improve the quality of care provided to patients and their family members in the ICU. There is no right or wrong answer as I am interested in your input on the subject.

If you agree to take part in the study, you will be asked to sign an informed consent form. This will serve as proof of your consent to take part in the two-round Delphi study. The Delphi will be conducted in two rounds. In round one, you will be required to rate the various items under each domain using a 4-point rating scale recommended by Lynn (1986), which will be added to the package. You are requested based on expertise to assess the relevance and clarity of each item under each domain. A comment section is provided for your input and any additional items not covered, however, relevant to the domain. The various comments and suggestions from you as an expert at each session will be used to refine the provisional instrument.

In round two, the researcher will revise the provisional instrument based on your comments and resend it to you for another round of rating using the same scale. This time, your ratings will be used to calculate the content validity index of the individual items and the overall scales.
A short instruction sheet is added to guide the process.

What are the benefits and risks of taking part in the study?

There is no direct benefit or compensation you will get from taking part in this phase of the study. However, your expert input will greatly influence the development of the measuring instrument. Your participation is voluntary. The subject area may bring to mind certain emotional areas and experiences along the clinical journey. If the need be, you will be referred to a professional counsellor who will discuss your concerns with you and reassure you. You may wish to discontinue at any point without any penalty.

What about permission to conduct the study?

I have already obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics Committee (Medical) [M210229], Department of Health and the ethics committee of the Charlotte Maxeke academic Hospital.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +27 612920238; Email: ekorsah8912@gmail.com or my supervisor: Prof Shelley Schmollgruber on email: shelley.schmollgruber@wits.ac.za

Thank you for making time to go through the information sheet.

Emmanuel Kwame Korsah
(Researcher)

Professor Shelley Schmollgruber
(Supervisor)

APPENDIX R

Participant Consent Form (Experts - Delphi Study)

Project title: **Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult ICU**

I……consent to participate in the research project tilted: Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatments in the adult intensive care unit.

I acknowledge that:

I have been given the information sheet which explains what the study intends to achieve and the processes involved in this study. I was given time to read and understand the information sheet and all questions have been answered satisfactorily. I understand that it is up to me whether or not I would like to participate in the study and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Signature / Initials of participant:
Date:

APPENDIX S

EXPERTS DEMOGRAPHIC DATA

1. How old are you? …… years

2. Gender

Male	
Female	

3. Highest level academic of qualification …….

4. Please indicate your profession …….

5. Cumulative years of practice in the profession ……..

6. Please select which best fit your current place of work

Academic setting / Academic	
Clinical setting / Practice	
Both	

7. Have you participated in end of life care in the Intensive care unit before? ……

If Yes, please indicate your role…….

APPENDIX T

DELPHI ROUND ONE

Dear Expert,

Thank you for your willingness to participate in this study.

This is the **first round** in the Delphi study. Your comments, additions and suggestions will be used to revise the provisional instrument.

Instrument to Measure the Quality of Care after the Withdrawal of Treatment in the Adult Intensive Care Unit

Following an iterative process of instrument development, a provisional instrument consisting of **65 items** organised under **7 content domains** was developed. These domains and their items were synthesised from the findings from a scoping review and qualitative interviews with nurses, doctors and bereaved family members. The content domains serve as the content areas that are a relevant part of intensive care after the withdrawal of life-sustaining in the intensive care unit and are essential to the quality of care provided for patients and their family members. The items under each domain describe the measures that are undertaken to ensure quality care in the intensive care unit. The table below explains the domains:

Table 1: Domains and their definitions

Domain (s)	Explanation
Patient and family centred decision making	The domain focuses on measures that include the patient, if able, and the family in the end-of-life care decision-making process and elicit and attend to the wishes and preferences of the patient and the family members.
Communication within the ICU team and with patients and families	The domain focuses on the exchange of information among the healthcare team, patients and their family members. It focuses on both verbal and non-verbal forms of communication, who communicates the information, how the information is communicated and when it is communicated.
Continuity of care	The domain focuses on measures that ensure that the ICU team are cooperatively involved in the ongoing healthcare management and are working towards a shared goal of care
Emotional and practical support for patients and families	The domain focuses on measures that ensure the emotional preparedness and readiness of the family, patient and caregivers and provide a medium to prepare and support them emotionally.
Symptom management and comfort	The domain focuses on measures aimed at controlling pain and other symptoms (such as agitation, shortness of breath and anxiety) that are encountered during the end of life. It also includes minimising aggressive adjuncts, reducing suffering and promoting comfort for the patient through professional/ nursing practices including both pharmacological and non-pharmacological means.

Spiritual care	Measures that place importance on spirituality, rituals and meaning at the end of life and support the spiritual journey and cultural practices of the patient and family members.
Modifying the environment	The domain focuses on measures that facilitates appropriate environment of care environment and highlights on changes that are relevant to ensure a serene, non-technical and less intensive care environment for the support of the dying patient and family. It focuses on the ICU space, facilities, lightning and other measures that create a conducive and friendly environment for patients and family members.

INSTRUCTIONS

The instrument is designed to measure the quality of care provided for patients and their family members after the withdrawal of life-sustaining treatment in the adult intensive care unit. The focus is on both the structures of care (e.g. facilities available) and processes of care. We ask you to assess the **relevance** and **clarity** of each item under the 7 domains using the rating scale shown below. Comments sections are created for each item for your revisions and inputs. Again, an overall comment box is provided for any additional missing items that are relevant to any of the domains.

Relevance: This rating criterion focuses on rating the items according to their relevance to measuring the quality of care after the withdrawal of life-sustaining treatments in the intensive care unit. Thus, whether items reflect the concepts involved and are relevant.

Clarity: This rating criterion also focuses on rating the various items under each domain according to their level of clarity. Thus, the item is well-written, distinct and at the appropriate reading level. This rating intends to eliminate terms ambiguous terms and words, complex and difficult items, jargon and value-laden words which may confuse participants.

Criteria for measuring the content validity (Relevance/ Clarity)	
Relevance	**Clarity**
1 [not relevant and should be deleted] **2** [Item needs major revision] **3** [Relevant but needs minor revision] **4** [very relevant]	**1** [Not clear and should be deleted] **2** [item needs some revision] **3** [clear but needs minor revision] **4** [very clear and concise]

Content Validity Testing

Content validity refers to the degree to which an assessment instrument is relevant to, and representative of the targeted construct it is designed to measure. Content validity testing includes an assessment of the relevance, representativeness and clarity of the items measuring a particular construct. In this study, the construct is quality end-of-life care after the withdrawal of treatment in the adult intensive care unit.

With reference to the criteria above rating scale (relevance/ clarity), kindly assess each of the items under each domain. Indicate your rating using the symbol "X" or "√". A comment section is provided for your suggested revision or input and any suggested items for the domain.

Note: In case an item needs revision, please indicate the suggested revision in the comment section.

Domain (s)	Items	Rating criteria	Rating Scale				Comments/ Suggested revision
			1	2	3	4	
Patient and family centred decision making	**1.** Recognise the patient and family as a unit of care	*Clarity*					
		Relevance					
	2. Assess the patient's and family's wishes and preferences, note and address any conflicts in decision-making within the family	*Clarity*					
		Relevance					
	3. Share with the patient and family information about the options of treatments	*Clarity*					
		Relevance					
	4. Ask the family if they want to be involved, their preferences of care and what the patient's wishes are and if there is any advanced directive in place	*Clarity*					
		Relevance					
	5. Engage the family in a meeting updating them on the process, current state and how it will unfold	*Clarity*					
		Relevance					
	6. Ask the family and identify the preferred choice to be the surrogate	*Clarity*					
		Relevance					
	7. Assure patients and families that their preferences will be incorporated into the decision-making process	*Clarity*					
		Relevance					
Domain	**Items**	***Rating Criteria***	**Rating scale**				**Comments/ Suggested revision**
			1	**2**	**3**	**4**	
	1. Meet as an interdisciplinary ICU team to discuss the patient's condition, clarify the goals of treatment, and identify the patient's and family's needs and preferences	*Clarity*					
		Relevance					

Communication with the ICU team and with patients and families	**2.** Address any disagreement among the ICU team before meeting the patient and family	*Clarity*					
		Relevance					
	3. Assess family readiness to receive before relaying information on the disease process	*Clarity*					
		Relevance					
	4. Reach a consensus with the family about what is happening to the patient and the goals of care	*Clarity*					
		Relevance					
	5. Provide clarity in communication about the burdens and benefits of critical care treatment	*Clarity*					
		Relevance					
	6. Keep communication consistent with an identified family member to ensure no communication breakdown and misinformation	*Clarity*					
		Relevance					
	7. Communicate all information to the patient and family in a clear, sensitive, unhurried manner, and in an appropriate setting	*Clarity*					
		Relevance					
	8. Keep the family informed of the patient's condition, any changes and interventions given	*Clarity*					
		Relevance					
	9. Assist family to understand patient's condition, prognosis, interventions given and impending death	*Clarity*					
		Relevance					
	10. Ensure the family has an understanding of the reason behind the withdrawing of the treatment	*Clarity*					
		Relevance					
	11. Meet the family on a regular basis to review the patient's condition and answer their questions	*Clarity*					
		Relevance					
	12. Clarify the family's understanding of the patient's conditions and goals of care at the beginning and at the end of each meeting	*Clarity*					
		Relevance					
	13. Prepare the family for the dying process	*Clarity*					
		Relevance					

Domain	Items	Rating criteria	Rating scale				Comment / Suggested revision
			1	2	3	4	
Continuity of care	**1.** Handover the plan of care, patient and family preference for the patient care to the oncoming ICU team	*Clarity*					
		Relevance					
	2. Liaise with other members of the ICU team to meet the identified needs of the patient and the family	*Clarity*					
		Relevance					
	3. Introduce other members of the team that will provide services such as palliative care, pastoral care and counselling to the ICU team, patient and family members	*Clarity*					
		Relevance					
Domain	**Items**	***Rating criteria***	**Rating scale**				**Comment / Suggested revision**
			1	**2**	**3**	**4**	
Emotional and practical support for patients and families	**1.** Elicit and attend to the emotional needs of the dying person and families	*Clarity*					
		Relevance					
	2. Provide the family with the needed assurance that their loved one will continue to receive good care	*Clarity*					
		Relevance					
	3. Healthcare provider available and have a debriefing session after the decision to withdraw treatment	*Clarity*					
		Relevance					
	4. Make counselling sessions readily available as an option for the family and caregivers	*Clarity*					
		Relevance					
	5. Encourage the family to share their feelings in the moment	*Clarity*					
		Relevance					
	6. Ask them how they are coping	*Clarity*					
		Relevance					
		Clarity					

	7. Facilitate strengthening patient-family relationships and communication	*Relevance*					
	8. Value and support the patient's and family's cultural traditions	*Clarity*					
		Relevance					
	9. Arrange for social support for patients without family or friends	*Clarity*					
		Relevance					
	10. Give the family time and space and allow them to go through the grieving process	*Clarity*					
		Relevance					
	11. Encourage the family to talk to the patient and speak in a voice the patient can recognise	*Clarity*					
		Relevance					
	12. Allow family members to hold the patient hands at the last moment	*Clarity*					
		Relevance					
	13. Allow the family to speak to the patient about what is happening outside the hospital	*Clarity*					
		Relevance					
	14. Treat the patient and family with respect and protect their dignity	*Clarity*					
		Relevance					
	15. Talk to the patient and families during procedures	*Clarity*					
		Relevance					
	16. Provide bereavement care to the family members after the death of the patient and send messages of condolences	*Clarity*					
		Relevance					
Domain	**Items**	***Rating criteria***	**Rating scale**				**Comment/ Suggested revision**
			1	**2**	**3**	**4**	
		Clarity					

Symptom management and comfort	**1.** Reduce the amount of unnecessary technical equipment to humanise patient care and promote comfort	*Relevance*					
	2. Eliminate unnecessary tests and procedures such as routine vital signs	*Clarity*					
		Relevance					
	3. Assess the patient's pain and administer necessary pain medication for pain relief	*Clarity*					
		Relevance					
	4. Assess and manage patient's symptoms such as agitation, restlessness and shortness of breath using standardise best practices for symptom management	*Clarity*					
		Relevance					
Symptom management and comfort	**5.** Attend to patient's appearance and hygiene needs by keeping the patient clean and well-kept in bed, providing mouth care and skin care	Clarity					
		Relevance					
	6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by the patient and family	*Clarity*					
		Relevance					
	7. Minimize noxious stimuli such as monitors and strong lights	*Clarity*					
		Relevance					
	8. Ensure the family's and healthcare providers' presence so the patient is not dying alone	*Clarity*					
		Relevance					
Domain	**Items**	**Rating criteria**	**Rating scale**				**Comment / Suggested revision**
			1	**2**	**3**	**4**	

Spiritual care	**1.** Assess and talk to patients and family about their religious or spiritual beliefs and cultural beliefs associated with death and dying on a regular basis	*Clarity*					
		Relevance					
	2. Attend to patients and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner	*Clarity*					
		Relevance					
	3. Align care to suit the spiritual and cultural beliefs of patients and their families	*Clarity*					
		Relevance					
	4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed with/in the plan of care	*Clarity*					
		Relevance					
	5. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	*Clarity*					
		Relevance					
	6. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	*Clarity*					
		Relevance					
Domain	**Items**	**Rating criteria**	**Rating Scale**				**Comments/ Suggested revision**
			1	**2**	**3**	**4**	
Modifying the environment	**1.** Create a calm, peaceful environment	*Clarity*					
		Relevance					
	2. Silence alarms on all monitors and equipment	*Clarity*					
		Relevance					
	3. Turn off machines completely	*Clarity*					
		Relevance					
	4. Move the patient to a more private and quiet area in the ICU to create space for the patient and family	*Clarity*					
		Relevance					
		Clarity					

	5. Have flexible and unrestricted visiting hours to reduce the distance between the patient and family	*Relevance*					
	6. Provide adequate time and space for the dying patient and family to say goodbye	*Clarity*					
		Relevance					
	7. allow the family to see their loved one in the last moment of life and be there until the end	*Clarity*					
		Relevance					
	8. Allow the family to bring in personal items that held particular memories or importance and were connected to the dying person	*Clarity*					
		Relevance					
	9. Draw nearby curtains to provide privacy for the patient and the family members	*Clarity*					
		Relevance					
	10. Allow the family to play the patient's favourite music or musical instrument	*Clarity*					
		Relevance					
	11. Place additional chairs around the bed to create space for the family	*Clarity*					
		Relevance					
	12. Adjust (dim or turn off) the lighting around the patient's bed space	*Clarity*					
		Relevance					

Overall Comments: An overall comment section is provided below for your additional input regarding any missing items that will be relevant to the study.

APPENDIX U

REVISIONS MADE FROM ROUND ONE FEEDBACK

Appendix X: Revised instrument based on comments on level of clarity and relevance and their I-CVI from Round one feedback

Domain	Item	Suggested changes	I-CVI
Patient and family centred decision making	1. Recognise the patient and family as a unit of care	No change	1.00
	2. Assess the patient's and family's wishes and preferences, note and address any conflicts in decision-making within the family	No change	1.00
	3. Share with the patient and family information about the options of treatments	Share with the patient and family information about the options of treatments **or lack of treatment options at the earliest stage if possible**	1.00
	4. Ask the family if they want to be involved, their preferences of care and what the patient's wishes are and if there is any advanced directive in place	Ask the family about their preferences of care and if patients have 'living wills' in place and respect patients' wishes	1.00
	5. Engage the family in a meeting updating them on the process, current state and how it will unfold	**Schedule a regular** meeting with the multidisciplinary team and families, updating them on the patients' condition and the likely outcome	1.00
	6. Ask the family and identify the preferred choice to be the surrogate	Ask the family to identify **a designated family member or next of Kin to liaise with or to whom all information will be relayed**	1.00
	7. Assure patients and families that their preferences will be incorporated into the decision-making process	Assure patient and family that their **surrogate** preferences will be incorporated into the decision-making process	0.89
Communication among the ICU team and with patients and families	1. Meet as an interdisciplinary ICU team to discuss the patient's condition, clarify the goals of treatment, and identify the patient's and family's needs and preferences	No change	1.00
	2. Address any disagreement among the ICU team before meeting the patient and family	No change	1.00
	3. Assess family readiness to receive before relaying information on the disease process	**Enquire about patient and family readiness** to receive before relaying information on the disease process **and include a psychologist**	0.89
	4. Reach a consensus with the family about what is happening to the patient and the goals of care	Reach a consensus with the **patient and/ or** family about the clinical state of the patients, treatment plans and the goals of care	1.00

	5. Provide clarity in communication about the burdens and benefits of critical care treatment	Communicate clearly about the burdens and benefits of critical care treatment	1.00
	6. Keep communication consistent with an identified family member to ensure no communication breakdown and misinformation	Keep communication consistent with an identified **surrogate** to **prevent** communication breakdown and misinformation	1.00
	7. Communicate all information to the patient and family in a clear, sensitive, unhurried manner, and in an appropriate setting	No change	1.00
	8. Keep the family informed of the patient's condition, any changes and interventions given	Keep the family informed of the patients' conditions, any changes and interventions given **via the designated family members or next of Kin**	1.00
	9. Assist family to understand patient's condition, prognosis, interventions given and impending death	No change	1.00
	10. Ensure the family has an understanding of the reason behind the withdrawing of the treatment	No change	1.00
	11. Meet the family on a regular basis to review the patient's condition and answer their questions	No change	1.00
	12. Clarify the family's understanding of the patient's conditions and goals of care at the beginning and at the end of each meeting	No change	0.89
	13. Prepare the family for the dying process	**Delete,** similar to modifying environment under items 6 and 7	0.78
Continuity of care	1. Handover the plan of care, patient and family preference for the patient care to the oncoming ICU team	Handover ***patient's Care Plan*** and family preferences **to the other members of the ICU team and document**	1.00
	2. Liaise with other members of the ICU team to meet the identified needs of the patient and the family	Liaise with other members of the ICU team **[such as psychologists, nurses, and physicians]** to meet the identified needs of the patients and the families	0.89
	3. Introduce other members of the team that will provide services such as palliative care, pastoral care and counselling to the ICU team, patient and family members	No change	1.00
Emotional and practical	1. Elicit and attend to the emotional needs of the dying person and families	Elicit and attend to the emotional needs of the dying patients and families **and refer to an expert where necessary**	1.00
	2. Provide the family with the needed assurance that their loved one will continue to receive good care	No change	1.00

support for patients and families	3. Healthcare provider available and have a debriefing session after the decision to withdraw treatment	Healthcare provider **[attending physician and/or nurse] should** be available for a debriefing session with families after the decision to withdraw treatment	0.78
	4. Make counselling sessions readily available as an option for the family and caregivers	**Merge 4 and 6**	0.89
	5. Encourage the family to share their feelings in the moment	Encourage the family to share their feelings at each encounter or session with the healthcare team	1.00
	6. Ask them how they are coping	**Merge 4 and 6** Ask the families how they are coping and arrange for counselling sessions to be readily available as an option for the family	0.89
	7. Facilitate strengthening patient-family relationships and communication	Facilitate strengthening **of** patient-family relationships and communication	0.78
	8. Value and support the patient's and family's cultural traditions	Value and support the patients' and families' cultural traditions **provided such traditions are non-hazardous to the patients and the hospital**	1.00
	9. Arrange for social support for patients without family or friends	Arrange for social support for patients without family	1.00
	10. Give the family time and space and allow them to go through the grieving process	No change	0.89
	11. Encourage the family to talk to the patient and speak in a voice the patient can recognise	Encourage and **support** the family **to touch patients**, talk to the patients and speak in a voice the patients can recognise	1.00
	12. Allow family members to hold the patient hands at the last moment	Allow family members to hold the patients' hands, **kiss the forehead or stroke the hair or hands and hug the patients if preferred**	1.00
	13. Allow the family to speak to the patient about what is happening outside the hospital	**Encourage** the families to speak to the patients about what is happening outside the hospital environment **and avoid stressful conversations**	0.89
	14. Treat the patient and family with respect and protect their dignity	No change	1.00
	15. Talk to the patient and families during procedures	**Communicate** with patients and families **on** procedures **performed when possible**	1.00

	16. Provide bereavement care to the family members after the death of the patient and send messages of condolences	No change	0.89
Symptom management and comfort	1. Reduce the amount of unnecessary technical equipment to humanise patient care and promote comfort	No change	1.00
	2. Eliminate unnecessary tests and procedures such as routine vital signs	Eliminate unnecessary tests and **invasive** procedures such as **taking blood for arterial blood gas monitoring**	0.89
	3. Assess the patient's pain and administer necessary pain medication for pain relief		1.00
	4. Assess and manage patient's symptoms such as agitation, restlessness and shortness of breath using standardise best practices for symptom management	No change	1.00
	5. Attend to patient's appearance and hygiene needs by keeping the patient clean and well-kept in bed, providing mouth care and skin care	No change	1.00
	6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by the patient and family	No change	1.00
	7. Minimize noxious stimuli such as monitors and strong lights	Merge with item 2 under Domain: Environment / add item to domain: modifying the environment	1.00
	8. Ensure the family's and healthcare providers' presence so the patient is not dying alone	No change	1.00
Spiritual care	1. Assess and talk to patients and family about their religious or spiritual beliefs and cultural beliefs associated with death and dying on a regular basis	**Enquire** and talk to patient and family about their religious and cultural beliefs associated with death and dying on a regular basis	1.00
	2. Attend to patients and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner	No change	1.00
	3. Align care to suit the spiritual and cultural beliefs of patients and their families	No change	1.00
	4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed with/in the plan of care	Allow the family members to observe their last prayers and perform their rituals as discussed and agreed upon in the plan of care	1.00

	5. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	No change	1.00
	6. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	**Delete repetition; item 5**	1.00
Modifying the environment	1. Create a calm, peaceful environment	No change	1.00
	2. Silence alarms on all monitors and equipment	Replace with item 7 under symptom management and comfort Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible	0.78
	3. Turn off machines completely	Turn off machines **[such as ventilator/ dialysis/ monitors]** completely	0.67
	4. Move the patient to a more private and quiet area in the ICU to create space for the patient and family	No change	1.00
	5. Have flexible and unrestricted visiting hours to reduce the distance between the patient and family	**Allow** flexible and unrestricted visiting times to reduce the distance between the patient and family and communicate	0.89
	6. Provide adequate time and space for the dying patient and family to say goodbye	Arrangement change; use as item 11 Provide adequate **visiting** time and space for the dying patients and families to say goodbye	1.00
	7. Allow the family to see their loved one in the last moment of life and be there until the end	No change	1.00
	8. Allow the family to bring in personal items that held particular memories or importance and were connected to the dying person	No change	1.00
	9. Draw nearby curtains to provide privacy for the patient and the family members	No change	1.00
	10. Allow the family to play the patient's favourite music or musical instrument	No change	0.89
	11. Place additional chairs around the bed to create space for the family	Place additional chairs around the bed to create space for the family members **or as preferred for the families**	1.00
	12. Adjust (dim or turn off) the lighting around the patient's bed space	No change	1.00

APPENDIX V

DELPHI ROUND TWO

Dear Valued Expert,

Thank you for your willingness to participate in this study.

This is the **second** and **final round** of the Delphi study. In this round, your comments, additions, and suggested revisions from **round one** were used to revise the provisional instrument.

Clarity Items were reworded as indicated for easy understanding and to be devoid of any ambiguities. The researcher incorporated all the comments from the various experts. The researcher and supervisor also discussed the comments thoroughly.

Relevancy: Validity is defined as the extent to which any instrument measures what it is intended to measure. Content validity refers to the adequacy with which a measure assesses the domain of interest. In this study, the content validity of the instrument refers to the extent to which the domains and items assess the quality of care provided for patients and their families after the withdrawal of treatment in the adult ICU.

The content validity of each item is quantified using the content validity index (**CVI**). The content validity index was calculated for each item under each domain. The item content validity index **(I-CVI)** was calculated by dividing the number of items judged as 3 [Relevant but needs minor revision] or 4 [very relevant] by the number of content experts.

In this study, judgement on each item's content validity (I-CVI) was made as follows: if the I-CVI is **higher than 0.79 or 79 percent** (i.e., 80 percent agreement or higher), **the item was considered appropriate**, as proposed by Davis (1992) and Abdollahpour *et al*. (2010). If the I-CVI is **between 70 percent (0.70) and 79 percent (0.79), the item needs revision**; if it is less than 70 percent, the item is eliminated.

From the round one results, all items except **four** had an **I-CVI below 80** percent (0.80). These four items are presented for further revision in **Section A**.

In Section B, new items suggested for inclusion from Round One are also presented for your expert comments and ratings using the relevance rating scale.

In Section C, a draft of the measuring instrument as revised according to the ratings and experts' comments is presented in a table. You are required to evaluate the instrument in terms of its comprehensiveness to measure the quality of care provided for patients and their families after treatment withdrawal in the adult intensive care unit.

Section A

This section focuses on items that require further revision and rating. The items have been modified based on the various comments. *With reference to the criteria**: 1*** [not relevant and should be deleted], **2** [Item needs major revision]**, 3** [Relevant but needs minor revision]**; and 4** [very relevant] *kindly reassess each of the items. Indicate your rating using the symbol **"X" or "√".***

Domain	Items	Relevance Rating			
		1	2	3	4
Emotional and practical support for patients and families	Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment*				
	Facilitate strengthening of patient-family relationships and communication*				
Modifying the environment	Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible *				
	Turn off machines [such as ventilator/ dialysis/ monitors] completely according to families' wishes*				

Note: Items marked **(*)** recorded a level of agreement on relevance below 80% (0.80 **I-CI**). A further rating on their relevance will be required for their inclusion or exclusion**.**

Section B

This section rates the relevance of the **suggested items** for inclusion and the possible domain the items should fall under [**D1**: *Patient and family decision making*; **D2**: *Communication*; **D3**: *Continuity of care*; **D4**: *Emotional and practical support for patients and families*; **D5**: *Symptom management and comfort*; **D6**: *Spiritual care*; **D7**: *Modifying the environment*]. *Indicate your rating using the symbol **"X" or "√".***

New Items suggested	Relevance Rating				Possible Domain {e.g. D2}	Comments / Suggestions
	1	2	3	4		
Discuss with patients and families who will take patients belonging or valuables, document and allow the families to sign						
Speak to patients and families about organ donation, if there is one, and respect the wishes of patients and families						
Discuss with patients and families the funeral parlour they intend to use						

Encourage and allow families if they are comfortable to take part in the direct care of the patients under the supervision of healthcare workers						

Section C

This section presents a draft of the measuring instrument as revised using the suggested comments from round one of the Delphi study. A total of **62 items** organised under **7 domains** emerged. The section also requires you to judge whether the instrument items and any of their dimensions are a complete and comprehensive sample of the content as far as the definitions of the domains and their dimensions are concerned. Please indicate [**1-** Yes, I agree OR **2** – I disagree] under the section 'Comprehensive of instrument dimensions'.

*Indicate your rating using the symbol **"X" or "√" in the box provided against the options (Yes or No)***

Domain 1: Patient and family-centred care decision making

Items	**Comprehensiveness of instrument dimensions**	
	Indicate Yes or No using **'X'** or **"√"**	
1. Recognise the patients' and families' as a unit of care		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and overall instrument
2. Assess the patients' and families' wishes and preferences, note and address any conflicts in decision-making within the families		
3. Share with the patients and families information about the options of treatments or lack of treatment options at the earliest stage if possible		
4. Ask the families and/or patients about their preferences of care and if patients have 'living wills' or advance directive in place and respect patients' wishes stated in the living will or advance directive		***No***, I disagree that the domain and its items are complete and comprehensive for the instrument
5. Schedule a regular meeting with the Multidisciplinary team and families, updating them on the patients' condition and the likely outcome	***Any comments:***	
6. Ask the patients and families to identify a designated family member or next of Kin to liaise with or to whom all information will be relayed		

7. Assure patients and families that their surrogate preferences will be incorporated into the decision-making process	

Domain 2: Communication among the ICU team and with patients and families

Items	**Comprehensive of the items for the domain**	
	Indicate Yes or No using **'X'** or **"√"**	
1. Meet frequently as an interdisciplinary ICU team to discuss the patients' conditions, clarify the goals of treatment, and identify the patients' and families' needs and preferences		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and overall instrument
2. Address any disagreement among the ICU team before meeting the patients and families		
3. Enquire about patients' and families' readiness to receive before relaying information on the disease process and include a psychologist who will assist the families with coping with the diagnosis of the patients		***No***, I disagree that the domain and its items are complete and comprehensive for the domain and overall instrument
4. Reach a consensus with the patients and/ or families about the clinical state of the patients, treatment plans and the goals of care	***Any comments:***	
5. Communicate clearly about the burdens and benefits of critical care treatment		
6. Keep communication consistent with an identified surrogate to prevent communication breakdown and misinformation		
7. Communicate all information to the patients and families in a clear, sensitive, unhurried manner, and in an appropriate setting		
8. Keep the families informed of the patients' conditions, any changes and interventions given via the designated family members or next of Kin		
9. Assist families to understand patients' conditions, prognoses, interventions given and impending death		
10. Ensure the families have an understanding of the reason behind the withdrawing of the treatment		
11. Meet families regularly to review the patient's condition and answer their questions		
12. Clarify the families' understanding of the patient's conditions and goals of care at the beginning of each meeting		
13. Clarify the families' understanding of the patient's conditions and goals of care at the end of each meeting		

Domain 3: Continuity of care

Items	Comprehensive of the items for the domain	
	Indicate Yes or No using **'X'** or **"√"**	
1. Handover patients' Care Plans and family preferences to the other members of the ICU team and document		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and overall instrument
2. Liaise with other members of the ICU team [such as psychologists, nurses, and physicians] to meet the identified needs of the patients and the families		***No***, I disagree that the domain and its items are complete and comprehensive for the domain and overall instrument
3. Introduce other members of the team that will provide services such as palliative care, pastoral care and counselling to the ICU team, patients and family members	***Any comment(s):***	

Domain 4: Emotional and practical support for patients and families

Items	Comprehensive of the items for the domain	
	Indicate Yes or No using **'X'** or **"√"**	
1. Elicit and attend to the emotional needs of the dying patients and families and refer to an expert where necessary		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and overall instrument
2. Provide the families with the needed assurance that their loved one will continue to receive good care		
3. Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment*		***No***, I disagree that the domain and its items are complete and comprehensive for the domain and overall instrument
4. Encourage the families to share their feelings at each encounter or session with the healthcare team		
5. Ask the families how they are coping and arrange for counselling sessions to be readily available as an option for the families	***Any comments:***	
6. Facilitate strengthening of patient-family relationships and communication*		
7. Value and support the patients' and families' cultural traditions provided such traditions are non-hazardous to the patients and the hospital		
8. Arrange for social support for patients without families		
9. Give the families time and space and allow them to go through the grieving process		

10. Encourage and support the families to touch patients, talk to the patients and speak in a voice the patients can recognise	
11. Allow family members to hold the patients' hands, kiss the forehead or stroke the hair or hands and hug the patients if preferred	
12. Encourage the families to speak to the patients about what is happening outside the hospital environment and avoid stressful conversations	
13. Treat the patient and family with respect and protect their dignity	
14. Communicate with patients and families on procedures performed when possible	
15. Provide bereavement care to the family members after the death of the patient and send messages of condolences	

Note: Items marked (*****) recorded a level of agreement on relevance below 80% (0.80 **I-CI**). A further rating on their relevance will be required for their inclusion or exclusion**. Details are provided in Section A.**

Domain 5: Symptom management and comfort

Items	**Comprehensive of the items for the domain**	
	Indicate Yes or No using **'X'** or **"√"**	
1. Reduce the amount of unnecessary technical equipment to humanise patient care and promote comfort		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and overall instrument
2. Eliminate unnecessary tests and invasive procedures such as taking blood for arterial blood gas monitoring		
3. Assess the patients pain and administer necessary pain relieving medications and other non-pharmacological interventions where possible		***No***, I disagree that the domain and its items are complete and comprehensive for the domain and overall instrument
4. Assess and manage patients for common symptoms such as agitation and restlessness using standardised best practices for symptom management		
5. Attend to patients' appearance and hygiene needs by keeping the patients clean and well-kept in bed, providing mouth care and skin care	**Any comments:**	
6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by the patients and families		
7. Ensure the families and/ or healthcare providers' presence so the patients are not dying alone		

Domain 6: Spiritual care

Items	Comprehensive of the items for the domain	
	Indicate Yes or No using **'X'** or **"√"**	
1. Enquire and talk to patients and families about their religious and cultural beliefs associated with death and dying on a regular basis		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and overall instrument
2. Attend to patients' and families' needs for closure of important relationships, spirituality and transcendence in a sensitive manner		***No***, I disagree that the domain and its items are complete and comprehensive for the domain and overall instrument
3. Align care to suit the spiritual and cultural beliefs of patients and their families		
4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed upon in the plan of care	**Any comments:**	
5. Allow the religious leaders at the bedside to perform their rituals and last rites in accordance with their religious practices		

Domain 7: Modifying the environment

Items	Comprehensive of the items for the domain	
	Indicate Yes or No using **'X'** or **"√"**	
1. Create a calm, peaceful environment		***Yes,*** I agree that the domain and its items are complete and comprehensive for the domain and the overall instrument
2. Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible *		
3. Turn off machines [such as ventilator/ dialysis/ monitors] completely according to families' wishes*		
4. Move the patient to a more private and quiet area in the ICU to create space for the patients and families		***No***, I disagree that the domain and its items are complete and comprehensive for the domain and the overall instrument
5. Allow flexible and unrestricted visiting times to reduce the distance between the patients and families and communicate with them that it is open visiting hours		
6. Allow the families to bring in personal items that held particular memories or importance and were connected to the dying person		
7. Draw nearby curtains to provide privacy for the patients and the family members or as preferred for the families	***Any comments:***	
8. Allow the families to play the patients' favourite music in a low tone to avoid disturbing other patients		

9. Place additional chairs around the bed to create space for the family members or as preferred for the families	
10. Adjust (dim or turn off) the lighting around the patients' bed space	
11. Provide adequate visiting time and space for the dying patients and families to say goodbye	
12. Allow the families to see their loved ones in the last moment of life and be there until the end	

Note: Items marked (*) recorded a level of agreement on relevance below 80% (0.80 **I-CI**). A further rating on their relevance will be required for their inclusion or exclusion**. Details are provided in Section A.**

Overall, do you agree that the instrument's domains and items, as well as any of its dimensions, are a complete and comprehensive sample for measuring the quality of care for patients and their families after the withdrawal of treatment in the adult intensive care unit? *Indicate your level of agreement using the symbol "X" or "√" in the box provided below.*

	Yes, I agree
	No, I disagree

Comments if any

APPENDIX W

FINAL VERSION OF THE INSTRUMENT AND I-CVIs

Table: Final revised version of the instrument (64 items under 7 domains) and I-CVIs

Domain	Items	I-CVI Relevance
Patient and family centred decision making	1. Recognise the patient and family as a unit of care	1.00
	2. Assess the patient's and family's wishes and preferences, note and address any conflicts in decision-making within the family	1.00
	3. Share with the patient and family information about the options of treatments or lack of treatment options at the earliest stage if possible	1.00
	4. Ask the family about their preferences of care and if patients have 'living wills' in place and respect patients' wishes	1.00
	5. Schedule a regular meeting with the multidisciplinary team and families, updating them on the patients' condition and the likely outcome	1.00
	6. Ask the family to identify a designated family member or next of Kin to liaise with or to whom all information will be relayed	1.00
	7. Assure patient and family that their surrogate preferences will be incorporated into the decision-making process	0.89
	8. Discuss with the family who will take patient's belongings, document and counter sign together with the family	0.89
	9. Speak to the patient and/or family about organ donation where possible and respect their wishes	0.89
Communication among the ICU team and with patients and families	1. Meet as an interdisciplinary ICU team to discuss the patient's condition, clarify the goals of treatment, and identify the patient's and family's needs and preferences	1.00
	2. Address any disagreement among the ICU team before meeting the patient and family	1.00
	3. Enquire about patient and family readiness to receive before relaying information on the disease process and include a psychologist	0.89
	4. Reach a consensus with the patient and/ or family about the clinical state of the patients, treatment plans and the goals of care	1.00
	5. Communicate clearly about the burdens and benefits of critical care treatment	1.00
	6. Keep communication consistent with an identified surrogate to prevent communication breakdown and misinformation	1.00
	7. Communicate all information to the patient and family in a clear, sensitive, unhurried manner, and in an appropriate setting	1.00
	8. Keep the family informed of the patients' conditions, any changes and interventions given via the designated family members or next of Kin	1.00
	9. Assist family to understand patient's condition, prognosis, interventions given and impending death	1.00
	10. Ensure the family has an understanding of the reason behind the withdrawing of the treatment	1.00

	11. Meet the family on a regular basis to review the patient's condition and answer their questions	1.00
	12. Clarify the family's understanding of the patient's conditions and goals of care at the beginning and at the end of each meeting	0.89
Continuity of care	1. Handover *patient's Care Plan* and family preferences to the other members of the ICU team and document	1.00
	2. Liaise with other members of the ICU team [such as psychologists, nurses, and physicians] to meet the identified needs of the patients and the families	0.89
	3. Introduce other members of the team that will provide services such as palliative care, pastoral care and counselling to the ICU team, patient and family members	1.00
Emotional and practical support for patients and families	1. Elicit and attend to the emotional needs of the dying patients and families and refer to an expert where necessary	1.00
	2. Provide the family with the needed assurance that their loved one will continue to receive good care	1.00
	3. Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment	1.00
	4. Encourage the family to share their feelings at each encounter or session with the healthcare team	1.00
	5. Ask the families how they are coping and arrange for counselling sessions to be readily available as an option for the family	0.89
	6. Facilitate strengthening of patient-family relationships and communication	0.89
	7. Value and support the patients' and families' cultural traditions provided such traditions are non-hazardous to the patients and the hospital	1.00
	8. Arrange for social support for patients without family	0.89
	9. Give the family time and space and allow them to go through the grieving process	0.89
	10. Encourage and support the family to touch patients, talk to the patients and speak in a voice the patients can recognise	1.00
	11. Allow family members to hold the patients' hands, kiss the forehead or stroke the hair or hands and hug the patients if preferred	1.00
	12. Encourage the families to speak to the patients about what is happening outside the hospital environment and avoid stressful conversations	0.89
	13. Treat the patient and family with respect and protect their dignity	1.00
	14. Communicate with patients and families on procedures performed when possible	1.00
	15. Provide bereavement care to the family members after the death of the patient and send messages of condolences	0.89
	16. Encourage and allow the family (if they are comfortable) to take part in the direct care of the patient under the supervision of the healthcare workers	1.00
	1. Reduce the amount of unnecessary technical equipment to humanise patient care and promote comfort	1.00
	2. Eliminate unnecessary tests and invasive procedures such as taking blood for arterial blood gas monitoring	0.89

Symptom management and comfort	3. Assess the patients pain and administer necessary pain relieving medications and other non-pharmacological interventions where possible	1.00
	4. Assess and manage patient's symptoms such as agitation, restlessness and shortness of breath using standardise best practices for symptom management	1.00
	5. Attend to patient's appearance and hygiene needs by keeping the patient clean and well-kept in bed, providing mouth care and skin care	1.00
	6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by the patient and family	1.00
	7. Ensure the family's and healthcare providers' presence so the patient is not dying alone	1.00
Spiritual care	1. Enquire and talk to patient and family about their religious and cultural beliefs associated with death and dying on a regular basis	1.00
	2. Attend to patients and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner	1.00
	3. Align care to suit the spiritual and cultural beliefs of patients and their families	1.00
	4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed upon in the plan of care	1.00
	5. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices	1.00
Modifying the ICU environment	1. Create a calm, peaceful environment	1.00
	2. Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible	1.00
	3. Turn off machines [such as ventilator/ dialysis/ monitors] completely	1.00
	4. Move the patient to a more private and quiet area in the ICU to create space for the patient and family	1.00
	5. Allow flexible and unrestricted visiting times to reduce the distance between the patient and family and communicate	0.89
	6. Provide adequate visiting time and space for the dying patients and families to say goodbye	1.00
	7. Allow the family to see their loved one in the last moment of life and be there until the end	1.00
	8. Allow the family to bring in personal items that held particular memories or importance and were connected to the dying	1.00
	9. Draw nearby curtains to provide privacy for the patient and the family members	1.00
	10. Allow the family to play the patient's favourite music or musical instrument	0.89
	11. Place additional chairs around the bed to create space for the family members or as preferred for the families	1.00
	12. Adjust (dim or turn off) the lighting around the patient's bed space	1.00

APPENDIX Y

ITERATIVE SUMMARY OF CHANGES MADE TO THE SURVEY INSTRUMENT

Version	**Reviewers**	**Total number of domains and items in the beginning/ Total number of domains and items in the end**	**Substantial (Important changes)**
First version	Three-member panel [Researcher, supervisor and content expert]	7 domains plus several themes-subthemes (143) / 7 (65)	-Duplicate items deleted - Items merged and reworded -Items rearranged to the most appropriate domains
Version 2	Delphi panel of experts (n = 9)	7(65) / 7(61)	-Repeated item deleted -Two items merged into one -Four new items suggested for inclusion
Third and final version	Delphi panel of experts (n = 9)	7(61)/ 7 (64)	-Three out of the four items suggested added based on their I-CVIs

APPENDIX Z

FINAL VERSION OF INSTRUMENT

Instrument to measure the quality of care after the withdrawal of treatment in the adult intensive care unit

Domain	Items
Patient and family centred decision making	1. Recognise the patient and family as a unit of care
	2. Assess the patient's and family's wishes and preferences, note and address any conflicts in decision-making within the family
	3. Share with the patient and family information about the options of treatments or lack of treatment options at the earliest stage if possible
	4. Ask the family about their preferences of care and if patients have 'living wills' in place and respect patients' wishes
	5. Schedule a regular meeting with the multidisciplinary team and families, updating them on the patients' condition and the likely outcome
	6. Ask the family to identify a designated family member or next of Kin to liaise with or to whom all information will be relayed
	7. Assure patient and family that their surrogate preferences will be incorporated into the decision-making process
	8. Discuss with the family who will take patient's belongings, document and counter sign together with the family
	9. Speak to the patient and/or family about organ donation where possible and respect their wishes
Communication among the ICU team and with patients and families	1. Meet as an interdisciplinary ICU team to discuss the patient's condition, clarify the goals of treatment, and identify the patient's and family's needs and preferences
	2. Address any disagreement among the ICU team before meeting the patient and family
	3. Enquire about patient and family readiness to receive before relaying information on the disease process and include a psychologist
	4. Reach a consensus with the patient and/ or family about the clinical state of the patients, treatment plans and the goals of care
	5. Communicate clearly about the burdens and benefits of critical care treatment
	6. Keep communication consistent with an identified surrogate to prevent communication breakdown and misinformation
	7. Communicate all information to the patient and family in a clear, sensitive, unhurried manner, and in an appropriate setting
	8. Keep the family informed of the patients' conditions, any changes and interventions given via the designated family members or next of Kin
	9. Assist family to understand patient's condition, prognosis, interventions given and impending death
	10. Ensure the family has an understanding of the reason behind the withdrawing of the treatment
	11. Meet the family on a regular basis to review the patient's condition and answer their questions
	12. Clarify the family's understanding of the patient's conditions and goals of care at the beginning and at the end of each meeting
	1. Handover patient's Care Plan and family preferences to the other members of the ICU team and document
	2. Liaise with other members of the ICU team [such as psychologists, nurses, and physicians] to meet the identified needs of the patients and the families

Continuity of care	3. Introduce other members of the team that will provide services such as palliative care, pastoral care and counselling to the ICU team, patient and family members
Emotional and practical support for patients and families	1. Elicit and attend to the emotional needs of the dying patients and families and refer to an expert where necessary
	2. Provide the family with the needed assurance that their loved one will continue to receive good care
	3. Healthcare provider [attending physician and/or nurse] should be available for a debriefing session with families after the decision to withdraw treatment
	4. Encourage the family to share their feelings at each encounter or session with the healthcare team
	5. Ask the families how they are coping and arrange for counselling sessions to be readily available as an option for the family
	6. Facilitate strengthening of patient-family relationships and communication
	7. Value and support the patients' and families' cultural traditions provided such traditions are non-hazardous to the patients and the hospital
	8. Arrange for social support for patients without family
	9. Give the family time and space and allow them to go through the grieving process
	10. Encourage and support the family to touch patients, talk to the patients and speak in a voice the patients can recognise
	11. Allow family members to hold the patients' hands, kiss the forehead or stroke the hair or hands and hug the patients if preferred
	12. Encourage the families to speak to the patients about what is happening outside the hospital environment and avoid stressful conversations
	13. Treat the patient and family with respect and protect their dignity
	14. Communicate with patients and families on procedures performed when possible
	15. Provide bereavement care to the family members after the death of the patient and send messages of condolences
	16. Encourage and allow the family (if they are comfortable) to take part in the direct care of the patient under the supervision of the healthcare workers
Symptom management and comfort	1. Reduce the amount of unnecessary technical equipment to humanise patient care and promote comfort
	2. Eliminate unnecessary tests and invasive procedures such as taking blood for arterial blood gas monitoring
	3. Assess the patients pain and administer necessary pain relieving medications and other non-pharmacological interventions where possible
	4. Assess and manage patient's symptoms such as agitation, restlessness and shortness of breath using standardise best practices for symptom management
	5. Attend to patient's appearance and hygiene needs by keeping the patient clean and well-kept in bed, providing mouth care and skin care
	6. Use non-pharmacological measures [such as turning the patient regularly, pressure area care and skin care] to maximise comfort as appropriate and desired by the patient and family
	7. Ensure the family's and healthcare providers' presence so the patient is not dying alone
Spiritual care	1. Enquire and talk to patient and family about their religious and cultural beliefs associated with death and dying on a regular basis
	2. Attend to patients and family needs for closure of important relationships, spirituality and transcendence in a sensitive manner
	3. Align care to suit the spiritual and cultural beliefs of patients and their families
	4. Allow the family members to observe their last prayers and perform their rituals as discussed and agreed upon in the plan of care

	5. Allow the priest and religious leader at the bedside to perform their rituals and last rites in accordance with their cultural practices
Modifying the ICU environment	1. Create a calm, peaceful environment
	2. Minimize noxious stimuli such as noisy alarms on the monitors and bright lights where possible
	3. Turn off machines [such as ventilator/ dialysis/ monitors] completely
	4. Move the patient to a more private and quiet area in the ICU to create space for the patient and family
	5. Allow flexible and unrestricted visiting times to reduce the distance between the patient and family and communicate
	6. Provide adequate visiting time and space for the dying patients and families to say goodbye
	7. Allow the family to see their loved one in the last moment of life and be there until the end
	8. Allow the family to bring in personal items that held particular memories or importance and were connected to the dying
	9. Draw nearby curtains to provide privacy for the patient and the family members
	10. Allow the family to play the patient's favourite music or musical instrument
	11. Place additional chairs around the bed to create space for the family members or as preferred for the families
	12. Adjust (dim or turn off) the lighting around the patient's bed space

APPENDIX AA

HUMAN RESEARCH ETHICS COMMITTEE (HREC) CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Mr Emmanuel Korsah

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M210229

NAME: (Principal Investigator)	Mr Emmanuel Korsah
DEPARTMENT:	Nursing Education - School of Therapeutic Sciences Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult intensive care unit
DATE CONSIDERED:	26/02/2021
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Shelley Schmollgruber
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	17/09/2021

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

Principal Investigator Signature

21/09/2021
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX AB

SUDY SETTING PERMISSION TO CONDUCT RESEARCH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA
MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Office of the Nursing Director
Enquiries: Mr. Moses Tshabuse
Tel: (011) 488-4558
Email: Moses.Tshabuse@gauteng.gov.za
22 September 2021

GP_202107_010

Dear Mr. Emmanuel Kwame Korsah

STUDY TITLE: Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult intensive care unit

Permission is granted for you to conduct the above-mentioned study as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic Hospital will not anyway incur or inherit costs as 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 HOD 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~~

Signed by:Motlagomang Martha Pule
Signed at:2021-09-22 15:51:19 +02:00
Reason:Witnessing Motlagomang Martha

Ms. M Pule
Nursing Director

Approved/~~not approved~~

Signed by:Gladys Magugudi Bogoshi
Signed at:2021-09-22 22:47:46 +02:00
Reason:Witnessing Gladys Magugudi Bo

Ms. G.M Bogoshi
Chief Executive Officer

APPENDIX AC

LETTER OF APPROVAL OF STUDY TITLE

UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

Private Bag 3 Wits, 2050

Tel: 02711 7172076

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

23 September 2020
Person No: 1636507
PAG

Mr EK Korsah
DEPARTMENT OF NURSING EDUCATION
UNIVERSITY OF THE WITWATERSRAND
Parktown
2193
South Africa

Dear Mr Emmanuel Korsah

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled *Development of an instrument to measure the quality of care after the withdrawal of life-sustaining treatment in the adult intensive care unit.* 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