NURSES’ EXPERIENCES OF END-OF-LIFE CARE IN THE INTENSIVE CARE UNIT: AN INTEGRATIVE LITERATURE REVIEW

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DECLARATION

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

....

Signed at Johannesburg

On the .... day of ...., 2019

Protocol number W-CBP-180508-01

DEDICATION

I dedicate this work to my brother and close friend,

Mr. Daniel Korsah

(Mining Engineer- Gold Fields Limited -Ghana)

PRESENTATIONS ARISING FROM THIS STUDY

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ABSTRACT

Background: End-of-life (EOL) care has become a significant area of expertise in the intensive care unit. The current multi-cultural society and growing ageing population, characterised by life-threatening illnesses and chronic conditions, makes the provision of high quality end-of-life care within the intensive care unit a stressful and challenging process. Nevertheless, intensive care nurses remain the frontline caregivers of end-of-life care for patients and their families. Nurses have described end-of-life care as difficult and demanding work, yet, they have also described their experiences of providing end-of-life care as rewarding and a valued opportunity to provide special nursing care.

Purpose: The purpose of the integrative review is to gather evidence related to nurses experiences in the provision of end-of-life care to patients and families in the intensive care unit.

Design: An integrative review using the Whittemore and Knafl (2005) framework. These stages included problem identification, literature search, data evaluation, data analysis and presentation of findings.

Methods: a comprehensive literature search was performed using PubMed, SCOPUS, ProQuest, MEDLINE, Cumulative Index to Nursing and Allied Health Literature, Nursing academic search databases and Goggle Scholar to locate primary studies, both published and unpublished, in English from January 2007 to June 2018. A total of 1078 papers were screened, with 86 read in-depth and 38 selected for this review based on the eligibility criteria.

Results: Five themes emerged from the review. Doing the right thing; Emotional labour, conflicts and uncertainties; Remaining committed and develop coping strategies; Barriers to the provision of EOL care; Facilitators of EOL care in the ICU.

Key words: Nurses, intensive care nurses, end-of-life care, intensive care unit, experiences, terminal care, withdrawal of treatment

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TABLE OF CONTENTS

CHAPTER TWO: LITERATURE SEARCH AND DATA COLLECTION

CHAPTER THREE: DATA EVALUATION

CHAPTER SIX: DISCUSSION, STRENGTH AND LIMITATIONS, AND IMPLICATION FOR PRACTICE

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

DNR	-	Do-not-resuscitate
EOL	-	End-of-life
ICU	-	Intensive Care Unit
SUPPORT	-	Study to Understand Prognosis and Preference for Outcomes and Risks of Treatment

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

The quest to ensure quality end-of-life (EOL) care for critically ill patients and the family in the intensive care unit (ICU) has gained immense attention over the past decades. This is pertinent, considering the current multi-cultural society, growing ageing population characterised by a life-threatening illness and the reported increasing number of deaths that occur during or shortly after ICU admission. The use of intensive care services at the end-of-life has equally increased over the past years from 24.3% in 2000 to 29.2% in 2009 (Teno et al., 2013). Research studies further reveal that the mortality rate in the adult intensive care unit (ICU) has also increased, however the rate varies from 10 to 30% (Angus et al., 2004; Capuzzo et al., 2014; Society of Critical Care Medicine, 2018).

Intensive care nursing remains an area of speciality practice, with the purpose of providing special care and monitoring services for patients with life-threatening illnesses and chronic conditions. Nursing the critically ill patient aided by technology in the intensive care environment is often described as a continuous process that requires support and frequent training. In such a fast-paced and technological environment, intensive care nurses remain the primary caregivers of end-of-life (EOL) care to patients and their families. As frontline healthcare providers, nurses continually provide specialised care for a multi-cultural ageing population with different healthcare needs and demands. In meeting the needs and demands of this population with diverse cultural, religious and belief systems, research studies report that nurses are faced with various challenges and stressors, and result in the expression and description of varied experiences and perspectives about the provision of EOL care. These experiences vary across the globe and differ about cultural backgrounds, religious beliefs, countries, regions, individual ICUs and even healthcare professionals. In order to understand the varied nurse's experiences about EOL care provision in the ICU from a global perspective, this integrative review seeks to gather and synthesise related evidence on the experiences of nurses in the provision of end-of-life care for patients and families in the ICU.

1.1 BACKGROUND OF THE STUDY

Historically, the intensive care unit has been a specific area within the hospital where critically ill patients receive the most advanced life-sustaining interventions that centre on the restoration of function and survival. Patients admitted into these units are often critically ill, requiring special care and close monitoring that can only be provided in the ICU. Interventions and advanced care are rendered by specialised healthcare professionals who have received additional training in Intensive care with the aim of providing optimal management for both acute and chronic conditions (Efstathiou & Clifford, 2011; Myburgh et al., 2016). Despite the curative care focus, patients continue to die in these settings, yet some recover with functional limitations. The World Health Organization (2018), with key facts on ageing and health, projects an upsurge in the world’s population over 60 years and beyond between 2015 and 2050; this will have a cumulative effect on intensive care demand, intensive care resources and interventions, especially end-of-life care (Nguyen et al., 2011).

End-of-life (EOL) care forms an integral part of intensive care practice. It is defined as the total, and supportive care healthcare providers' offer to the dying patients and their family, as curative therapy becomes physiologically inappropriate, thereby promoting a dignified and peaceful death (Badir et al., 2016; Latour, Fulbrook & Albarran, 2009). The EOL care processes involve complex decision-making and discussions that transpire among the healthcare team regarding the withdrawal of life-sustaining treatment decisions, the nursing care patients and their family receive, a good death for the patient and the support for the care providers and the family after the patient's death. This form of care focuses predominately on the physical, psychological, spiritual, emotional and cultural concerns of patients and family members by ensuring their comfort, supporting their individuality, reducing inappropriate burdensome healthcare interventions, as well as the follow-ups meetings and care for the family after the death of the patient (Curtis & Vincent 2010; Kirchhoff et al., 2000; Ranse, Yates & Coyer, 2012).

Patients and family are often hopeful of a quick recovery following intensive care admission, as the setting sustains the critically ill patients for prolonged periods using advanced life-sustaining treatments and interventions. Unfortunately, many of these patients die, whilst others survive with obvious functional limitations. Most of these deaths precede a decision to withdraw life-sustaining treatments. The decision to withdraw treatment often commences when there is an absolute realisation and increased awareness amongst the intensive care clinical team of further deterioration in the patients' illness despite the clinical interventions administered. Discussions with the patient, family and the extended intensive care team then focus on palliation and finally end-of-life care management (Azoulay et al., 2009; Coombs, Addington-Hall & Long-Sutehall, 2012; Sprung et al., 2003; Truog et al., 2008). Once an agreement has been made to proceed, EOL care can be achieved through the withdrawal of life-sustaining treatment, including supportive drugs and ventilation together with maximising patients and family comfort while ensuring a peaceful, dignified and controlled good death.

Nurses and physicians are the dominant health professionals when it comes to providing EOL care in the ICU; nurses, however, remain the constant front-line caregivers of critically ill patients and the dying patient within the intensive care environment. They are directly involved in all care patients, and their family, receive including end-of-life care (Efstathiou & Walker, 2014; Beckstrand & Kirchhoff, 2005). As a result, nurses form a much longer and closer therapeutic relationship with patients and their families than other members of the healthcare team. Due to this relationship, they possess a more comprehensive insight regarding the emotions, needs and preferences of patients and the family during these sensitive stages. Likewise, they face the consequences and challenges of life-sustaining interventions and treatment rendered to the critically ill and dying patients, including the outcome of treatment decisions, medical conflicts and uncertainties, loneliness in responsibility, barriers to optimal care, emotional labour, family members' issues and eventual death of the patient (Brooks, Manias & Nicholson, 2017; Espinosa et al., 2010; Hov, Hedelin & Athlin, 2007; Ryan & Seymour, 2013).

Nurses learn EOL care through personal experience as opposed to guidelines and scientific knowledge. They are not empowered to act on their own decisions regarding the plan of care, as they often have to carry out orders physicians make, whether they support this or not, while providing continuous care for patients and their family as well as attending to their responsibilities. Ranse, Yates and Coyer (2012) describe the current intensive care practice as an excellent opportunity to provide quality care, albeit a challenging area for nurses especially in the provision of end-of-life care. The medical perspective of cure is frequently emphasised, whereby nursing and caring are often marginalised. The experiences in these settings are often described as morally challenging and represent professional and personal struggles for nurses (Beckstrand & Kirchhoff, 2005; Halcomb et al., 2004; Sprung et al., 2014).

1.1.1 Nursing Care in the intensive care unit

Nursing is described as a caring, nurturing profession with a unique perspective, and caring for dying patients has always been an integral part of nursing practice. As the medical paradigm of care focuses on cure and treatment of the disease or illness, basing judgement on objective signs, the nursing paradigm centres on the patient as a whole, not just the present illness, using a holistic approach and interventions that focus on ways to relieve patient suffering and promote comfort (Espinosa et al., 2010; Miller, Forbes & Boyle, 2001).

Intensive care nurses make up the majority of the extended healthcare team. From the day of admittance into the unit, nurses remain the primary provider of care until the patient is discharged, or dies peacefully. As primary caregivers, nurses spend the highest amount of time with the patients and their relatives than any other member of the healthcare team. Consequently, they have first-hand information and additional understanding of patients' care goals. The caring and monitoring role is one of the most significant responsibilities of nurses in the intensive care unit. They provide special care to both the patient and the family. Care ranges from monitoring of patients' vital signs, pain and symptom management to the provision of both psychological and spiritual support to both the patient and the family. They assist in relieving patients' suffering through constant care and presence at the bedside (Langley et al., 2014; Latour, Fulbrook & Albarran, 2009; Ranse, Yates & Coyer, 2012).

As per their professional roles and conduct, nurses perceive a peaceful death for all patients as promoting dignity, well-controlled pain, symptom management, not allowing the patient to die alone, following patient's wishes for end-of-life care and meeting families and friends needs to participate in end-of-life rituals, as well as allowing them sufficient time with the dying patient (Beckstrand, Calister & Kirchhoff, 2006; Bratcher, 2010). Nurses are undoubtedly described in literature as the best-suited professionals to provide care for patients at the end-of-life and their families (Fridh, Forseborg & Bergbom 2009). In the intensive care environment, nurses are directly involved in end-of-life care, including the withdrawal of life-sustaining treatment. During EOL care, nurses provide specialised nursing care to both patients and their families. In a recent review, Noome et al. (2016a) describe a nurses' role during EOL care as caring for the patient, the family and the environment as well as organisational aspects of EOL care. They advocate for their patients in their challenging times, provide special physical care to relieve pain and suffering, support family through the end-of-life process by providing necessary information, facilitating their involvement, honouring their wishes and ensuring a conducive and safe environment for the dying process (Langley et al., 2014; Long-Sutehall et al., 2011; Hov, Hedelin & Athlin, 2007; Ranse, Yates & Coyer, 2012).

Although nurses provide the best of nursing care for every patient admitted into the intensive care setting, they feel that the care they provide at the end-of-life is woefully inadequate. Technologically, they provide excellent care interventions for critically ill patients, yet they are emotionally uninvolved. Nurses are less satisfied with the quality of care provided, the low level and insufficient autonomy and nurse-physician collaboration in the current intensive care setting (Hamric & Blackhall, 2007; Papathanassoglou et al., 2012). The human impact of providing this care to the dying may contribute to moral distress, burnout, emotional turmoil, job dissatisfaction, adverse effects psychologically and physically, and may even lead to nurses exiting the profession (Elpern, Covert & Kleinpell, 2005; Langley, Kisorio & Schmollgruber, 2015).

1.1.2 Issues relating end-of-life care in the intensive care unit

The dramatic technological, procedural and pharmacological advances in the intensive care setting may have improved intensive care and promoted positive outcomes among the growing global numbers of life-threatening illness amongst the ageing population. Several concerns, however, exist due to the lack of a consistent process for addressing end-of-life issues in the ICU (Westphal & McKee, 2009).

Although literature agrees that a good death is achievable in the ICU (Beckstrand, Calister & Kirchhoff, 2006; Bratcher, 2010), a good death may be difficult to achieve in our present intensive care environment. In 1996, an American study, the landmark, multi-centred Study to Understand Prognosis and Preference for Outcomes and Risks of Treatment (SUPPORT) trial, an attempt to improve the care patients and their family receive in the ICU, highlighted several irregularities in EOL care practices. This study aimed at improving the EOL decisions and the overall experiences critically ill patients and their loved ones received in the ICU and found several irregularities and inadequacies in the quality of care provided. These included communication issues between patients and the healthcare team, the frequency of aggressive treatment patients received before death, and healthcare professionals lack of knowledge on patient’s preferences at the end-of-life.

Several decades after the SUPPORT trial, Fridh (2014) looked at the present state of science regarding end-of-life care in the intensive care unit from the nursing perspective. Although there has been much improvement in the care of patients, as highlighted in the study, there have equally been areas that pose a threat to the quality of care patients receive, especially at the end-of-life. These problem areas include issues of end-of-life decision making, challenges in the transition from curative care to end-of-life care, nurses involvement in the EOL planning and decision making, EOL care-related stressors, communication barriers amongst the healthcare team, disagreements in EOL care planning, inadequate training and support for healthcare providers, as well as noticeable variations and differences in EOL care practices across the globe.

These, among other concepts, are discussed in detail in the next sections in order to provide context for the study.

1.1.2.1 End-of-life decision making in the intensive care unit

End-of-life decision-making can be defined as the processes and discussions that take place among healthcare providers, patients and their families when considering the kind of life-sustaining treatment that will either be continued or ceased for critically ill patients at the end-of-life (Thelen, 2005). In the ICU, it is estimated that out of five patients admitted, one will die in the intensive care unit, with the death mostly preceded by an end-of-life decision (Angus et al., 2004; Azoulay et al., 2009). Considering the global ageing population characterised by chronic illnesses, the need for end-of-life decisions within the intensive care units are likely to increase.

The various forms of end-of-life decision making in the intensive care unit include advance care directive decisions, decisions of resuscitative efforts (do-not-resuscitate order), and withdrawal or withholding of life-sustaining treatments decisions. The advance care directives provide patients with life-threatening illnesses the opportunity to express their end-of-life care preferences in writing before any sudden incidences. Unfortunately, due to the unexpected nature and severity of illness, patients admitted into the ICU are less likely to have an advance care directive in place. Usually, the healthcare team and patients' family make a collaborative decision on behalf of the patient (Luce, 2010; Sprung et al., 2014). Except for advance care directives, most end-of-life decision making only occurs when the patient gets closer to the end-of-life. Usually, the do-not-resuscitate order (DNR orders) is made, followed by the decision to discontinue or not to start a life-sustaining treatment at all (Stroud, 2002). Throughout these processes, literature indicates that the decision-making process regarding end-of-life care remains a shared responsibility. End-of-life decisions are made after interaction and discussions amongst the healthcare team, patients and families or patient's surrogate. This implies that the healthcare providers, patients and their family play vital roles in the process, in normal circumstances end-of-life decisions are made based on patients and family wishes and futility of medical interventions (Jensen et al., 2011).

In the intensive care setting, however, the attending physician is solely responsible for making end-of-life decisions with minimal input from other healthcare providers, especially nurses. Heland (2006), in a qualitative study, admits that physicians hold the authority to make or initiate end-of-life decisions. This was not different from a recent ethnographic study (Baggs et al., 2012), conducted across four ICUs in New York, which included over 78 healthcare providers (30 physicians and 48 nurses) across four ICUs. It was found that the attending physician initiates and leads the end-of-life discussions. Regardless of how the end-of-life decisions are made, literature indicates they are often influenced by physician's knowledge and beliefs of end-of-life, coupled with the prediction of the outcome of the patient's illness (Luce, 2010, Westphal & McKee, 2009).

Research studies by Adams and colleagues (2011) and McMillen (2008) indicated that nurses make important contributions to EOL decisions and care despite physicians' responsibility for EOL decisions. Calvin, Lindy and Clingon (2009) reported that nurses can realise the point where medical treatment becomes futile and an EOL decision is needed due to their constant interaction with patient and family. There is no universal way of approaching end-of-life decisions (Westphal & McKee, 2009), as nurses and physicians have different ways of addressing and approaching this decision (Jensen et al., 2011). Baggs et al. (2007), in an ethnographic study, also found there were obvious similarities but significant differences in end-of-life decision-making across cultures. These were identified in physician roles and relationships, formal and informal rules, the timing of initiation and the meaning and use of technology.

In the current context, when a patient's condition deteriorates with no positive expectations of survival, the healthcare providers, especially nurses, will face several ethical dilemmas associated with end-of-life decisions. These decisions will be even more difficult considering the strong social, legal, cultural, moral and religious values affecting attitudes and practices.

1.1.2.2 Transition from curative to end-of-life care

Admission into the intensive care unit is regarded as a therapeutic trial (Truog et al., 2008). Once the trial fails the intensive care goal changes from curative care to end-of-life care. This process can be described as the most difficult, although important aspect of nursing and medical practice in the intensive care environment. Due to the technological, procedural and pharmacological advancement, death can be regarded as a failure in the intensive care environment (Nelson et al., 2006). The inability to precisely diagnose the dying or predict death in such an environment further compounds the difficulties in the transition process.

In the ICU, the transition process commences following a collaborative team decision based on the further deterioration of patients' condition or patients' inability to respond to clinical interventions and treatments administered. If a firm decision is sustained amongst the healthcare team and the family, the care then focuses on palliation and finally EOL care. The decision-making process within this period is often characterised by diagnosing the dying, managing end-of-life consensus and breaking the news to facilitate the grieving process among the family. In most cases, diagnosing the dying serves as a prelude to re-focusing interventions and objectives to facilitate the dying process. Diagnosing the dying is mostly informed by objective clinical data, individual religious and cultural beliefs, viewpoints and experiences of the medical staff (Coombs, Addington-Hall & Long-Sutehall, 2012).

The challenging aspect for the healthcare team may not be the management of the patient at the end-of-life per se, but facilitating the process. Coombs, Addington-Hall and Long-Sutehall (2012), in a qualitative study, looked at the challenges healthcare professionals encounter in making the transition from curative therapy to end-of-life care in the intensive care unit. The study used a semi-structured interview involving 43 participants (13 nurses, 13 medical doctors and 17 patients that had undergone the withdrawal of treatment earlier) from two large ICUs in a large hospital in England. It was found that patients who did not survive after the treatment withdrawal underwent three-stage end-of-life trajectories. These included admission with the hope of recovery, the transition from curative care to end-of-life care and finally a controlled death. Throughout these stages, the study highlighted that the transition process was the most challenging and gruesome experience and stage for the healthcare professionals in the intensive care unit with regards to the end-of-life trajectory.

It may be argued that due to the complex nature of the transition process, it should be a shared responsibility of the extended healthcare team. It is also expected that junior, inexperienced physicians may find it difficult to make a precise diagnosis about the dying. Despite these, literature indicates that physicians hold the authority to make the diagnosis of the dying. Prognostic uncertainties in patients admitted, coupled with inappropriate and conflicting decisions often delay EOL care discussions, preventing timely recognition and individualised care planning (Nelson et al., 2006; Hamric & Blackball, 2007). Again, achieving consensus between nurses and physicians on the right timing for the transition is always problematic, in this regard, the issues of seniority, specific knowledge-base, experience, personal beliefs and values come to play instead of the critical illnesses itself. These are described as confounding factors that often impact on the smooth transition to end-of-life care in the ICU (Coombs, Addington-Hall & Long-Sutehall, 2012). Nurses understand the essence of consensus during the transition process, however, the decisions should not solely be on mortality and morbidity issues as the quality of care for the dying also plays a relevant part.

Nurses often associate themselves with the patient and family during the preliminary stages of the disease process. In most cases, they have fair knowledge on whether there is a futile response to interventions administered or not. Unfortunately, their rich contributions and experiences are marginalised at this stage, however, once the transition is made, in all cases nurses are left alone to manage both the patient and the family, as well their personal frustration and grief (Hov, Hedelin & Athlin, 2007). The transition from a curative approach to a comfort-oriented approach presents challenges to Intensive Care nurses as they attempt to provide comprehensive and complicated care in an environment where the focus remains on life-sustaining treatment. Beckstrand and Kirchhoff (2005) emphasise how caring for a dying patient is stressful and painful for nurses who are continuously at the bedside, while other healthcare professionals come and go as the need arises.

1.1.2.3 Nurses involvement in end-of-life decision-making in the intensive care unit

Nurses, undoubtedly, remain the single professional group present at every hospitalised patient's bedside in the intensive care setting. They have first-hand information about patient and family, which places them a unique position to influence healthcare decisions as well as deliver safe and competent care. Arguably, nurses should be the main protagonist in contributing to EOL care planning owing to their special nursing care and proximity to patients and their family. Evidence from literature indicates that nurses' involvement in the patients care as well as EOL planning is associated with improved job satisfaction, increased retention and recruitment, positive patient clinical outcomes, family satisfaction, reduced stressors and burnouts, and is vital for communication between the physician and the family (Puntillo & McAdam, 2006; Badir et al., 2016). On the contrary, failure to incorporate the perspectives and experiences of these nurses in day-to-day clinical and operational decisions can be harmful and costly errors, as the holistic, caring perspective of nursing will be missing (Miller, Forbes & Boyle, 2001).

Bach and colleagues (2009), Efstathiou and Clifford (2011) and Thelen (2005) highlight that nurse's play vital roles in EOL decisions. Despite these roles, nurses play limited roles in the end-of-life care decision process in the ICU. The attending physician often decides their involvement. Most often involvement is decided based on physician's preference, their level of experience or seniority within the team; this may sound contradictory, judging from the essential role nurses play and the kind of perspectives and care approaches they bring into the patient and family care in the ICU. Although nurses have wished to ensure peaceful and dignified death for patients at the end-of-life, their actual involvement is far below the expected (Badir et al., 2016; Langley et al., 2014; Latour, Fulbrook & Albarran, 2009).

In a study by Latour, Fulbook and Albarran (2009), only 48% out of the 68% of nurses who recognised the need for EOL care discussions and decisions were included in the decision-making process; more than half of the 162 nurses included in the study indicated they wanted to be involved in the decision-making process. This resonates with recent studies by Langley et al. (2013) and Badir et al. (2016) in South Africa and Turkey respectively, which found similar results.

1.1.2.4 Stressors regarding end-of-life care planning in the intensive care unit

Naturally, intensive care nurses work in a physically demanding and psychologically challenging environment that requires them to provide competent nursing care for both critically ill patients and their families, as well as be knowledgeable and use the advanced technological equipment; these combined challenges of caring further create a high-level of work-related stressors for intensive care nurses. These nurses encounter ethical dilemmas, uncertainties and several conflicts as they provide care for the dying patient in the ICU (Efstathiou & Walker, 2014; Espinosa et al., 2010; Hov, Hedelin & Athlin, 2007); they experience personal pain, feelings of grief and suffering as they journey with patients through weeks and months of life-sustaining and burdensome treatments that they view as futile (Shorter & Stayt, 2010). Repeated exposure to these conflicts and misunderstanding in intensive care environments represent a great source of burnout and moral distress, which affects the emotional, physical, psychological and spiritual health of care providers, especially nurses (Elpern, Covert & Kleinpell, 2005; Langley, Kisorio & Schmollgruber, 2015).

In an ideal health work environment in the ICU, nurses prefer an explicit role in the decision-making process, more time for patient and family, adequate communication between nurses and physicians, as well among the healthcare team, patients and the family (Noome et al., 2016a). Unfortunately, the intensive care environment's practices are far below the expected. Nurses are less satisfied with the current EOL care practice in the ICU than are physicians, as they describe the setting as unfavourable for end-of-life care. The environment is full of conflicting, over-optimistic opinions from physicians and is undoubtedly dominated by the medical model and interventions (Beckstrand & Kirchhoff, 2005; Espinosa et al., 2010; Truog et al., 2008).

Intensive care nurses offer their best to ensure that patients and their families receive high quality of care (Efstathiou & Walker, 2014), however in doing this they are faced with lots of physical, psychological and emotional stressors from colleagues, family and the intensive care environment. Patient and family care in the ICU is mostly dominated by nurses and physicians. Physicians spend less time with the patient at the end-of-life, yet they initiate and make important final decisions on the patient's plan of care. Nurses opinions on a patient's plan of care are often not regarded, however when a decision is made, nurses operationalise the interventions. Although both nurses and physicians place value on the patient's wellbeing, how it is attained varies greatly from their distinct perspectives of care (Sole, Klein & Moseley, 2009 pg. 12). The medical model of care only focuses on treatment interventions, and is often implemented with the nursing model marginalised (Espinosa et al., 2010). These situations can be described as frustrating and stressful, and can dent nurses' interests in patient care. Ensuring peaceful death and dying, particularly when it is unexpected, often presents a challenge for nurses. There can be a sense of failure when a patient's condition deteriorates, which influences nurses' feelings about decisions and care.

1.1.2.5 Inadequate support and training on end-of-life care

End-of-life (EOL) care practice demands similar expertise and competence just like any other intensive care practice (Truog et al., 2008). The nature of this care demands that nurses are well trained and supported to render EOL care for patients and their families when curative therapy becomes physiologically inappropriate. The growing aging-population further indicates that intensive care nurses will have to deal with more end-of-life care issues and situations. In such a technologically advanced environment, nurses are required to be skilled in complex assessment, life-saving interventions and therapies as well as constant monitoring of patients on mechanical equipment such as ventilators.

Although, intensive care nurses are described as the best healthcare professionals to provide EOL care for the critically ill patient and the dying, in actual practice they learn most from constant exposure and past experiences (Fridh et al., 2009); they are however inadequately prepared to deliver appropriate end-of-life care to dying patients (Holms et al., 2014; Zomorodi & Lynn, 2010). In the proper delivery and provision of excellent end-of-life care for patients and their families, several research studies have advocated for robust, evidence-based guidelines to inform these practices (Efstathiou & Walker, 2014; Langley et al., 2014). Unfortunately, the existing ones have failed in ensuring the quality end-of-life care needed.

In such a demanding care environment, with an absence of formal guidelines and formal support through education and training, nurses will struggle to meet the demands of the growing aging population at the end-of-life.

1.1.2.6 Diversities and variation in end-of-life care practices

End-of-life care practices remain a routine practice in most European intensive care units (Sprung et al., 2003). Globally, healthcare providers have realised that not all critically ill patients will benefit from intensive care, therefore, most patients should be allowed to die peacefully (Azoulay et al., 2009). Mark and colleagues (2015), in a systematic review, found substantial variability and differences in withdrawing life-sustaining treatments between regions, countries, individual ICUs within a country and Intensive Care providers within the same ICU. The prevalence of life-sustaining treatment withdrawal varied between 0 and 84%. These practices vary on the basis of geographical location, culture, religion, legal factors, level of religiosity, different attitude between physician, nurses, patients and family, and institutional characteristics (Azoulay et al., 2009; Myburgh et al., 2016; Sprung et al., 2003). How and when the dying process happens in the ICU equally varies globally. Most of the variations are dependent on the patient's disease pattern and demographics, resources available as well as cultural, religious and financial factors (Myburgh et al., 2016). These differences reflect the diversity of human culture and societies as well as responses about decisions at the end-of-life.

Despite these differences in end-of-life care practices, a worldwide consensus was developed to clarify these key ethical issues regarding end-of-life care (Sprung et al., 2014). A consensus was obtained for most of the ethical statements raised, however, areas such as withdrawal and withholding of life-sustaining treatment, still remained without global consensus. Intensive care nurses provide end-of-life care for an increasingly multi-cultural population. Ever-changing diversity in societies and cultures further presents challenges to nurses to equally match up to the needs of these various cultures and religions, as well as deal with their personal issues.

Although a number of ethical consensus papers have been developed and published, most are not applicable to all countries, especially low-middle income countries and places where non-Western culture dominates (Myburgh et al., 2016). Considering the marked global differences, a singular generic criterion cannot be applicable to all countries and societies. The absence of a concise evidence-based guideline will further heighten the challenging and struggling experiences in these settings, with nurses mostly affected.

1.1.3 Related Research Currently Known

Several studies have reported on the experiences of nurses in the provision of end-of-life care for patients and families in the intensive care unit. These experiences, however, differ in terms of cultural backgrounds, spiritual beliefs, individual ICUs, geographical locations and healthcare providers' attitudes. Despite, the differences, few research reviews have been conducted in this area. Vandersprank-Wright, Efstathiou and Vandyk (2018) and Mani (2016), in a systematic literature review, respectively reported on nurses experiences in the provision of care for patients at the end-of-life and family.

The common areas of study between these reviews are the variables in focus, which included nurses in the intensive care unit and their experiences in relation to the provision of end-of-life care, and the intent to gather and synthesise evidence from existing literature on the subject of interest. Both studies solely focused on empirical studies (qualitative, quantitative and mixed-methods) with no place for grey literature. Mani (2016), for instance, used only two databases that focused on qualitative and quantitative studies collected between 2004 and 2014. The review focused on 16 articles from an initial list of

57 articles found in the search process. The findings highlighted nurses' challenges in the provision of end-of-life care and the support for the critically ill and dying patient.

Vandersprank-Wright, Efstathiou and Vandyk's (2018) study reviewed only qualitative studies (12) and mixed method studies (1) specifically on the experiences of nurses regarding the provision of care to patients and families during the life-sustaining treatment withdrawal process. The study integrated research articles from four databases using general search terms such as nursing, withdrawal of treatment and intensive care unit. Thirteen articles published between 1999 and 2015 met the eligibility criteria. Quantitative literature, grey literature (theses, dissertation and conference proceedings) and studies that were published after 2015 were excluded. Thus, there is an indication of a need for another current integrative review that permits the inclusion of empirical, theoretical and grey literature that uses several study designs and includes recent studies that may not have been captured in previous reviews.

1.2 PROBLEM IDENTIFICATION

In an integrative review, a well-defined problem statement and purpose facilitates the ability to operationalise variables and enhance the extraction of appropriate data (Whittemore & Knafl 2005). This stage serves as the foundation for the entire review process. It starts with a precise identification of the research problem the researcher intends to address and the purpose. This sets the stage for the way variables will be identified in the study, as well as precisely limit and operationalise the variables for inclusion (Russell, 2005; Whittemore & Knafl, 2005).

The provision of EOL care for patients and family in the ICU requires a dramatic shift in attitudes and therapeutic interventions. Nurses, the primary caregivers of end-of-life care, work in a physically demanding and psychologically challenging environment that requires them to provide competent nursing care for both critically ill patients and families, as well as deal with other colleagues and use advanced technological equipment. These combined challenges of caring for critically ill patients and demands, creates a high-level of work-related stressors for intensive care nurses leading to varied experiences. The increasing aging population globally, for instance, highlights the need for more quality of care at the end-of-life for the critically ill and dying patients.

Several concerns have been raised, through various nurses' experiences, about the quality of care the critically ill and dying patient receives in the intensive care unit (ICU). Recent literature indicates that understanding nurses' experiences in the provision of end-of-life will be a starting point for effecting changes in the quality of care the critically ill and dying receive in the ICU. Fortunately, nurses from different cultures, countries, religious backgrounds and perspectives have expressed their experiences in various forms. Rich sources of primary studies that focus on the nurses' experiences of end-of-life care in the Intensive Care Unit abound, however, the evidence is yet to be explored. Pulling together these rich sources of literature will help understand the phenomena from a global perspective.

A guiding research question enables the researcher to determine the kind of studies that will be included in the study, and the means to identify and gather the information in each selected study (De Souza et al., 2010). Russell (2005) suggests a broadly defined conceptual definition of variables, with much attention paid to the differences in study designs in order not to overlook important study details and interpret results correctly. In this study, the research problem and research question were conceptualised and approved with the assistance of the supervisor. The PICOT format was followed assiduously at this stage to ensure a focused research question.

PICOT is an acronym useful in summarising a research question. The mnemonic stands for population of interest (P), intervention or issue of interest (I), comparison intervention (C), outcome of interest (O) and time of the intervention to achieve the outcome (T). For this study, the mnemonic was denoted:

Population (P)	- Nurses working in the intensive care unit or intensive care nurses
Issue of interest (I)	- End-of-life care for patient and families
Comparison (C)	-No intervention compared
Outcome of interest	- The influence of EOL care provision on nurses experiences
Time (T)	-Research evidence from January 2007 to May 2018

The following research question was formulated:

> ***What is the best evidence available from January 2007 to May 2018 regarding the nurses' experiences of end-of-life care for patients and their families in the Intensive Care Unit?***

1.3 PURPOSE OF THE STUDY

The purpose of the integrative review is to gather evidence related to nurses experiences in the provision of end-of-life care to patients and families in the Intensive Care Unit.

1.4 OBJECTIVES

The objective of the study is:

- To explore the experiences of nurses in providing end-of-life care to patients and their families in the Intensive Care Unit.

1.5 SIGNIFICANCE OF THE STUDY

Understanding the experiences of nurses providing end-of-life care has a significant impact on nursing practice, education, research, and health/public policy. Evidence from this review will help in understanding nurses concerns and experiences in the provision of end-of-life care in the ICU, and draw out similarities and differences in experiences across countries, regions, cultures and individual ICUs. This will project areas for further research to enhance the provision of EOL care in the ICU.

1.6 DEFINITION OF KEY VARIABLES

Definitions of the key variables used in the study are as follows:

- **Critically ill patient**

The American Association of Critical Care Nurses (AACN, 2006 pg. 5) defines critically ill patients as "*those who are at high risk for actual or potential life-threatening health problems.*" These are patients admitted into the ICU with a life-threatening and terminal illness that necessitate constant and close monitoring, support from machines and medication to keep normal body functioning (World Federation of Critical Care Medicine, 2018). For the purpose of this study, critically ill patients refer to those admitted into the intensive care units for the purposes of their illnesses that need constant monitoring and interventions.

- **Intensive care unit (ICU)**

Merriam-Webster Dictionary (2018) defines this as “a section of a hospital where special medical equipment and services are provided for patients who are seriously injured or ill.” The World Federation of Societies of Intensive and Critical Care Medicine (Marshall et al., 2017) defines an ICU as a specially organised system essential for the provision of intensive specialised nursing and medical care to critically ill patients through continuous monitoring and interventions to enhance and support organ system failure.

In this study, intensive care unit (ICU) refers to specialised sections in the hospital, managed by specialised health professionals using specialised equipment aimed at caring for the critically ill and dying patients.

- **Intensive Care nurse**

An Intensive Care nurse refers to a type of specially trained nurse working in the ICU who provides care to critically ill patients. They have undergone additional specialised nursing education and training in the field of study and registered with a recognised Nursing Professional Council. The term is synonymous with Critical Care Nurse.

For the purpose of this study, intensive care nurses refer to nurses with an undergraduate nursing qualification who may or may not have an additional qualification in intensive care nursing, however, working in the intensive care unit and involved in EOL care.

- **End-of-life care**

This is defined as the total and supportive care healthcare providers offer to dying patients and their families when curative therapy becomes physiologically inappropriate, promoting a dignified and peaceful death (Badir et al., 2015; Latour, Fulbrook & Albarran, 2009). End-of-life care of critically ill patients generally consists of the withdrawal and withholding of life-sustaining treatment and the administration of palliative care (Luce & Alpers 2001; Sprung et al., 2003). The EOL care processes also involve complex decision-making and discussions that transpire among the healthcare team regarding the withdrawal and withholding of life-sustaining treatment, and the nursing care patients and their families receive in the ICU.

- **End-of-life**

End-of-life, also known as terminal phase, refers to the last few days of a person's life where death is irreversible.

- **Withdrawing of life-sustaining treatment**

This refers to the processes through which various life-sustaining interventions being given to a patient are actively stop or removed. This is often after a decision is made that the patient will not benefit from such interventions, or will die of the underlying illness (Luce & Alpers, 2001; Sprung et al., 2003).

- **Withholding of life-sustaining treatment**

This also refers to the processes through which various life-sustaining interventions deemed to support the patient are not given or started This often follows a decision that patients condition will not benefit from such intervention or not necessarily reverse the disease process (Luce & Alpers, 2001;Sprung et al., 2003).

- **Experiences**

Merriam-Webster Dictionary (2018) defines experience as “the fact or state of having been affected by or gained knowledge through direct observation or participation.” These are life-changing events and occurrences, which include social, psychological and environmental factors that cause an individual to adjust or change their pattern of living.

For the purpose of this study, nurses’ experiences refer to the feelings, concerns and perspectives nurses harbour, and face, during the care for the critically ill and the dying at the end-of-life. As a decision is made by physicians to withdraw treatment, these are the reactions, feelings and concerns nurses show in response to the care of the critically ill and dying patient at the end-of-life. Experiences are what they feel as they practice their caring attributes in an Intensive Care environment, as they go about meeting patients’ needs at the end-of-life, managing machines and dealing with several characters in the ICU; the emotional and psychological issues nurses face.

1.7 OVERVIEW OF THE RESEARCH METHODOLOGY

This study used an integrative review design. This is a non-experimental research design that combines all relevant studies (experimental and non-experimental studies) on a phenomenon under study to draw conclusions from the body of literature on a particular topic. This review was organised using the five-stage review approach as informed by Whittemore and Knafl (2005), which was chosen because it permits the combination of diverse research methodologies to understand the subject the researcher intends to explore. The review approach also helps to determine the current knowledge about a specific topic as it sets out to identify, analyse and synthesise results of independent studies (both experimental and non-experimental) on the same subject. This, therefore, serves to have a positive impact on the quality of care delivered to patients and the entire beneficiaries of healthcare.

The stages as outlined by Whittemore and Knafl (2005) include:

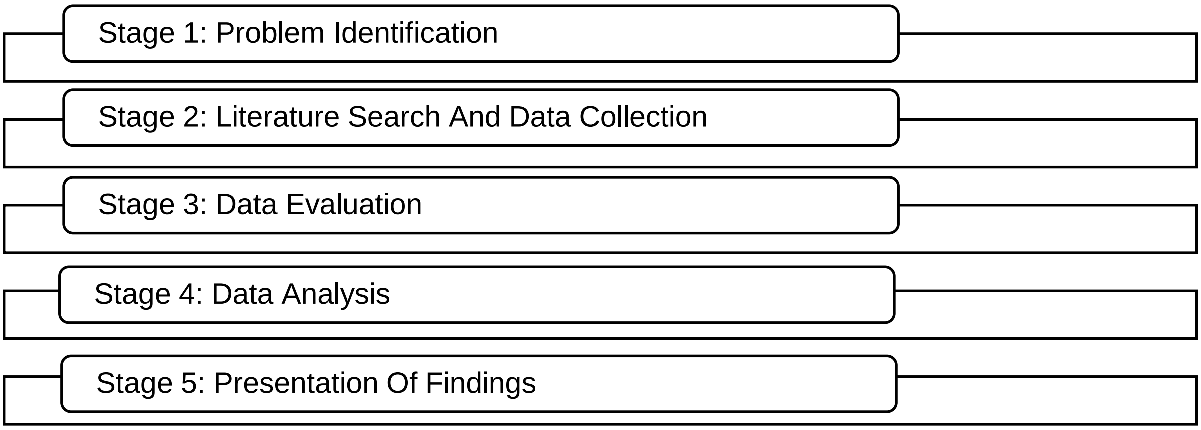

Figure 1.1 Outline of the stages of integrative review

Prior to the commencement of the study, the research proposal was presented and peer-reviewed for input from the department of Nursing, School of Therapeutic Sciences, Faculty of Health Science, University of the Witwatersrand. An approval was obtained from the Health Sciences Postgraduate Research Committee. An ethical clearance waiver, reference number W-CBP-180508-01, was obtained from the Human Research Ethics Committee (Medical). Permission was acquired prior to the usage of the individual data extraction and quality appraisal tools. The researched adhered to the developers’ terms of usage for the various instruments.

1.8 LAYOUT OF THE STUDY

The layout of the research report chapters is guided by the five-stage review approach informed by Whittemore and Knafl (2005). The research report is organised into six chapters. Stages one to five guided the chapters one to five respectively. **See Table 1.1**

The current chapter provides the formulation and identification of the research problem, the background and the aim of the study. This is followed by a brief overview of the research methodology as used in the integrative review.

In Chapter Two, literature search and data collection, a detailed literature search stage is discussed. The chapter begins with a brief overview of the integrative literature review as a method, and subsequently discusses the literature search process as used in the study. Detailed in this chapter are the search methods, eligibility criteria, databases, the search strategy and process, followed by a detailed description of the selection process and documentation. Finally, a discussion of the methodological strategies employed that contributed to the rigour of the integrative review is provided.

Chapter Three, data evaluation, focuses on the evaluation of data, which includes the data extraction and quality appraisal process and finally methodological rigour as ensured in the process. The chapter begins with the data extraction procedure, followed by the quality appraisal and ends with the methodological strategies that contributed to the rigour of the review at the data evaluation.

Chapter Four, data analysis, focuses on the data analysis stage, which included data reduction, data display, data comparison, and verification and conclusion. The chapter ends with the methodological strategies that contributed to the rigour of the review at the data analysis stage.

Chapter Five presents the results of the integrative review, the study characteristics as retrieved in the review process, a discussion of the appraisal of the methodological quality and evidence and a narrative description of the results as aggregated thematically after thorough synthesis. Lastly, the chapter ends with discussion of the measures taken to ensure the rigour of the study.

Finally, Chapter Six presents the discussion, summary of findings and conclusion. In this chapter, findings synthesised from the integrative literature review are compared to research literature, current policy and guidelines. The strengths and potential limitations related to the review are then provided. Finally, recommendations for future nursing research, policy, training and practice are presented.

Table 1.1: Layout of the Study

Chapter	Purpose	Application
Chapter 1: Problem identification	Clear identification of the problem of interest	Answer the question *"What is the best evidence available from January, 2007 to May, 2018 regarding the nurses' experiences of end-of-life care for patients and their families in the Intensive Care Unit?"*
Chapter 2: Literature search and data collection	Identify and collect all relevant literature sources to answer the research question	Searching of PubMed, SCOPUS, ProQuest, CINAHL plus, MEDLINE, Academic Search Complete, Health Source: Nursing and Google Scholar. Hand search from relevant nursing journals
Chapter3: Data evaluation	Extract data and determine authenticity, methodological quality, informational value of the data extracted	Use valid data extraction tools to extract data and critically appraise the literature using valid evaluation tools (CASP, 2018) and MMAT, developed by Pluye et al., (2011)
Chapter 4: Data analysis	Provide a thorough, unbiased interpretation and synthesis of evidence	Data reduction, data display, data comparison, conclusion drawing and verification
Chapter 5: Presentation of findings	Capture the breadth and depth of the topic and contribute new understanding	Report prepared to demonstrate chain of evidence to support the conclusion
Chapter 6: Discussion, implications for practice, strengths and limitations	Present and discuss the synthesised findings in relation to research literature, current policy and guideline	Themes generated discussed in relation to literature, strength and limitation of the study and implication for practice highlighted

1.9 SUMMARY

This opening chapter presented an overview of the study, which included the background, problem identification, purpose of the study, objectives, significance, key variables, overview of the research methodology and the layout of the study.

The next chapter discusses the literature search and data collection stage as used in the integrative review process.

CHAPTER TWO

LITERATURE SEARCH AND DATA COLLECTION

2.1 INTRODUCTION

This chapter provides a brief overview of the integrative literature review as a method, and discusses the literature search process as used in the study and the methodological rigour ensured at each stage of the review.

2.2 INTEGRATIVE LITERATURE REVIEW AS A METHOD

An integrative literature review is a non-experimental research design that allows the simultaneous inclusion of studies with diverse designs (experimental and non-experimental research) that addresses related question or hypothesis in order to make a comprehensive conclusion on a specific phenomenon of interest. The review approach also enhances the presentation of a condensed view on previous empirical and theoretical literature to understand fully a particular area of interest (Beyea & Nicoll, 1998; Russel, 2005; Whittemore & Knafl, 2005).

Most researches term it as the broadest and most comprehensive methodological approach for reviews, as it seeks to review, integrate, analyse and synthesise existing literature to maintain and enhance the knowledge base of a particular area of research as well as lead to the conceptualisation of new or emerging topics (De Souza et al., 2010; Torraco, 2005; Whittemore & Knafl, 2005). As a research design, it is often carried out to critically appraise the quality of existing scientific literature, discover gaps in these studies, project areas for further research, discover pressing issues for urgent attention, identify a theoretical and conceptual framework in a research area, and explore the strength and weaknesses of research methodologies used (Torraco, 2005; Whittemore & Knafl, 2005: Russell, 2005). A good integrative literature review fits the same standard as primary research in terms of rigour, clarity and replication, as well as having direct relevance to evidence-based practice, theory development and policy development. This serves to have a direct and positive effect on the care delivered to patients and families, as well as other beneficiaries of healthcare (Beyea & Nicoll, 1998; De Souza et al., 2010; Whittemore & Knafl, 2005).

The study sought to gather evidence on nurses' experiences in the provision of end-of-life care for patients and family in the ICU. An integrative literature review, as the research method, was used, as it allows the combination of several studies with diverse methodologies to answer the research question. This seeks to identify, analyse, and synthesise results from independent research studies to determine the current knowledge of nurses' experiences regarding end-of-life care in the ICU. It further expands on the subject to understand what is known about nurses experiences of end-of-life care in the Intensive Care Unit, the quality of the information available, establish what should be known in this area and finally project the next step for research or practice as well as make a workable recommendation to improve current practice.

The review framework outlined by Whittemore and Knafl (2005) guided this integrative review. This allowed the researcher to organise the review process for easy presentation on the experiences of nurses regarding end-of-life care in the Intensive Care Unit.

2.3 LITERATURE SEARCH

Literature search can be described as a systematic and well-organised search from already existing data (published and unpublished) to identify the breadth and depth of relevant references on a specific topic (Raul, 2004). The literature search stage represents one of the crucial stages in conducting a quality research review. Various research studies indicate that the approach to obtaining all relevant literature that answers the research question can sometimes be challenging and costly, however, complete and unbiased searches using consistent search terms and precise search criteria can be helpful in ensuring an exhaustive literature search (Conn et al., 2003; Ganong, 1987; Russell, 2005; Whittemore & Knafl, 2005).

A comprehensive literature search utilises as many search strategies as possible in order to maximise the number of eligible studies. These include precise sampling criteria, a broader and diverse literature search using electronic databases, manual hand search from journal articles, ancestry searching, references from eligible articles, and the use of unpublished literature and contact with researchers (Beyea & Nicoll, 1998; Conn et al., 2003; De Souza et al., 2010; Jadad et al., 1998). In this literature, the researcher included all these strategies in order to broaden the literature search and to be assured of a good representation of eligible data. Russell (2005) also emphasises that identifying the target population and accessible population are crucial to the literature search process. In this review, the target population referred to all the previous studies that focused the experiences of nurses regarding end-of-life care in the Intensive Care Unit, while the accessible population included those studies that the researcher obtained after a complete literature search using the eligibility criteria, selected electronic databases and keywords.

One key element in an organised integrative review is an exhaustive literature search that captures all the relevant data (Beyea & Nicoll, 1998; Conn et al., 2003).

Russel (2005) outlined that to ensure and enhance validity in the literature search and data collection stage, the researcher ought to conduct an exhaustive literature search, explicitly define the data collection information such as data sources, years and keywords, indicate all sources of selection biases and finally summarise the important features of subjects included in the samples. In order to ensure quality and find representative data, the reviewers outlined the literature search process, which included search methods, databases used, additional search strategies and eligibility criteria used in determining the relevant literature for the review. A broad and diverse database search, which included the use of electronic databases, manual search in journals, reference list check for relevant studies and the use of both published and unpublished literature were all explored to enhance a detailed literature search. These among others are discussed in detail below.

2.4 SEARCH METHODS

2.4.1 Eligibility Criteria

In formulating the criteria for the literature search, De Souza et al. (2010) suggest the criteria must agree with the research question, taking into consideration the participants, the interventions and the results of interest. The criteria for sampling the literature must assure representativeness of the sample of interest, as it helps to improve the reliability and veracity of the review results. In this review, the researcher took into consideration the central focus of the research study, which included nurses working in the Intensive Care

Unit, care for patients and their families, Intensive Care Unit, end-of-life care and nurses' experiences.

Table 2.1: Eligibility criteria

Criteria	Inclusion	Exclusion
Type of studies and study design	All empirical (qualitative, quantitative and mixed methods) and theoretical literature published and unpublished (grey) literature	Literature reviews, editorials, book reviews, systematic reviews
Concept	End-of-life care/ Withdrawal of life-sustaining treatment/ death and dying/ terminal care	Hospice care, acute care
Phenomena of interest	Experiences of end-of-life care or withdrawal of life-sustaining treatment	
Population/ type of participants	Intensive Care nurses, nurses working in the Intensive Care Unit or all qualified nurses	Other healthcare professionals (physicians, social workers, intensivists)
Context/ Setting	Adult Intensive Care Unit (ICU)/Adult Critical Care Unit	Neonatal ICU/setting, Paediatric ICU and all non-intensive care settings
Language	English	Any other language
Publication year	January 2007 to June 2018	Before 2007

2.4.2 Information Sources and Search Strategy

Prior to the detailed search, a preliminary search was done to identify and define the search words and search strings reliable for a detailed literature search. The main concepts used in the search, included nurses, experiences, end-of-life care and Intensive Care Unit. These words were preliminarily tested with PubMed and CINAHL plus to identify the indexed words in the databases.

A comprehensive and systematic search was then undertaken for relevant literature from relevant sources over a 10-year period. Three methods of literature search and literature collection were performed between January 1, 2018 and May 30, 2018:

i) Articles were obtained from a computerised database search.

ii) Obtaining articles from a hand search of certain Intensive Care journals and relevant search engines.

iii) Articles search from the reference list of articles that were obtained in the earlier search.

The literature search was conducted using the Wits Health Sciences Library online databases.

2.4.2.1 Databases

Research evidence indicates that the literature search can be tedious therefore, it is important to set priorities on the kind of sources to use. The thumb rule, however, is to select as many literature sources as possible (Conn et al., 2003; Jadad et al., 1998). These include the use of a wider number of bibliographical databases to enhance a broader literature search and identify relevant studies. In determining the electronic databases to be used, the researcher consulted a library scientist and the supervisor for further expert advice.

The search was completed using the following electronic databases: PubMed, SCOPUS, EBSCO host databases (CINAHL Plus, MEDLINE, Academic Search complete and Health Source: Nursing/Academic edition), ProQuest, and Google Scholar. These databases were chosen because they were most likely to house articles on the subject of interest: CINAHL Plus with Full test database, provides a robust collection of full-text coverage for a large quantity of nursing literature and is therefore a rich means for addressing the research question; Academic search complete, is one of the most comprehensive scholarly, multi-disciplinary full-text database, with over 7000 peer-reviewed journals, with abstracts, conference proceeding and reports; PubMed contains over 20 million citations from MEDLINE for biomedical research that dates back from the 1950s; SCOPUS has a broader coverage, with the largest abstracts and citation database for research literature with a large part of EMBASE included. In order not to miss unpublished or grey literature, the researcher added the ProQuest database, which provides a great source for health and medicine research as well as grey literature, such as theses, dissertations and conference proceedings.

2.4.3 Search Terms and Search Strings

In the literature search, both keywords and index or subject terms were used (refer to figure 2.2). Most of these databases used in the literature search recognise their own words as indexed therefore, index terms were used in addition to the keywords. The search terms or words were restricted to the inclusion and exclusion criteria to represent current knowledge and literature on the subject of interest in this study. These words were deduced out of the four main concepts namely nurses, experiences, end-of-life care and Intensive Care Unit. The search terms were framed by the researcher in consultation with a librarian and a preliminary search trial included the search words: nurses, experiences, Intensive Care Unit, end-of-life care, nurses' experiences, and withdrawal of treatment. Upon a preliminary search using the various databases, other subjects' headings were included: terminal care, life change events, withholding of treatments, death and dying, do-not-resuscitate order.

PubMed did not have the word "experience" indexed, instead recommended "life change events" as the Mesh term. These terms were used in addition to text words and synonyms of the keyword "experience," such as feelings. End-of-life care also was indexed as terminal care and hospice care. Withdrawal of treatment was also indexed as withholding of treatment. In all cases, Boolean operators "AND" and "OR" were used to combine the search terms in specific ways to broaden or narrow the search results. For example, "end-of-life care OR terminal care OR withholding of treatment AND Intensive Care Unit OR Critical Care Unit AND experiences OR feelings OR life change events." In some cases, the words nurses and experiences were combined as "nurses' experiences" with other synonyms, such as "nurses' feelings," also used. A similar situation also occurred in the CINAHL database.

The words end-of-life care and experiences were also not indexed however, it recommended life and work experiences for experiences and terminal care for end-of-life care as subject headings. These search terms in addition to the free text words were again combined with the Boolean operators to search for relevant articles.

Search strings were developed after thorough consultations with the librarian and the supervisor. This was to determine the main concepts and synonyms that needed to be together or separated by the Boolean terms (AND, OR and NOT). Keywords in various articles discussing similar subject also helped to formulate the search strings. The search strings, as used in the study, are displayed in **Figure 2.1**

(“nurses” OR “Intensive Care nurses”)

AND

(“experiences” OR “feelings” OR “work experiences” OR “life experiences” OR “life change events” OR “perceptions”)

AND

(“end-of-life care” OR “terminal care” OR “Palliative care” OR “withdrawal of treatment” OR “do-not-resuscitate order” OR “death and dying”)

AND

(“Intensive Care Unit” OR “Critical Care Unit”)

Figure 2.1: Search String used in this study

2.4.4 The Search Process

The search strategy, as devised in consultation with the librarian and the supervisor, guided the detailed search process. In the first literature search, the researcher used the search strings for each database included in the study. The search filters, as indicated in the inclusion and exclusion criteria, were also used for each search; these included date limit and language. The outcome of each database search was documented and saved. The CINAHL Plus search strategy was translated into the other EBSCO host databases (MEDLINE, Academic Search complete and Health Source: Nursing/Academic edition) as they had a similar approach. PubMed, SCOPUS and ProQuest were also searched for relevant articles using similar search terms and search strings. The researcher also used the Boolean terms ALL FIELDS, TITLE, TITLE/ABSTRACT and KEYWORDS as provided in the search box.

In addition to the electronic databases search, a hand search was also done to complement the literature search process. This approach complements the search process as it also identifies relevant articles that may have been missed in a database search. Specific Intensive Care and nursing journals, such as Nursing in Critical Care Journal, Journal of Advanced Nursing, Journal of Clinical Nursing and South African Journal of Critical Care, were hand searched for additional articles. These were done through the Wiley online library database, with the exception of the South African Journal of Critical Care, which was searched using the Google search engine.

Lastly, in the literature search, reference list of articles retrieved in the literature search process was scanned for relevant articles. References of these articles were copied into the Google Scholar database and searched. Relevant articles may have been missed in the electronic database search, as they may not have been indexed as of the time of the search. Google Scholar was used to search for such relevant articles.

2.4.5 Supplement Search methods

Google search engine was also helpful in retrieving articles that the researcher missed earlier. The researcher searched using a full sentence “nurses experiences of end-of-life care in the Intensive Care Unit”. This resulted in studies that were missed in the previous search strategy.

2.4.6 Documenting the Search

Each search was done and recorded separately, using the eligibility criteria, search filters and search terms. The search filters were initially limited to date and language. Articles obtained from each database search were recorded.

Table 2.2: Summary of literature Search

Database		Search string	No. of articles
SCOPUS		TITLE-ABS-KEY (("nurses" OR "intensive care nurses")) AND TITLE-ABS-KEY (("experiences" OR "feelings" OR "life experiences" OR "life change events")) AND TITLE-ABS-KEY (("end-of-life care" OR " terminal care" OR "withdrawal of treatment" OR " palliative care" OR “ do-not-resuscitate order” OR “death and dying”)) AND TITLE-ABS-KEY (("intensive care unit" OR "critical care unit")))	166
PubMed		(("nurses"[All Fields] OR "intensive care nurses"[All Fields]) AND ("experiences"[All Fields] OR "feelings"[All Fields] OR "life experiences"[All Fields] OR "life change events"[All Fields])) AND ("end-of-life care"[All Fields] OR "terminal care"[All Fields] OR "palliative care"[All Fields] OR "withdrawal of treatment"[All Fields] OR "do-not resuscitate order"[All Fields])) AND ("intensive care unit"[All Fields] OR "critical care unit"[All Fields])	164
ProQuest		("nurses" OR "intensive care nurses") AND ("experiences" OR "feelings" OR "life experiences" OR " life change events") AND ("end-of-life care" OR "terminal care" OR "palliative care" OR "withdrawal of treatment" OR " do-not resuscitate order") AND ("intensive care unit" OR "critical care unit")	205
		("nurses experiences" OR "nurses feelings" OR "nurses attitudes") AND ("end-of-life care" OR "terminal care" OR "withholding of treatment" OR “death and dying”) AND ("intensive care unit" OR "critical care unit")	183
EBSCOhost	CINAHHL	("nurses" OR "intensive care nurses") AND ("experiences" OR "feelings" OR "life experiences" OR " life change events") AND ("end-of-life care" OR "terminal care" OR "palliative care" OR "withdrawal of treatment" OR " do-not resuscitate order") AND ("intensive care unit" OR "critical care unit")	40
	Academic Search Complete	("nurses" OR "intensive care nurses") AND ("experiences" OR "feelings" OR "life experiences" OR " life change events") AND ("end-of-life care" OR "terminal care" OR "palliative care" OR "withdrawal of treatment" OR " do-not resuscitate order") AND ("intensive care unit" OR "critical care unit")	36
	MEDLINE	("nurses" OR "intensive care nurses") AND ("experiences" OR "feelings" OR "life experiences" OR " life change events") AND ("end-of-life care" OR "terminal care" OR "palliative care" OR "withdrawal of treatment" OR " do-not resuscitate order") AND ("intensive care unit" OR "critical care unit")	47
	Health Source: Nursing	("nurses" OR "intensive care nurses") AND ("experiences" OR "feelings" OR "life experiences" OR " life change events") AND ("end-of-life care" OR "terminal care" OR "palliative care" OR "withdrawal of treatment" OR " do-not resuscitate order") AND ("intensive care unit" OR "critical care unit")	18
Hand-searched Journals	Nursing in Critical Care		89
	South African Journal of Critical Care		14
	Journal of Advanced Nursing		51
	Journal of Clinical Nursing		47

2.4.7 Search Outcome: Results from the Electronic Search

Using the search strategy, which included electronic database and hand search, an initial 1078 articles (861 from the electronic database search, 201 from journal hand search and 16 from reference list) were obtained, as indicated in **Table 2.2**. The 1078 articles (861 from the electronic database search and additional 201 from journal hand search and 16 from reference list), as indicated in the summary of the initial search outcome, were subjected to further scrutiny by two independent reviewers. This time the inclusion and exclusion criteria were strictly followed.

2.4.8 Selection and Screening Process

General selection criteria were applied to the titles and the abstracts of the articles obtained from the literature search. The aim was to determine the sources relevant in answering the research question and which fell into the eligibility criteria as indicated. Criteria followed for inclusion of articles included:

i) Title of article screening
ii) Removal of duplicates
iii) Abstract
iv) Full-text reading for article inclusion

All articles initially obtained were screened by two independent reviewers (EK and SS). For each article, the title was critically analysed for further inclusion. For those with titles that fell within the inclusion and exclusion criteria, the abstract was further read. However, in some cases, the title of the article was different from the content in the abstract, hence both the title and the abstract were screened concurrently in order not to exclude relevant articles. Articles that replicated were removed as the titles were scanned. After the initial selection, the remaining articles were screened full text by the two independent reviewers (EK and SS) and were included if they met the inclusion criteria. In cases of misunderstanding between the two reviewers, an independent third reviewer (VH) was consulted and agreement was reached in all cases. The preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram was used to map the search process (**see Figure 2.2**).

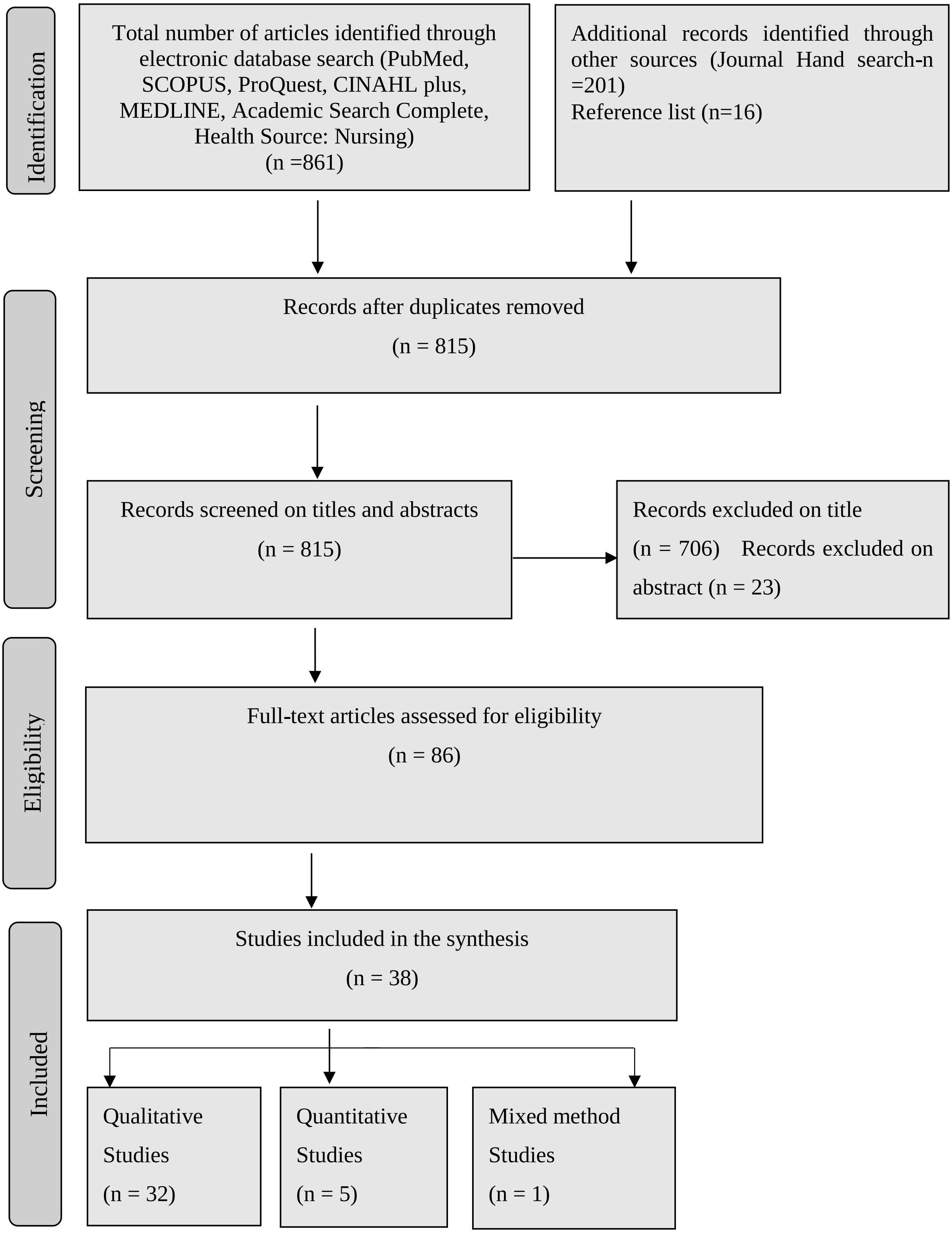

Fig 2.2 PRISMA flow diagram.

Source: Moher D, Liberati A, Tetzlaff J, Altman DG, The Prisma Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLos Med 6(7): e1000097. Doi:10.1371/journal.pmed1000097.

2.5 REASONS FOR EXCLUSION

The selection and screening process of articles for inclusion was based on the inclusion and exclusion criteria. A clear, objective and well-formulated criteria was set by the reviewers' beforehand and adhered to during the decision making process of excluding studies. First, articles were excluded based on their titles. Studies that were clearly irrelevant to the subject were initially excluded. Duplicates were also excluded as the titles were screened independently. Of the eligible 1078 studies, 969 articles were excluded based on their irrelevant titles, duplicates and titles that did not focus on the topic.

Several studies (23) were also excluded based on the content of their abstracts that did not adhere to the inclusion and exclusion criteria. From the 86 full-text articles that were fully read and assessed for their eligibility, 48 studies were excluded. A number of these excluded articles focused on nurses in the acute ward, nurses' experiences in the neonatal and paediatric ICUs, nurses working in the obstetric units, and nurses working in a community hospital. Two reviews studies were excluded because they did not meet the inclusion and exclusion criteria. Two other studies were published in Portuguese and Spanish, hence they were excluded because the reviewer could not translate the respective studies into English.

2.6 METHODOLOGICAL RIGOUR

It is well reported in the research literature that research review should meet the same standards in terms of methodological rigour just like any other primary research. Literature also indicates that systematic bias and error are bound to occur at any stage of the review. Therefore, it is important to pay great attention to any sources of threat to the validity in order to maintain scientific integrity while conducting an integrative review (Ganong 1987; Whittemore & Knafl 2005). Whittemore and Knafl (2005) suggest maintaining methodological rigour throughout the research phases to reduce biases.

The measures taken to ensure methodological rigour are discussed below.

2.6.1 Literature Search: Search Strategies

Well-defined literature search strategies are crucial for enhancing the rigour of a research review, as incomplete and biased search strategies limit the accuracy of search results (Whittemore & Knafl, 2005).

The strategies as used by the reviewers to minimise threats and are discussed below.

In order to conduct an exhaustive literature search, a broad and well-defined search strategy, which included search terms and index databases, were devised prior to the search process to enhance a thorough literature search. Inadequate sampling poses a threat to internal validity, however, a well-formulated literature search plan and process enhances rigour (Russell, 2005; Whittemore & Knafl, 2005). A clearly worked-out plan is necessary for conducting an exhaustive literature search (Conn et al., 2003). Several electronic databases, which included PubMed, SCOPUS, ProQuest and EBSCO host databases, were used to ensure a comprehensive search. A librarian was also consulted at the literature search stage for expert advice and directions regarding a well-articulated plan for literature search. Hand searches from relevant databases and direct contact with researchers and research organisations complimented the process.

2.7 SUMMARY

This chapter discussed briefly the integrative review as a method. This was followed by a detailed discussion of the literature search stage of the integrative literature review as informed by Whittemore and Knafl (2005), the literature search that included the search methods, databases, selection strategies, eligibility criteria and documentation of search results. The chapter finally ends with a discussion of the methodological rigour as ensured at each of the explained stages.

In the next chapter, the data evaluation stage is described and discussed.

CHAPTER THREE

DATA EVALUATION

3.1 INTRODUCTION

This chapter focuses on the evaluation of data, which included the data extraction and quality appraisal process and finally discusses the methodological rigour as ensured in each stage.

3.2 DATA EVALUATION

Once an exhaustive literature search has been completed, the data evaluation stage follows. Several researchers (Beyea & Nicoll, 1998; Whittemore & Knafl, 2005) term this stage as crucial in enhancing the integrity of the integrative review however, admit it is difficult to achieve. This stage comprises the extraction of common features from the included primary literature followed by appraising the individual quality of each literature for subsequent data analysis.

In order to provide a detailed explanation for the data evaluation stage, the researcher categorised the stage into two sub-stages, namely:

i) Data extraction stage
ii) Quality appraisal stage

3.2.1 Data Extraction

Data extraction refers to a process where the researcher sources and records relevant results from the individual primary literature that will finally be included in the review (Whittemore, 2005). Data extraction, in this case, meant the literature obtained was summarised in a data matrix format, which included the relevant characteristics of each study. At this stage, research evidence recommends reliable and valid instruments and procedures in ensuring methodological rigour; these include a standardised, valid data extraction instrument and coding procedures. This enables to the researcher to collect and capture all relevant data in the included individual primary study, minimise errors in data transcription in order to guarantee precision in information checking and finally serve as a source of reference in data synthesis (De Souza et al., 2010; Russell, 2005; Whittemore, 2005).

A valid data extraction tool developed by De Souza et al (2010) was used for the data extraction. Prior to the commencement of the review, the data extraction tool was pilot tested to ensure its accuracy in capturing all relevant data needed. The data extraction instrument was found important as it captured all the relevant features of the individual primary studies to solve the research problem. In order to ensure accuracy and methodological rigour during the data extraction stage in this study, two independent reviewers coded the content of the individual studies. As a certified co-coder, the supervisor (SS) complemented the researcher to extract the relevant data features using the valid instrument as indicated. Data matrix suggested by De Souza et al. (2010) was used to extract study characteristics, which included author, year, journal, study objective, research method, population, data collection, results/findings, and limitations **(Table 3.1).** The table was crosschecked for accuracy by the two reviewers (EK and SS).

Refer to **Appendix A** for the data extraction tool.

DATA MATRIX

Table 3.1: Characteristics of included studies

	"Author(s), year & setting	**Journal**	**Aim of the study**	**Research methodology Design**	**Population & Sample**	**Data collection & data analysis**	**Findings**	**Recommendation/ Limitation**
1	Kisorio & Langley **(2016)** South Africa	Intensive and Critical Care Nursing	To explore the experiences of nurses regarding end-of-life care in the Intensive Care Unit	An exploratory, descriptive qualitative approach	Purposive sampling method 24 Intensive Care nurses from adult ICUs in three hospitals with more than 6 months bedside experience	Focus group long table approach (Krueger and Casey, 2000) Thematic analysis	-Nurses face psychological distress and emotional stress that are described as painful, touching -Emotional labour experienced due to family reactions to information disclosure -Support for family psychologically, respect their cultural/beliefs, ritual practices, family presence at the bedside, visitation and involvement, nurses presence with the family, gradual preparation with information -**Support for nurses**: Meeting the challenges nurses face through team work, training, counselling, debriefing sessions -**Support for patients**: spiritual/religious support, patients' comfort, family presence, respect for patient, minimise noise - Inadequate involvement of nurses in the decision making	-Support nurses during the end-of-life care process -End-of-life education Development of end-of-life practice guidelines **Limitation**: Study limited to just three adult ICUs in one of nine provinces

2	Rafii et al. (**2016)** Iraq	Nursing in Critical Care	To explore nurses' lived experiences of providing end-of-life care for terminally ill patients in the ICU	Van Manen's (1990) hermeneutic phenomenological design	Purposive sampling 10 registered Intensive Care nurses, working in the ICU, with at least 2 years of experience	In-depth semi structured interviews Thematic analysis	-**Emotional labour** as a result of caring for young patient/hopeless patient and family reactions regarding decisions -**Death as a positive dimension**: getting used to the job (more experience with time, make better plans), personal growth and development (clinical skills, confidence, greater assurance for future challenges -**Optimistic rather than futile care:** being under religious influence (cultural religious and ethical beliefs mandates nurses to provide regardless of the illness), being compassionate (support patient and family, provide hope, assurance) -**Working within constraints:** insufficient resources (shortage of staff, lack of equipment, medicine) and poor coordination among healthcare professionals (nurse-physician)	Effective communication among the healthcare professionals **Limitation**: study was limited to only nurses working in only two public hospital as well as using purposive sampling of 10 nurses. Other settings might differ
3	Efstathiou & Walker **(2014)** UK	Journal of Clinical Nursing	To explore the experiences of Intensive Care nurses in the provision of end-of-life care for patients and families	Descriptive exploratory qualitative study.	Purposive sampling 13 Intensive Care nurses from a major university ICU	Semi - structured face-to-face interview Interpretative phenomenological analysis-thematic analysis	-Caring for the dying patient and their family (physical care, symptom management, comfort and support-providing information to the family, offering reassurance) -Providing and encouraging presence: family presence and involvement, family time with the patient -Connecting the patient and family: increasing privacy and proximity, reduce distance between patient and the family and creating a less technical environment, - Uncertainties on relationships, what to do and not to, lack of clear communication between nurses and doctors	-EOL care practice guidelines -Improve the communication pathways between nurses and doctors **Limitation**: Transferability of findings as study was done in one local university hospital in the UK

4	Holms, Milligan & Kydd **(2014)** Scotland	International Journal of Palliative Nursing	To explore nurses experiences of providing end-of-life care for patients and families	Qualitative study, Phenomenological approach	Purposive sampling Five Intensive Care nurses	In-depth interviews Thematic content analysis	-The use of integrated care systems such as guideline use improved end-of-life care practice - Distressing personal experience: feelings described were helplessness, anger, frustration and sadness. -Communication breakdown, disagreement with decisions lead to inconsistencies in end-of-life practice -The Intensive Care environment affected EOL care: the busy, noisy and multi-bed rooms environment -Education: inadequate training and education on end-of-life care, learn from their experiences	Communication, education and training supports. Further guidance on the guidelines Limitation: Study limited to a small sample size
5	King & Thomas **(2013)** **United States**	Western Journal of Nursing Research	To explore the lived experiences of nurses caring for the dying patient patients in the ICU	Phenomenology study	A snowball networking approach 14 Critical Care nurses	In-depth interviews Thematic analysis	- Promises to keep: promise to be truthful, advocate, remain connected, discuss pending death to patient and the family, provide comfort care -the focus on the dying and the promises made to them; compassionate care at all times -Morally obligated -Emotional suffering	
6	Valiee et al **(2012)** Iran	Nursing in Critical Care	To explore the experiences of Intensive Care nurses providing care for end-of-life patients.	Qualitative design	Purposive sample 10 nurses working in a general ICU, with experience in practice ranging from 1to18 years	In-depth interview Qualitative content analysis	-Emotional burden experienced from the psychological pressure in providing care -Emotional burden experienced from the nature of the family reaction (the reactions from distressed and anxious family: -the effect of patients condition: patient's condition had an impact on the caring experience) -Values and beliefs fundamental to the experience: Religious and cultural influence -Being an advocate: supportive and provide holistic care	Specialised training and support are required to assist nurses in providing end-of-life care Limitation: Study was limited to only one ICU and a cohort size

7	Vanderspank-Wright et. al **(2011)** Canada	Dynamics	To explore the experiences of nurses providing care for patients during the withdrawal of life-sustaining treatment in the Intensive Care Unit	Interpretive phenomenology study	Purposive sampling Six Intensive Care nurses from a 24-bed medical-surgical ICU, with at least 6 months experience in caring for patients	In-depth interviews Colaizzi data analysis (Thematic analysis)	Nurses are trying to do the right thing - Nurses establish rapport with the family - assist them to accept the death of the patient, - Comfort the patient and family - caring for the patient and the family, as well as reflect on their experiences working in professional angst - Nurses navigate the conflict from lack of clear and consistent communication with the healthcare team. -The nurse becomes the middleman dealing with the healthcare team as well as patient and their family. -Providing memories: leave positive experience for the family, provide comfort	More research is required on how critical care nurses contribute to the end-of-life experience for patients and families.
8	Espinosa et al (**2010**) United States of America	Critical Care nursing Quarterly	To understand the experiences of nurses in the provision of end-of-life care in the ICU	Explorative qualitative study Phenomenological approach	Purposive sampling 18 registered nurses working in five different ICUs in a teaching hospital, with 2 to 40 years of experience	Interviews and focus group Colaizzi data analysis (thematic)	**Barriers to optimal care** - lack of nurses involvement in the plan of care -the differences in the nursing practice model and the medical model, -disagreement between doctors and other members of the health care team -perception of futile care and unnecessary suffering -unrealistic expectations from family members - lack of experience and education of nurses **Internal conflict** -internal conflict among nurses -feeling of relief -desire to support patient and family -abandonment and powerless -conflict with medical administration -difficulty with younger patients **Coping issues: coping strategies** -building trust in the family, crying, humour, talking to others, avoiding care for patients	Proper education, training and support and open communication among the healthcare team. Team collaboration

9	Calvin, Lindy & Clingon **(2009**) United states	Intensive & Critical Care nursing	To understand nurses feelings for caring for patients who are approaching end-of-life	Descriptive qualitative approach	Purposive sampling 19 nurses from one Cardiovascular ICU	Interviews Thematic analysis	-Exhausting patient treatment -Promoting family presence and involvement - -Acknowledging physician authority -Physicians do not perceive the medical treatment has been exhausted and patient’s condition is irreversible (unwilling to let go) -Physicians are the final decision makers -Walking a fine line: nurse perform her duties despite the end-of-life -Lead the family through the process -walking a fine line on what to say to the family, to avoid physician confrontations or reprimands	Supporting systems and good communication among the healthcare providers
10	Hov, Hedelin & Athlin **(2007)** Norway	Journal of Clinical Nursing	To understand what it is to be a nurse in end-of-life care situations	Qualitative interpretive phenomenology	Purposive sampling 14 Intensive Care nurses, with at least 15 months working experience	Group interview Thematic analysis: Colaizzi model of analysis	- Nurses are in a difficult situation, unable to judge whether the right thing has been done, perform doctors responsibilities, lack of regular meeting with physicians, lack of conclusion on discussions -**Uncertainties**: constant ethical dilemmas between accepting a natural death and saving -vague and unclear goals for the patients’ treatment, physicians conflicting messages. - nurses fall between joy and despair, patient’s condition becomes worse and at a point recovers, ups and downs - Different perspectives of nurses and physicians, and their interaction. Physicians only occasionally listen to nurses	-Measures to promote open and effective communication among nurses and physicians -Formal support strategies for the healthcare providers

11	McMillen England/ UK (**2008)**	Intensive & Critical Care Nursing	To explore the experiences of ICU nurses caring for patients who have had their treatment withdrawn	Constructivist Grounded Theory	Purposive sampling eight Intensive Care nurses, with at least 6 months experiences	Semi-structured interview Richie and Spencer (1994) Framework analysis	- Getting the timing right regarding end-of-life decisions -Emotional labour: stressful, being upset especially when the patient is young -Experience counts, not really a nurse's decision, planting the seed (initiate discussions), supporting the family and being a patient advocate	Adequate support for nurses in providing their roles
12	Fridh, Forseberg & Bergbom (2009) Sweden	Intensive & Critical Care nursing	To describe nurses experiences of caring for the dying in the ICU, with the focus on unaccompanied patient, the proximity of family members and the environmental aspects	An explorative qualitative design	Purposive sampling 9 ICU nurses	Interview Content analysis	-Ensuring patient comfort and dignity -caring for the unaccompanied patient: the nurse acting as a substitute -caring for the family: support for them, reassurance, information sharing, involvement -environmental obstacles to EOL care: lack of privacy, nursing patients in multi-bed rooms -Lack of collaboration in decision making process	
13	Leung et al **(2017)** Canada	Nursing in critical Care	To understand nurses experiences of caring for patients with chronically ill and their families in the ICU	Qualitative interpretive descriptive method	Sampling- 16 Intensive Care nurses working an academic hospital, with at least 4years of experience	Semi-structures interviews Thematic analysis	-internal tension during communication with the family and the healthcare team: tensions in relation to knowledge on patients poor prognosis and anticipation of their death. -Families naïve expectations on preventing death, preserving family trust -Constraints to their participation in care planning: conflicting messages within the inter-professional team and with the family	A well-explained nurses roles regarding the initiation and provision of end-of-life care Limitation: study was limited to a single setting

14	Jordan et al. **(2014)** South Africa	African Journal of Nursing & Midwifery	To explore and describe nurses experiences with regards to end-of-life issues in the ICU	Qualitative, explorative, descriptive contextual design	Purposive sampling Nine Intensive Care nurses	Semi-structured interview Thematic analysis	-Conflicting emotions in the caring of the patient: following conflicting instructions from doctors, feeling of helplessness, mixed emotions of sadness, grief and anger - Support the family, promote involvement -multidisciplinary team relations: the need for collaborative work approach, teamwork. Nurses do not feel part of the team, lack of support -the need for supportive strategies: debriefing, psychological support and education	**Nursing education**-include end-of-life issues in the curriculum content, short learning programmes and in-service educations programmes **Nursing practice**- debriefing sessions, multidisciplinary team discussions and care meetings
15	Brysiewicz & Bhengu (2010) South Africa	South African Journal of Critical Care	To explore the experiences of nurses in the provision of support to families of critically ill patients in the ICU	Interpretive hermeneutic phenomenological approach	Purposive sampling Nine Intensive Care trained nurses from three hospitals, with at least 6 months experience	Semi-structured interview Thematic analysis	-Cultural awareness: attend to the cultural needs of the family -Communication challenges: between nurses and the physicians, family and the physician -Providing assistance for the family-involvement in the care, psychological and emotional support -Lack of training for nurses: insufficient resources and training	Training needed
16	Naidoo & Sibiya (2014) South Africa	Journal of Nursing and Care	To explore the experiences of nurses regarding death and dying in the ICU	Qualitative descriptive approach Descriptive phenomenological approach	Purposive sampling Four Intensive Care nurses working in the ICU, with more than 2 years experiences	Interview Giorgi's Thematic analysis	-Thoughts about Caring for the dying: death of an elderly or aged patient often crossed a nurse's mind, while that of the young becomes very sad and unmanageable at times for all staff in an ICU -Feelings about caring for a dying patient: feelings of despair, anger and even denial. -Communication with dying patients -Support systems: lack of education and support for caring for the dying	A supportive networks for the provision of care and promote emotional support and well-being

17	Velarde-Garcia **(2016)** Spain	Contemporary nurses	To explore the lived experiences nurses who face patient’s death in the ICU	Qualitative Phenomenological	Purposive and snowballing sampling 22 nurses working in the ICU with at least one year’s experience	In-depth interview, semi-structured field notes and personal documentation Giorgi proposal analysis	-Dealing with expectations of recovery: nurses reflection of experiences surrounding death; feeling of intolerance -Accepting the age of death: the death of the elderly is perceived as naturally acceptable, sense of relief and rest for both the patient and the family, whereas the younger one is shocking , which triggers sadness, pain and helplessness -Experiencing emotional attachment: a clear attachment and involvement on behalf of the nurses for patients and the family	The development of support programmes for nurses
18	Kongsuwan (2011) Thailand	Nursing Science Quarterly	To explore nurses lived experiences of caring for patients who had a peaceful death in the ICU	Van Manen’s hermeneutic phenomenological approach	10 Intensive Care nurses	Interviews	-Mindful readiness to care - prior experience to care -Offering self authentically for others- offering self to be with the dying patient -Communicating through touch - Honouring self for giving care - Providing care and completing responsibilities -Relationships with the family: family members involvement, psychological support -Environment: siren environment for the dying patient, friends and family express their last love and respect -Value the ongoing care regardless of the time, accepting death as natural	
19	Popejoy et al. (2009) USA	Journal of Hospice and Palliative Nursing	To explore nurses viewpoints about caring for critically ill and dying patients in the ICU	Qualitative preliminary study	22 Intensive Care nurses of a private tertiary hospital	Focus group interviews	-Helping patient and family: supporting the patient and the family -telling bad news: knowing when to disclose information to the family, conflicting versions between nurses and physicians on patients condition and probability of recovery -grieving as a process: nurses support the family through the grieving process -see the family as a patient: supported through	The need for a collaborative approach to patient and family care in the ICU

							the process, accept patients situation and eventual death - nurse becomes vulnerable to painful feeling, emotional pain and experience profound moral distress due to the emotional bond with the dying patient	
20	Heidari & Norouzade **(2014)** Iran	Holistic nursing Practice	Experiences of nurses supporting families of patients at the end-of-life care	Qualitative, grounded theory method	Purposive sampling 23 Critical Care nurses	Interviews Thematic analysis	-Promoting death with dignity -Caring for the dead without the presence of the family, preparation of the private environment for reading the Quran -Facilitate family visitation - Provide privacy, explain the cause of patient death, attention to different cultures in mourning -preparing: inform the family -distress: severe emotional reactions by nurses	
21	Arbour & Wiegand (2014) US	Intensive and Critical Care nursing	To understand nurses experiences and perceptions while caring for patients at end-of-life and their family	A descriptive phenomenological study	Purposive sampling 19 Intensive Care nurses	Interviews Coliazzi's method of data analysis Thematic analysis	- Educating the family-the treatment plan, - Advocacy role-follow patient wishes, support their wishes, spiritual support for patient, -Encouraging and supporting family presence -managing symptoms (patient support) -Protecting family and creating positive memories -Family support: advocacy, information needs, -Mentoring and teaching- assist new, novice nurses	Educational and training support for nurses
22	Nankundwa & Brysiewicz **(2017)** Rwanda	South African Journal of Critical Care	To explore the lived experiences of nurses caring for a patient with a DNR order in an Intensive Care Unit	Phenomenological approach	Purposive sampling Six Intensive Care nurses from an ICU in a tertiary hospital	Semi-structured in-depth interviews Giorgi's phenomenological approach	-Feeling emotional distress: feeling of despair, sadness, helplessness, painful experience, moral conflict with the decision made -Barrier to optimal care: Patient receive less intensive care, nurses activities are not well done, negative impact of care given -Not part of decision-making: Doctors make the decisions, nurses are not involved	Adequate training on DNR

23	Wu et al. (2015) Canada	American Journal of Men’s Health	To explore male nurses experiences of caring for the dying patient and family in the ICU	Qualitative interpretive descriptive	Snowball, convenience sampling 15 male Intensive Care nurses	Interviews Thematic analysis	-Ensuring a dignified death: comfort care, pain control, fear relief, meeting patient’s wishes, ensure peaceful death -Changing the focus from patient to family: family support/ emotional support, family involvement, touch patient, empathy -Being emotionally attached: a powerful experience, feel the pain of the family	Education of healthcare providers using stress management strategies
24	de Swardt & Fouché (2017) South Africa	Intensive and Critical Care Nursing	To describe Intensive Care nurses experiences of performing post mortem care on patients who had died in an Intensive Care Unit	Qualitative descriptive approach	Purposive sampling Six nurses	Semi-structured interviews Colaizzi's (1978) data analysis	-Care for the dead: appearance, comfort, the last office, meeting the religious and spiritual needs of patients and families -Sense of detachment: to say goodbye	Debriefing and education
25	Yu & Chan (2010) Hong Kong	Journal of Clinical Nursing	To describe the response of Intensive Care nurses to death of patients and how it influenced the care offered to dying patients	Qualitative study	Purposive sampling 12 Intensive Care nurses with work experience from 3 to 14 years	Interview Content analysis	-Nurses displayed emotional reactions to the provision of EOL care -Nurses develop coping strategies along the care journey -Facilitators of care nurses render :support and sharing of feelings with colleagues, education -Barriers to care: lack of manpower(less voice), conflicts between nurses and physicians (medical dominance	Educational programmes that teach effective coping strategies
26	Ong, Ting & Chaw (2018) Singapore	Journal of Clinical Nursing	To understand critical care nurses perceptions towards the provision of end-of-life care	Qualitative descriptive design	Purposive sampling 10 Intensive Care nurses working in an ICU, with 2 or more years of experience	Thematic analysis	-The culture of care: family perspective and professional perspective, less of emotional and psychological support -Tensions: lack of autonomy (power imbalance), suboptimal of end-of-life care, under-preparedness to provide end-of-life care -Emotional meaning of life and death (discomfort, grief and relief, sadness), -control their emotions and develop active coping (formal and informal support), passive	Implement policies to empower nurses and improve support and education

							coping (just do your job) to adapt	
27	Limbu, Kongsuwan & Yodchai (2018) Nepal	Nursing in Critical Care	To describe Intensive Care nurses lived experiences of caring for the critically ill patients in the Intensive Care Unit	Hermeneutic phenomenological study	Purposive sampling, recruited 13 nurses from 3 ICUs	Face-to-face, in-depth individual interviews van Manen's approach for data analysis	- Insufficient resources and low technology of care -Psychological and physical stress: Health problems from fewer staffs to unpleasant feelings, stress and frustrations -Requiring competency in caring: Knowledge and skills, formal education -Connecting relationship as a family: Value both patient and family -Trusting technology of care -Realising team work: Cooperation, team efforts -Less time with patient as a whole: time constraints, limited nursing staff	Education and training programs
	QUANTITATIVE STUDIES							
	Author(s), year & setting	Journal & Year	Aim of the study	Research methodology Design	Population & Sample	Data collection & data analysis	Findings	Recommendation/ Limitation
1	Latour, Fulbrook & Albarran (2009) Europe	Nursing in Critical Care	To investigate the experiences and attitudes of nurses regarding end-of-life care in the ICU	Quantitative approach	Convenience sampling European ICU nurses (164)	Questionnaire Descriptive and inferential statistics	-Patient comfort/support (patients religious views, pain management) -Family support(family visit, family involvement in the decision making -Lack of involvement -Religious belief effects	Formal guidelines and education
2	Badir et al (2016) Turkey	Nursing in Critical Care	To explore the experiences and views of nurses regarding EOL care	Quantitative Cross-sectional	Survey (Venice tool) 626	Descriptive analysis	-Patient and family support-religion important, spiritual support, psychological care, pain management, nutrition support -Nurses not involved in the EOL discussions	EOL care practice guideline and specific national policies are recommended
3	Langley et al. (2014)	Nursing in Critical Care	To investigate the experiences and perceptions of EOL	Quantitative approach	100 nurses working in the	Survey (VERNICE tool)	-Patients religious view important -Lack of involvement in end-of-life care decisions	Development of formal guidelines around EOL care will enhance communication

	South Africa		care among intensive care nurses		ICU	Descriptive and inferential statistics	-Family involvement -Ensuring patient comfort and support through essential nursing care	
4	Tripathy, Routray & Mishra (2017) Eastern India	Indian Journal of Critical Care Medicine	To investigate knowledge, attitude, and beliefs of intensive care nurses toward EOL in the ICU	Quantitative	Survey using the Venice scale 138 Intensive Care nurses	Self-administered questionnaire Descriptive statistics	Wanting unrestricted family visitation -Discontinuing monitoring and investigations at EOL -Being a part of EOL team discussions - Equating withholding and withdrawal of treatment	Greater emphasis on palliative care in Critical Care curriculum may improve awareness among critical care nurses
5	Khalailleh (2014) Jordan	International Journal of Palliative Nursing	To explore Intensive Care nurses attitudes and experiences of do-not-resuscitate decision in clinical practice	Cross sectional survey	Survey 111 Intensive Care nurses	Questionnaire Descriptive statistics	-Majority indicate the DNR decision should involve the family, nurses and physician -Family involvement in the decision -Lack of involvement of nurses in the DNR process	Having clear guidelines can minimise dilemmas relating to DNR decisions
				MIXED-METHOD STUDY				
	Author(s), year & setting	Journal & Year	Aim of the study	Research methodology Design	Population & Sample	Data collection & data analysis	Findings	Recommendation/Limitation
1	Coombs et al. **(2015)** New Zealand	Australian Critical Care	To investigate Intensive Care nurses' experiences and attitudes towards EOL care	Sequential mixed methods study Both cross sectional survey and focus groups	Convenience sampling 221 ICU nurses (203 for web-survey and 18 for interview)	43-item web-based survey and interview Content analysis Descriptive and inferential statistics	-Patient comfort/support and family support important during EOL care - Religious belief had no influence on views about EOL care -Nurses have limited role in decisions made at the end-of-life - Nursing care at the EOL care brought both great rewards and challenges	Formal guidance for nurses on specific aspects of nursing care at EOL is recommended
				QUALITATIVE- THESES/DISSERTATIONS				

1	Garwood (2016) USA	Dissertation	To explore the lived experiences of Critical Care nurses caring for the dying patient in Critical Care Unit	A qualitative, descriptive phenomenological methodology	Convenience sampling Twelve Critical Care nurses	Interviews field notes Colaizzi's data analysis	-Communication: lack of communication among the healthcare team, Physicians especially - Family: resistance, unwillingness to stop care and denial - Technology- older patient, technology increases pain and suffering; younger patient, improves recovery -Lack of education: less classroom teaching on EOL care - Dying with dignity: comfort measures, following patient wishes	Promote early EOL care discussions with patients and families Formal support for nurses in the provision of end-of-life care. EOL care education for health care providers, patients and families
2	Templeman (2015) UK	ProQuest Dissertation	To explore the experiences of nurses following withdrawal of treatment decisions in the ICU	An ethnographic study	Purposive sampling Eight Intensive Care nurses	Semi-structured interviews/ field notes Data analysis using Ricoeur's analytical framework	-Decision to withdraw treatment included creating space for dying, respect for dying, protecting patients, maintaining privacy - nurses' actions following the withdrawal of treatment decision included ensuring patient was pain free, comfortable, support family, break the news, involve family - Shared experiences in the journey towards death, family present at patient's bedside, allow dignity in dying	formal and informal support for nurses during the patient's withdrawal of treatment in the ICU
4	Kaldem (2009) USA	ProQuest Dissertation	To explore the views of Critical Care nurses caring for family members of dying patients	Qualitative, descriptive phenomenological	Purposive sampling Four female Critical Care nurses	Semi-structured interviews Colaizzi's (1978) method of analysis as framework	- Factors that hinder a positive death and dying experience: the degree of family acceptance of patients impending death, mistrust in the healthcare team, limitations of the nurse, family interest first not patient, - Factors that promote a positive dying experience: family acceptance of patients death, nurses presence at the bedside, family showing appreciation - Interventions utilised by nurses during the dying process: role adjustment, promoting family expression, continuity of care	The development of educational programmes specific to the difficulties experienced with caring for family members of dying patients in the Critical Care environment
5	Fuller (2018)	ProQuest dissertation	To explore and understand Critical	Qualitative, phenomenological	Purposive and snowballing	Interviews	-Integration of Palliative care orders set: improved communication, advocate for	End-of-life care education and training

	USA		Care nurses lived experiences caring for patients at the end-of-life	method	sampling Five Critical Care nurses with at least five years of Critical Care experience	Thematic analysis	patient, promote comfort, -Lack of training: lack of education-fear of death, younger nurses experience moral distress, learning by continuous doing -Moral distress: from personalising the situation, fragmented and lacking communication among the healthcare team and family, and futile care provided, religious beliefs -Physician reluctance: personal values-not ready to let go, less communication with the family and the nurse	-debriefing sessions following patients death Limitation: limited to only nurses from one hospital with more than 5 years of experience
6	Campbell (2008) Canada	ProQuest Dissertation	To explore the experiences of nurses regarding the transitions in death in the ICU	Hermeneutic phenomenological study	Six Critical Care nurses	In-depth interviews	- Sense of peace and comfort to each individual - Reinforced their individual belief patterns about life”	

3.2.2 Quality Appraisal Stage

Critical appraisal refers to the examination and evaluation of the methodological quality of the included research studies. This involves a careful complete examination of each study to judge its strengths, weakness, meaning, credibility and significance for practice, as well as their inclusion (Burns & Grove 2011, pg. 419). This phase of data evaluation demands an organised approach to weigh the rigour and characteristics of each study. Research studies (De Souza et al., 2010) indicate that the clinical experience of individual researchers contributes greatly to the validity of the methods and the applicability of results to practice. Both the researcher and the supervisor had extensive experience in clinical practice and research. The supervisor, a Critical Care expert and certified Joanna Briggs Institute reviewer and researcher, complemented the researcher with extensive clinical experiences and knowledge on the subject under discussion.

Evaluating and interpreting the quality of primary studies with different research designs can be complex as there is no gold standard to achieve that. However, how the quality of each study in an integrative review is evaluated often depends on the sampling frame. Whittemore and Knafl (2005) suggest strict adherence to the inclusion/exclusion criteria and the use of a quality data appraisal instrument will help ensure the authenticity, methodological quality and informative value of the included studies. In this review, the inclusion and exclusion criteria were used to screen the initial articles. Conn and Rantz (2003) added that the research quality can also be determined by evaluating the internal validity of the primary studies or the extent to which each study design conducts and analyses systematically to avoid or minimise potential bias. These scores can be incorporated into the research review as eligibility criteria for selecting relevant primary studies for review, or displayed graphically according to the specific outcome of studies and considered when analysing the variability of results. In this review, it was graphically displayed according to their specific outcomes and further incorporated when analysing the results.

A threat to the validity in the data evaluation stage, according to Russel 2005, is the reviewer’s own beliefs that can influence the evaluation of the included studies. In this review, two independent reviewers (EK and SS) evaluated each article using a validated quality rating instrument. Where consensus differed, a third independent researcher (VH) was consulted until consensus was reached.

In this study, each paper was independently assessed and systematically appraised for methodological rigour using separate critical appraisal tools for each research design used in the included studies. The literature included in this research review involved research from qualitative, quantitative and mixed method research. Given the variations in research methodologies, quality assessment required different assessment approaches.

The quality assessment rating for each methodology will be discussed in the section below.

3.2.2.1 Critical Appraisal of Qualitative studies

The Critical Assessment Skills Programme (CASP) critical appraisal tool was used to determine the quality of included qualitative studies. The CASP systematic review checklist tool uses a 10-question checklist that assesses qualitative study-based validity of the results and the usefulness of the research result in informing practice and expanding existing knowledge (CASP, 2018). The tool requires reviewers to systematically check whether each included study meets the criteria set in the 10 questions by selecting ‘yes,’ ‘no,’ ‘can’t tell’ for each question. The criteria included and covered the statement of clear research aim, appropriate qualitative methodology, appropriate research design, appropriate recruitment strategy, data collection approach, study reflexivity, ethical issues, rigorous data analysis, a clear statement of research finding and research usefulness or value. Every included paper was independently appraised by two independent reviewers (EK, SS) using a standard and validated checklist. Refer to **Appendix D** for the CASP tool.

Summary of the individual quality rating score is presented in **Table 3.2**

3.2.2.2 Critical Appraisal of Quantitative studies

The McGill Mixed Method Assessment Tool (MMAT), 2011 version, developed by Pluye et al. (2011) was used to provide a systematic approach for quality assessment of the quantitative studies included in this integrative review. The tool provides a 5-items checklist for evaluating quantitative descriptive studies. The tool obliges independent reviewers to respond “Yes” OR “No” OR “Can’t tell” to each of the items provided. For the sake of this review, the quantitative descriptive component was used for critically appraising the included quantitative studies. The criteria included a relevant sampling strategy, the sample representative of the target population, appropriate measurements, low risk-response bias and appropriate statistical analysis approach. The reviewers respond by selecting ‘yes,’ ‘no,’ ‘can’t tell’ for each question.

A summary of the individual quality rating score is presented in **Table 3.3**

3.2.2.3 Critical Appraisal of Mixed method studies

The McGill Mixed Methods Appraisal tool (MMAT), 2011 version, developed by Pluye and colleagues was used (Pluye et al., 2011). This tool (MMAT) permits research reviewers to critically appraise studies using diverse designs, and can be used for appraising qualitative, quantitative and mixed-methods research (Pluye et al., 2011) due to its reliability and flexibility. The MMAT criteria propose quantitative criteria for evaluating the quantitative component of the mixed method studies, qualitative criteria for evaluation the qualitative component and finally, specific mixed-method criteria for mixed-method component (Pluye & Hong, 2014). (**Refer to Appendix E** for the detailed MMAT tool.)

Although the authors of the MMAT indicate no cut-off point for rating the studies as low or high quality, the reviewers used the mid-score (50%) as a cut-off point to grade the studies. The 2011 MMAT version (Pluye et al., 2011) scoring metric was adopted for the quality scoring. Summary of the individual quality rating score is presented in **Table 3.4**

Table 3.2: “Quality appraisal of Qualitative studies using the Critical Appraisal Skills Programme (CASP, 2018)

	Clear aims /purpose	Methodology appropriate	Research design appropriate to answer the aim	Sampling strategy appropriate to the aims	Data collection address issue	Reflexivity, researcher considers participants relationship	Have ethical issue been taken into consideration ?	Was the data analysis sufficiently rigorous?	Clear statement of findings	How valuable is the research?	Score
Kisorio & Langley (2016)	√	√	√	√	√	*	√	√	√	√	9/10
Rafii et al. (2016)	√	√	√	√	√	*	√	√	√	√	9/10
Eftathiou & Walker (2014)	√	√	√	√	√	*	√	√	√	√	9/10
Holms, Milligan & Kydd (2014)	√	√	√	√	X	*	√	√	√	√	8/10
King & Thomas (2013)	√	√	√	√	√	*	√	√	√	√	9/10
Valiee et al (2012)	√	√	√	*	√	X	√	√	√	√	8/10
Vandersprank-Wright et al. (2011)	√	√	√	√	√	*	√	√	√	√	9/10
Espinosa et al. (2010)	√	√	√	√	√	X	√	√	√	√	9/10
Calvin et al. (2009)	√	√	√	√	√	X	√	√	√	√	9/10
Hov, Hedelin & Athlin (2007)	√	√	√	√	√	√	√	√	√	√	10/10
McMillen (2008)	√	√	√	√	√	X	√	√	√	√	9/10
Fridh et al. (2009)	√	√	√	√	√	*	√	√	√	√	9/10
Leung et al. (2017)	√	√	√	√	√	*	√	√	√	√	9/10
Jordan et a.l (2014)	√	√	√	*	√	X	√	√	√	√	8/10
Brysiewicz & Bhengu (2010)	√	√	√	*	√	X	√	*	√	√	7/10

Naidoo & Sibiya (2014)	√	√	√	*	√	X	√	*	√	√	7/10
Velarde-Garcia (2016)	√	√	√	√	√	*	√	√	√	√	9/10
Kongsuwan (2011)	√	√	√	*	√	X	√	√	√	√	8/10
Popejoy et al. (2009)	√	√	√	*	√	X	√	*	√	√	7/10
Heidari & Norouzade (2014)	√	√	√	√	√	X	*	*	√	√	7/10
Arbour & Wiegand (2014)	√	√	√	√	√	*	√	√	√	√	9/10
Nankundwa & Brysiewicz (2017)	√	√	√	√	√	X	√	*	√	√	8/10
Wu et al. (2015)	√	√	√	√	√	X	√	√	√	√	9/10
Ong & Ting (2018)	√	√	√	√	√	√	√	√	√	√	10/10
Hoi & Sally (2009)	√	√	√	√	√	X	√	*	√	√	8/10
de Swart & Fouche (2017)	√	√	√	√	√	X	√	√	√	√	9/10
Limbu, Kongsuwan & Yodchai (2018)	√	√	√	√	√	*	√	√	√	√	9/10
Garwood (2016)	√	√	√	√	√	√	√	√	√	√	10/10
Templeman (2015)	√	√	√	√	√	√	√	√	√	√	10/10
Kaldem (2009)	√	√	√	√	√	*	√	√	√	√	9/10
Campbell (2008)	√	√	√	√	√	√	√	√	√		
Fuller (2018)	√	√	√	√	√	√	√	√	√	√	10/10

CASP (Critical appraisal skill program) - Key to ratings: √ = Yes, detailed coverage of the screening question; X = No, screening question not addressed; * = Can’t tell, screening question indicated but not clear in the write-up

Table 3.3: Quality assessment of Quantitative studies using MMAT-version 2011 (Pluye et al., 2011)

Criteria Study	Relevant sampling strategy to address the research question	Is the sample representative of the population understudy?	Are measurements appropriate?	Is there an acceptable response rate (60% and above)?	Quality (%)	Comment (s)
Latour et al. (2009)	√	√	√	X	75	The study yielded a response rate of 39%
Badir et al. (2015)	√	√	√	√	100	
Langley et al. (2013)	√	√	√	√	100	
Tripathy, Routray & Mishra (2017)	√	√	√	√	100	
Khalilaileh (2014)	√	√	√	√	100	

Key to ratings: √ = Yes, detailed coverage of the screening question; X = No, screening question not addressed; * = Can't tell, screening question indicated but not clear in the write-up"

Table 3.4: “Quality assessment of mixed method using MMAT (Pluye et al., 2011)

MMAT critical appraisal component		Study	Comments
		Coombs et al (2015)	
Qualitative component	Are the sources of qualitative data relevant to address the research question (objective)?	√	
	Is the process for analysing qualitative data relevant to address the research question (objective)?	√	
	Is appropriate consideration given to how findings relate to the context, in which the data were collected?	√	
	Is appropriate consideration given to how findings relate to researchers’ influence, e.g., through their interactions with participants?	*	
Quantitative component	Is the sampling strategy relevant to address the quantitative research question?	√	
	Is the sample representative of the population understudy?	√	
	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	√	
	Is there an acceptable response rate (60% or above)?	X	Response rate of 44%
Mixed method	Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives)?	√	
	Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	√	
	Is appropriate consideration given to the limitations associated with this integration?	*	

Overall rating- 75%

Key to ratings: √ = Yes, detailed coverage of the screening question; X = No, screening question not addressed; * = Can’t tell, screening question indicated but not clear in the write-up”

3.3 METHODOLOGICAL RIGOR

This section discusses the biases that may have occurred during the data evaluation and data analysis phases, as well as the measures undertaken to minimise bias and enhance the rigour of the study.

3.3.1 Data Evaluation

The measures undertaken to ensure rigour at the data evaluation stage will be discussed under the headings, data extraction and critical appraisal.

3.3.1.1 Data extraction

A reliable and valid data extraction tool developed by De Souza et al. (2010) was followed to extract the relevant features in each of the included articles. The tool was initially pilot tested to ensure its accuracy in capturing the needed data. Permission was sought before using the tool. A registered co-coder (SS) assisted the first reviewer to extract data from the articles, and two independent reviewers coded the content of the individual studies. Extracted data were further cross-checked individually by the two independent reviewers. Further clarifications were sought from the developers of the tool when needed.

3.3.1.2 Critical appraisal

A thorough and adequate discussion of authenticity, methodological quality, informational value and representativeness of the available primary resources will enhance the rigour of the integrative literature review (Whittemore & Knafl, 2005). The primary studies identified were representative of the research question. A threat to validity during critical appraisal is the evaluation of studies according to the beliefs of the reviewers (Russell, 2005). The influence of personal beliefs on decisions about the quality of the literature, or at any other stage of the review, reduces the validity of the study. The use of critical appraisal evaluations tools increases the objectivity of the review process (Russell, 2005).

Making relevant judgement by way of appraising the quality of each included study requires experience and training. The reviewer (EK), although knowing the available appraisal tool, underwent a special hands-on session on how to critically appraise literature before the appraisal process. Research literature (Hong et al., 2018; Whittemore & Knafl, 2005) recommend at least two independent reviewers during the appraisal process; at this stage, two independent reviewers (EK and SS) appraised each included study. The second co-reviewer had a published study (Langley et al., 2014) included in the review. A third independent reviewer (VH) complemented the first reviewer (EK) to critically appraise that study. With exception of that study (Langley et al., 2014) all the other included studies were critically appraised by the two independent reviewers (EK and SS). In instances where there was any misunderstanding, a third party independent reviewer (VH), was consulted until consensus was reached.

There is no universally accepted standard critical appraisal tool (De Souza et al 2010; Whittemore & Knafl, 2005), however using a validated tool enhances the methodological rigour of the integrative review. The CASP (2018) and MMAT tools, developed by Pluye and colleagues (2011), were both used to critically appraise the various primary studies included in this review. These are globally accepted, validated and frequently used tools that enhance study validity and reliability. Individual permissions were sought to use the various tools. Where there was further clarification on the various criteria, corresponding authors were consulted for input and further explanations.

3.4 SUMMARY

This chapter discussed the evaluation of data which included the data extraction and quality appraisal process and finally discussed the methodological rigour as ensured at each stage was also discussed.

In the following chapter, findings and themes synthesised from the integrative review are discussed.

CHAPTER FOUR

DATA ANALYSIS

4.1 INTRODUCTION

This chapter focuses on the data analysis, which included the data reduction, data display, data comparison and data conclusion and verification. The chapter finally discusses the methodological rigour as ensured in each stage.

4.2 DATA ANALYSIS STAGE

At this stage, the researcher orders, codes, categorises and equates the data in order to reduce the data points gathered from the individual primary studies and present a unified conclusion about the research problem. The goal is to have a thorough and unbiased approach to interpret and synthesise accurately the evidence gathered from the individual primary studies (Cooper, 1998; Russell, 2005; Whittemore & Knafl, 2005). The procedure for analysing data often depends on the purpose and the type of research review. In an integrative literature review, the data analysis stage is one of the aspects potentially fraught with errors. Whittemore and Knafl (2005) recommend explicit identification of a systematic analytic method beforehand in order to minimise these errors.

In this integrative review, the data analysis process was informed by Whittemore and Knafl's (2005) proposed phases. This was suitable in organising the data gathered and ensuring appropriate representation of the synthesised information. The approach enables the researcher to model the data analysis stage and enhance easy tracking of how data synthesis was performed. The data analysis phases involved data reduction, data display, data comparison, conclusion drawing and verification.

Each process will be discussed in detail.

4.2.1 Data Reduction

In this phase, attempts are made to reduce the separate data points that characterise each study to identify common threads (Cooper, 1998). This demands the reviewers to develop categories to group the data based on the main concepts and ideas from the primary research (Whittemore & Knafl, 2005). This helps the reviewers to extract possible information needed to answer the research question from the included studies.

Reducing data involves determining a general classification system to manage diverse methodologies. Relevant study characteristics from each study were extracted in a way to reduce the retrieved data to suit the reviewers' objective. The study characteristics, as deduced from De Souza and colleagues' (2010) data extraction tool, were followed to reduce the selected data.

4.2.2 Data Display

The extracted information for each study was tabulated to capture relevant information in a concise and focused manner. Each article was summarised by recording setting, aim, sample, method and findings to provide a means by which to organise the literature and systematically compare sources for coding by the reviewers without complicating the review process (Whittemore, 2005, Whittemore & Knafl, 2005). This was then tabulated to allow for constant and easy comparison of study features as well as to be used to identify patterns, commonalities and differences. The types of information tabulated were the names of the authors, country, year of publication, journal, the aim of the study, setting, sample, type of study, the method of data collection and analysis, the quality score and the key findings (refer to **Table 3.1**).

4.2.3 Data Comparison

The codes generated and displayed in the data matrix were examined by the reviewers for commonalities and differences. This was followed by careful and attentive examination of the codes to follow and understand the patterns, and relationships between the codes for data interpretation (Whittemore & Knafl, 2005). The findings from the included primary studies were then coded inductively. This involved reading and re-reading the findings of each study, and grouping similar findings into codes. Codes that were similar were grouped under one category, whilst separate codes generated additional categories. Themes emerging from the synthesis were categorised and presented for easy comparison. (Refer to **Figure 5.1).**

4.2.4 Data Conclusion and Verification

The themes were generated and each primary source reviewed to verify that the new conceptualised evident was congruent with primary sources. After making comparisons of the findings with those of the referenced primary studies, revisions, where necessary, were made to ensure the captured information reflected the true findings from the primary studies (data verification). Furthermore, frequent discussions and data examinations were undertaken to cross-examine the data analysis process and the developing themes. (Refer to **Figure 5.1**).

4.3 METHODOLOGICAL RIGOUR

This section discusses the biases that may have occurred during data analysis phases, as well as the measures undertaken to minimise bias and enhance the rigour of the study.

4.3.1 Data Analysis

The analysis phase requires careful attention to prevent subjectivity and bias. Whittemore and Knafl (2005), recommend explicit identification of a systematic analytic method beforehand in order to minimise these errors. The researcher used Whittemore and Knafl's (2005) proposed data analysis phases, which assisted the researcher to organise, display, compare and make an objective conclusion based on the data collected. The phases were systematically followed.

4.4 SUMMARY

This chapter discussed the data analysis stage as informed by the Whittemore and Knafl (2005) data analysis approach; data reduction, data display, data comparison, and data conclusion and verification. The methodological rigour as ensured was also discussed.

In the following chapter, findings and themes synthesised from the integrative review are discussed.

CHAPTER FIVE

PRESENTATION OF FINDINGS

5.1 INTRODUCTION

This chapter presents the last stage of the research review, provides the results of the integrative review, the study characteristics as retrieved in the review process, a discussion of the appraisal of the methodological quality, and evidence and a narrative description of the results as aggregated thematically after thorough synthesis.

The first section presents an overview of the presentation and interpretation stage.

5.2 INTERPRETATION AND PRESENTATION

This represents the final stage of the integrative review. New research evidence gathered from an integrative review can be presented as a summary, an analysis or a synthesis. However, results reported as a synthesis represent the highest level of abstraction and include the creation of a framework for the research problem (Whittemore & Knafl, 2005).

Whittemore and Knafl (2005) indicate that results from the individual primary studies included in the review ought to capture the depth and breadth of the study in order for readers to evaluate the basis for the final conclusion drawn. In this case, major design characteristics, sample characteristics, variables, and outcomes are often displayed (i.e., sample size, type of design, setting). The provision of explicit data from primary studies allows the reader to ascertain that the conclusions of the review did not exceed the evidence and the appropriate reasons for variability have been explored (Whittemore & Knafl, 2005).

The next sections provides a detailed discussion of the review findings.

5.3 FINDINGS

This review aimed at gathering research evidence on the nurses’ experiences of providing end-of-life care for patients and family in the Intensive Care Unit. The initial search using six databases, SCOPUS, PubMed, ProQuest, CINAHL plus, MEDLINE, Academic search complete and Health Source: Nursing/Academic edition, for published and unpublished literature from January 2007 to May 2018, revealed 1078 potentially relevant studies (861 from the electronic database search and additional 201 from journal hand search and 16 from reference list). Duplicates and publications prior to 2007 were discarded and irrelevant literature excluded on the basis of title and abstract. Finally, 86 full-text studies were further assessed for relevance against the inclusion and exclusion criteria. Data from 38 research studies were finally extracted to answer the research question.

(Refer to **Figure 2.2** for the PRISMA flow chart).

5.3.1 Study Characteristics

Major characteristics were extracted from each included study according to a predefined data extraction tool that was deemed important in answering the research question. (**Refer to Appendix A).**

The following section reports the characteristics of the included studies.

5.3.1.1 Study location

The papers presented data from studies conducted in the five different continents, representing 18 countries with diverse cultures. Twelve (12) papers from North America (United States of America - 8, Canada - 4), seven from Africa (South Africa - 6, Rwanda-1), seven papers from Europe (United Kingdom - 3, one joint from Europe, and one each from Norway, Sweden and Spain), 10 from Asia (2 papers from Iran, one each from Iraq, India, Nepal, Thailand, Jordan, Iraq, Singapore and Turkey), and finally one from Australasia (one New Zealand paper).

5.3.1.2 Research method and study designs

Of the primary studies included in this research review, 32 were qualitative, five were quantitative and one was a mixed method study. The qualitative studies predominantly used study designs such as phenomenology and qualitative descriptive, with a few studies using Grounded Theory and ethnography. The quantitative studies utilised descriptive cross-sectional and survey as their study designs. The mixed-method study included a cross-sectional survey and focused group discussion.

5.3.1.3 Study population and sampling

Participants included in the various studies were Intensive Care nurses, with a few registered nurses working in the ICU. Sampling strategies used in the recruitment of participants for the qualitative studies were identified predominantly as purposive sampling (n = 29), followed by convenience sampling and snowball sampling. The samples size for each study ranged from four to 603 Intensive Care nurses. The total sample size for all the included studies was 1723 (381 participants for the qualitative study, 1139 for the quantitative studies and 203 for the mixed method study).

5.3.1.4 Data collection and analysis

Among the studies included in the review, most of the qualitative studies utilised semi-structured to group interviews as their data collection technique. Few among those indicated used focus group discussions. The majority of the qualitative data were mostly analysed using thematic analysis, with most studies using Giorgi, Coliazzi and Van Manen's data analysis approach, whilst a few used content analysis. Conversely, quantitative research studies utilised a mixture of researcher developed questionnaires and established instruments to collect data; descriptive and inferential statistics were their data analysis approach.

5.3.1.5 Study journals

The review included 33 published and five unpublished studies. The published studies were in different nursing and medical journals; seven studies were published in Nursing in Critical Care, six in Intensive and Critical care Nursing journal, three from Journal of Clinical Nursing, two from South African Journal of Critical Care and one each from other journals. (Refer to **Table 5.1)**

Table 5.1: Study distribution in various journals

Journal	Number of studies	Country	Quality	Impact factor
Nursing in Critical Care	7	United Kingdom	Q2	1.173
Intensive and Critical Care Nursing	6	United States of America	Q1	1.653
Journal of Clinical Nursing	4	United Kingdom	Q1	1.635
South African Journal of Critical care	2	South Africa	Q3	
Australian Critical Care	1	Australia	Q1	1.930
Critical Care Nursing Quarterly	1	United States of America	Q2	
International Journal of Palliative Nursing	2		Q2	
Indian Journal of Critical Care Medicine	1	India	Q2	
Western Journal of Nursing research	1	United States of America	Q1	1.323
African Journal of Nursing & Midwifery	1		Q4	
Contemporary Nurse	1	United Kingdom	Q2	
Journal of Hospice and Palliative Nursing	1	United States of America	Q2	
Holistic Nursing Practice	1	United States of America	Q3	
American Journal of Men's Health	1	United States of America	Q2	
Dynamics	1	Canada	Q	
Journal of Nursing and care	1		Q	
Nursing Science Quarterly	1	United States of America	Q	0.83

5.3.2 Participants Characteristics

The majority of participants, as reported in the studies, were qualified Intensive Care nurses. In the studies that reported participants' work experience, this ranged from 6 months to 40 years working in the Intensive Care Unit. Sampled nurses were Intensive Care trained nurses working in various ICU departments ranging from the Coronary Care Unit to Trauma ICU. Demographic data indicated that most participants were female, with few males included.

5.3.3 Methodological Quality Score

Detailed results from the quality assessment of qualitative, quantitative and mixed method studies are presented in Tables 2.5, 2.6 and 2.7 respectively. Using the Critical Appraisal Skills Programme (CASP), 2018 version, the quality score of qualitative studies ranged from 7 to 10 out of a possible score of 10. Most of the qualitative studies showed a limitation in the lack of reflexivity in the study report and incomplete description of the selection strategy.

For the descriptive quantitative studies, using MMAT critical appraisal tool (Pluye et al., 2011), the quality score ranged from 75% to 100% of a possible score of 100% **(see Table 2.6).** Most quantitative studies showed limitations with regards to response rate and incomplete description of subject selection. One study included in this review that combined methods was also evaluated for quality using the MMAT critical appraisal tool. The study achieved an overall quality score 75% out of 100%, with study limitation including low response rate from eligible subjects in the quantitative report, lack of reflexivity in the qualitative report and less consideration of the limitation of the integration of the research methods.

5.4 THEMES

The synthesis of research findings on the nurses' experiences regarding the provision of end-of-life care in the Intensive Care Unit resulted in several coded categorised under five main themes: "Doing the right thing;" "Emotional labour, conflicts and uncertainties;"

“Remaining committed and developing coping strategies;” “Barriers to EOL care provision;” “Facilitators to EOL care provision.” To see **Figure 5.1**

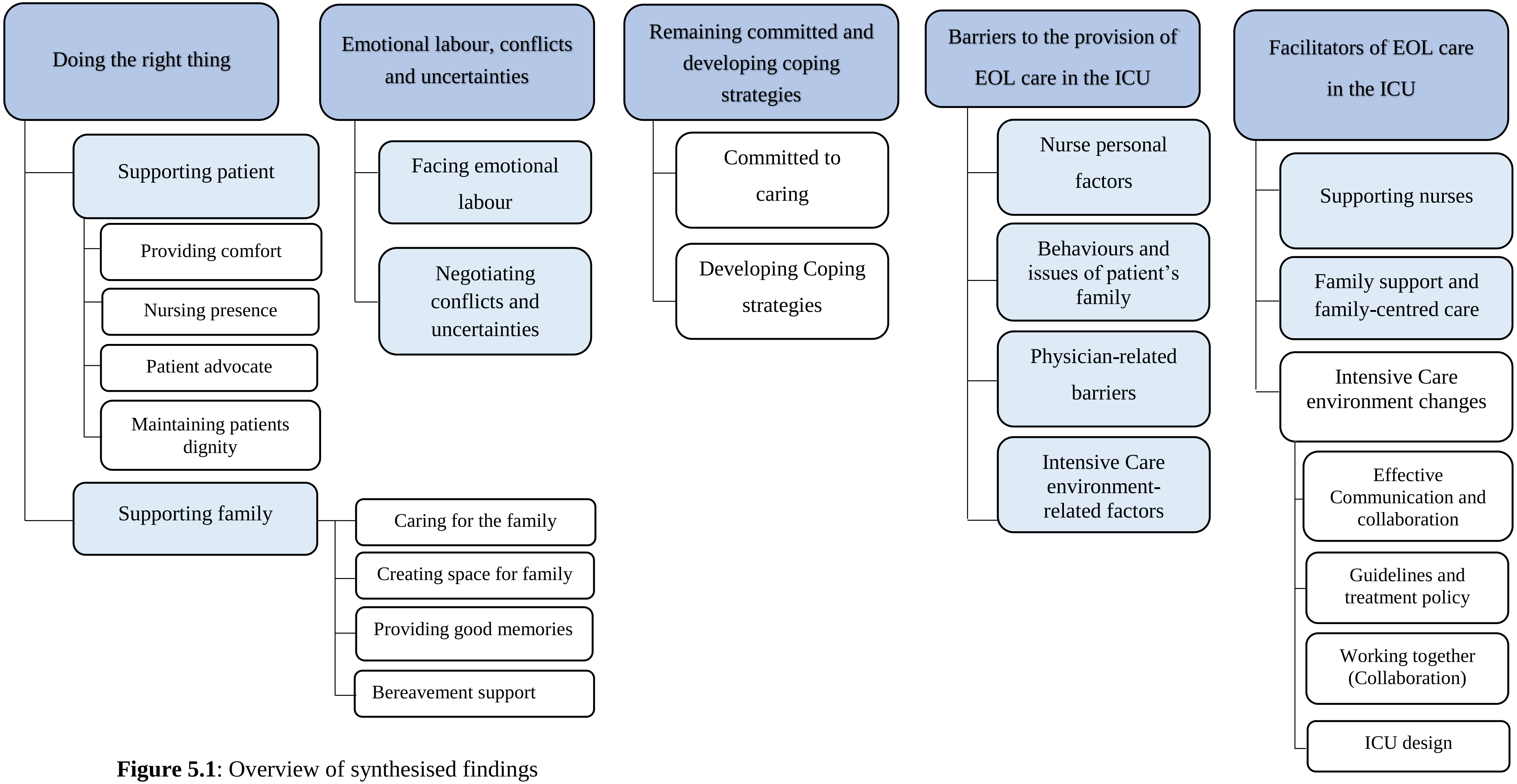

Figure 5.1: Overview of synthesised findings

5.4.1 Theme 1: Doing the Right Thing

The synthesised findings indicate that nurses at all time want to do the right thing for both the patient and the family as part of the EOL care journey. The majority of indicated that the experiences of nurses in the provision of end-of-life care related to the provision of patient-centred care and family-focused care, through supporting both patient and the family (Arbour & Wiegand, 2014; de Swardt & Fouche, 2017; Kisorio & Langley, 2016; Efstathiou & Walker, 2014; Heidari & Norouzadeh, 2014; Vandersprank-Wright et al., 2011; Fridh et al., 2009; Wu et al., 2015).

Intensive Care nurses place a value on the well-being of both the patient and the family in the provision of end-of-life care. As soon as the critically ill patient is admitted into the ICU, nurses focus on the patient. Once curative therapy proves futile, both the patient and the family are supported through the transition to end-of-life to a controlled death. Nurses, as part of their responsibilities, provide several forms of care from the transition from curative care to the operationalisation of the withdrawal of life-sustaining treatments and the death of the patient. This theme was further categorised into two sub-themes, namely: supporting patient care and supporting families

5.4.1.1. Sub-theme: Supporting patient

Nurses provide direct patient care through the provision of comfort measures to the ensuring of a peaceful and dignified death for the critically ill patient through their presence at the patient’s bedside throughout the period of hospitalisation. Intensive Care nurses provide direct patient care through comfort care, maintaining the patient’s dignity at the end-of-life and being there for the patient (Arbour & Wiegand, 2014; Kisorio & Langley, 2016; Efstathiou & Walker, 2014; Vandersprank-Wright et al., 2011; Fridh et al., 2009; Wu et al., 2015).

- **Providing comfort care**

Ensuring patients comfort through comfort measures was a predominant finding in the reviewed studies. The provision of comfort care begins as soon as the patient is admitted into the ICU, extends through to the withdrawal of treatment, with emphasis on end-of-life care, to the pain relief measures through symptom management (Arbour & Wiegand, 2014; Kisorio & Langley, 2016; Efstathiou & Walker, 2014; Vandersprank-Wright et al., 2011; Fridh et al., 2009;Wu et al. 2015) through to the last office provided to patients, which include comfort and meeting the religious and spiritual needs for the dead (de Swardt & Fouche, 2017).

Several reviewed studies reported effective pain management, constant physical care and control of pain as essential elements of promoting comfort. These are illustrated in the following quotes:

> *‘‘Once the patient’s decision was made . . . the ventilator was discontinued and the morphine drip was started, he was finally able to get what he and his family wished. In the end, I was happy to be able to see that.’’* (Intensive Care nurse cited in Arbour & Wiegand, 2014: pg. 215).

> *‘‘We do all nursing care that you do to a person who has a potential to live. We don’t stop, we bath, turn, suction, change. ..’’. To ensure that the patient remained as pain free as possible, nurse 21 explained: ‘‘usually they don’t remove sedatives and analgesics; as a nurse, you ensure that this patient is not in pain by administering these medications as needed’’.* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg.34).

> *“You have to think about comfort for the patient primarily…I think primarily, it’s comfort for the patient and doing those little things like turning them, mouth care, all those little things and making them look as comfortable, and hopefully they are as comfortable as possible.”* (Intensive Care nurse cited in Efstathiou & Walker, 2014: pg. 3191).

> *“There’s only two things that I need to worry about if I go to a dying patient; one of them is that he’s not in pain, and the other one is that they’re not scared. . . . That’s my job.* (Intensive Care nurse cited in Wu et al., 2015: pg. 46).

The provision of comfort care also extended to the deceased patients. Nurses, again ensured that the patient’s dead body appeared clean during post-mortem care. This was done by providing physical care through a clean appearance of the body, body placed comfortable and the last office performed (de Swardt & Fouche, 2017).

> *“With a clean sheet, we just close it with a clean sheet over the patient.” “Now normally we are two persons. It is not easy to handle a dead body, so you help with the turning and washing.” “I must make sure that the patient looks comfortable,*

> *straighten the limbs." "The patient must lay on the bed flat and straight, if it is possible the arms must be straight."* (Intensive Care nurse cited in de Swardt & Fouche, 2017).

- **Maintaining patients' dignity**

As much as nurses show concern about providing comfort care for the critically ill patient, maintaining a patient's dignity at the end-of-life was also an important experience, as expressed by Intensive Care nurses in the provision of end-of-life care in the ICU (de Swardt & Fouche 2017; Heidari & Norouzadeh, 2014; Wu et al., 2015). In most of the included studies, nurses reported maintaining patients' dignity at the end-of-life as showing respect for the patient, maintaining privacy, meeting patients' wishes, fear relief and care for the dead body.

Maintaining patient's dignity was also described in two of the review studies as ensuring a peaceful death through the removal of invasive and tubes, following patient's wishes to proper handling of patient's dead body, as well as respecting the spiritual and cultural needs of both the patient and the family (de Swart & Fouche, 2017; Heidari & Norouzadeh, 2014). Intensive Care nurses continue to provide care for the dead body by providing physical care through a clean appearance of the body, body placed comfortable and last office performed. The appearance of the dead body was an important issue to nurses as the closing up of the body finally signified the purity of death. Participants preferred to ensure it was clean, as expressed in the quotes below:

> *"With a clean sheet, we just close it with a clean sheet over the patient." (Intensive Care nurse cited in de Swardt & Fouche, 2017: pg. 110).*

> *"We had covered the patient, because his face was dirty and bloody, I left the expired patient in the isolation and said to clean his face and body and we even removed the bandage and got a clean bed linen over him."* (Intensive Care nurse cited in Heidari & Norouzadeh, 2014: pg. 319).

Nurses illustrated the importance of providing nursing care even after a patient's death by ensuring the body appeared comfortable, as expressed in illustrated below:

> *"I must make sure that the patient looks comfortable, straighten the limbs." "The patient must lay on the bed flat and straight, if it is possible the arms must be straight."* (Intensive Care nurse cited in de Swardt & Fouche, 2017: pg. 110).

The touching therapy was also regarded as a therapeutic measure to show respect and maintain the dignity of the deceased patient. Participants reflected as follows:

> *"I make sure that the body is handled in a correct way [softly]. I am in charge of that body. You cannot handle this body bad because this person is alive although we know this is a dead body."* (Intensive Care nurse cited in de Swart & Fouche, 2017: pg.111).

- **Being there**

Nurses’ presence at all times for the dying patient was a common theme across the experiences, expressed in the provision of end-of-life care for the patient in the Intensive Care Unit (Efstathiou & Walker, 2014; Fridh, Forseberg & Bergbom, 2009). This was described through the physical presence at patient’s bedside from admission to the sudden death of the patient.

For patients unaccompanied by family, for instance, nurses act as the substitute for the family and provide family duties as well as performing the nursing role (Efstathiou & Walker, 2014; Fridh, Forseberg & Bergbom, 2009). Participants in two studies described this as a tragic incident, when a patient died without any family member present. Nurse’s continuous bedside presence promoted the provision of warm and compassionate care at all times.

> *‘‘It is important that they are not alone . . . that there is no difference between a person who has twenty relatives present or none at all. I think it is self-evident that there should be no difference.’’ (Intensive Care nurse cited in* Fridh, Forseberg & Bergbom, 2009: pg. 236).

> *“... and I suppose to ensure they don’t die alone as well. Sometimes the family can’t be there, so it is important that a nurse should be there at all times with the patient.”* (Intensive Care nurse cited in Efstathiou & Walker, 2014: pg. 3192).

- **Advocating for patient**

The majority of patients admitted into the ICU are unable to make sound decisions due to their conditions and invasive procedures and medical interventions such as intubation, sedation, etc. Several findings from the synthesised studies indicated that nurses act as an advocate for patients at some point in the EOL care journey (Arbour & Wiegand, 2016; McMillen, 2008).

Intensive Care nurses in one study indicated that the advocating for the patient in the ICU takes the form of making sure patients receive pain medication, supporting the patient to document their wishes and paying attention to these wishes (Arbour & Wiegand, 2016). In most instances, nurses' act on behalf of the patient to meet the patient's wishes, as expressed in the following quote:

> *''. . . they (the patient) suffered because a lot of times physicians don't want to administer pain medication . . . and the patients need more than just the minimum dose. I've had physicians order acetaminophen and I'm like, that's just not going to cut it. I got them to order more appropriate drugs at the right dose and the patient was far more comfortable.''* (Intensive Care nurse cited in Arbour & Wiegand, 2016: pg. 215).

Some participants further reported that the best way to get a proper picture was to involve relatives or trusted friends. Further clarification was sought in addition to nurses already established information about the patient. This promotes patients' safety, and for legal purposes (Arbour & Wiegand, 2016; McMillen, 2008). This is supported by the extract below:

> *“So we got the case manager, social worker and her (the patient’s) person of choice in the room, sat down and talked with her. We got all the paperwork that needed to be done and it went smooth. I felt good about the referral and being able to follow through.*”(Intensive Care nurse cited in Arbour & Wiegand, 2016: pg. 215).

5.4.1.2 Sub-theme: Supporting family

Although patients admitted into the Intensive Care Unit are central to the experiences of nurses in the provision of end-of-life care, providing a family-focused care through working and supporting the family was also highlighted in most of the studies (Arbour & Wiegand, 2016; Calvin et al 2009; Efstathiou & Walker 2014; Fridh, Forseberg & Bergbom 2009; McMillen, 2008; Kisorio & Langley 2016; King & Thomas 2013; Vandersprank-Wright et al 2011). Evidence synthesised from the included studies indicated that once a decision was made to operationalise end-of-life care based on the poor prognosis of patients conditions, nursing care further shifts onto the family members, relatives and significant others. This form of support is expressed by providing several forms of support systems as well as working with the family.

This sub-theme further includes the categories: caring for the family, creating space for the family, protecting family and providing good memories, and bereavement care for the family.

- **Caring for the family**

Intensive Care nurses caring the patient’s family was a central theme in the provision of end-of-life care. Caring for the family was equally important for Intensive Care nurses, just like the care given to the dying patient. This included providing support for the family through information sharing, nurses being there for the family, psychological support, offering reassurance, family involvement and respecting their cultural and ritual practices (Brysiewicz & Bhengu 2010; Calvin et al 2009; Efstathiou & Walker 2014; Fridh, Forseberg & Bergbom, 2009; Kisorio & Langley, 2016; King & Thomas, 2013; McMillen, 2008; Vandersprank-Wright et al., 2011).

Intensive Care nurses assist the family through the end-of-life care journey, establish a good rapport with the family and get to know them, and get involved and assist them through the dying process (Vandersprank-Wright et al., 2011).

> *“I think if you have a good… rapport with the families… I always feel a lot more at ease, if you’ve developed some sort of relationship with them… you’ve developed a good bond with the family.”* (Intensive Care nurse cited in Vandersprank-Wright et al., 2011: pg. 33).

> *“... we involve them [the family] in the nursing care of the critically ill patients so they know what is happening ... we phone them now and again to let them know about the condition of their patients and they choose a spokesperson whom we liaise with so that we can give them the news.”* (Intensive Care nurse cited in Brysiewicz & Bhengu, 2010: pg. 48).

As nurses get to know the family through frequent interactions, they provide psychological support through reassurance as they provide the family with information on the treatment regimen, procedures and patients' prognosis (Efstathiou & Walker 2014; Popejoy et al., 2009). Nurses pay attention to the family, listen to them and provide them with the needed information as well reassure them. This is shown in the extract below:

> *"I think that the relatives' care is something that we do not necessarily talk about, but it is important that they feel as they are being cared for and that all of their needs are being taken into consideration…"* (Intensive Care nurse cited in Efstathiou & Walker, 2014: pg. 3191).

Respecting the patient's family cultural practices and rituals were also seen as an important expression of nurses' experiences regarding the provision of end-of-life care (Brysiewicz & Bhengu, 2010; Kisorio & Langley, 2016). This was seen as a way to support the family through the end-of-life care journey so that it was not hazardous to both the patient and the institution. Nurses stated allowing family members to perform any rituals as long as it did not affect other patients, as expressed in the following quotes:

> *''We respect their culture and beliefs. If they believe in inyangas (traditional healers), let them have them around, not only the religious people. We give them opportunity to practice their beliefs as long as they don't give anything orally or affect other patients.''* (An Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 34).

> *"We know there is cultural diversity; they [the family] usually come back after the person has demised to collect the spirit because they believe the spirit of the person is still here ... so we do allow them to do that."* (Intensive Care nurse cited in Brysiewicz & Bhengu, 2010: pg. 46).

- **Creating space for the family**

Nurses, as part of their experiences in the provision of end-of-life care, assist the family by creating enough space for them in the Intensive Care environment. This is done through family presence at patient's bedside, reconnecting the patient and the family by creating a less technical environment, permit visitations, reduce the distance between patient and the family, and increasing privacy and proximity (Arbour & Wiegand, 2014; Calvin et al., 2009; Efstathiou &Walker, 2014; Heidari & Norouzadeh, 2014; Kisorio & Langley, 2016; McMillen, 2008).

Nurses provide and encourage family presence and involvement in patient's care, as well as allow the family enough time patient especially when the patient is at the end-of-life stage (Efstathiou & Walker, 2014; Heidari & Norouzadeh, 2014; Kisorio & Langley, 2016). A patient dying alone in the ICU was considered an undesirable death. Family members were often allowed to visit and be present during patient care in the ICU, as expressed in these quotes:

> *''. . . that having family presence at end-of-life was an opportunity to help family understand what was happening.''* (Intensive Care nurse cited in Arbour & Wiegand, 2014: pg. 215).

> *"…there is always time given to people who want to bring certain family here or people who are waiting for offspring, children to come back or even children that are in prison, you know. Whatever the scenario, time is allowed, for the whole immediate requirements of that family involved to be able to attend."* (Intensive Care nurse cited in Efstathiou & Walker, 2014: pg. 3192).

> *''. . .if they want to come in 24 hours it is allowed. We frequently tell them to come and stay with the patient as they wish. It might be their last moments together.''* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 34).

> *"Generally, when the patient reaches the end stage, from the corridor whoever comes to visit, we allow them and give them the key to open the door and come to see their patient . . . but we let them to come and see their patient even for diseases that may not lead to patient death. But the moment that patient is very ill, just we try to calm family mentally."* (Intensive Care nurse cited in Heidari & Norouzadeh, 2104: pg. 318).

Nurses in several studies were concerned about reconnecting patients and their families through increasing privacy and proximity, creating a less technical Intensive Care environment and reducing the distance between the patient and the family (Efstathiou & Walker 2014; Heidari & Norouzadeh, 2014*;* McMillen, 2008). Family members were allowed enough time and space to be with the patient; noticeable barriers such as invasive lines and monitoring equipment were removed to promote family access and reduce technical care.

> *"When it comes to family involvement, as much as you want them to be involved, sometimes there's just so many things. I mean, in a bed space when a patient is really poorly and the risk is full-on, there are loads of equipment, and it can be like a barrier for them to actually touch the patient because of all the equipment.*" (Intensive Care nurse cited in Efstathiou & Walker, 2014: pg. 3192).

> *''I always try to bring the relatives with us so that if their relative is deteriorating and is not going to get any better when the doctor does come round and speak to them the groundwork has been done, they are prepared for bad news.''*(Intensive Care nurse cited in McMillen, 2008: pg. 255).

- **Protecting and providing good memories**

Nurses in several studies consistently placed emphasis on family protection and the provision of good memories. This was seen as a common theme across the experiences expressed by Intensive Care nurses in the provision of end-of-life care in the Intensive Care setting (Arbour & Wiegand 2014; Vandersprank-Wright et al., 2011). The provision of good memories for the family included the little things nurses performed for patients that were far from the advanced monitoring and sophisticated intensive care. Caring and washing for patient's hair in front of a family member, for instance, brought good memories.

> *I still say it's a privilege… to be with them, this is something that family members will remember all of their lives when the family member died and so if you can*

> *make that experience as positive as you possibly can, it's not going to be a good experience, it can be a positive one without actually being good."* (Intensive Care nurse cited in Vanderspank-Wright et al., 2011: pg. 34).

Protecting the family of the critically ill and dying patient was equally articulated, as was providing good memories. These measures included limiting invasive procedures and technology. Participants in one study equated protecting the family to the provision of tender, love and care, as well going beyond the call of duty (Arbour & Wiegand, 2014). Nurses explained the transfer of the dying patient to a general medical ward in order to accommodate another patient as a dissatisfying moment for the family. Participants at all times wanted to protect the family, as well as provide good memories, as illustrated in the following quote:

> *''. . . I feel that's very rude to the family . . . it's rude to the patient and it's a disservice to the patient . . . and personally stressful getting rid of that patient to get another crashing patient.''*
> *"Having to transfer a dying patient out quickly under those circumstances ''is . . . one of the crappiest things you can have a family watch, yes, I am passionate about this. Death is supposed to be nice. It's supposed to be comfortable (for the patient) and comforting (for the family). You want the last thoughts or memories to be nice rather than stressful.''* (Intensive Care nurses cited in Arbour & Wiegand, 2014: pg. 215).

- **Bereavement support**

Findings from the synthesised studies indicated that bereavement care for the family also promoted family-focused care. The care occurs throughout the dying process, i.e. when death is imminent, at the time of death and after the death. This was realised, from several reviewed studies, through the preparation of the family as patients get to the end-of-life, allowing the family to take control at some point through the passing on of the bad news to the grieving process and regular family visit after patient’s death (Heidari & Norouzadeh, 2014; Popejoy et al., 2009).

Intensive Care nurses continue to provide care for the family through tactful presence and psychological support at and after the patient’s death. Initially, as a patient’s condition deteriorates, nurses prepare the family through clear and consistent communication (Heidari & Norouzadeh, 2014).

Nurses communicate bad news indirectly to patients’ families while providing psychological care. This is done by explaining interventions to the family, and creating enough space and room for the family to grieve. They assist the family after the death of a family member through regular visits, referring a family to a social worker for psychological support, and making provision for a separate private room for the family to express their feeling during the grieving process.

5.4.2 Theme 2: Emotional Labour, Conflicts and Uncertainties

The theme appeared predominantly as one of the experiences expressed by nurses in the provision of EOL care for patients and their families. Findings from the studies reviewed, reported that nurses’ encountered and experienced several emotions, conflicts and uncertainties throughout the EOL care trajectory (Fuller, 2018; Kisorio & Langley; Efstathiou & Walker, 2014; Holms et al., 2014; Valiee et al., 2012; Espinosa et al., 2010; Leung et al., 2017; Jordan et al., 2014; Wu et al., 2015).

Although nurses love to do their best within the demands of their scope of practice, they face lots of psychological pressures and stressors through the journey. This included the moral and ethical dilemmas, tensions, conflicts and uncertainties associated with the provision of quality end-of-life care to both patients and their family.

This theme was subdivided into two sub-themes, namely Facing emotional burden, and Negotiating conflicts and uncertainties.

5.4.2.1. Sub-theme: Facing emotional labour

Nursing patients at the end-of-life in the Intensive Care Unit can be challenging as its provision comes with several emotional attachments coupled with adverse effects on nurses' emotional expressions. Initially, as part of Intensive Care nurses scope of practice and responsibilities, they become emotionally attached to patients and their families as they provide compassionate care and assist them through end-of-life care (Wu et al., 2015).

However, in the provision of this form of care, negative effects on their spirits are equally presented as it is described as challenging and a difficult process. Synthesised findings indicate that nurses experience psychological and emotional challenges, which places an emotional burden on them (Kisorio & Langley, 2016; Holms, Heidari & Nouzadeh, 2014;

Holms, Milligan & Kydd, 2014; Jordan, Clifford & Williams 2014; McMillen, 2008; Rafii, Nasrabadi & Karim, 2016; Valiee, Negarandeh & Nayeri, 2012; Un Yu & Chan, 2009).

Findings from several studies (Kisorio & Langley, 2016; Holms, Milligan & Kydd, 2014; McMillen, 2008; Rafii, Nasrabadi & Karim, 2016; Valiee, Negarandeh & Nayeri, 2012) described the experience of caring for a patient at the end-of-life as a great source of emotional burden. These psychological and emotional challenges were related to the psychological pressures in providing EOL care, the distressing nature of family reactions, the effect of the patient's condition and the demanding nature of the Intensive Care environment.

Patient's condition had an impact on nurses caring experiences. Caring for a younger patient, an unresponsive, brain-dead patient and a potential organ donor patient were reported as stressful, traumatising, difficult and painful (Kisorio & Langley, 2016; McMillen, 2008; Rafii, Nasrabadi & Karim 2016; Valiee, Negarandeh & Nayeri 2012; Naidoo & Sibiya, 2014). These were expressed in the extracts below:

> *"The age of the patient is touching and has got effect; the young ones touch me the more because they still have the future."* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 33).

> *"Taking care of those patients who are at the end-of-life phase is way too difficult and painful, especially when patient is young."* (Intensive Care nurse cited in Valiee, Negarandeh & Nayeri, 2012: pg. 312).

> *"Because most of these patients are not able to express their feelings, reactions and symptoms, working with them is way tougher compared with working with the alert patient who has been witness to the progression of therapies and can express his/her feelings."* (Intensive Care nurse cited in Valiee, Negarandeh & Nayeri, 2012: pg. 312).

The nature of patient's family reactions to situations and patients' prognosis were also described as a great source of emotional labour for Intensive Care nurses. Three studies described the reactions from anxious and distressed families as an upsetting experience, challenging to deal with, and draining (Kisorio & Langley, 2016; Rafii, Nasrabadi & Karim, 2016; Valiee, Negarandeh & Nayeri, 2012). These were illustrated in the quotes below:

> *"One of the personal problems in caring for end-of-life patients is the painful feeling that is caused for me….the patient's condition on their family, e.g., I saw their discomfort and I myself did not have a good feeling…. I am only obliged to commiserate with their families."* (Intensive Care nurse cited in Valiee, Negarandeh & Nayeri, 2012: pg. 312).

> *"I have seen some of them respond with anger, anxiety and are trouble makers."* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 33).

The distress nurses experience were reported to be related to lack of experience, poor communication, insufficient training in EOL care, lack of support from other staffs and managers, differences in the consultants EOL care decisions and a lack of involvement in EOL care decision making (Coombs et al., 2015; Espinosa et al., 2010; Holms, Milligan &

Kydd, 2014). In most cases, nurses are not prepared to provide such care as they lack the experience and support to do that. These are expressed in the following quotes:

> *"It's something I've never been comfortable with and I will tend to avoid unless I think I've worked a lot with that patient and family."* (Intensive Care nurse cited in Coombs et al., 2015: pg. 84).

> *"All we are doing is prolonging the inevitable for this person and family but we don't have control over that and so that's very difficult, it's very difficult to not be part of that decision or discussion process with the physicians."* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 275).

> *It is hard dealing with so many dying patients. It's heartbreaking, upsetting and exhausting, sometimes it's an occupational hazard unfortunately. There have been numerous occasions when I've been really upset and to be honest not well supported, you are left to get on with it."* (Intensive Care nurse cited in Holms, Milligan & Kydd, 2014: pg. 553).

5.4.2.2 Sub-theme: Negotiating conflicts and uncertainties

In the provision of end-of-life care in the Intensive Care Unit, the process was closely linked with high levels of conflicts, tensions, ethical dilemmas and uncertainties. As a collaborative team approach in the ICU, nurses work together with physicians, patients, families and other significant healthcare members. Although nurses are constant primary caregivers to the critically ill patients, they also manage the inter- and intra-relational concerns that come with the care being provided. These multifaceted processes create conflicts and tensions within and among the healthcare providers, as well as uncertainties in most practices, with the most affected being nurses. These conflicts, tensions and uncertainties were noted at various times across the end-of-life care trajectory (Efstathiou & Walker, 2014; Espinosa et al., 2010; Hov, Hedelin & Athlin 2007; Jordan et al., 2014 ; Leung et al., 2015; Nankundwa & Brysiewicz, 2017; Vandersprank-Wright et al., 2011; Ong & Ting, 2018).

Participants in several qualitative studies described the experience of providing EOL care for patients and their families in the ICU as a professional and personal struggle. These forms of struggle and conflict stemmed from the lack of end-of-life care guidelines, absence of definite answers to EOL care questions, the complexity of Intensive Care nursing and unclear communication between nurses and physicians and unclear, constantly changing and vague goals about patients treatment during EOL care (Efstathiou & Walker, 2014; Hov, Hedelin & Athlin, 2007; Vandersprank-Wright et al., 2011).

Participants in one study described instances where disagreement among nurses, physicians and family members lead to tension and conflict. These conflicts stemmed from the family wanting one thing and physicians saying otherwise (Vandersprank-Wright et al., 2011). In these cases, nurses acted as a mediator between the two opposing sources of conflict as well as dealing with the healthcare team, as well as patients and their families. This is expressed in the extract below:

> *"We do need to work as a team….there's nothing worse than walking into a family conference when you think you're going in there for one thing and the doc starts*

> *taking and he's going in a completely different direction.....we need to be all on the same page at the same time…it's number one."* (Intensive Care nurse cited in Vandersprank-Wright et al., 2011: pg. 33).

The continuous changes in the attending medical team and frequent additions from the different specialists at any time, were described by some study participants as a setback to the initial plan of care as most are altered and changed for the worse ((Vandersprank-Wright et al., 2011). These changes create many conflicts among nurses, family and the other members of the healthcare team, as expressed in the following quote:

> *"It makes the nursing staff or myself, it makes me angry that we put all this work into the patient, into the family and this is halted…so now you've got to back pedal because this person will have spoken to the family perhaps, and I say perhaps because maybe they haven't and now we're trying to explain to the family what we're doing…it's just an emotional yoyo for them and so for us, if we are all not on the same page. End-of-life issues are just not going to be dealt with."* (Intensive Care nurse cited in Vandersprank-Wright et al., 2011: pg. 34).

Nurses in the ICU spend most of their time with the patient and their family. Physicians are often present only for a short period, however, they write orders for nurses to operationalise. The opinions expressed by nurses was that in most cases they were not taken into consideration or respected, and neglected. Participants in one review study described this as hard to believe, as they felt abandoned and powerless as primary caregivers.

> *"Yeah, I felt like I had failed. I mean, even after a patient codes or doesn't survive, it feels like- like you couldn't do enough. You should have…we save lives…I mean, that's the way you were taught….and then you are withdrawing everything"*. (Intensive Care nurse cited in Espinosa et al., 2010: pg. 277).

Most participants in Espinosa et al's (2010) study, expressed their conflict characterised by medications prescribed to their patients. This was described as an internal struggle, with the knowledge that the prescribed medication would have an untoward effect on the patient and worsen their present condition.

The lack of regular meetings between nurses and physicians, or the lack of conclusion on the discussion about the transition from curative care to EOL care, sometimes made the nurses feel alone in the responsibility (Hov, Hedelin & Athlin, 2007). The absence of clear answers to the "if" or "when" and "why" puts nurses into constant ethical dilemmas and uncertainties between doing good or bad and accepting a natural death or saving a life.

> *"We all know that the discussion will come sooner or later, but it drags on and on. Will it be tomorrow or in a week or…? Then we often ask: What now? How long? And they only say: No, let's see tomorrow. They certainly know that the treatment will be withdrawn, but we want to start the discussion earlier."* (Intensive Care nurse cited in Hov, Hedelin & Athlin, 2007: pg. 206).

5.4.3 Theme 3: Remaining Committed and Developing Coping Strategies

Findings from the studies reviewed reported that nurses remain committed to their care duties as they develop coping strategies to maintain their professional demeanour. As qualified professionals, they uphold their duty to be with patients at all times. With time, nurses tend to develop and use various forms of coping strategies to deal with the challenges at each stage of the EOL care journey. As a result of continuous exposure to the frequent occurrences of the similar situation, these coping strategies assist the patient through the process. Initially, nurses tend to stay committed to their caring roles as per their practice responsibilities, remain optimistic about patient care and finally develop coping strategies when the occurrences become routine and frequent without any form of support or assistance (Calvin et al., 2009; Espinosa et al., 2010; King & Thomas 2013; Ong & Ting, 2018; Rafii et al., 2016; Kongsuwan, 2011; Yu & Chan, 2010).

The theme was further categorised into two sub-themes, namely commitment to caring and developing coping strategies

5.4.3.1 Sub-theme: Commitment to caring

In this sub-theme, findings of the reviewed studies reported that nurses expressed their experiences through the provision of end-of-life care in the ICU by remaining committed to caring for patients and their family (King & Thomas 2013; Kongsuwan, 2011; Rafii et al., 2013; Valiee et al., 2012). Caring for critically ill patients in the ICU especially at the end-of-life was associated with a unique sense of commitment of nurses. Commitment to caring, according to the synthesised findings, were expressed through nurses remaining optimistic and obligated to providing patient care until the last moment, accepting the dying process and keeping their promises made to every admitted patient.

Intensive Care nurses are morally obligated to care for the critically ill and dying patient through mindful readiness to care and authentically offering of themselves through the process. They value the ongoing care regardless of the time as they accept death as a natural part of human life (King & Thomas, 2013; Kongsuwan, 2011). This was expressed in the extract below:

> *"We come to care for the dying patients sincerely. Peaceful mind and good wishes will become caring power and will be sent out to the persons who are dying to be peaceful and comfortable." (Intensive Care nurse cited in Kongsuwan 2011: pg. 378).*

Participants in one study indicated that their cultural background and spiritual beliefs mandate them to provide confident and optimistic services even if chances of survival were minimal for patients (Rafii et al., 2016). Nurses continue to provide compassionate care for patient in the Intensive Care environment, as expressed in the quote below:

> *'Working in the ICU involves a great level of hopelessness. However, our religion helps us, as nurses, to be hopeful under any circumstances. Therefore, we never truly feel hopeless.' (Intensive Care nurse cited in Rafii et al., 2016: pg. 108).*

The synthesised findings from three studies reported that Intensive Care nurses are morally obligated despite the challenges that comes with end-of-life care. They have offered themselves authentically and sincerely to care for the dying patient and their family, therefore they remain emotionally attached to the patient and regard them as important clients (Kongsuwan 2011; King & Thomas 2013; Rafii et al., 2016).

> *'I am sympathetic to the patients and regard them as my own family. I cannot neglect them because my conscience does not allow me to. We take care of them very carefully and eagerly. I have even laughed and cried with them because they are human too.'* (Intensive Care nurse cited in Rafii et al., 2016: pg. 109).

> *"We must understand their feelings as we take their heart to our heart. Supposing that we are in a situation the same as them, how will we feel?"* (Intensive Care nurse cited in Kongsuwan 2011: pg. 378).

The provision of EOL care to patients and their families was reported as a valued and rewarding opportunity for nurses to provide special care. Initially, the provision of end-of-life care is seen as tiring, however participants in one study described the experience as positive and rewarding as it helps them to get used to the job, build confidence and skills and have greater assurance for future challenges (Rafii et al., 2016). This is expressed in one participant's extract:

> *"The experience of death is more difficult at the beginning. Then, continuous contact with dying patients in the ICU makes a nurse get used to everything." (Intensive Care nurse cited in Rafii et al., 2016: pg. 108).*

As part of the end-of-life journey, nurses promised patients and their families they would stay with them, give them updates on any decisions, support them and remain truthful at all times. Findings from the synthesis reported that despite the challenges encountered, nurses remain honest, truthful and connected to the promises made. They are committed to ensuring comfort care, being an advocate for the patient and family, staying connected throughout the care period (King & Thomas, 2013) and being compassionate at all times. This is illustrated in the extract below:

> *I try very hard to present things very factually based without opinions . . . It is a very fine line, the facial expression . . . I don't ever want to be the reason somebody made an inappropriate decision."* (Intensive Care nurse cited in King & Thomas, 2013: pg. 1301).

> *"It was a touch-and-go situation whether the patient wanted to be kept alive by mechanical means; his family was making the decision. And we had to have the Ethics Committee come in on it . . . I was wanting to give the patient one more day . . . They gave the patient one more day, and I think the very next day they did decide that it was his choice to be removed from mechanical means."* (Intensive Care nurse cited in King & Thomas, 2013: pg. 1302).

5.4.3.2 Sub-theme: Developing coping strategies

The experiences shared by Intensive Care nurses across most of the reviewed findings reported that nurses develop and adopt coping strategies as they provide end-of-life care to patients and their families. Intensive Care nurses develop several coping behaviours that enable them to maintain their professional demeanour while providing quality end-of-life care and to meet the pressures and demands of such care in the ICU. The reviewed findings indicated that nurses develop cognitive, affective and behavioural coping strategies as they navigate the end-of-life care journey (Espinosa et al., 2010; Calvin, Lindy & Clingon, 2009; Hoi & Sally, 2009; Rafii et al., 2016; Ong & Ting, 2018).

From the reviewed findings, nurses develop cognitive strategies by putting up empathetic measures as they visualise the process. Often, they learn from previous experiences, reminisce on these experiences and put things into perspective. They often revert to past experiences in the absence of support and guidelines to provide end-of-life care (Rafii et al., 2016; Ong & Ting, 2018). Some participants see the process as a means to get used to the job, build on their clinical skills and confidence for future challenges as well as achieve full control of future end-of-life care. These were expressed in the extract below:

> *"The experience of death is more difficult at the beginning. Then, continuous contact with the dying patients in the ICU makes a nurse get used to everything reported."* (Intensive Care nurse cited in Rafii et al., 2016: pg. 108).

> *"When my patients die, my whole body is covered by sweat and I get paled. I console myself that I have done my best to save his life and that I've put all my efforts. This gives me strength for future challenges."* (Intensive Care nurse cited in Rafii et al., 2016: pg. 108).

Participants from one study reported that nurses further adopt affective coping strategies through the EOL care journey by externalising their feelings as they provide end-of-life care to both patients and the family (Espinosa et al., 2010). Nurses tend to verbalise to each other their feelings, or have debriefing sessions with other colleagues. Often, they find a safe place to air their complaints as well as a forum for seeking aid from peers to voice difficult feelings. These conversations with colleagues, according to the literature, provided support and reassurance. This extract was expressed by one participant:

> *[She is] a good director and sometimes I'll go to her and she worked in the same area that I came from before and she is a good person to talk to because she'll let you just sit down and tell your story and then she'll say something in the right place, like "Well that was good that you were there." So you get to feel like somebody else acknowledged that you did the right thing because usually when you need to talk about it, it's something where you feel like you really needed to have it confirmed that you did the right things, so you couldn't have done something more or something less or that it was just right. And so other nurses are really the people that you talk to. That's the people that I find best to talk to, are other nurses that experience the same thing."* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 278).

Reviewed findings from two studies (Espinosa et al., 2010; Ong & Ting, 2018) reported that one other coping strategy was the use of humour. This was expressed in participants extracts below:

> *"If we don't mix the humour in—a lot of times even in a code, we're bantering a little bit, just trying to keep it light hearted. We're focused on what we're doing, but it's okay if we smile or chuckle during a code because we're not being insensitive to the patients' needs. We're taking care of ourselves to keep our frame of mind in the right frame."* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 278).

> *"You can cry, but you cannot keep on crying. [laugh]. Ya, you can cry, maybe for a short while . . . and quickly come back to reality. You still have another patient to nurse"* (Intensive Care nurse cited in Ong & Ting, 2018: pg. 264).

When the provision of the care overwhelms nurses, findings from the reviewed studies reported that they adopt behavioural coping strategies in order to cope with the situation (Espinosa et al., 2009; Hoi & Sally, 2009). They retreat, avoid and distance themselves from the situation. More often, nurses walk away from the situation for reasons of personal frustrations and moral distress. Some participants also expressed the need to avoid care for critically ill patients. These are illustrated in the extracts below:

> *"I do not get too involved emotionally with the patients, as this would make me even unhappier when they die. I distance myself from patients because it makes me feel more comfortable."* (Intensive Care nurse cited in Hoi & Sally, 2009: pg. 1168).

> *"Should certain nurses not take care of a dying patient because they literally can't? That's something I think we should look at. And I know in my unit there are a couple nurses who can't do it. When they do its awful. It's just awful for the family, for the patient, for themselves. They shouldn't do it."* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 279).

Participants in one study reported that they do not describe EOL care as difficult, however, they tend to walk a fine line when clarifying patients' values and treatment wishes (Calvin, Lindy & Clingon, 2009). Nurses act behaviourally, taking into consideration physicians' receptivity to the subject of changing patients' code status. They tend to be careful with their words or keep silent. These are measures are to avoid any verbal reprimand by the physician, as expressed one participant's quote below:

> *"He's jumped down the nurse's throat. And if the family ever says 'the nurses said . . .,' he comes and jumps down the nurse's throat because you said something he didn't want the family to know. And he's done it; he's come in and chewed out the nurse at the bedside, 'You told the family and you shouldn't have told them that.' So, it's a very fine line that you're walking on with what to let them [family members] know."* (Intensive Care nurse cited in Calvin, Lindy & Clingon, 2009: pg. 218).

5.4.4 Theme 4: Barriers to the Provision of EOL Care

A reoccurring theme across the reviewed studies was the obstacles or barriers to the provision of end-of-life care to patients and their families in the Intensive Care Unit. The majority of these studies reported several of these obstacles as an important theme expressed by nurses in their their experiences (Kisorio & Langley, 2016; Rafii et al., 2016; Efstathiou & Walker, 2014; Holms et al., 2014; Vanderspank-Wright et al., 2011; Espinosa et al., 2010; Calvin et al., 2009; Hov et al., 2007; Fridh et al., 2009; Coombs et al., 2015; Leung et al., 2015; Brysiewicz & Bhengu, 2010; Langley et al., 2013; Latour et al., 2009; Badir et al., 2016; Hoi & Sally, 2009; Ong & Ting, 2018; Limbu et al., 2018; Kaldem, 2009; Garwood, 2016; Fuller, 2018).

This synthesised theme was represented by four sub-themes namely: Patients family behaviours and issues, nurses' personal factors, physician-related barriers and environmental/ institutional-related obstacles.

5.4.4.1 Sub-theme- Behaviours and issues of patients' families

Patients' family members and friends, as well as significant others, were seen across the reviewed studies as a great source of barrier to the provision of end-of-life care in the Intensive Care Unit. Families' issues and behaviours pose much concern for the Intensive Care nurses in the provision of end-of-life care. Although patients' family are seen as contributors to the success of end-of-life care, the reviewed findings indicated that their attitudes, behaviours and interaction posed a threat to the quality of end-of-life care in the ICU. These were seen in the synthesis through the unrealistic expectations from family members during patient's hospitalisation period, for instance, limited knowledge on lifesaving interventions, difficult nature of family's reactions, naïve expectations on preventing death, family's absence when patient gets closer to end-of-life, resistance and unwillingness to accept the transition to end-of-life care and the cultural differences the family presents (Espinosa et al., 2010; Leung et al., 2017; Garwood, 2016; Rafii et al., 2016; Valiee et al., 2012).

Patients' families mostly have less medical knowledge on their relative's condition, hence demand nurses to do everything possible to help the patient. In most cases, they are not ready to accept the patient's poor prognosis. Meanwhile, nurses know that all possible medical interventions have been exhausted, with only palliative and end-of-life care measures remaining. In three of the reviewed studies, nurses deem this attitude as a barrier to the provision of end-of-life care in the ICU (Espinosa et al., 2010; Garwood, 2016; Leung et al., 2017). These are illustrated by participants in the quotes below:

> *“It was horrible because he’s a very large guy, and we coded him and he’s keeping going on and off, on and off. I left and they coded him six more times, and he ended up dying about 11:23 last night. But they didn’t want to give up. The son said, “I cannot live with it if you just extubate him and let him go.” So they wanted us to do everything, and he was haemorrhaging from his lung. It was pretty bad. Blood was just pouring from the tube, we kept pumping on his chest, it was really very traumatic. It was a bad situation.”* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 276).

> *“Because of my inside knowledge, my decisions may be different than the general public who thinks they save lives at hospitals: ICUs can do everything and they also have no idea what they’re getting into.”* (Intensive Care nurse cited in Leung et al., 2017: pg. 232).

> *“Most families do not have enough knowledge base to make a decision when it comes to the dying patient.”* (Intensive Care nurse cited in Garwood, 2018: pg. 83).

The nature of family reactions towards Intensive Care nurses was an aspect that shifts nurses’ focus from the provision of end-of-life care to patients. Facing the distress and anxious behaviours of the family upon seeing their relative’s condition, nurses shift the focus to attend to the needs of the family (Valiee et al., 2012). This added emotional discomfort and makes the care challenging. This is supported by the quotation:

> *"Facing families . . . coming and seeing their beloved in that pathetic condition and I, as a nurse, cannot be a good support for them, because once you try to keep your cool and explain the condition of the patient gradually and calmly, you have to admit that their patient's condition would not change till his/her heart stops beating." (Intensive Care nurse cited in Valiee et al., 2012: pg.311).*

Participants in three studies (Garwood, 2016; Kisorio & Langley, 2016; Valiee et al., 2012) reported instances where family's state of denial and refusal to accept the patient's state, posed challenges for nurses in providing end-of-life care. Nurses become emotional distressed, which takes their minds from caring for the patient. This is seen in the extracts below:

> *"One of the problems that we faced with, when taking care of the end-of-life patients especially those suffering from brain death, is their families; the more we try to tell them that the patient's condition remains stable and won't change, the more they would deny and show different psychological reactions that are painful for us too." (Intensive Care nurse cited in Valiee et al., 2012: pg. 312).*

> *".....difficulty we get is denial from the families who will tell you what you are telling us is not right. When you talk to them you will hear them, they want to hear what they want to hear. But as a nurse you know we have stages of grieving, they will deny/cry/shout/blame and eventually accept. So you take it as one of those steps and deal with it as it comes."* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 33*).*

> *“We see our dog suffering and we take them to the vet but families see their mom or dad suffering and refuse to stop.”* (Intensive Care nurse cited in Garwood, 2016: pg. 83).

Family acceptance of patients’ dying appeared to be a common predictor of their peace at the death (Kaldem, 2009). Families’ difficulties in accepting patients’ death were as a result of the perceived treatment by the healthcare team. This is expressed in the extract below:

> *“The family would not agree or accept that it was not going to get better. They had issues themselves. They thought we were not treating the patient; the patient didn't have insurance, so they thought we weren't treating her because she didn't have insurance. They were of [sic] minority, so they thought we weren't treating her how she should because she was a minority. There were lots and lots of issues. There were many family conferences, with the family and doctors. And that her prognosis was poor and the woman had coded multiple times and we did C.P.R. and all that stuff on her multiple times. It was a really bad situation that we weren't able to, I guess, get the family to be at peace that she wasn't going to make it.”* (Intensive Care nurse cited in Kaldem, 2009: pg. 35).

The family interjections, interfamily dynamics and conflicts often delay the EOL care process for the patient. Most family members due to several issues fail to agree to certain interventions that are beneficial to the patient. This is expressed in the quote below:

> *"It's just a really difficult decision to make and then its conflict and 1 feel really bad for those family members when they can't all agree on what to do."* (Intensive Care nurse cited in Kaldem, 2009: pg. 38).

5.4.4.2 Sub-theme: Nurses' personal factors

The finding of the reviewed studies reported that most of the barriers, as expressed in nurses' experiences in the provision of end-of-life care in the ICU, were personal-related barriers. These barriers included the level of nurses' knowledge on EOL care, lack of education and training, busy workload, inadequate training and support in the provision of end-of-life care, lack involvement in the plan of care for the dying patient, communication barrier due to patient's condition (Espinosa et al., 2010; Hov et al., 2007; Holms et al., 2014; Leung et al., 2017; Jordan et al., 2014; Naidoo & Sibiya, 2014; Brysiewicz & Bhengu 2010; Garwood, 2016; Limbu et al., 2018; Ong & Ting, 2018; Hoi & Sally, 2009).

Several review findings indicated that Intensive Care nurses receive inadequate education and training to competently provide quality end-of-life care to patients and their family in the Intensive Care Unit. Most nurses indicated that they receive no formal education on EOL care, however, they learn from continuous exposure EOL care situations and experiences (Brysiewicz & Bhengu 2010; Espinosa et al., 2010; Fuller, 2018; Holms et al., 2014; Naidoo & Sibiya, 2014; Ong & Ting, 2018). Nurses in most of the studies admitted they were under-prepared to provide end-of-life care, as reflected in the extracts below:

> *"[There's no] training that I have ever experienced that teaches us how to deal with that. It's not there." "I don't think it's good enough. See one, do one, teach*

> *one, if you get to see one, you get to do one."*(Intensive Care nurses cited in Espinosa et al., 2010:pg. 276).

> *"I have learned through repeatedly dealing with dying patients and their families, I have also learned from watching other more experienced nurses and doctors. It is a complicated task to teach end-of-life skills, it is very difficult to be able to read all types of diverse situations and offer all different types of comfort." (Intensive* Care *nurse cited in Holms et al. 2014: pg. 552).*

> *"The (end-of-life care) course is helpful, but it's mostly about cancer patients . . . not really on critical care . . . some of it doesn't really relate to [my setting] . . . there must be a model [for us to] improvise on [from the course.]"* (Intensive Care nurse cited in Ong & Ting, 2018: pg. 262).

> *"... there is no specific training ... we don't have anything, we just* use our *experience so there is no specific training that we have done". (Intensive care nurse cited in Brysiewicz & Bhengu 2010 pg. 49).*

As a result, Intensive Care nurses in most studies reported they are not involved in the plan of care, especially end-of-life care for patients and their families and the decisions made (Badir et al., 2015; Coombs et al., 2015; Espinosa et al., 2010; Fuller, 2018; Latour et al., 2009; Langley et al., 2015; Khalaileh, 2014).

> *"It's not very often that they'll [physicians] come to the bedside nurse and say, "What do you think is going on here?" And we're the one that's standing there.*

> *You know, 12 hours a day, and they come by and interact in little snippets."* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 275).

5.4.4.3 Sub-theme: Physician-related barriers

Findings from the synthesised studies reported physician-associated barriers that served as a barrier to the provision of end-of-life care in the Intensive Care Unit. This sub-theme was expressed as physician attitude to end-of-life care, the physician paradigm of care, multiple physician differences and opinions (Brysiewicz & Bhengu, 2010; Espinosa et al., 2010; Calvin et al., 2009; Hov et al., 2007; Nankundwa & Brysiewicz, 2017).

Several studies indicated that the attitude of most physicians made the successful delivery of end-of-life care a challenge for the nurses and entire healthcare team (Calvin et al. 2009; Espinosa et al., 2010). Nurses expressed in their experiences that physicians' are unwilling to let go when a patient's prognosis is bad. Physicians perceive that the patient's condition can be reversed and therefore exhaust all possible treatments, as expressed in the extract below:

> ''I think physicians are unwilling to let go . . . doctors fight for life beyond all else. Sometimes I feel like they're using the patients as experiments.'' (Intensive Care nurse cited in Calvin et al., 2009: pg. 218).

Nurses often assume a tight position to prepare the family as the patient's end-of-life seems to be approaching, but the attending physician thinks otherwise as they hold the authority to make the final end-of-life decision (Calvin et al., 2009). Nurses, in such situations, acknowledge physicians’ authority as they are perceived to be the rightful initiator and final end-of-life decision makers. Nurses indicate this attitude delays the end-of-life care provided to both the patient and the family.

> *“Usually, I don’t talk to the families, unless I’ve already talked to the doctors and know what’s going on. I want the doctors to talk to the families first, because there are a lot of questions they’ll ask and I’ll just tell the family, ‘That is a doctor question. I, as a nurse, can’t answer that for you.”* (Intensive Care nurse cited in Calvin et al., 2009: pg. 218).

> *“I’ve asked physicians, ‘Are we going to change code status?’ ‘Well, why would we want to do that?’ That’s the response I got one day; yet, the day before, he said, ‘Well, I don’t think there’s much else we can do for this person.’ I’m like, ‘I must have missed something.” (Intensive Care nurse cited in Calvin et al., 2009: pg. 218).*

Most physicians avoid conversations with the family by way of trying to avoid the situation. As such, nurses are meant to play the role of providing information to the family. Unfortunately, most of the physicians do not share the plan of care with nurses.

The medical paradigm of care that focuses on only curative measures makes it difficult to deliver end-of-life care to the patient and their family. Participants in two studies indicated that the attending physician only focuses on one aspect without taking into consideration the whole picture (Espinosa et al., 2010; Hov et al., 2007).

> *"I get mad sometimes when they [physicians] kind of like tap dance around the whole thing and like, oh, they're [only] looking at this much. It looks like the patient is getting better. The CBC went a notch, he's getting better. It's like the chemistry is—the creatinine is—it's a little better. And the family latches on to that like—like a thread—to hold on to anything."(Intensive Care nurse cited in Espinosa et al., 2010: pg. 275).*

Participants in several studies reported that physicians rarely listen to their contributions (Hov et al., 2007; Nankundwa & Brysiewicz, 2017). Physicians prefer information from colleague physicians, objective signs in patients and laboratory results. As Intensive Care nurses, their constant bedside presence gives them a preview of the important signs. However, physicians pay little to no attention to their opinions regarding the plan of care. There are clearly no formal meetings and discussions on patients plan of care and important decisions.

> *"It is the surgeons and the internists who are responsible for the treatment. They often show little understanding for what we see. What we nurses try to discuss is brushed aside in a way. So instead of discussing it, you are attacked and in a way you feel like a hangman and a wolf who want to kill the patient. Nevertheless, I am very pleased with what I said, but I felt so humbled."* (Intensive Care nurse cited in Hov et al., 2007: pg. 208).

> *"Most of the time we are not part of the discussion and the views of nurses are ignored. The doctors are the one who make this order." (Intensive* Care nurse cited *in Nankundwa & Brysiewicz, 2017: pg. 21).*

When it comes to the Intensive Care Unit, several attending specialist physicians concentrate on the patients' organ of dysfunction. Intensive Care nurses indicated that conflicting opinions, disagreement and discrepancies regarding prognosis among these specialist physicians further makes it difficult to initiate end-of-life care for patients and their family (Brysiewicz & Bhengu, 2010; Espinosa et al., 2010). In most cases, families are kept confused about the patient's situation. This is illustrated in the quotes below:

> *"I find that the families aren't well informed by the physicians. . . .they're given a lot of false hope. . . . And, understandably, the physicians want to make everybody better. . . .but some give a lot of false hope. And you feel bad. I mean I have a patient tonight who will never get off dialysis we just started. And she said, "Oh, he'll be fine." The family just doesn't understand yet. And I don't think the education is there. They [families] look at the nurses as knowing everything."* (Intensive Care nurse cited in Espinosa et al., 2010: pg. 276).

> *"... it is even worse when there's more than one doctor involved. So there is a neurosurgeon, there is a general surgeon, there is a physician involved and each one has their own thing, they all have their say on just their part of the body ... the doctors don't discuss anything with each other."* (Intensive Care nurse cited in Brysiewicz & Bhengu, 2010: pg. 48).

Communication challenges between nurses and physicians, as well as patients' family, were predominantly seen across the synthesised finding as a barrier to the provision of end-of-life care to patients and family in the ICU (Brysiewicz & Bhengu, 2010; Nandunkwa &

Brysiewicz, 2017). What the physician tells the family is often different, as expressed in participant's quote below:

> *... it's very difficult for you to actually interact with the family ... you will always have the barrier of a doctor because of how much the doctor is telling the family and how much you are telling the family ... so you always have the barrier where you cannot overstep the mark."* (Intensive Care nurse cited in Brysiewicz & Bhengu, 2010: pg. 46).

5.4.4.5 Sub-theme: Intensive Care environment-related factors

In most studies, the Intensive Care environment appeared as a predominant finding as a barrier to the provision of end-of-life care to patients and family. Numerous aspects of the Intensive Care environment were found to impede the normal delivery of EOL care in a number of reviewed studies (Rafii et al., 2016; Holms et al., 2014; Vanderspank-Wright et al., 2011; Fridh et al., 2009). These environmental-related barriers reported in the literature included the poor ICU layout, the noise and high-technology level, busy schedules, nurses' heavy workload and limited time, conflicts and tensions, lack of manpower and resources.

The Intensive Care Unit design was seen as incompatible with the provision of end-of-life care for patients and their families. The busy nature of the ICU due to numerous tasks, crowded situations and high levels of noise from monitors and ventilators makes the place not ideal for caring for dying patients and their families (Fridh et al., 2009; Holms et al., 2014). Participants mentioned the lack of peace and privacy as a challenging factor, as expressed in the quote below:

> *“It is not always the most peaceful environment in ICU, although we do strive where possible to rectify the noise pollution. The lack of single rooms and lack of relative’s rooms in this Intensive Care Unit is detrimental to end-of-life provision, which means dying patients and their relatives do not have the privacy they need.”*(Intensive Care nurse cited in Holms et al., 2014: pg. 552).

The Intensive Care Unit is designed in such a way that it does not make provision for single rooms for patients and their family. There are multi-bed rooms, where several patients are managed together, however this compromises the level of privacy for patients and family and is detrimental to the provision of end-of-life care. The lack of private rooms often meant that Intensive Care nurses have to find other efforts to ensure the privacy for the patient and family. (Fridh et al., 2009; Holms et al., 2014). This is illustrated in one participant’s expression as quoted below:

> *‘‘One wishes, most of us wish that the patient could always have a private room, as it feels much much better, actually. At the same time it can be extremely distressing for the fellow patient on the other side of the screen to overhear that now they are doing cardiac-pulmonary resuscitation and now they are intubating the patient and now they are stressed, now things are happening. We often hear that the person in the next bed becomes severely distressed. It’s something that people should actually not have to experience. Being in hospital and having someone dying beside you.’’* (Intensive Care nurse cited in Fridh et al., 2009: pg. 238).

In a multi-bedroom, Intensive Care nurses provides care for the dying patients and their family as well focus on the well-being of other patients and their families. Family members' time with patients is also restricted as they do not get the opportunity to be with the patient and express fully their sorrows and love. The busy and multi-task oriented nature of the ICU increases nurses' workload, limiting time to provide end-of-life care for the dying patient and the family (Fridh et al., 2009).

Intensive Care nurses in four studies acknowledged the busy nature of the Intensive Care Unit as a barrier to the provision of end-of-life care to patients and their family.

Participants in one reviewed study described the shortage of staff and inadequate resources to work with as a barrier to the provision of adequate end-of-life care (Rafii et al., 2016). In the absence of adequate staffing and resources, nurses are unable to perform all scheduled duties as well having less time with the patient and family, as expressed in the quote below:

> *"Due to the lack of sufficient nursing staff, it is difficult to perform all the duties in the ICU and compensate for the shortage of personnel."* (Intensive Care nurse cited in Rafii et al., 2016: pg. 109).

Lack of collaboration and poor coordination among healthcare professionals, and with patient and family in the Intensive Care environment appeared in most synthesised findings as a predominant barrier to the provision of EOL care for patients and their families (Rafii et al., 2016).

> *“The bad relationship between nurses and doctors affects patient treatment because doctors always regard themselves superior to nurses. This will create a gap between them and the nurses. The gap will then grow and the patient will be deprived of good care.” (Intensive* Care nurse cited in Rafii et al., 2015: pg. 109).

Communication breakdown, conflicts between nurses and doctors were also perceived findings in most studies as major barriers to the provision of EOL care in the ICU (Espinosa et al., 2010; Holms et al., 2014; Yu & Chan, 2010).

5.4.5 Theme 5: Facilitators of End-of-life Care

A majority of the synthesised findings on nurses’ experiences in the provision of EOL care in the ICU reported on the factors that facilitate the efficient provision of EOL care (Arbour & Wiegand, 2014; Kisorio & Langley 2016; Yu & Chan, 2010). These findings were categorised into subthemes, namely: supporting nurses, supporting the patient’s family members, Intensive Care environment changes through effective communication and collaboration, family support, Guideline and treatment policy,

5.4.5.1 Sub-theme: Supporting nurses

In this category, the sub-theme supporting nurses emerged as a fundamental facilitator to the effective provision of end-of-life care for patients and family in the ICU. The majority of findings synthesised reported supporting nurses through the provision of adequate training and education on EOL care and peer support (Arbour & Wiegand, 2014; Kisorio & Langley 2016; Yu & Chan, 2010)

Intensive Care nurses receive little formal education and training on EOL care. More often, they learn these skills from good and bad experiences and the frequent exposure to the dying patient (Holms et al., 2014). Drawing from previous experiences enables nurses to get used to caring for the dying patients (Rafii et al., 2016). These are illustrated in the following quotes:

> *"I have learned through repeatedly dealing with dying patients and their families, I have also learned from watching other more experienced nurses and doctors. It is a complicated task to teach end-of-life skills, it is very difficult to be able to read all types of diverse situations and offer all different types of comfort."* (Intensive Care nurse cited in Holms et al. 2014: pg. 552).

> *"The experience of death is more difficult at the beginning. Then, continuous contact with the dying patients in the ICU makes a nurse get used to everything."* (Intensive Care nurse cited in Rafii et al., 2016: pg. 108).

Participants in two studies asserted that the provision of end-of-life care in the ICU is challenging and therefore various forms of support for nurses are important to strengthen their abilities to provide quality end-of-life care before and after the death of the patient (Kisorio & Langley 2016; Yu & Chan, 2010). Participants appreciated the need to receive formal education, training, counselling and debriefing sessions as they go through the EOL care journey with patients and the family. These are illustrated in participants' quotes as expressed below:

> *‘‘. . . offer training on how we can handle families and patients. With us seniors we are much better but junior nurses get a lot of stress and trauma. They need somebody to support them.’’* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 35).
>
> *‘‘We need counselling or debriefing sessions, just to talk with someone because the things we get exposed to on a daily basis are deep but we survive, we get desensitised, nothing is done to us.’’* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 35).

Witnessing a patient deteriorate is draining and exhausting for Intensive Care nurses. Nurses prefer time to overcome the bereavement, or if possible not be immediately assigned to care for another dying patient. Participants articulated in their expressed experiences the importance of taking some time off patient care.

> *‘‘. . . after it has happened (death), there is an admission. They need this bed for another patient and you find you are not alert. Your brain goes back, you slow down, because you are still disturbed, you were not given time to adjust.’’* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 36).

Less experienced and new Intensive Care nurses find it difficult to provide end-of-life to patients and their families. They have difficulties coping with the dying patients and the expectations of the family members. Participants in two studies reported the importance of peer support through mentoring and teaching new Intensive Care nurses as a means of promoting care for patients and their families in the ICU (Arbour & Wiegand, 2014; Yu & Chan 2010). These were expressed in the extracts below:

> *‘‘It’s important to work with people through the process, to make sure they don’t feel like they are being abandoned. Even guidance on things like creature comforts . . . enough chairs, tissues, water in the room . . . knowing that is very helpful for a new nurse to start with in helping the family.’’ (Intensive* Care *nurses cited in Arbour & Wiegand, 2014: pg. 216).*

> *“The support from peers in the ICU is the most important. If a person’s background and job are different, then they might not understand what you are talking about. If they do not work in the ICU, then they may not understand our experiences even though they are nurses…..It is very important to share our feelings with our peers. Although it can’t help me to forget all the unhappy things, at least they can share my pain and sorrow. After taking to them [peers], you can get a clearer picture of the situation. You know that it was not your fault that the patient died. We need reassurance; this is what peer support gives us.”* (Intensive Care nurse cited in Yu & Chan 2010: pg. 1169).

Good and open communication between nurses and physicians as well as other colleagues promotes patient and family care. Participants in several studies described the essence of effective communication as a way to enhance patient care.

5.4.5.2 Sub-theme: Supporting patient’s family

The sub-theme supporting patients’ family members was central to the experiences expressed by nurses throughout the synthesised findings as an area for facilitating the provision of quality EOL care in the ICU. The majority of studies reported the essence of placing patients' families at the centre of care by working with them and supporting them throughout the EOL care journey (Arbour & Wiegand, 2014; Efstathiou & Walker 2014; Kaldem, 2009; Kisorio & Langley, 2016; Popejoy et al., 2009; Vanderspank-Wright et al., 2011). This sub-theme was further categorised into promoting family-centred care and providing family support after the patient's death. These were realised from the findings by educating and teaching the family, psychological support for the family, promoting family involvement and presence, permitting family adequate time with the patient, psychological preparation of the family before the patient's death and support after death.

Family members of most dying patients are mostly not prepared for the death of their relatives. Most study findings described the importance of educating and preparing the family gradually, by giving constant information on the patient's prognosis as an important measure to support the family and promote effective EOL care (Arbour & Wiegand, 2014; Kisorio & Langley, 2016). Teachings often took the form of responding to family concerns, needs and questions, as well as providing necessary information on essential treatment interventions.

> *"I have realised that the family is not prepared days before. They will just be called on that particular day when the decision has been made and the patient is going to die. They need to be told from day one by the doctor. Explain every day about the prognosis. Just prepare them for that. Even the language must be understood."* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 34).

Participants in several studies described the family having adequate time with the patient as a helpful approach to the provision of EOL care to dying patients and their family (Arbour & Wiegand, 2014; Kisorio & Langley, 2016).

> *"….If they want to come in 24hours it is allowed. We frequently tell them to come and stay with the patient as they wish. It might be their last moment together."* (Intensive Care nurse cited in Kisorio & Langley, 2016: pg. 34).

> *"It was like a lifetime movie…….all in there…and actually caring for the patient, you could almost see them embracing her and embracing the process of death. They knew at that point she's going to die and she's accepted it."* (Intensive Care nurse cited in Arbour & Wiegand, 2014: pg. 215).

Several review findings highlighted the importance of psychological preparation for the family before as well as after a patient's death as an important facilitator to the provision of EOL care in the Intensive Care Unit (Heidari & Nourazadeh, 2014; Popejoy et al., 2009). This promotes and contributes to the family acceptance of the demise of the patient.

Participants in one study reported family acceptance to patient's dying as rewarding, joyful and ensured a peaceful end-of-life care (Kaldem, 2009). Family giving permission to proceed created a good environment for the provision of EOL care, as expressed in the quote below:

> *"I remember her saying 'It's ok, you can go. I'll be fine. You can go now, you can let go."* (Intensive Care nurse cited in Kaldem, 2009: pg. 41).

5.4.5.3 Sub-theme: Intensive Care environment

The Intensive Care environment was indicated in most reviewed findings as an area to facilitate the provision of end-of-life care for patients and their families (Holms et al., 2014; Jordan et al., 2014; Kongsuwan, 2011; Limbu et al., 2018). The sub-theme reflects changes in the Intensive Care environment and measures that promote the provision of effective EOL care for patients and their families. This sub-theme is further categorised into ICU design, working together, open and effective communication, and treatment policy and guidelines.

- **ICU design**

The Intensive Care Unit's design was seen across the review findings as having an impact on the provision of EOL care. A noise free, siren environment should be available for the dying patient, friends and family to express their last love and respect (Kongsuwan, 2011). An environment that promotes patients and family privacy is essential in the provision of end-of-life care in the ICU. An environment that facilitates family visitation, especially patients at the end-of-life also promotes excellent provision of EOL care.

- **Working together**

The modern approach to Intensive Care delivery lies in the multidisciplinary model where collaboration and responsibility are shared between nurses and physicians. Working together was considered fundamental to optimise the intensive care provided to the critically ill patient and family. Findings from several studies described proper coordination among nurses, doctors and the family as a good measure to promote effective EOL care (Limbu et al., 2018; Jordan et al., 2014; Khalailleh, 2014).

This is illustrated in one of the study participant's quote:

> *"Only the care provided by the nurse is not enough. There should be family support as well. The ICU is teamwork. Proper coordination among the doctors, charge nurse and the family (patient's family) can lead to a better outcome of the patients. There should be proper coordination among us."* (Intensive Care nurse cited in Limbu et al., 2018: pg. 3).

- **Promoting good and effective open communication**

Findings from several studies reported good and open communication both within the multidisciplinary team and also with the patient and the family as an area that will promote effective end-of-life care in the Intensive Care environment (Espinosa et al., 2010; Fuller, 2018; Holms et al., 2014; Hov, Hedelin & Athlin, 2007). It was emphasised and recommended that effective communication between healthcare providers improves family satisfaction, clinical decision making, and the psychological well-being of family members.

> *"Good communication for the patient and the families is extremely important so they know the plan and so they know exactly what is involved when someone dies, even all the fine intricate details like removing tubes and line."* (Intensive Care nurse cited in Holms, Milligan & Kydd, 2014: pg.552).

- **Treatment policy and guideline**

Findings from several synthesised studies recognised the importance of treatment policy and specific guidelines for EOL care as a positive measure to promote the provision of excellent EOL care for patients and their families (Holms, Milligan & Kydd, 2015). Several review studies emphasised the need for of practice guideline to streamline EOL care activities in the ICU (Badir et al., 2015; Efstathiou & Walker, 2014; Fuller, 2018; Khalailleh, 2014; Kisorio & Langley, 2016; Latour et al., 2009).

Participants in one study, for instance, reported the use of specific care guidelines improved and standardised end-of-life practice (Holms, Milligan & Kydd, 2014). The presence of guideline structured activities regarding patients care, as expressed in the quote below:

> *"Now that the LCP is used, I feel EOL care has a better structure, I think there's more dignity been put on patients now that we have implemented the LCP."* (Intensive Care nurse cited in Holms, Milligan & Kydd, 2014: pg. 552).

5.5 METHODOLOGICAL RIGOUR

The presentation of the review findings is essential in building the knowledge base of the research problem. Whittemore and Knafl (2005) suggest that reported findings should be reported explicitly, taking into consideration only the available evidence so that readers can follow through the conclusion made as well as assess the basis for the conclusion drawn without exceeding the evidence. The strategies implemented by the reviewers to reduce biases and enhance the rigour of the study will be discussed below.

Data extracted from the individual studies were constantly cross-checked to ensure they represented the exact findings reported. The full test of each study was read by two independent reviewers, with data extracted compared at any stage for any differences. A certified co-coder, the second reviewer (SS), assisted the first reviewer during the categorisation of codes to ensure equal representation of the individual findings extracted.

Themes generated through a thorough thematic analysis were discussed and supported with direct verbatim illustrations from participants so as to maintain the integrity of the primary data and present the true quotes from participants or subjects. All findings were supported by referencing the page number of the articles. The presentation of data, interpretations and findings were devoid of the reviewers' values, beliefs and biases. Two independent reviewers cross-examined the findings with the themes at each stage. Full text were read and re-read again, and further discussions made when any findings were misquoted. An audit trail was maintained and kept to record the thought processes behind the formulated themes, decisions and codes, to track when concepts, similarities or relationships were identified in the data analysis, and to record rationales and consequences of decisions.

5.6 SUMMARY

The chapter presented the results of the research review. The findings generated were presented according to the study characteristics, participants' characteristics and methodological quality. Themes synthesised from the review were also discussed and finally the methodological rigour as ensured discussed.

The chapter that follows highlights the discussion, summary of findings and conclusion.

CHAPTER SIX

DISCUSSION, STRENGTHS AND LIMITATIONS AND IMPLICATION FOR PRACTICE

6.1 INTRODUCTION

In this chapter, findings synthesised from the integrative literature review are presented and discussed in relation to research literature, current policy and guidelines. The strengths and potential limitations of this study will also be presented, as well as implications and recommendations for future nursing research, policy, training and practice.

6.2 DISCUSSION OF FINDINGS

The integrative review sought to retrieve, analyse and synthesise research evidence from existing literature on the experiences of nurses in the provision of end-of-life care for patients and their family in the Intensive Care Unit. The study provides unique understanding of nurses' experiences in the provision of EOL care for patients and their families in the ICU. Five (5) themes were generated from the 38 studies that met the eligibility criteria and answered the research question, *"What are the experiences of nurses in the provision of EOL care for patients and family in the Intensive Care Unit?"* The five synthesised themes that characterised the experiences of nurses in the provision of EOL care for patients and family in the ICU included: Doing the right thing; Facing emotional labour; Negotiating tensions; Conflicts and uncertainties; Remaining committed and develop coping strategies; Barriers to the provision of EOL care; Facilitators of EOL care.

6.2.1 Doing the Right Thing

It was evident from the review findings that nurses remain the primary EOL for patients and family. Despite the challenging and demanding nature of the intensive care environment, nurses always want to the right thing for the patient and family. They see the provision of EOL care as a rewarding experience and a unique opportunity to promote the well-being of patients and their family. Doing the right thing, as synthesised from the study findings, was related to supporting both patients and families throughout the EOL care trajectory, which included providing comfort care, maintaining patients' dignity, nurses' constant presence at patient's bedside and being patient's advocate.

Additionally, the family members are supported through constant care, information sharing, good communication, building a trusting relationship, creating enough space for them with patients, protecting and providing good memories and assisting them through the grieving process. Presence, preparing the family and the provision comfort care are considered both professional and moral obligations in EOL care (Epstein, 2010). These findings are consistent with earlier evidence from Kirchhoff et al. (2000) that described "good" end-of-life care in the ICU as one that involves the family, and ensures the patient is pain-free, comforted and their dignity maintained. This is further confirmed in a study by Ranse et al. (2012), which reported that nurses play a vital role in supporting the patient and their family to have a positive and meaningful experience at the end-of-life.

Evidence suggests that when family members are supported adequately during EOL care, they feel satisfied with the EOL care provided and appreciate the efforts of the healthcare team (Henrich et al., 2011; Hinkle, Bosslet & Torke, 2015). These interventions provided by nurses are globally consistent with the concept of ensuring a good and dignified death in the Intensive Care Unit (Beckstrand, Callister & Kirchhoff, 2006; Bratcher, 2010; Cook & Roker, 2014).

6.2.2 Emotional Labour, Conflicts and Uncertainties

The provision of EOL care in the ICU is however associated with emotional labour (Stayt, 2009; Ryan & Seymour, 2013). The transition from curative care, through to the operationalisation of the withdrawal of life-sustaining treatment to the provision EOL care were identified as challenging and complex processes and practices that come with emotional attachments and commitments. As a result, nurses encounter some forms of emotional labour, and face conflicts and uncertainties as they support patients and their families. It was evident from the synthesised findings that the provision of EOL care had negative effects on nurses. These experiences were described as exhausting, challenging and draining, as well as a great source of moral distress.

The emotional labour, conflicts and tension regarding the provision of EOL care were reported in the studies reviewed to be related to the nature of a patients' condition, family behaviours and reactions to EOL care, the lack of clear communication and disagreement between nurses and physicians, and the demanding nature of the Intensive Care environment. These situations are often associated with high levels of moral distress that adversely affected the provision of EOL care for patients and their families (Elpern, Covert & Kleinpell, 2005; Langley, Kisorio & Schmollgruber, 2015). The emotional labour, conflicts and uncertainties witnessed by nurses in the ICU have been shown to be associated with job strain, distress and burnout syndrome, as well as affecting the quality of care provided for patients and their families. While Intensive Care nurses provide nursing care, they also manage conflicts within the healthcare team, colleague healthcare professionals, as well as meet institutional demands and personal issues. These represent significant personal and professional struggles (Halcomb et al., 2004).

The technological, procedural nature of the ICU and the nature of patients' illnesses also demand nurses to perform their roles adequately, as well as make decisions in quick succession. At the same time, nurses are professionally obligated to manage and provide clear, consistent and honest information to the patient and family. As a result, there is often less time and energy to satisfy the needs of every patient and family, and accomplish the plan of care. In this study, the synthesised findings reported that these conflicts stemmed from disagreement among the healthcare team, lack of end-of-life care guidelines, absence of definite answers to EOL care questions, the complexity of intensive care nursing and unclear communication between nurses and physicians and unclear, constantly changing and vague goals about patients treatment during EOL care. These findings agree with global studies, which indicated that these conflicts and tensions are commonly due to the procedural, organisational, contextual and relational issues and factors that affects various decisions and interventions in the ICU regarding patient care during the provision of EOL care (Azoulay et al., 2009; Hartog & Benbenishty, 2015). These conflicts create several obstacles to good communication and decision making that eventually affect the quality of EOL care. Most of these conflicts are predominantly nurse-physician, followed by those amongst fellow nurses and nurse-family conflicts (Azoulay et al., 2009).

6.2.3 Remaining Committed and Developing Coping Strategies

Despite the demanding and stressful nature of the ICU that comes with emotional burdens, conflicts and uncertainties, it was evident from the review findings that nurses continue to remain committed to patient and family care. Although nurses receive varying and inadequate levels of emotional support and education in relation to the provision of EOL care, they fall on their previous experiences to provide care. Intensive care nurses attached a unique sense of commitment to the provision of EOL care. End-of-life care becomes a valuable opportunity and rewarding experience to care for patients and their family, therefore nurses continue to focus on the physical and spiritual care of the patient. They remain optimistic despite the pending patients' death as they do their utmost for the patient and their family. This is consistent with other studies, which reported that nurses valued the opportunity to provide compassionate EOL care, to remain committed and facilitate positive end-of-life care experience for both patients and their families (Borhani, Hosseini & Abbaszadeh, 2014; Ranse, Yates & Coyer, 2012).

The absence of formal educational support systems and structures in the ICU make nurses less confident and skilled to provide EOL care, as well as the development of negative attitudes towards caring for dying patients' families. It was evident from the reviewed findings that nurses, as a result of continuous exposure and practice, develop and adopt certain coping strategies to deal with the challenges associated with EOL care and intensive care practice. As frontline caregivers in the ICU, these coping strategies assist nurses to maintain professional demeanour while dealing with the complex situations and conflicts that comes with patient and family care. These reported coping strategies were related to cognitive, affective and behavioural coping strategies and techniques. For instance, nurses fall on their past experiences to build clinical skills and confidence to gain control over future EOL care. Others externalise their feelings to others or engage in debriefing sessions with colleagues as a means of coping with the situation. As the practice overwhelms their abilities, behaviourally, nurses distance themselves from patients for a while. These findings were substantiated by Badger's (2005) study, which reported intensive care nurses develop varieties of coping behaviours to cope with the EOL care transitions.

6.2.4 Barriers to the Provision of End-Of-Life Care in the Intensive Care Unit

The intensive care environment is described in literature as an unfavourable environment for providing excellent EOL care for patients and their families (Noome et al., 2016b; Hansen et al., 2009). The setting is designed to care for acutely ill patients, not for critically ill and dying patients and their families (Hansen et al., 2009). It was evident from the reviewed findings that several factors serve as major barriers to the provision of excellent EOL care in the current intensive care environment. Behaviours and issues of patient's families, the intensive care environment, physician behaviours and nurse-associated factors were reported in the studies reviewed as major barriers to providing EOL care in the Intensive Care Unit.

The family behaviours, for instance, were reported to due to their limited knowledge on lifesaving measures, unrealistic expectations and demands, untoward reactions towards patient's plan of care, refusal and denial to accept patient's prognosis and wanting life-sustaining interventions to be continued. These findings are consistent with other studies that reported family behaviours as a factor that prolongs patients' suffering, takes nurses' attention from patient care and delays the provision of excellent EOL care (Attia et al., 2013; Beckstrand & Kirchhoff, 2005; Iglesias et al., 2013; Nelson et al., 2006).

Intensive care nurses receive inadequate basic educational preparation and training for the provision of EOL care (Holms et al., 2014; Kirchhoff & Kowalkowski, 2010). This was also apparent across the reviewed findings as a major barrier to providing EOL care in the ICU. This confirmed earlier studies that reported deficiencies in education about EOL care for nurses as a major threat to the provision of excellent EOL care (Attia et al., 2013; Truog et al., 2008). It has been suggested that intensive care nurses need to be trained and well educated to provide EOL care (Hansen et al., 2009). This resonates with the findings of other studies that nurses identified adequate training and education as a means to improve their knowledge and skills in providing EOL care (Halcomb et al., 2004; Espinosa et al., 2010; Latour, Fulbrook & Albarran, 2009).

The busy, highly technological level intensive care environment, characterised by many tasks, multi-bed rooms, crowded situations and high levels of noise from monitors and ventilators, poses a major barrier to the provision of quality EOL care for critically ill patients and their families. The technological and highly demanding nature of the ICU environment requires nurses to constantly manipulate monitors as well as provide quality care for patients. The heavy workload in the ICU further limits nurses' time caring for dying patients and their family. These are attributed to the inadequate staffing that is reflected in the inadequate nurse-to-patient ratio and the involvement in several lifesaving activities for several patients at the same time. These findings support the evidence from the study of Zomorodi and Lynn (2010), which illustrated that the nurses are often in between satisfying the needs of newly admitted intensive care patients, dying patients' family, other healthcare providers and their other responsibilities and duties.

The poor ICU design, characterised by multi-bed rooms and high levels of noise, makes it difficult for families to spend as much time with patients as they wish. The lack of privacy and peace also hinders quality of EOL care. These reviewed findings resonate with the evidence from several studies that report the ICU layout as a major barrier to the provision of EOL care (Attia et al., 2013; Brooks, Manias & Nicholson, 2017; Zomorodi & Lynn, 2010).

The medical paradigm of care, which focuses on curative care, demands that all medical interventions need to be exhausted. Nurses describe physicians' unwillingness to let go and allow death to happen naturally as a barrier to a successful end-of-life care. The conflicting opinions, disagreement and discrepancies among multiple attending physicians regarding prognosis and patients direction of care further hindered the provision of EOL care. These issues were raised in the Beckstrand and Kirchhoff (2005) study and further illustrated in recent studies (Iglesias et al., 2013; Nelson et al., 2006).

Physicians preferred information from colleague physicians, objective signs in patients and laboratory results; nurses' opinions were less appreciated, and they were less involved in the plan of care and important decisions. Neglecting nurses' opinion about the direction of patient care was perceived as another barrier to providing EOL care. This finding was similarly raised by Hansen et al (2009), and congruent with several other research findings (Beckstrand & Kirchhoff, 2005; Miller & Boyle, 2001), which showed that physicians neglecting the opinions and inputs of nurses in EOL decisions may affect the quality of EOL care.

Although physicians perceive that they involve nurses in EOL care decision making, nurses perceive their inputs into a patients’ plan of care to be minimal. Physicians often avoided conversation with patient’s family members. This behaviour and attitude was seen in this review as one of the barriers to the provision of EOL care; studies by Beckstrand and Kirchhoff (2005) and Iglesias et al., (2013) reported similar findings. Evidence suggests that when family members are supported adequately during EOL care, they feel satisfied with the EOL care provided and appreciate the efforts of healthcare team (Henrich et al., 2011).

6.2.5 Facilitators of End-Of-Life Care in the Intensive Care Unit

It was evident from the synthesised findings that the provision of excellent EOL care is dependent on factors associated with nurses’ support, families’ support and changes in the intensive care environment. The modern approach to intensive care delivery lies in the multidisciplinary model where collaboration and responsibility is shared between nurses and physicians. Therefore, effective collaboration and open communication is considered fundamental to optimising the intensive care provided to critically ill patients and improving staff outcome (Hamric & Blackhall, 2007; Papathanassoglou et al., 2012).

The reviewed findings suggest supporting nurses, patients’ family members and making changes in the intensive care environment are essential in facilitating excellent provision of EOL care. Factors that supported nurses’ ability to provide excellent end-of-life care in the intensive care unit included adequate training and education on EOL care, EOL care guidelines, effective open communication, team work both within the multidisciplinary team and also with patients and their families. Measures centred on supporting the knowledge base of nurses and family through teaching were reported as crucial for facilitating the provision of EOL care.

The nature of the ICU design has an impact on the organisational performance and clinical outcomes (Thompson et al., 2012). The provision of private rooms, liberalisation of visiting hours and regulation of noise from monitors equally promoted a conducive and siren free environment for providing EOL care. These reviewed findings are consistent with the evidence from several studies that reported nurses support, patient and family-centred, team work, effective communication, ICU design changes and the practice guidelines development as major areas that facilitate and are helpful to providing EOL care for dying patients and their families (Attia et al., 2013; Beckstrand & Kirchhoff, 2005; Brooks, Manias & Nicholson, 2017; Clarke et al., 2003; Zomorodi & Lynn, 2010).

6.3 IMPLICATIONS

The implication for practice, education and further studies will be discussed in the sections below:

6.3.1 Implications for Practice

The findings of the review not only illustrated the challenging aspects of EOL care in the ICU, it also highlighted what has been done, through the experiences of nurses, in the provision of EOL care for patient and families. The findings of the review have reported and supported clearly that nurses offer their absolute best and play key roles in supporting both patients and families along the entire EOL care trajectory, from the transition from curative care, operationalisation of withdrawal of treatment to EOL care and bereavement support. Despite these roles reported from the synthesised evidence, nurses are still less involved in EOL care planning and decision. It was evident that the provision of EOL care comes with lots of conflict, tension and uncertainties. Nurses are less supported and inadequately prepared to provide excellent EOL care.

Although nurses remain committed to care, they continue to fall on their past experiences to provide EOL care for patients and their families. Nurses receive limited to no formal support and education around EOL care or the skills to lead this process, hence they face several challenges meeting the EOL care demands of the growing aging population. Existing guidelines have also failed to factor nurses concerns and recommendations. Specialised training, education and support are required to assist nurses in providing EOL care for patients and families in the ICU. Measures targeted at improving communication among the healthcare professionals should be included in quality improvement programmes. Debriefing sessions and mentoring were identified as important measures to support nurses in the provision of EOL care. Formal, evidence-based supporting and coping strategies to promote the provision of excellent EOL care should be offered as a standard procedure.

Finally, the development and implementation of a researched-based EOL care practice guideline for the provision of EOL care could reduce the challenges associated with the care. Conflicts, tensions and uncertainties among the healthcare team could be reduced and facilitate effective team-work and promote excellent EOL care. The recently published guideline for the withdrawal of life-sustaining treatments, by Downar et al., (2016), could form the basis for the development of specific EOL care practice guidelines. Addressing the effectiveness of their recommendations could be a step forward to the testing the existing guideline and project gaps for further research.

6.3.2 Implications for Research

The findings from this review would suggest the experiences of nurses with regard to the provision of EOL care for patients and their families has been well described within literature from varying research approaches, religious backgrounds and country-specific perspectives. This indicates much has been done from a global perspective. It can be suggested that nurses' lived experiences in the provision of EOL care centre on practices that are evidence-based and build on the identified facilitators and barriers of EOL care provision in the ICU.

Nurses' exact roles in the multidisciplinary decision making regarding the transition to EOL care still need to be extensively investigated. Existing protocols and practice guidelines need to be critically evaluated and developed further to establish best practices for EOL care in the ICU. Formal supportive systems, such as mentoring and debriefing sessions, have been evidenced in the synthesised literature to support nurses in the ICU. There is the need to explore more supportive strategies grounded in evidence to equip nurses. Debriefing models can further be explored to ascertain their effectiveness in supporting nurses in the provision of EOL care for patients and their families.

Although much has been done on the experiences of nurses globally, few studies are done in the African context. As Africa presents a unique context, with distinct disease profiles and population, further studies are important to assure adequate representation of findings in the development of specific EOL care practice guidelines.

6.4 STRENGTHS OF THE STUDY

The studies reviewed originated from five different continents, Africa, Asia, North America, Australia and Europe. This indicates that most experiences from different cultural, religious backgrounds were captured and confirms nurses' experiences from a global perspective. The integrative review also included both published (Empirical-qualitative, quantitative and mixed method) and unpublished (grey) literature. In order to ensure an exhaustive literature search, a qualified librarian assisted in the literature search and literature documentation. Search terms used were initially tested for any changes to ensure a broader search. Similar search terms and indexed words, such as End-of-life care, terminal care, withdrawal of treatment, death and dying and do-not-resuscitate, were used interchangeably during the literature search to broaden the search.

The systematic approach outlined by Whittemore and Knafl (2005) was followed for conducting an integrative review, structuring the study and presenting a transparent process. The data analysis stages for instance, enabled the reviewers to easily follow and track the data synthesis performed.

6.5 LIMITATIONS OF THE STUDY

The limitations identified throughout the research review process are described below:

- **Participants**

Most of the participants used in the individual studies were females. The experiences expressed were mostly from female Intensive Care nurses. The overall experiences described in this review did not represent accurately the experiences of male nurses.

- **Time**

In this integrative literature review, literature search was limited to a 10-year period, with only published and unpublished studies identified between January 2007 and May 2018 used. Research studies published before January 2007 and after May 2018 that may have influenced and expanded the findings were not included. A significant amount of studies on nurses' experiences in the provision of EOL care were published between 1998 and 2007; these may have influenced the findings, however were excluded for academic reasons.

- **Scope of Databases**

Literature search was conducted using only SCOPUS, PubMed, ProQuest, EBSCO host databases (MEDLINE, CINAHL, Academic Search complete, Health Source: Nursing). Articles published in other databases that may have influenced the findings were also missed.

- **Language**

The study included articles published only in English. Considering the multi-population and cultural diversity that practices and accesses intensive care, several important studies published in other languages were not included. Relevant articles published in other languages were missed.

6.6 CONCLUSION

The integrative review of research studies from various countries presented the experiences of nurses in the provision of EOL care from a global perspective. The experiences of nurses within this context of care is complex, multifaceted and has noticeable similarities across the world where EOL care is practiced, and further confirms the evidence of variabilities in practice. Intensive Care nurses see the provision of EOL care as a rewarding experience and a great opportunity to support both patients and their families despite the challenges, conflicts and stress surrounding its provision. These challenges, however, affect the quality of EOL care the patient and family receive. Effective communication and collaboration among the healthcare professionals, patients and their families are necessary to effect changes in the current state of EOL care in the ICU. Adequate training and formal education of EOL care will be beneficial to build confidence and improve nurses’ skills in the provision of EOL care.

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APPENDIXES

APPENDIX A: DE SOUZA, DA SILVA and DE CARVALHO (2010) DATA COLLECTION TOOL

DATA EXTRACTION TOOL	
Author (s)	
Year of publication	
Country	
Title of publication	
Type of publication	
Aim/objective	
Population/sample	
Data collection	
Data analysis	
Results/findings	
Implications/Recommendations	
Limitations	

APPENDIX B: Ethical Clearance from Human Research Ethics Committee (Medical), University of the Witwatersrand

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

08/05/2018

Ref: W-CBP-180508-01

***TO WHOM IT MAY CONCERN*:**

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical).

Investigator: Mr EK Korsah
Student No. (if appropriate): 1636507
Staff No. (if appropriate):

Supervisor: Professor S Schmollgruber

School: Therapeutic Sciences
Department: Nursing Education
Medical School
University

Project title: *Nurses' experiences of end-of-life care in the Intensive Care Unit - an integrative literature review*

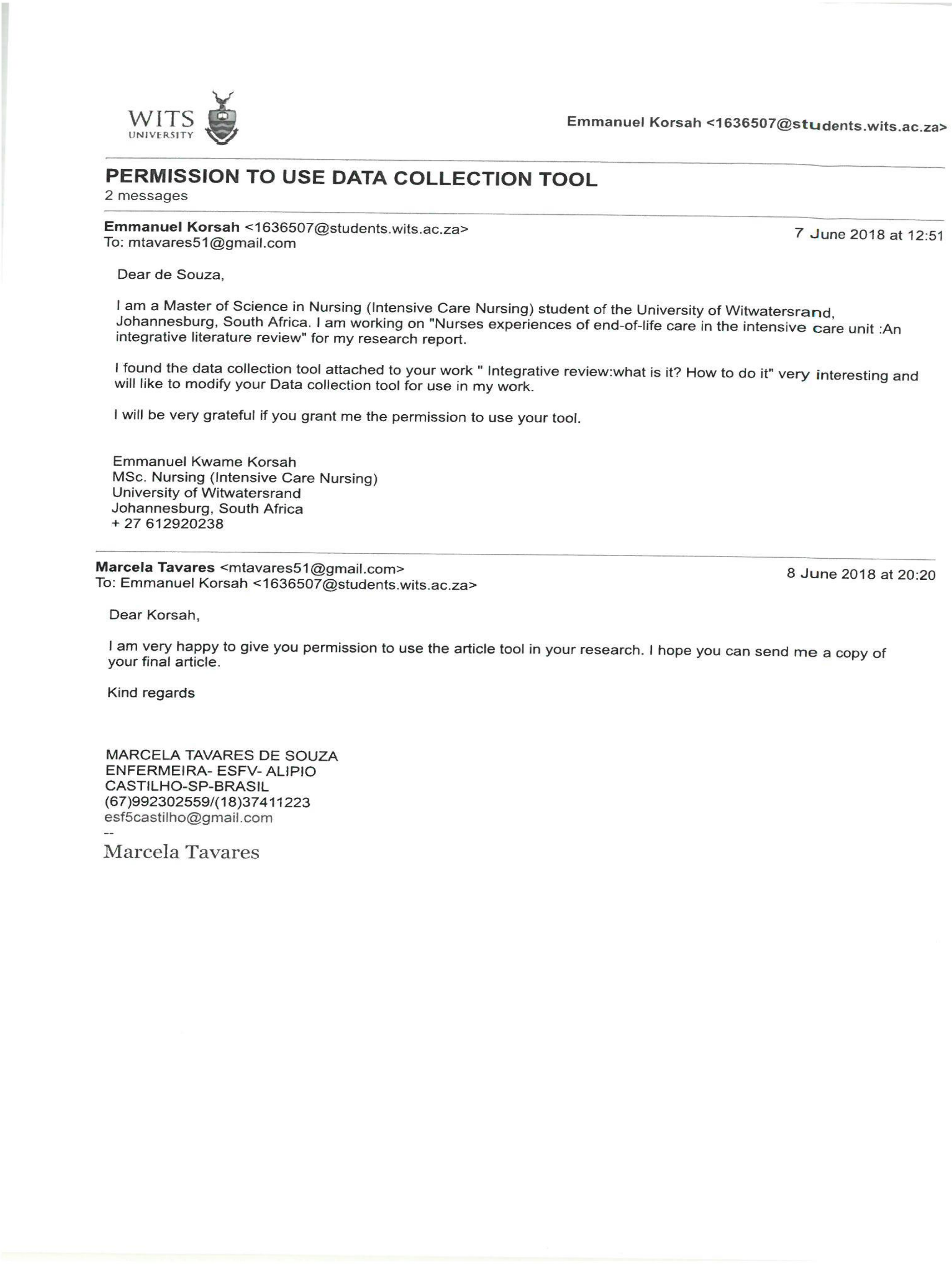
Reason: Literature review.
No human participants will be involved in the study.

Professor CB Penny
Chairperson: Human Research Ethics Committee (Medical)

Copy – HREC (Medical) Secretariat: Zanele Ndlovu and Rhulani Mkansi.

Research Office Secretariat:
Physical address: Phillip Tobias Building, 3rd Floor, Office 302, Corner York Road and Princess of Wales Terrace, Parktown, Johannesburg 2193.
Postal address: Private Bag 3, Wits 2050
Tel Nos. +27 (0)11-717-1234/2656/2700/1252
Office E-mail: HREC-Medical.ResearchOffice@wits.ac.za.
Website: http://www.wits.ac.za/research/about-our-research/ethics-and-research-integrity/

APPENDIX C: Permission to Use Data Collection Tool



WITS
UNIVERSITY

Emmanuel Korsah <1636507@students.wits.ac.za>

PERMISSION TO USE DATA COLLECTION TOOL
2 messages

Emmanuel Korsah <1636507@students.wits.ac.za>
To: mtavares51@gmail.com

7 June 2018 at 12:51

Dear de Souza,

I am a Master of Science in Nursing (Intensive Care Nursing) student of the University of Witwatersrand, Johannesburg, South Africa. I am working on "Nurses experiences of end-of-life care in the intensive care unit :An integrative literature review" for my research report.

I found the data collection tool attached to your work " Integrative review:what is it? How to do it" very interesting and will like to modify your Data collection tool for use in my work.

I will be very grateful if you grant me the permission to use your tool.

Emmanuel Kwame Korsah
MSc. Nursing (Intensive Care Nursing)
University of Witwatersrand
Johannesburg, South Africa
+ 27 612920238

Marcela Tavares <mtavares51@gmail.com>
To: Emmanuel Korsah <1636507@students.wits.ac.za>

8 June 2018 at 20:20

Dear Korsah,

I am very happy to give you permission to use the article tool in your research. I hope you can send me a copy of your final article.

Kind regards

MARCELA TAVARES DE SOUZA
ENFERMEIRA- ESFV- ALIPIO
CASTILHO-SP-BRASIL
(67)992302559/(18)37411223
esf5castilho@gmail.com
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Marcela Tavares

APPENDIX D: Critical Appraisal Tool for Qualitative Studies - Critical Appraisal Skills Programme (CASP, 2018)

	Yes	**Can’t tell**	**No**
1. Was there a clear statement of the aims of the research?	☐	☐	☐
2. Is a qualitative methodology appropriate?	☐	☐	☐
3. Was the research design appropriate to address the aims of the research?	☐	☐	☐
4. Was the recruitment strategy appropriate to the aims of the research?	☐	☐	☐
5. Was the data collected in a way that addressed the research issue?	☐	☐	☐
6. Has the relationship between the researcher and participants been adequately considered?	☐	☐	☐
7. Have ethical issues been taken into consideration?	☐	☐	☐
8. Was the data analysis sufficiently rigorous?	☐	☐	☐
9. Is there a clear statement of findings?	☐	☐	☐
10. How valuable is the research?	☐	☐	☐

Note. Reproduced from The Critical Appraisal Skills Programme for use in Critical Appraisal of Qualitative Studies, Checklist for Qualitative Research (Critical Appraisal Skills Programme (CASP, 2018)

APPENDIX E: MIXED MEDTHOD APPRAISAL TOOL (MMAT-VERSION 2011)

Types of mixed methods study components or primary studies	Methodological quality	Response			
		Yes	No	Can’t tell	comments
Screening questions (for all types)	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	Does the collected data address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	Further appraisal may be not feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analysing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers’ influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomisation (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3.Quantitative nonrandomized	3.1. Are participants (organisations) recruited in a way that minimises selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument, and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				

	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.				

Scoring metrics: For each retained study, an overall quality score may be not informative (in comparison to a descriptive summary using MMAT criteria), but might be calculated using the MMAT. Since there are only a few criteria for each domain, the score can be presented using descriptors such as *, **, ***, and ****. For qualitative and quantitative studies, this score can be the number of criteria met divided by four (scores varying from 25% (*) -one criterion met- to 100% (****) -all criteria met-). For mixed methods research studies, the premise is that the overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components. The score is 25% (*) when QUAL=1 or QUAN=1 or MM=0; it is 50% (**) when QUAL=2 or QUAN=2 or MM=1; it is 75% (***) when QUAL=3 or QUAN=3 or MM=2; and it is 100% (****) when QUAL=4 and QUAN=4 and MM=3 (QUAL being the score of the qualitative component; QUAN the score of the quantitative component; and MM the score of the mixed methods component).

APPENDIX F: Permission to Use Critical Appraisal Tool (MMAT)

Emmanuel Korsah <1636507@students.wits.ac.za> 17 September 2018 at 15:44
To: pierre.pluye@mcgill.ca

Dear Dr Pluye,
I am a Master of Science in Nursing (Intensive Care Nursing) student at the University of Witwatersrand, Johannesburg, South Africa. I am working on "Nurses experiences of end-of-life care in the Intensive Care Unit: An integrative literature review" for my research report. I would like to seek permission to use the tool to critically appraise the individual studies (mixed method and quantitative) included in the review report.
I would be very grateful if you could grant me permission to use your tool.
Thanking you in anticipation,

Emmanuel Kwame Korsah
MSc. Nursing (Intensive Care Nursing)
University of Witwatersrand
Johannesburg, South Africa
+ 27 612920238

Pierre Pluye, Dr. <pierre.pluye@mcgill.ca> 17 September 2018 at 16:47
To: Emmanuel Korsah <1636507@students.wits.ac.za>
Cc: "Quan Nha Hong, Ms" <quan.nha.hong@mail.mcgill.ca>
Hello,
Thanks for your message and interest in our work. The 2018 version the Mixed Methods Appraisal Tool (MMAT) is available at http://mixedmethodsappraisaltoolpublic.pbworks.com (public and free for use in education and research).
Please contact Ms Quan Nha Hong for more information (quan.nha.hong@mail.mcgill.ca). I cc her.
In addition, you may be interested in our toolkit for designing, conducting and reporting systematic mixed studies reviews (http://toolkit4mixedstudiesreviews.pbworks.com), and the following 2 papers on mixed studies reviews (including types of synthesis designs):
Hong, Q.N., Pluye, P., Bujold, M., Wassef, M. (2017). Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. Systematic Reviews. 6(1), 61. DOI: 10.1186/s13643-017-0454-2

Pluye P, Hong QN, & Vedel I (2016). The plurality of review methods and synthesis methods: Opening-up the definition of systematic reviews. Journal of Clinical Epidemiology. Published online; doi:10.1016/j.jclinepi.2015.08.033
Best regards,
Pierre

APPENDIX G: Postgraduate Approval of Study

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

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

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

16 May 2018
Person No: 1636507
PAG

Mr EK Korsah
Williston Court 222
17 Clarendon Pl
Parktown
2193
South Africa

Dear Mr Korsah

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Nurses experiences of end-of-life care in the intensive care unit: an integrative literature review* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX H: Language Editing and Proofing

Gill Smithies

Proofreading & Language Editing Services
59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal
Cell: 071 352 5410 Email: moramist@vodamail.co.za

Work Certificate

To	Prof. Shelley Schmollgruber
Address	Wits Dept of Nursing Education
Date	02/12/2018
Subject	NURSES' EXPERIENCES OF END-OF-LIFE CARE IN THE INTENSIVE CARE UNIT: AN INTEGRATIVE LITERATURE REVIEW
Ref	SS/GS/23

I certify that I have edited the following thesis for language, grammar and style,
Chapters 1 to 5 and Forward: Nurses' experiences of End-of-Life Care in the Intensive Care Unit: an integrative literature review, by Emmanuel K. Korsah, to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies