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STRATEGIES TO IMPROVE FAMILY MEMBERS' EXPERIENCES OF END-OF-LIFE CARE IN A HIGH CARE UNIT

by

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DECLARATION

I, Litana Sibiya, declare that this thesis, entitled, **strategies to improve family members' experiences of end-of-life care in a high care unit,** is my own work, and that all the sources used or quoted in this research study have been indicated and acknowledged by means of complete references. Furthermore, I declare that this work has not been submitted for any other degree at any other institution.

Researcher's signature

Date

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ABSTRACT

Introduction

When death of a loved one happens in a hospital setting it can be even more painful as the family is not familiar with the environment. End-of-life care to support the family in the high care unit is vital for long term grieving outcomes. However, healthcare professionals often omit the needs of family members. The experiences of families regarding end-of-life care may be used to identify strategies to improve quality of end-of-life care.

Aim

The aim of the study was to identify strategies to improve the end-of-life care experiences of family members in the high care unit.

Objectives

The objectives were to:

i)explore adult family members’ experiences of end-of-life care in the high care unit, and

ii)collaboratively identify_strategies that can be implemented by healthcare professionals

Design and methods

A qualitative descriptive research design was used to achieve the aim of the study. The study was conducted in one high care unit in a central hospital where approximately 70 patients are managed each month. Family members and/or significant other of patients managed in the high care unit were selected using a purposive sampling method. Ten family members whose loved one received end-of-life care in the high care unit were interviewed. Data was analysed using the collaborative hermeneutic data analysis method to identify__strategies to be implemented to improve the family member's experience of end-of-life care in future.

Findings

The following main themes emerged: 1) quality of care 2) compassion 3) support structure and 4) communication.

Supporting and involving families in the care of the critically ill family member may improve family satisfaction, reduce complaints and ultimately lead to good death.

Conclusion

Understanding the experiences of family members whom their loved ones had been given end-of-life care in the high care unit, expanded the healthcare professionals understanding of the current practices of end-of-life care as experienced by the family members. Collaboratively identifying strategies to improve the family member's experiences in future contributed to better the experiences of families when the strategies are implemented in practice.

Keywords: Collaborative data analysis; end-of-life care; family experiences, high care unit; healthcare professionals.

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LIST OF ABBREVIATIONS AND ACRONYMS

ABBREVIATION	MEANING
EOLC	End of Life Care
HC	High Care
HCP	Health Care Provider
HCPs	Health Care Providers
SANC	South African Nursing Council
WHO	World Health Organization

CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Patients' critical illness is a disruptive and fearful experience for their family members (Lind 2017:273). Facing the death of a critically ill patient is a painful experience for the family (Salins, Deodhar & Muckaden 2016:97; Zimmerman, Bergstraesser, Enberg, Ramelet, Marfurt-Russeberger, Von der Weid, Grandjean, Fahrni-Nater & Cignacco 2016:2). The death of a loved one in a hospital setting is even more painful as the family is not familiar with the environment. When patients are admitted in the high care unit (HCU) following a sudden illness, they or their families are not prepared for it and suddenly have to cope not only with their loved one being critically ill and possibly dying, but also with an unfamiliar environment in which their loved one is cared for. The goal in the HCU is to promote patients' survival and restore functionality. In South Africa, however, the burden of HIV/AIDS and other diseases and high level of violence greatly affect morbidity and mortality of patients managed in the HCU (Langley, Schmollgruber, Fulbrook, Albarran & Latour 2013:9). Healthcare professionals in South Africa and many countries are challenged daily with providing end-of-life care to patients and their families (Myburgh, Abillama, Chiumello, Dobb, Jacobe, Kleinpell, Koh, Martin et al 2016:126).

End-of-life (EOL) care involves the care for patients and their families from the moment the health care team have doubts about the purpose of life-sustaining treatment (Noome, Beneken genaamd Kolmer, Dijkstra, van Leeuwen & Vloet 2016:645). End-of-life care (EOLC) involves the patient, their family and the healthcare professionals working in the unit. The physician plays a vital role in withholding life-sustaining treatment whilst nurses spend a lot of time with patients and their families, which make their roles important in the EOLC decisions (Noome, Dijkstra, van Leeuwen & Vloet 2015:212). A survey in Johannesburg, South Africa found that despite direct involvement in EOLC, nurses were usually not involved in the decision-making process (Langley, et al 2013:14). The core purpose of admission to the HCU is to diagnose, monitor, prevent, and treat multiple organ failure in severely ill patients (Rocker, Puntillo, Azoulay & Nelson 2010:49). HCUs have diverse activities ranging from simple to complex such as central line insertion procedure to airway protection and initiation of life support, and technological advances have led to increased survival (Flannery, Ramjan & Peters 2016:98). In high care, nurses look after critically ill patients who are ventilated, while waiting for referral to an ICU bed in the central hospital. Critical care in South Africa is considered in a broader sense as incorporating HCU (Langley, Schmollgruber, Fulbrook et al 2013:10). Patients who require additional monitoring and evaluation are placed in the HCU.

EOLC refers to the care and support that critically ill patients and their family receive following the decision to end treatment. In a review of the nursing role during EOLC in the ICU, Noome, Beneken genaamd Kolmer et al (2016:657) found that the ICU nurses' role concerned care for the patient, family and environment and it was difficult for nurses to provide this care. Care for the family mainly consisted of advice on how to care for the patient but not care for the family members themselves. Therefore, the family did not always receive adequate care which could help in preventing problems like depression, anxiety or post-traumatic stress disorder (Noome, Beneken genaamd Kolmer et al 2016:658). Lind (2017:278) found that relatives of ICU patients felt a sense of responsibility in decision-making and a need to be consulted because they knew the patients' needs and wishes. Consequently, nurses and physicians should acknowledge and address relatives' sense of responsibility, include them in regular dialogue and help them distinguish between their and the professionals' responsibility (Lind 2017:279). Salins, Deodhar and Muckaden (2016:103) found that family members' satisfaction with ICU EOLC was positively influenced by communication; family support, including respect, compassion and courtesy; family meetings; shared decision-making and environmental factors such as flexible visiting hours and safe hospital environment. Support for the family and family involvement in decision-making also affected long-term grieving outcomes.

Family members provide first-hand information about the patients, especially when patients are unconscious, in which case they become the patients' voice. By involving family members in EOLC planning, they become part of patient care. Moreover, understanding family experiences of EOLC assists healthcare professionals to employ strategies to improve practice.

1.2 RATIONALE FOR THE STUDY

As a critical care nurse in a high care unit (HCU) in Gauteng Province, South Africa, the researcher wished to

- Understand the experiences of adult family members who had a member who had received end-of-life care (EOLC) in the unit.
- Allow family members to share their experiences during the phase of EOLC provided to their family member.
- Raise healthcare professionals' awareness of EOLC.
- Identify strategies to improve EOLC practice and family members' experience of EOLC in a high care unit.

1.3 PROBLEM STATEMENT

A research problem is "a troubling condition which can be solved by generating evidence through research" (Polit & Beck 2012:73). A problem statement "articulates the problem and describes the need for a study through the development of an argument" (Polit & Beck 2012:73). During EOLC at times the focus is on a patient, forgetting that the patient forms an integral part of the family.

EOLC is complex and family satisfaction is one of the most important ICU outcomes. Families of patients admitted to ICU value respect, compassion, empathy, communication, involvement in decision-making, and dignified EOLC (Salins, Deodhar & Muckaden 2016:101). In addition Salins, Deodhar and Muckaden (2016:101) emphasise that the family and caregiver burden in the ICU setting is high and it is important for health care providers to remember the needs of family members and provide holistic care and support to them.

EOLC is an important component of palliative care and aims to provide patient care during the last stage of life (Wai Keung Tse, Shuk Yu Hung & Mei Che Pang 2015:224). The scope of care shifts to include making dying patients as comfortable as possible by minimising invasive and life-prolonging therapies and helping patients and their families to adapt to mourning. So, health professionals not only provide treatment to relieve symptoms and pain but also respond to the psychosocial and spiritual needs of patients and families and emphasise dying with dignity (Wai Keung Tse, Shuk Yu Hung & Mei Che Pang 2015:225). Patients need nursing care and their families need comfort and support, as most of these events are sudden and family members become overwhelmed with their loved ones' situation (Noome, Beneken genaamd Kolmer, van Leeuwen et al 2016:657; Fridh 2014:310).

End-of-life decisions are difficult in critical care units for both patients and doctors (Connolly, Miskolci, Phelan & Buggy 2016:143). Understanding families' viewpoints and experiences of EOLC could help improve healthcare professionals' day-to-day care of these patients as well as their involvement of family members. Moreover, knowing families' experiences and perceptions could improve the quality of EOLC (Connolly, Miskolci, Phelan & Buggy 2016:144).

A study in Melbourne, Australia, found that positive communication, collaboration and culture were vital to achieving safe, optimal EOL care in the intensive care unit context. The participants emphasised the need for education and training, and collaborative discussions to assist patients and their families in the transition to EOL care (Brooks, Manias & Nicholson 2017:165).

1.4 AIM AND OBJECTIVES

The aim of the study was to identify strategies to improve the end-of-life care experiences of adult family members in the high care unit.

In order to achieve the aim, the objectives were to:

- Explore adult family members' experiences of end-of-life care in the high care unit.

- Collaborate with HCP to identify strategies that could be implemented by healthcare professionals to enhance family members' experiences of end-of-life care provided.

1.5 RESEARCH QUESTION

Based on the problem, the study wished to answer the following question:

What strategies can healthcare professionals identify to improve the end-of-life care based on the experiences of adult family members in the high care unit?

1.6 PARADIGM

A paradigm refers to a "basic set of beliefs that guide action" (Creswell 2014:6). A paradigm is a way of looking at natural phenomena that encompasses a set of philosophical assumptions and guides a researcher's approach to inquiry (Polit & Beck 2017:11). Polit and Beck (2017:15) add that paradigms are lenses that help to sharpen the researcher's focus on a phenomenon.

According to Botma, Greeff, Mulaudzi and Wright (2010:40), a paradigm "explains the phenomenon that the researcher intends to study; the questions to be asked; how to ask them, and the process to be followed in interpreting the answers. Research is underpinned by a paradigm or the researcher's philosophical worldview and it is important to be aware of the underlying philosophical assumptions." Assumptions are "principles that are accepted as true based on logic or reason, without proof" (Polit & Beck 2017:20).

In this study the researcher used interpretivism as a paradigm because the study took place in the participants' natural setting. Interpretivists strive to understand individuals and their interpretations of the world around them (Mustafa 2011:25). The study wished to explore family members' experiences of EOLC in a high care environment.

Interpretivism is underpinned by ontological, epistemological and methodological assumptions.

1.6.1 Ontological

Ontology is the study of being or reality. Botma, Greeff, Mulaudzi and Wright (2010:40) describe ontology as the way individuals perceive life. In addition, multiple realities exist and the content and form depend on how individuals interpret them. Ontological assumptions refer to the nature of reality and its existence. Reality is socially constructed and a product of subjective experience (Mustafa 2011:25).

Ontological assumptions are concerned with the reality that is being investigated. In this study, the researcher investigated adult family members' experiences of end-of-life care in the high care unit. The researcher considered adult family members involved in EOLC suitable sources of information on their experiences of EOLC. Sharing their experiences would give healthcare providers a deeper understanding of family needs.

1.6.2 Epistemological

Epistemology is concerned with the nature of knowledge, its possibility, scope and general basis. Epistemology refers to the way individuals understand reality from what they know and what is observed through interaction with the environment (Botma et al 2010:40). Knowledge is created and sustained by social processes (Mustafa 2011:25). In qualitative research, the interaction between researchers and participants generates knowledge and insight into the phenomenon under study (Polit & Beck 2012:13; Guba & Lincoln 1994:108). The researcher assumed that understanding adult family members' EOLC experiences would assist the development of strategies to improve practice.

1.6.3 Methodological

Methodology is a strategy or plan of action that links methods to outcomes and governs researchers' choice and use of methods and the process of the research (Creswell 2014:17; Crotty 1998:3). Methodological assumptions refer to how the researcher will gain knowledge from the participants (Polit & Beck 2017:10). The researcher selected a qualitative research design to explore the participants' experiences and portray the phenomenon under study (Polit & Beck 2012:725). The researcher assumed that the participants would truthfully share their experiences of EOLC, which would assist healthcare professionals to reflect on how to improve families' experiences of EOLC.

1.7 DELINEATION

The study focused on adult family members' experiences of EOLC in one HCU in a public hospital in an urban area in Gauteng. Only healthcare professionals working in the specific HCU of the selected hospital were invited to participate and collaborate to analyse the data and identify strategies to improve family members' EOLC experiences.

1.8 RESEARCH DESIGN

A research design is "a set of logical steps taken by the researcher to answer the research question" (Brink, van der Walt & van Rensburg 2012:92). The researcher used a qualitative and descriptive research design to explore and describe the participants' experiences of EOLC in the HCU. Qualitative research is a means of exploring and understanding people's conduct, perceptions and views of the world in which they live (Creswell 2014:246). Qualitative research investigates phenomena in an in-depth and holistic manner through the collection of rich narrative information using a flexible research design (Polit & Beck 2012:226). The purpose of descriptive research is to observe, describe, and document a situation as it naturally occurs (Polit & Beck 2012:226). The researcher considered a qualitative and descriptive research design appropriate to explore and describe the participants' experiences of EOLC.

1.9 RESEARCH METHODOLOGY

Research methodology is the plan for conducting the specific steps of a study (Burns & Grove 2014:707). Qualitative research methodology is both flexible and evolving as the researcher explores the depth, richness and complexity of the information (data) (Burns & Grove 2014:707). Research methods are the techniques or tools researchers use to collect, structure and analyse data systematically (Polit & Beck 2012:741). The research methodology includes the setting, population, sample and sampling, data collection, analysis and interpretation, and ethical considerations.

1.9.1 Setting

In research, the setting is “the site or location used to conduct a study” (Burns & Grove 2014:373). The study was conducted in one selected regional public hospital in an urban area in Gauteng. The hospital has 242 utilised beds and 222 approved beds and a total of 718 employees. Of these, 398 are health care professionals: professional nurses (193), enrolled nurses (66), enrolled assistant nurses (67) and all categories of medical doctors (72). The hospital has one six-bed HCU which also functions as an intensive care unit (ICU) due to a shortage of ICU beds. Patients admitted are critically ill and often mechanically ventilated and require specialised haemodynamic monitoring and interventions. As a result, critically ill patients and their family members often require EOLC. The unit has 90% to 100% bed occupancy, with an average of 50 to 60 patients admitted per month, of whom 3 to 4 are mechanically ventilated and 2 to 3 patients require EOLC. There is a cluster support system in place whereby the doctors working at the central hospital to which referrals are made do ward rounds in the HCU on a daily basis. These specialist doctors rotate in the HCU on a monthly basis. The number of healthcare professionals permanently employed in the unit include ICU trained registered nurses (3), ICU experienced nurses (6), enrolled nurses (5), medical doctors (2) and one senior medical officer.

1.9.2 Population

Polit and Beck (2012:273) describe a population as “the entire aggregate of cases in which a researcher is interested”. A research population refers to “an aggregation of elements from which the sample is actually selected” (Babbie 2015:199).

This study was conducted in two phases with two populations, namely adult family members of patients admitted in the HCU where EOLC was initiated and healthcare professionals working in HCU and involved in EOLC. In phase 1, the researcher collected data from the participant family members. In phase 2, the researcher and the participating healthcare professionals collaboratively analysed the data and identified strategies.

1.9.2.1 Phase 1: Participant family members

A sample refers to a subset of a population (individuals, elements or objects) or a group selected to act as representatives of the population as a whole (Polit & Beck 2012:275). The researcher used purposive sampling to select participants who were knowledgeable about the study phenomenon (Polit & Beck 2012:279). The researcher purposively selected participants who would provide rich information for the purpose of the study. Accordingly, the researcher asked adult family members whose loved ones had been admitted in HCU and died at least three months prior to the study to participate. Ten adult family members were selected.

1.9.2.2 Phase 2: Healthcare professionals

The healthcare professionals working in the HCU comprised doctors and nurses. The researcher selected ten HCPs who were off duty (two doctors and eight nurses) to collaboratively work together with the researcher in the data analysis and to identify strategies to improve family members’ EOLC experiences in the HCU.

1.9.3 Phase 1: Data collection

Data collection is a process of gathering information related to the research question in a systematic way to address a research problem (Polit & Beck 2012:725). The researcher established rapport with the participants and collected data by means of face-to-face interviews, using a semi-structured interview guide (Polit & Beck 2012:532). The researcher used field notes to capture observed nonverbal communication, posture and emotional responses (Polit & Beck 2012:548; Arbour & Wiegand 2014:213).

1.9.4 Phase 2: Data analysis

Data analysis is the systematic organisation and synthesis of research data (Polit & Beck 2012:725). The researcher transcribed the interviews verbatim, reviewed the transcriptions and extracted significant statements and feelings (Abour & Wiegand 2014:213). The researcher considered collaborative data analysis appropriate for the study as the participant HCPs were able to read through and analyse the data collected by the researcher. The data was analysed using a creative hermeneutic approach (Boomer & McCormack 2010:644). Collaborative data analysis enhanced working relations and facilitated learning amongst the participants. A facilitator experienced in Boomer and McCormack’s (2010:638) six-step hermeneutic data analysis method led the process. Chapter 3 discusses the research design and methodology in detail.

1.9.5 Trustworthiness

Trustworthiness is “the degree of confidence that qualitative researchers have in their data, using the strategies of credibility, dependability, confirmability, transferability and authenticity” (Polit & Beck 2012:745). In this study, the researcher applied the strategies of credibility, dependability, transferability, and confirmability to ensure trustworthiness (see chapter 3 for full discussion).

1.10 SIGNIFICANCE OF THE STUDY

A research study should be significant to the nursing profession and contribute to the body of knowledge (Brink et al 2012:61). Satisfaction of the family is an important factor influencing the outcomes for patients with life-limiting illness (Salins et al 2016:101). The findings of the study should assist healthcare professionals to reflect on their practices in EOLC. Understanding adult family members' experiences and challenges when the death of a loved one is inevitable should influence healthcare professionals' interaction with families as well as the implementation of strategies to improve EOLC in the HCU. The findings should assist policy development and amendment of existing policy, assist curriculum development specific to EOLC at all levels, and enhance the quality of nursing care thereby improving family and patient satisfaction with care delivered.

1.11 DEFINITIONS OF KEY TERMS

For the purposes of this study, the following terms are used as defined below:

- **Critical illness**

Critical illness refers to patients who have a life-threatening illness who are on supportive treatment and close monitoring to prevent life-threatening complications (De Beer & Brysiewicz 2016:22). In this study, critical illness referred to different medical conditions which result in patients' rapid deterioration in condition, leading them to require EOLC in the HCU.

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

End-of-life care refers to the care and supportive services that seriously ill patients and their families receive following the decision to end treatment (Noome, Beneken genaamd Kolmer, van Leeuwen et al 2016:657). Razmaria (2016:115) refers to EOLC as the care that healthcare professionals deliver to patients and their families at the end of the patient's life when death is imminent and normal life-saving treatment is futile. In this study, EOLC referred to the care healthcare professionals delivered in the selected HCU to patients and their families at the end of a patient’s life when death was imminent and normal life-saving treatment was futile.

- **Family member**

A family member refers to a person who has a close, meaningful relationship with the patient with end-of-life needs, who is not necessarily blood related (De Beer & Brysiewicz 2017:22). In this study, family members included spouses, parents or children 18 years or older, not necessarily blood related and who play a significant role in the patient’s life.

- **High care unit**

A high care unit or high dependency unit is a unit between the ICU and general ward that provides care and has been developed in a hospital to improve patient care, facilitate high-risk surgery and reduce workload in the ICU (Gould, Ho & Dobb 2010:855). In this study, the high care unit referred to the unit caring for patients who were too ill to be in the ward and too stable to be in ICU.

- **Healthcare professional**

Healthcare professionals refer to individuals who are responsible for providing care for patients (Sabyani, Wiechula, Magarey & Donnelly 2016:103). In this study, healthcare professionals referred to all the medical doctors registered with the Health Professionals Council of South Africa and registered nurses registered with the South African Nursing Council who worked in the selected HCU in Gauteng, South Africa.

- **Strategy**

The *Oxford Advanced Learner’s Dictionary* (2010:1475) defines *strategy* as “a plan that is intended to achieve a particular purpose; a plan for doing something”. In this study, strategies referred to the steps, plans and methods identified by the participant healthcare professionals to improve the EOLC experiences of adult family members in the HCU.

1.12 ETHICAL CONSIDERATIONS

When humans are used as study participants care must be taken in ensuring that their rights are protected (Polit & Beck 2012:748). Babbie (2015:62) points out that the researcher must adhere to set rules or standards of ethical conduct, in order to safeguard the safety of research participants. Accordingly, the researcher obtained permission to conduct the study, obtained informed consent from the participants, and observed the ethical principles of beneficence, respect for human dignity, and justice (Polit & Beck 2012:748). The *Belmont Report, 1979* states there are three broad principles of ethical conduct in research, namely respect for persons or human dignity, beneficence, and justice (Polit & Beck 2017:210). Prior to the commencement of the study the researcher signed the *Declaration of Helsinki* (see Annexure B). Accordingly, the researcher obtained permission to conduct the study, obtained informed consent from the participants, and observed the ethical principles of beneficence, respect for human dignity, and justice (Polit & Beck 2017:210).

- **Permission**
  The researcher obtained written permission to conduct the study from the Research Ethics Committee of the University of Pretoria (see Annexure D). Permission and approval were also obtained from the Gauteng National Department of Health through the hospital CEO of the selected hospital (see Annexure D).

- **Informed consent**
  The researcher informed the participants of the purpose and significance of the study, that participation was voluntary and that they were free to withdraw from the study at any time should they so wish. To ensure that the participants were fully informed and prevent any deception, the participant information leaflet outlined the ethical aspects of the study and what was expected of them (Allen 2017:359). The participants were allowed to ask any questions they might have regarding the study and participation. The participants then signed informed consent (see Annexure B1) for family member who participated in phase 1 of the

study and the healthcare providers (see Annexure C2) who participated in Phase 2.

- **Beneficence**

  The principle of beneficence states that one should do good and, above all, do no harm (Burns & Grove 2014:165). Accordingly, the researcher ensured that the participants were not exposed to any physical, emotional, social or other harm. The researcher was aware that the study could perhaps trigger emotional discomfort when participants discussed their experiences, however, and ensured that a psychologist was on standby should the discussion trigger their emotions.

- **Justice**

  The principle of justice refers to the right to respect privacy and the right to fair treatment (Polit & Beck 2017:174). The participants had the right to fair selection and treatment. The researcher assured the participants of privacy, confidentiality and anonymity, and treated all the participants with respect and fairly (Burns & Grove 2014:186). The researcher informed the participants that no names would be given in the research report and their information would be treated with the utmost confidentiality. In addition, all the collected data would be kept safely in a password protected file. Prior to data analysis the participant HCPs signed a confidentiality agreement (see Annexure C 2).

- **Respect for human dignity**

  The principle of respect for human dignity includes the right to self-determination and the right to full disclosure. The researcher informed the participants that they had the right to decide whether to volunteer to participate, and the right to disclosure. In addition, they had the right to ask questions, to refuse to give information or to withdraw from the study (Polit & Beck 2017:154). The researcher explained the nature and purpose of the study and what would be required from them (Polit & Beck 2017:154).

1.13 DISSEMINATION OF RESULTS

The researcher will share the results with colleagues and healthcare professionals in the HCU, as well as the hospital management through a power point presentation. The results will be shared at the biannual Gauteng leadership seminar and an article published in an accredited journal. An abstract will be submitted and the findings presented at the annual South African Critical Care Congress.

1.14 LAYOUT OF THE CHAPTERS

The study consists of five chapters. Table 1.1 lists and describes the chapters.

Table 1.1 Layout of the chapters

CHAPTER	TITLE	DESCRIPTION
1	Orientation to the study	Outlines the problem, purpose, research design and methodology of the study, and defines key terms and ethical considerations.
2	Literature review	Discusses the literature review conducted for the study on EOLC.
3	Research design and methodology	Describes the research design and methodology, including trustworthiness.
4	Data analysis and strategies	Discusses the data analysis and strategies developed with reference to the literature review.
5	Findings and recommendations	Briefly summarises the findings, strategies and limitations of the study, makes recommendations for practice and further research, and presents the researcher's reflection on the study.

1.15 CONCLUSION

This chapter outlined the problem, purpose, research design and methodology of the study and defined key terms. Chapter 2 discusses the literature review conducted for the study.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 outlined the research problem, purpose, research design and methodology of the study. This chapter discusses the literature review conducted for the study on EOLC. As the HCU in which the study was conducted functioned as an intensive care unit (ICU), the literature review focused on EOLC in the critical care setting.

Burns and Grove (2014:67) describe a literature review as “a written, well-organised presentation of what has been published on a topic. A literature review lays the foundation for the research as it gives a representation of what is known and not known about the research problem.”

2.2 RATIONALE FOR A LITERATURE REVIEW

The purpose of a literature review is to convey what is currently known regarding the topic of interest and to assist researchers to comprehend and extend their knowledge of the phenomenon under study (Polit & Beck 2017:99; Hart 2018:3; Xiao & Watson 2017:93). **.**A literature review assists researchers to select research methods to answer research questions (Al Mutair, Al Shaer, Al Ghamdi & Al Ghamdi 2018:376).

2.3 SEARCH STRATEGY

The researcher used the SAGE (including MEDLINE), CINAHL and EBCOHOST and Google Scholar databases between August and November 2018 to search for ‘intensive care units’, ‘critical care unit’, ‘end-of-life’, ‘end-of-life care’, ‘family experiences’ and related terms, and scrutinised reference lists in articles relevant to the study. The researcher consulted studies about the development and related research on end-of-life care in the ICU published between 2016 and 2019.

2.4 DEMYSTIFYING END-OF-LIFE CARE

End-of-life care (EOLC) and palliative care are interlinked and are often used interchangeably (Hartog & Reinhart 2018:195). Furthermore Round (2016:4) describes end-of-life care as care that “helps all those with advanced, progressive, incurable illness to live as well as possible until they die”. End-of-life care refers to the care of patients with progressive, incurable conditions and considered to be in the last moments of life (Lewis 2018:41). In the critical care environment, EOLC is commonly understood as the care of patients who are dying or who will do so after a decision has been made to withhold or withdraw life-sustaining therapy (Hartog & Reinhart 2018:196).

There is no consensus on a single definition of ‘end-of-life care’. According to the National Institutes of Health (NIH), evidence supports the definition of end-of-life (EOL) as the presence of chronic diseases or symptoms or functional impairments that persist but may also fluctuate, and the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death (Hartog & Reinhart 2018:196). The National Council for Palliative Care (Lewis 2018:41) defines end-of-life care as “the provision of supportive and palliative care in response to the assessed needs of the patient and family during the last phase of life”. The process of dying in a critical care environment is complex due to the advanced technology used. The family plays a very important role in EOLC, because in a critical environment setting most patients are unconscious and thus not able to make decisions for themselves (O’Neill, Yaqoob & Faraj 2016:951). EOLC can be difficult if HCPs’ values differ from the family’s values (O’Neill et al 2017:951).

End-of-life care is medicine practised in order to “diminish the suffering and improve the quality of the remaining life of terminally ill patients” (Parker, Smith, Corzine, Mitchell et al 2012:440). End-of-life care refers to the care of patients with progressive, incurable conditions and considered to be in the last moments of life (Lewis 2018:41). The World Health Organization (2018) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. Norlander (2014:2) points out that the term ‘palliative care’ is often used when discussing end of life.

Lim (2016:457) refers to the UK National Council for Palliative Care’s working definition as care that helps all those with advanced, progressive illness to live as well as possible till they die and ensures supportive care for both patient and family. Palliative care aims to prevent and relieve suffering through “early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Sagha Zadeh, Eshelman, Setla & Sadatsafavi 2018:411). When providing palliative care, healthcare professionals aim to allow the patients and those close to them to maintain the best possible quality of life up until the point of death (Round 2016:4). Palliation is when the cure of their condition is no longer likely and death is inevitable. End-of-life care is medicine practised in order to “diminish the suffering and improve the quality of the remaining life of terminally ill patients” (Smith 2012:26). Kassim and Alias (2016:122) state that in healthcare, EOLC involves both palliative care and hospice care, aiming to provide a comfortable environment and improve patients’ quality of life until death occurs.

Palliative care and EOLC have common objectives and are interdependent (Lewis 2018:41). Palliative care and EOLC both involve the mobilisation of an interdisciplinary team of professionals comprising doctors, nurses, social workers and psychologists (Kassim & Alias 2016:123). According to Norlander (2013:3), hospice care is seen as a theme of palliative care focused on those patients who are no longer seeking active, curative treatment and have a life expectancy of less than six months. Hospice affirms the concept of palliative care as an intensive programme that enhances comfort and promotes individuals’ quality of life (Norlander 2013:3).

EOLC consists of both palliative care and hospice care and both share the same objectives (Kassim & Alias 2016:122). The difference between palliative care and hospice care is that palliative care focuses on reducing the severity of disease and can be rendered any time during the course of patients' illness (Kassim & Alias 2016:122). Palliative care is not restricted to EOLC, and is often seen as an element of end-of-life care within the critical care setting, which includes HCU (Pignatiello, Hickman & Hetland 2018:87). Hospice focuses on terminally ill patients who no longer seek curative medical treatment, generally rendered to patients whose life expectancy is less than 6 months. However, both involve the multidisciplinary team (Kassim & Alias 2016:122).

2.5 TIME FRAME OF EOLC

There is no agreement on a time frame for the 'end of life'. Generally, end of life is regarded as the last few days to 1 to 2 weeks of life (Lim 2016:456). In the United Kingdom, people are considered to be approaching the 'end of life' when they are likely to die within the next 12 months (Round 2016:5). EOLC includes people whose death is imminent (expected within a few hours or days) and those with advanced, progressive, incurable conditions at risk of dying from a sudden acute crisis in their condition (Round 2016:5). For some people, the start of end-of-life care might be at the time of diagnosis of a condition that usually carries a poor prognosis, such as a patient presenting with a motor neurone disease or advanced liver disease (Round 2016:5).

Some definitions of a time frame are based on a patient's survival duration, but survival can never be predicted (Round 2016:5). In practice, many patients receive EOLC when inactive curative treatment is ceased and standard therapies have failed (Round 2016:5). The definition of EOLC should therefore be based on the patient's needs rather than a time (Lim 2016:456).

2.6 PATIENT NEEDS

Patients receiving EOLC may have physical, psychosocial and spiritual needs, which are not always met (Lim 2016:456). It is important that HCPs should ensure that these needs are met, which could result in family satisfaction.

A dignified death includes meeting the physical, psychosocial and spiritual needs of the patient (Sagha Zadeh et al 2018:411). Physical comfort of patients in EOLC is paramount during their stay in critical care (Clark 2017:2). Patients' physical, psychosocial and spiritual needs are discussed next.

2.6.1 Physical

Nutrition is one of the physical needs which is an important component of life and not treatment (Choudry, Latif & Warburton 2018:27). The insertion of a feeding tube is considered essential in providing nutrition to the dying patient (Choudry et al 2018:27). Round (2016:9) states that people who are approaching death and their families often have complex clinical and social care needs. Norlander (2014:456) sighted pain and symptom management promotes physical comfort during EOLC.

2.6.2 Psychosocial

Psychosocial care is an important component during end of life, and its goals are to improve psychological and emotional well-being (Fan, Lin, Hsieh & Chang 2017:217).

2.6.3 Spiritual

Spirituality is an important part of quality of life and culture care (Rego & Nunes 2019:279). Spirituality is a dynamic, evolving process that impacts and is impacted by an individual's life experience and helps to give meaning or purpose to life (Richardson 2014:152).

During EOLC, relatives and patients commonly experience spiritual distress, which is a disruption of their beliefs and value system (Richardson 2014:156).

Norlander (2014:456) lists the following patient needs during EOLC:

- Family involvement: Patients want their families involved in decision making and in care.
- Completion: Patients want the opportunity to say good-bye and leave a legacy.

2.7 STAKEHOLDERS

EOLC decisions are a collaborated process which involves healthcare professionals, the patient and the patient’s family (Hidayat, Kongsuwa & Nilmanat 2017:2).Family members often discuss their ideas of and moral feelings about the decision regarding end-of-life care with nurses, therefore nurses play an important role during EOLC critical care. ICU clinicians comprising the team are expected to provide person-centred end-of-life care for the patient and their family (Coombs, Parker, Ranse, Endacott & Bloomer 2017:39).

EOLC physicians and critical care nurses play an instrumental role in ensuring quality of EOLC to both patients and family (Hartog, Schwarzkopf, Riedemann, Pfeifer, Guenther et al 2015:337). Physicians’ role cannot be overemphasised in the care of dying patients as they have expertise in disease pathology (Norlander 2014:7). Cooperation between ICU nurses and physicians are the basis for providing high quality EOL care to patients and their family members.

EOLC is embedded in the role of ICU nursing. In caring for patients at the end of life in the critical care setting the nurse fulfils the role of educator as she educates patients and their families, advocate, collaborator, care provider and supporter (Zadeh et al 2018:411). Physicians routinely make decisions on withholding or withdrawing critical care therapy (Zante & Schefold 2017:2). Additional role players include pharmacists. Pharmacists offer pharmacological management of the pain and symptom control for patients and advise on drug interaction, delivery mode and action of the drugs ordered, to ensure efficient use during EOLC (Norlander 2014:8).

Spiritual care also forms an aspect of EOLC whereby treatment decisions may be based on patients' and families' religious belief system, making a chaplain an integral part (Norlander 2014:8). Gordon (2015:113) refers to the importance of incorporating spiritual assessment of the patient and family as unmet spiritual needs may result in dissatisfaction with care.

Dieticians play an important role in ensuring nutritional support and advice to the family members (Norlander 2014:8). Continuous care to the dying patient is also offered in the form of nutritional support to the patient. Family members may struggle with nutritional issues given the fact that their family member is in the EOLC phase.

2.8 IMPORTANCE OF EOLC

The importance of EOLC is discussed in terms of family members and healthcare professionals.

2.8.1 Family members

The family plays a critical role in shaping the understanding and acceptance of death (Broom, Kirby, Kenny, MacArtney & Good 2016:1000). Family members are persons who have a close, meaningful relationship with the patient with end-of-life needs, and may not necessarily be blood related (de Beer & Brysiewicz 2017:22). Critical illness can bring a great deal of suffering for the patient as well as those who love and care about the person (Lim 2016:457). The character of end-of-life care is often rooted in family expectations and cultural ideas about dying (Broom et al 2016:999).Being the next of kin to someone approaching death is a complex and vulnerable situation. The death of patient is a source of distress leading to family bereavement with some members finding it difficult to cope with the loss, leaving the family emotionally scarred (Costello 2004:8).

Families are in a sense dysrhythmic and may display unpredictable thinking following the admission of a loved one to a critical care environment (de Beer & Brysiewicz 2016:21). Care planning should be defined in the context of the goals and what is realistically possible and likely for that patient (Dy 2016:794). Being a family member to someone whose death is eminent can be a difficult and vulnerable situation to them (Ramvi & Euland 2017:201). Family inform care decisions during end-of-life care process and it is important that the family be told the reality regarding prognosis (Coombs 2015:24; Hartog & Reinhart 2018:197). The involvement of family members is important as they act as the legal representative of a patient who is unconscious or sedated and want to be more involved in the final care (Noome, Beneken genaamd Kolmer, van Leeuwen et al (2016:646).

Noome, Dijkstra, van Leeuwen and Vloet (2015:215) found that families appreciated following the dying process until their loved one takes the last breath. Care planning for patients with serious illness and at the end of life may be better described as communication about serious illness care goals a process that ideally occurs over time from the start of a serious illness, occurs through structured formats once patients are ill, such as in the intensive care unit, and includes families as well as patients. Important elements include communication about the illness and prognosis, as accurate perceptions are key to patient and family goals for the end of life, such as being at home with family rather than receiving aggressive treatment of no benefit, and discussion of values and meaning. Broom (2016:77) point out that families and carers bear a heavy load and in turn learn a lot about how to care for the dying.

2.8.2 Healthcare professionals (HCPs)

HCPs working in end-of-life care should meet the needs and wishes of patients and their next of kin at this vulnerable time (Ramvi & Ueland. 2017:201). Conflicts with next of kin are emotionally demanding for care professionals and a source of moral distress (Ramvi & Ueland. 2017:202). Several HCPs play a role in the transition to end-of-life care and in the dying process, a large proportion of care is delivered by nurses (Broom et al 2016:91). Nurses play a major role in everything from acceptance of dying to people's experiences of the last few hours of their lives (Broom et al 2016:91).

2.9 ENABLERS TO IMPLEMENT EOLC

Collaboration between multi-disciplinary members and the family members is important during EOLC so all have similar goals for the patient. HCPs should be open minded and adaptive to changing needs to ensure a patient's spiritual needs are accommodated during the provision of end-of-life care (Al Mutair et al 2018:2).

Family members need information to be provided in a consistent manner and at a level that they can understand to assist them to make sense of the end-of-life experience. Effective communication with both patient and family regarding the reality and disease progression is important as it allows the family to face reality (Lewis 2018:41). The way EOLC information is communicated in terms of truthfulness and timing could enhance the family members' understanding (Bateman, Tofil, White, Dure, Clair & Needham 2016:935). Respecting families' knowledge, opinions, culture and beliefs regarding their loved ones enables good EOLC (De Beer & Brysiewicz 2017:26). Family members involvement is an important aspect of an African community in EOLC decisions is associated with high satisfaction, which also enables good EOLC (De Beer & Brysiewicz 2017:25).

Open communication between HCPs and family members allow them to support the patient in the best way possible (De Beer & Brysiewicz 2016:44). Fixed Furthermore, family members' familiar and caring presence during EOLC often significantly promotes critically ill patients' psychological wellbeing (De Beer & Brysiewicz 2016:47). Family members also need psychological support because they frequently experience high levels of stress. Integrating family members in the critical care environment enhances holistic care to patients and contributes to decreasing patients' and family members' stress (Sukraandini, Kongsuwan & Nilmanat 2017:57). Collaboration amongst HCPs and family members in decision making regarding EOLC promotes similar goals for the patient (Brooks, Manias & Nicholson 2017:164).

2.10 BARRIERS TO IMPLEMENTING EOLC

Differences in culture and/or religion between patients and HCPs may be a barrier to providing quality EOLC in the critical care setting. During EOLC, HCPs should set aside their cultural and spiritual beliefs and respect patients' or family members' culture and spirituality. Aspects of cultural diversity that could influence illness and death should be viewed and recognised (Al Mutair,Al Shaer, Al Ghamdi & Al Ghamdi 2018:2). It is important to recognise when the patient is entering the end-of-life phase by looking at the clinical picture and disease progression (Lim 2016:457). The earlier the HCP recognises the beginning of EOL could allow the family to prepare for death and dying and prepare to take leave of their loved one (Lim 2016:458).

The critical care environment is very busy and a barrier to providing optimum EOLC due to lack of privacy because it is not designed for family-oriented care (Sukraandini et al 2017:58; De Beer & Brysiewicz 2016:45; Brooks, Manias & Nicholson 2017:163). The setting may prevent families from showing emotion (Naome, et al 2015:62). Lack of information or inconsistent information could deny family members an opportunity to support the patient in the best possible way (De Beer & Brysiewicz 2016:48). Hospital policy, such as restrictive visiting hours, could hinder adequate EOLC (Sukraandini, Kongsuwan & Nilmanat 2017:58; Basal & Younis 2017:294). Treatment and management conflicts amongst HCP present unrealistic expectations of prognosis and delay EOLC implementation (Brooks et al 2017:163).

2.11 KNOWLEDGE GAPS IDENTIFIED

Nurses lack adequate education and training in end-of-life care to address the complexity of care required by dying patients (Norlander 2014:2). Dealing with EOLC needs specialised training and skills to render comprehensive EOLC (Norlander 2014:2; Hartog & Reinhart 2018:197). Families look to HCPs to guide them through these difficult times, and formal education and training on EOLC would equip HCPs to do so. A study in Italy found that nurses were not adequately trained in caring for the dying and there were few modules on end-of-life care (Garrino, Contratto, Massariello & Dimonte 2017:127). Structured education and training programmes are essential to equip HCPs with appropriate knowledge and skills to provide optimal EOLC in the critical care environment (Brooks et al 2017:165).

2.12 ETHICS IN END-OF-LIFE CARE

Medical ethics deals with moral principles linked to biomedical science in clinical areas (Kassim and Alias 2016:120). Ethical principles and moral obligations are a cornerstone of medical practice, including EOLC (Stensland & Sanders 2016:260). EOLC decisions are not limited to clinical assessments of what would be in the patient's best interests from a purely medical perspective (Kassim & Alias 2016:120). In the critical care environment which includes ICU, HCU and emergency departments, ethical challenges relating to EOLC decisions are complicated by patients who are unconscious and therefore unable to make their own decisions regarding EOLC (Kassim & Alias 2016:123).

Ethical principles are essential in guiding medical judgements. Autonomy, pain management, withholding and withdrawal of life-sustaining treatment, advance directives, living will and durable power of attorney are discussed next.

- ✓ **Autonomy** refers to self-governing (Burkhardt & Nathaniel 2013:41). Autonomy is the ability to obtain information and use it to make one's own decisions including medical decisions. An adult with the capacity to understand his/her medical problem can refuse any treatment or test regardless if it is simple, safe or risk free (Gendeh, Bhar, Gendeh, Yaakup, Gendeh, Kosai & Ramzisham 2019:260). A competent person who is mentally sound can make their own decisions reflecting their own values and preferences (Landman 2012:28). These decisions include end-of-life care, and patients have a right to refuse life-sustaining treatment and choosing that such treatment not to be provided to them (Landman 2012:28). Thus, one may autonomously judge a life consumed by suffering and stripped of dignity not worth living, and that judgment deserves respect. During the acute phase of care this principle is often omitted as the focus is on resuscitation. In a critical care environment, the autonomy principle more often than not is not practised. Personal autonomy comes in degrees and ethics requires that it be respected in whatever degree it comes (Landman 2012:28).

- ✓ **Pain management**: Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage (Rocker**,** Puntillo Azoulay & Nelson 2010:3). Pain is subjective and assessing pain in a patient who is unable to talk or cognitively impaired in a critical care environment can pose a challenge (Rocker et al 2010:60). There are several techniques a clinician can use to assess pain (Rocker et al 2010:60). Managing pain during the dying phase is an important aspect of care and the generous use of pain medication when carefully titrated to control pain in the dying patient is ethically justifiable, as long as the motive is to alleviate suffering (Rocker et al 2010:60; Gendeh et al 2016:262).The double effect doctrine, which outlines the important difference between aggressive pain management and active hastening of death should be taken in to account when managing pain (Rocker et al 2010:60; Landman 2012:29). HCPs should use their assessment skills using the pain assessment tool and titrate the pain medication with an objective to relieve pain or distress (Landman 2012:29; Kassim & Alias 2016:125). The use of injectable opioids to manage pain is recommended as the onset of action is faster (Gendeh et al 2016:261).

✓ **Withholding and withdrawal of potential life-sustaining treatment**

Withdrawing potentially life-sustaining treatment means refraining from commencing treatment that has the potential to lengthen or sustain a person's life (Landman 2012:40). Life-sustaining treatments include mechanical ventilation, inotropic support, transfusion of blood and blood products and cardio-pulmonary resuscitation (Gendeh et al 2016:261). The term "withdrawing/withholding potentially life-sustaining treatment" is used rather than the term "passive euthanasia'' (Landman 2012:43). The aim of withholding or withdrawing life-sustaining treatment is to eliminate treatments that no longer benefit the care but prolong the dying process. Decisions to limit life-sustaining treatment are influenced by many factors, including the severity and reversibility of the acute illness, the presence and severity of comorbidities, age, societal values, religious and other factors (Lobo, De Simoni, Jakob, Estella, Vadi et al 2017:327).

✓ **Advance directives**

During sickness it can be difficult to make decisions about medical care. Landman (2016:63) defines an advance directive as an arrangement made by a competent person regarding their healthcare treatment in an event where they are unable to make their own healthcare-related decisions. People use advance directives to make other people aware about their decisions about their medical treatment. Due to technological and scientific advances in health care people can choose to have an advance directive drawn because EOLC has ethical issues (Peicius, Blazeviciene & Kaminskas 2017:1).

Moreover, advance directives are a potential solution to protect a patient's rights, autonomy and dignity at the end of life (Peicius, Blazeviciene & Kaminskas 2017:1). Advance directives are designed to enable capable persons to express their preferences and give orders about such possible future situations (Landman 2016:17). An advance directive lifts this burden from the family who sometimes have to make medical decisions for a family member who is unable to make own decision. Advance directives have two components, namely a living will and a durable power of attorney for healthcare. These directives are taken as tools which legally direct treatment decision making, and work only when the patient has lost the capacity to make own decision and used to make personal will (Peicius, Blazevicience & Reminskas 2017:4).

- ✓ **Living will**

  A 'living will' is defined as a written instruction from a competent person instructing others to withhold or withdraw potentially life-sustaining treatment should they become incompetent to refuse such treatment themselves (Landman 2016:63). Dying is part of life and avoiding talking about death will not take death away (Landman 2016:65). A living will can guide the treating doctor and family members about patients' wishes regarding life-sustaining therapies when they are no longer capable of making decisions. In South Africa, advance directives are recognised by the Health Professional Council of South Africa.

- ✓ **Durable power of attorney**

  A 'durable power of attorney for healthcare' is a substitute directive where a competent person mandates a specific person as their proxy/surrogate (Landman 2016:64). A proxy/surrogate is the person selected to serve as an agent for the patient under a durable power of attorney for health care. The power of attorney involves decision making powers on behalf of a person. The decisions can involve all healthcare decisions on behalf of the patient. A durable power of attorney for health care is different from other durable powers of attorney in that it specifically addresses *only* health care issues.

  The power of attorney is called durable when it includes one of the following: 'This power of attorney shall not be affected by my incapacity' or 'This power of attorney will take effect upon my incapacity'. Landman (2016:64) states that the power of attorney is termed durable because once the patient becomes incompetent it remains in effect. Surrogates make end-of-life decisions on behalf of incompetent patients. Surrogate decision-makers also make healthcare decisions based on the patient's instructions, and in the absence of such instructions, make a substituted judgment on the basis of the patient's values (Wright 2017:1072). The family members/relatives act as surrogate decision-makers and informants about the patient's will because many critically ill patients lack the capacity for decision-making (Garrino et al 2018:197).

Any advance directive people sign when competent will remain in effect unless and until they revoke it. Only the authors thereof can revoke it. They can revoke it by completely destroying their current advance directive and, optimally, all existing copies. Advance directives are intended to help patients exercise their right to decide autonomously which medical therapies they want. Should patients have a signed living will or durable power of attorney, a copy should be kept in the patients' medical records at the hospital. Advance directives ensure that the principle of autonomy is upheld. A high occurrence of cognitive impairment and grim outcomes that preclude the critically ill patients from participating in their own healthcare decisions mean that the onus of healthcare decision making often falls on the patients' families or close friends (Pignatiello, Hickman & Hetland 2018:85).

2.13 CONCLUSION

This chapter discussed the literature review conducted for the study. Chapter 3 describes the research design and methodology of the study.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

Chapter 2 discussed the literature review conducted for the study. This chapter describes the research design and methodology of the study.

3.2 AIM OF THE STUDY

The aim of the study was to identify strategies to improve the end-of-life care experiences of adult family members in the high care unit. In order to achieve the aim, the objectives were to

- Explore adult family members' experiences of end-of-life care in the high care unit.
- Collaboratively identify strategies that could be implemented by healthcare professionals to enhance family members' experiences of end-of-life care provided.

Accordingly, the study wished to answer the following question:

- What strategies can healthcare professionals identify to improve the end-of-life care based on the experiences of adult family members in the high care unit?

3.3 RESEARCH DESIGN

A research design is "a set of logical steps taken by the researcher to answer the research question" (Brink, van der Walt & van Rensburg 2012:92). A research design is an overall plan of action for addressing a research question and helps researchers minimize bias and guide the process of answering the research questions (Polit &

Beck 2017:56). A research design is a blueprint for conducting a study (Burns, Gray & Grove 2014:201). Researchers may select a qualitative, quantitative or mixed methods research design (Creswell & Creswell 2017:53).

In this study, the researcher selected a qualitative and descriptive research design to explore and describe the participants' experiences of EOLC in the HCU.

3.3.1 Qualitative

Qualitative research is a means of exploring and understanding people's conduct, perceptions and views of the world in which they live (Creswell 2014:246). Researchers thus try to establish the meaning of a phenomenon from the participants' perceptions of social or human problems and experiences (Creswell & Creswell 2017:48; Tracy 2019:3; Florczak 2017:296). Polit and Beck (2017:741) describe qualitative research as "the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design".

The researcher considered a qualitative approach appropriate to understand the participants' experiences of EOLC, by means observing, questioning and listening in order obtain to rich data (Tracy 2019:4; Holloway & Wheeler 2016:6). Furthermore, a qualitative research design allowed the researcher to collaborate with the participant HCPs to propose strategies to enhance EOLC (Polit & Beck 2017:463).

3.3.2 Descriptive

The purpose of descriptive research is to observe, describe, and document a situation as it naturally occurs (Polit & Beck 2012:226). Descriptive research has the accurate portrayal of persons, groups, or real-life situations, and the frequency with which certain phenomena occur as its main objective (Polit & Beck 2017:726). In this study, the researcher used a descriptive design to describe the participants' lived experiences. Descriptive studies are designed to gain more information about concepts, variables, or elements in a field of study and to provide a picture of a situation as it naturally occurs (Grove &Gray 2018:258).

The descriptive research design allowed the participants to describe their experiences of EOLC in the HCU. Taylor, Bogdan and DeVault (2015:8) add that qualitative researchers empathize and identify with the people they study to understand how those people see things.

3.4 RESEARCH METHODOLOGY

Research methodology is the plan for conducting the specific steps of a study (Burns & Grove 2014:707). Qualitative research methodology is both flexible and evolving as the researcher explores the depth, richness and complexity of the information (data) (Burns & Grove 2014:707). Research methods are “the techniques researchers use to structure a study and to gather and analyse information relevant to the research question” (Polit & Beck 2017:743). The methodology includes the population, sampling and sample, data collection and data-collection techniques and data analysis.

3.4.1 Population

A population is the whole group that the researcher is interested in studying and meets the criteria (Polit & Beck 2017:249). In qualitative studies, a population is not chosen for generalisability, but consists of participants who have experienced the phenomenon of interest and are able to share information-rich accounts of their experiences (Gray, Grove & Sutherland 2016:407).

Polit and Beck (2017:249) distinguish between the target population and the accessible population. The target population is the aggregate of cases about which the researcher would like to generalise, and the accessible population is the aggregate of cases that meet the inclusion criteria and are accessible as participants for a study. In this study, the target population in phase 1 consisted of adult family members of patients admitted in the HCU where EOLC was initiated, and in phase 2, of healthcare professionals working in the HCU and involved in the EOLC of patients.

3.4.2 Sampling and sample

A sample refers to a subset of a population (individuals, elements or objects) or a group selected to act as representatives of the population (Polit & Beck 2017:250).

Sampling is the process of selecting cases to represent an entire population (Polit & Beck 2017:250). Purposive sampling refers to selecting subjects typical of the population in question or particularly knowledgeable about the issues under study' (Brink et al 2012:141). The researcher used purposive or non-probability sampling, to select participants who were knowledgeable about the study phenomenon (EoL) and would provide rich information for the purpose of the study (Polit & Beck 2017:741). In qualitative research the purpose is not generalisation and samples tend to be small (Ingham-Broomfield 2015:37). To be included in the study, participants (family members) had to be English speaking; be 18 years or older; have had a loved one who was admitted for more than 48 hours to the HCU, and had died in the HCU three months before data collection. The researcher selected 12 family members as a sample, but 2 declined to participate. A total of 10 adult family members were interviewed and data saturation was achieved. The interviews took place in the debriefing/counselling room. The interviews took place at the hospitals' debriefing room away from the high care unit, privacy was maintained by closing the door and putting do not disturb sign on the door.

The researcher contacted the adult family members who lost their loved ones in the HCU telephonically, expressed her condolences, briefly explained the aim and significance of the study and indicated that the interview would take approximately 45 minutes as suggested by (Noome, et al 2016:658**;** Tse et al 2015:225). When the family member showed an interest and volunteered to participate, the researcher arranged a place and time for the interview.

3.4.3 Gaining access to the research site

Gaining entry involved establishing relationships with the hospital executive committee (Polit & Beck 2017:168). The researcher arranged a meeting with the HCU head of department and requested permission to conduct the study. The head of the department then contacted the Chief Executive Officer, Clinical Manager, and Deputy Director of Nursing of the selected hospital. A meeting with the executive committee was arranged and the researcher presented the concept of the study to them. The executive committee members were also gatekeepers. Gatekeepers are persons who have the authority to allow entry to a research site (Polit & Beck 217:58). The research proposal was approved by the In-House Research Committee on 26 February 2019, entered into the National Health Research Database, and provisional ethical approval obtained from the Research Ethics Committee of the University of Pretoria on 31 May 2019.

3.4.4 Data collection

Data collection is the process of collecting information related to the research question in a systematic way to address a research problem (Polit & Beck 2017:725). The researcher established rapport with the participants and collected data by means of face-to-face interviews, using a semi-structured interview guide (Polit & Beck 2012:532) (see Annexure B 2). In qualitative research it is important to gain and maintain trust with participants (Polit &Beck 2017:507).

Prior to the interviews, the participants read the information leaflet (see Annexure B2) and were allowed to ask any questions before signing informed consent voluntary.
The interview commenced with the participants' demographic profile, which included age, gender and relationship. The researcher used probing questions to encourage the participants to elaborate (Polit & Beck 2017:310). The interviews took approximately 45 minutes and were conducted until data saturation was achieved. Data saturation occurs when no new information emerges (Polit & Beck 2017:62).

The researcher used field notes to capture observed nonverbal communication, posture and emotional responses (Polit & Beck 2017:548; Arbour & Wiegand 2014:213). The interviews were audio-recorded with the participants' permission. At the end of each interview, the researcher summarised the points discussed and asked the participants whether the information was correct. The researcher thanked the participants for their time and participation after each interview. The researcher ensured the family member were emotionally supported and gave them an opportunity following the interview to discuss any aspects they wish to.

3.4.5 Data organisation

Following data collection, the researcher organised the data by transcribing the tape-recorded interviews verbatim, and kept the transcriptions as well as the field notes in folders. The researcher kept all the data collected in a safe place (locked cupboard) to which only she had access.

The researcher transcribed the audio-recordings verbatim, ensuring that the transcripts had no information that could identify the participants. The transcribed interviews were checked against the audio-recordings to ensure that all data was captured. The researcher read and re-read the transcripts, and typed the handwritten field notes in preparation for data analysis. This enabled the researcher to immerse herself in the data. After all data was organised, the researcher made back-up copies of the data, and kept the master copy for safe keeping.

3.4.6 Creative hermeneutic approach

In phase 2, Boomer and McCormack's (2010:644) creative hermeneutic approach was used to analyse the data. Hermeneutics focuses on people's lived experiences and how they interpret those experiences (Polit & Beck 2017:730). Hermeneutic interpretation explains personal meaning and unveils hidden meanings in people's experiences. The researcher considered a hermeneutic approach appropriate to study the participants' experiences and interpretations of their loved ones' EOLC (Ramsook 2018:14).

3.4.7 Phase 2: Data analysis and strategy development

HCPs working in HCU and the researcher collaboratively analysed the data and developed strategies. Accordingly, 3 doctors and 7 nurses who worked in the HCU and rendered EOLC in the unit and were off duty analysed the data. The researcher considered collaborative data analysis appropriate for the study as the HCPs were able to read through and analyse the data collected by the researcher on the participant family members' experiences of EOLC provided in the HCU.

3.4.7.1 Workshop for collaborative data analysis

The 10 HCPs were formally invited (see Annexure C 1) to an interactive data analysis workshop. The workshop invitation was pasted on the notice board in the HCU and given to each HCP two weeks before the workshop, and they were asked to telephonically confirm their availability. Pavelin, Pundir and Cham (2014:1) describe interactive workshops as workshops which involve structured facilitated activities for groups who collaborate to explore a problem and develop ways to resolve it over a set period and in one location.

The researcher considered an interactive workshop as appropriate to collaboratively analyse the data and identify strategies that can be implemented by HCPs to enhance end-of-life care provided. The HCPs were able to reflect on how they cared for patients and their families during EOLC and how to change current practice related to EOLC (Flicker 2014:2). Collaborative data analysis enhanced working relations amongst the participants as it facilitated the learning process for each one. Individual perspectives were extended to incorporate other points of view.

3.4.7.2 Orientation and preparation for the workshop

The workshop was conducted on 12 March 2020 in the hospital boardroom. The researcher's supervisor, who is an experienced researcher, facilitated the workshop. Folders were made for each participant that contained the demographic data sheet (see Annexure C 2), a notepad and a pen. Table 3.1 indicates the participants' demographic profile.

Table 3.1 Workshop participants' demographic profile

Participant	Age	Gender	Rank	Years of experience	ICU trained	Key notes
1	26	F	**Doctor**	3	N	PN=professional nurse
2	44	M	PN	21	Y	EN=Enrolled nurse
3	29	M	**Doctor**	4	N	F=male
4	39	F	PN	13	Y	M=male
5	59	F	EN	20	N	

6	28	F	PN	5	Y	
7	42	F	PN	10	Y	
8	45	F	PN	22	Y	
9	38	F	PN	10	N	
10	31	F	**Doctor**	6	N	

3.4.7.3 Conducting the workshop

The researcher welcomed the participants. As the HCPs arrived they were requested to take their name tags and wear them. Meeting, greeting and introduction took place. Establishment of ground rules for the workshop was voluntarily discussed by participants. The participants discussed and agreed on the ground rules, which were written on the flipchart (see Table 3.2).

Table 3.2 Ground rules for the workshop

RULES
Cell phones on mute
Talk in English
Be non-judgemental
Listen to each other
Let us have fun
Everyone’s voice matters
Respect each other’s opinion

3.4.7.4 Ice breaker

The facilitator asked the participants to think of one word or phrase relating to EOLC that came to mind and share it with the group.

The participants stated the following:

- Support structure
- Love
- Dignity
- Fear

- Inevitable
- Respect

The facilitator facilitated the data analysis, using Boomer and McCormack's (2010:638) 6-step creative hermeneutic method:

- Step 1: The participants were paired and given transcriptions of the interviews to read. Each group was asked to create a visual image of the central ideas that emerged from the data. Each group appointed a person to draw the visual image and write down the main concepts on coloured paper. Using art during group activities is a way of incorporating an enjoyable element, increasing participants' interest and providing interesting ways to voice opinions other than just words (Stewart, Shamdasani & Rook 2015:20). Time allocated was 20 minutes.

- Step 2: The visual images were shared amongst the paired groups and they were asked to explain what they signified. Sharing and listening attentively raised mindfulness regarding the family experiences of EOLC in HCU. Time allocated was 10 minutes.

- Step 3: Using the written main concepts (themes) and the creative image as the centrepiece, the participants were asked to identify as many categories as possible from the transcribed data. The categories were written on separate pieces of coloured paper. The groups labelled the categories as follows: group 1 labelled the categories numerically (1, 2, 3 etc); group 2 labelled theirs alphabetically (A, B, C etc), and group 3 labelled theirs with Roman numerals (i, ii, iii etc). Using coloured highlighters, all the participants highlighted the sentences that matched the categories, using the symbols explained above. Next to each sentence they wrote the relevant category. The members of each group looked at the creative images and deliberated on categories and agreed as a group.

- Step 4: The participants were divided into smaller groups of 3 or 4 by combining pairs and asked to consider all the categories identified and then to reach agreement on shared categories. The groups considered and discussed the creative images and categories. The participants were asked to comment on the images, using the phrases "I see", "I feel", "I hear" and "I imagine". After discussing the creative images, the participants were asked to identify similar aspects in all the groups' artwork to reach consensus on the meaning of EOLC.

- Step 5: The groups then presented their categories to the other groups and a discussion followed to reach agreement on one set of categories. The participants were asked to write the main themes or big words first and the categories or small words next to the themes. The participants agreed on the following themes: quality of care, compassion, support structure and communication. The participants deliberated and reached consensus on all the themes and categories.

- Step 6: The participants were asked to each identify two strategies that could be implemented to improve end-of-life care in HCU and note each strategy on a separate coloured sticky note. The participants discussed and suggested strategies for implementation for 10 minutes. Then each group nominated a representative to present their suggested strategies and explain how they visualized EOLC in the HCU to the rest of the participants.

The facilitator then summarised the workshop. The participants were asked to reflect on what they had learned and what they liked most and least about the workshop. Most participants only had “like most” statements, which mainly reflected how they would make the change in practice moving forward (see Annexure N for the findings of the “like most, like least” activity).

The researcher thanked the facilitator and the participants for their time and invaluable inputs. The researcher explained to the participants that the research findings would be published and presented to the hospital. The workshop was adjourned, and refreshments were provided.

3.4.7.5 Reflection on the workshop

The workshop started an hour late because some of the participants were busy in their respective wards. Upon reflection, the researcher realised that she should have planned to have the workshop after lunch when most of the daily activities are over. The facilitator made the workshop exciting and enjoyable. Consensus was reached on the strategies identified, which could be implemented by healthcare professionals to improve end-of-life care in HCU.

3.5 CONCLUSION

This chapter described the research design and methodology of the study, including the interactive workshop conducted for collaborative data analysis. Chapter 4 discusses the data analysis and strategies developed with reference to the literature review.

CHAPTER 4
DATA ANALYSIS, INTERPRETATION AND FINDINGS

4.1 INTRODUCTION

Chapter 3 described the research design and research methodology used in the study. This chapter 4 discusses the data analysis and interpretation and the findings, with reference to the literature reviewed.

4.2 AIM OF THE STUDY

The aim of the study was to identify strategies to improve the end-of-life care experiences of adult family members in the high care unit. In order to achieve the aim, the objectives were to:

- Explore adult family members' experiences of end-of-life care in the high care unit.
- Collaboratively identify strategies that could be implemented by healthcare professionals to enhance family members' experiences of end-of-life care provided.

Accordingly, the study wished to answer the following question:

What strategies can healthcare professionals identify to improve the end-of-life care based on the experiences of adult family members in the high care unit?

4.3 DATA MANAGEMENT AND ANALYSIS

In phase 1 data was collected from adult family members of patients admitted in the HCU where EOLC was initiated by means of face-to-face interviews, using a semi-structured interview guide (Polit & Beck 2017:532) (see Annexure B1). The researcher conducted a pilot study with two family members to test the interview guide. The interviews were recorded and lasted between 20-35 minutes. The participants understood the questions and no changes were subsequently made to the interview guide. The researcher included the data from the pilot interviews for data analysis. Eight interviews were conducted between 25/08/2019 and 10/12/2019 with family members and data saturation was reached after 6 interviews but another two interviews was conducted to confirm data saturation.

Following data collection, the researcher organised the data by transcribing the tape-recorded interviews verbatim, and kept the transcriptions as well as the field notes in folders. The researcher kept all the data collected in a safe place (locked cupboard) to which only she had access.

In phase 2, Boomer and McCormack's (2010:644) creative hermeneutic approach was used to analyse the data. Hermeneutics focuses on people's lived experiences and how they interpret those experiences (Polit & Beck 2017:730). Ten HCPs who worked in the HCU and rendered EOLC in the unit and the researcher collaboratively analysed the data and developed strategies. Collaborative data analysis allowed the HCPs to read through and analyse the data collected on the participant family members' experiences of EOLC provided in the HCU.

Data analysis was done in the boardroom of the hospital on 12 March 2020 from 9:00 to 12:00. Of the HCPs, 3 were males and 7 were females; 3 were medical doctors, 6 were professional nurses, and 1 was an enrolled nurse. Of the professional nurses, 4 had an additional qualification in critical care nursing.

4.4 FINDINGS

Four main themes, 14 categories and 5 sub-categories emerged from the data. Table 4.1 lists the themes, categories and sub-categories. Each of the themes will be discussed in Sections 4.4.1 to 4.4.4.

Table 4.1 Themes, categories and sub-categories

THEMES	CATEGORIES	SUB-CATEGORIES
Theme 1: Quality of care	Dignity of patients	Cleanliness of patient and environment
		Pain free
	Comfort	
Theme 2: Compassion	Empathy	
	Flexible visiting times	
	Fear of family members	
Theme 3: Support structure	Cultural sensitivity	
	Spiritual coping	
	Coping strategies	Denial
		Hope
		Acceptance
	Emotional experiences	Anxiety
		Depression
	Psychological healing	
Theme 4: Communication	Access to medical information	
	Open communication	
	Honest communication	
	Use of language	

4.4.1 Theme 1: Quality of care

The first theme that emerged was ‘quality of care’. The HCPs agreed that a skilled HCP who understands end-of-life care can render quality care to dying patients. Some of the participants regarded the care rendered to the patients as “the best care” because the family members were allowed to “actively participate in the decision-making process”. Therefore, active participation by family members was viewed as quality care. When family members were involved in decision making, even though it was done informally, they appreciated that they were part of it. Some participants wished that the decision-making process could be formal and part of the process. According to participants,

The care rendered to my sister was the best care because we [family members] were included in the decision-making process. (P3)

I could see they give quality of care the nurse was next to the bed all the time and working with all the with all the machines. (P2)

They were doing their best to care for my sister. (P5)

The process of dying in a critical care environment is complex due to the advanced technology used. The family plays a very important role in EOLC, because in a critical environment setting most patients are unconscious and thus not able to make decisions for themselves (O’Neill, Yaqoob & Faraj 2016:951; Pascual 2014:11). When patients are unable to communicate themselves, a family member will assume the responsibility of taking decisions on diagnostic, treatment and therapeutic care (Lind 2017:273; Olding, McMillan, Reeves, Schmitt, Puntillo & Kitto 2015:1189; Chen, Michaels, Meeker 2019:143). The World Health Organization (WHO 2020:1) refers to quality of care as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes. It is based on evidence-based professional knowledge and is critical for achieving universal health coverage.

Two categories emerged from Theme 1, namely dignity and comfort. Dignity had two sub-categories: cleanliness and pain free. The categories and sub-categories are discussed next.

4.4.1.1 Dignity of patients

The participants indicated that the dignity of the patients in the HCU was related to ‘cleanliness’ and being ‘pain free’.

- ✓ **Cleanliness of patients and environment**

  The participants stated that a clean and tidy environment was important and gave them a sense of the patient’s dignity being maintained. They appreciated the way their relatives were cared for, which made them feel that their loved ones would die in dignity. According to participants,

  I am very happy about the overall cleanliness of the ward; my family member is going to die in a clean place and in dignity. (P7)

  The hospital clothes are changed regularly. (P5)

  My family member was always clean, changed and nursed on clean sheets. (P7)

  The dignity of patients should always be respected and HCPs should attempt to ensure that patients do not suffer indignity (Pols, Pasveer & Willems 2018:90). Dignity is the worth of a human being, and can be acknowledged by respectful behaviours (Brown, Azoulay, Benoit, Butler, Folcarelli, Geller, Rozenblum, Sands, Sokol-Hessner, Talmor & Turner 2018:1391). Brown et al (2018:1391) state that dignity and respect are interrelated, and ICU patients and family are vulnerable to disrespect, which overlaps with dehumanization. In Saudi Arabia, Muslim family members were concerned about critically ill patients’ dignity, cleanliness and comfort which made the journey to death more comfortable and dignified (Al Mutair, Al Shaer, Al Ghamdi & Al Ghamdi 2018:8). In Iran, Zaki-Nejad, Manookian and Shamshiri (2020:286) found that dignity therapy had a positive effect on the quality of life of patients with cancer receiving palliative care. Providing a clean environment and ensuring that patients are clean and tidy is related to dignity. A clean, welcoming environment enhances feelings of trust and eases family members’ anxiety.

- ✓ **Pain free**

  The participants indicated that the patients should be pain free and given pain medication. The participants indicated that a pain-free death was important to them and their loved ones as it gave them a sense of dignity. According to participants,

> *Even though she dies, she must die pain free.* (P2)
> *I wish that all patients here would die a pain-free death.* (P5)

The nurse said that the patient is on pain medication that reassured us [family] that she will die with dignity. (P5)

A dignified death includes meeting the physical, psychosocial and spiritual needs of the patient (Sagha Zadeh, Eshelman, Setla & Sadatsafavi 2018:411). Patients receiving EOLC may have physical, psychosocial and spiritual needs, which are not always met (Lim 2016:456). The goal of EOLC is to relieve the suffering of patients and their families through the comprehensive assessment and treatment of these needs.

The physical comfort of patients in EOLC is paramount during their stay in critical care (Clark 2017:2). The alleviation of suffering and pain is essential to provide a pain-free, comfortable and peaceful death. Pain is a common occurrence in EOLC and can be from many sources, such as the use of extra medical devices like endotracheal tubes and nasogastric tubes. It is important to maximise comfort once death is imminent as it is a major concern for family members during end-of-life care (Six, Laureys, Poelaert, Bilsen, Theuns & Deschepper 2018:2). Physical comfort can be achieved by administering opiates and symptom-controlling drugs (Six et al 2018:2). The use of opioids is not meant to hasten death. Patients who are sedated become unaware of their clinical situation and do not experience discomfort, which is common during the terminal phase (Six et al 2018:2). In Saudi Arabia, Al Mutair, Al Shaer, Al Ghamdi and Al Ghamdi (2018:8) found that family members indicated that when their loved ones were in ICU their dying journey seemed more comfortable and merciful.

4.4.1.2 Comfort

In addition to the patients' comfort, the participants indicated the importance of comfort and feeling comforted when spoken to by HCPs. They also appreciated and acknowledged that HCPs offered them comfort during visiting hours. According to participants,

The nurse had to comfort and counsel us [family members]. (P6)
The nurse called the counsellor to come and comfort us [family member]. (P3)
The nurse tried her best to explain the situation to us[family member} and support us when we were very sad (P8)

The main goal of comfort during EOLC is to address family members' concerns (Sampson, Candy, Davis, Gola, Harrington, King et al 2018:670). Family members are vulnerable to anxiety and helplessness and need assurance and comfort from those who are managing the patient's condition (Liew, Dharmalingam, Ganapathy, Muniandy, Ngu & Ng 2018:35).

4.4.2 Theme 2: Compassion

Compassion was the second theme that emerged from the data. The participants indicated that the nurses and doctors showed kindness and acts of caring towards family members and patients. Moreover, the way in which the HCPs talked to them showed compassion. According to participants,

I will never forget a nurse in the afternoon came in the unit and walked bed to bed greeting patients, us family asking how we are. That thought is still stuck in my mind. (P7).
She [the nurse] saw obviously that I was not OK. Thank you for her [the nurse] she realised that I was not OK. To me the nurse giving me water it spelt compassionate, understanding you know…. (P8).

Compassion should be fostered in the delivery of end-of-life care; is not merely a passive sense of pity, but is also about engagement and seeking to assist those who are suffering

(Clark 2017:2). In their review, Sinclair, Norris, McConnell, Chochinov, Hack, Hagen, McClement and Bouchal (2016:6) found that six themes emerged from studies that explored compassionate care, namely nature of compassion; development of compassion; interpersonal factors related to compassion; action and practical compassion; barriers and enablers of compassion, and outcomes of compassion. The review identified the limited empirical understanding of compassion in healthcare and highlighted the lack of patient and family voices in compassion research. Sinclair, Norris, McConnell, Chochinov, Hack, Hagen, McClement and Bouchal (2016:10) stress that the necessity of compassion within healthcare is evident in the first principle of the American Medical Association's 2001 code of ethics that states, "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights".

In the Netherlands, Van Mol, Brackel, Kompanje, Gijsbers, Nijkamp, Girbes and Bakker (2016:5) found that patient-centred care and compassion required HCPs to pay attention to patients' cultural aspects, beliefs, behaviours and personal needs. HCPs had to reflect not only on how they saw patients, but also on how they saw themselves in relation to patients.

Three categories emerged from Theme 2: Compassion, namely empathy, flexible visiting times, and fear. These categories are discussed next.

4.4.2.1 Empathy

The participants indicated that HCPs should show empathy when caring for patients and with family members. Empathy not only strengthens the relationship between the HCP and patients but also improves HCP and patient satisfaction. According to participants,
The nurse always waited for us as family to ask questions when we [family members] came to visit (P4)

She [nurse] was greeting us [family members] and the patients, asking how are we…that thought is still stuck in my mind. (P7)

An unbiased understanding of the patient's family members' perspective is gained through showing empathy and allows the nurse to establish a trusting nurse-patient relationship (Adams 2018:170). Empathy is essential in providing patient-centred care and strengthens trust between HCPs, patients and family members (Ratka 2018:1140; Hojat 2016:96).

Empathy and ethics are connected, and both play a vital role in nurses' decision-making, particularly for decisions involving uncertainty that require moral reasoning or values-based judgment (Barlow, Hargreaves & Gillibrand, 2018:232; Hojat 2016:96). Black and Helgason (2018:52) refer to empathy as an active interest to understand the other's internal perspective. Empathy, trust and respect are critical components of therapeutic nurse-patient relationships and quality nursing care (Heidke, Howie & Ferdous 2018:30).

4.4.2.2 Flexible visiting times

The participants wished that visiting hours could be extended or flexible. According to participants,

Don't restrict the visiting times… make it two hours rather than one hour. (P2)
Please do not consider specific visiting times, family should be allowed into the unit at any time. (P3)

Allow us [family members] to be there at his side throughout the day. (P8)

Hospital policy, such as restrictive visiting hours, could hinder adequate EOLC (Sukraandini, Kongsuwan & Nilmanat 2017:58). In Saudi Arabia, Al Mutair, Al Shaer, Al Ghamdi and Al Ghamdi (2018:2) found that Muslim families valued being able to spend as much time as desired close to the patient as the end of life approached. In their study and setting, Al Mutair, Al Shaer, Al Ghamdi and Al Ghamdi (2018:8) recommended that an open visitation policy would benefit everyone.

In a 24-bed ICU in a tertiary care hospital in the USA, Chapman, Collingridge, Mitchell, Wright, Hopkins, Butler and Brown (2016:48) found that the elimination of restricted visiting times reduced anxiety and depression and cardiovascular complications in critically ill patients, and improved families' satisfaction.

4.4.2.3 Fear of family mebers

The participants indicated that visiting the HCU was a frightening experience. According to participants,

[It was a] *fearful experience for us [family] to face when we all knew that she was dying.* (P8)

Really it is traumatising to see the loved one in that high care unit with all those machines surrounding her (P1)

Entering the high care unit, it was so scary al the pipes, machines and noises. (P2)

Patients' admission to ICUs exposes family members to a new environment, advanced monitoring systems and aggressive treatment, which is stressful and causes anxiety and fear (Imanipour, Kiwanuka, Akhavan Rad, Masaba & Alemayehu 2019:569). In addition Scott, Thomson and Shepherd (2019:699) found that family members are frequently overwhelmed by anxiety and worry due to fear of losing their loved one, deterioration of the family structure and concerns about the future, together with the stressful technological ICU environment.

4.4.3 Theme 3: Support structure

The participants indicated that support for themselves and each other and psychological support was important. According to participants,

Help from a counsellor would be of great benefit to us [family members]. (P6) *The counsellor also plays a major role in supporting us as family.* (P3)

Allow at least 2 visitors [family members] so that we can support each other next to his [patient] bed. All of us [family members] must be there … so that we can support each other. (P2)

In Tanzania, Kohi, Obogo and Mselle (2016:1) found that the admission of a family member in ICU often occurred without warning, which left the family feeling helpless and vulnerable with little knowledge of what was happening and what to expect. HCPs should identify family needs and provide psychological support by having frequent meetings with family members to provide information. Kohi, Obogo and Mselle (2016:5) point out that family members of critically ill patients serve as a bridge between the HCPs and the patients, who are physiologically and psychologically compromised, therefore it is important to support them.

The use of proactive support services, such as social workers, and meetings with family indicated that the support given to family members should be tailor-made to suit the unique needs of the members involved (Pignatiello, Hickman & Hetland 2018:109; Wiegand, Cheon & Netzer 2019:21). In Saudi Arabia, family members regarded support as crucial to assist them in coping with the shock and stress following the admission of a loved one with critical illness. The family required support and reassurance that the patient was getting the best care (Al Mutair, Plummer, Clerehan & O'Brien 2014:142).

Three categories emerged from Theme 3, namely culture, spiritual healing, and coping strategies. Coping strategies had three sub-categories: denial, hope, and acceptance. The categories and sub-categories are discussed next.

4.4.3.1 Cultural sensitivity

The participants indicated the importance of their culture to them and the patients. According to participants,

Nurses and doctors working in the hospital [HCU] should respect our [family members] cultural practices when we want to "fetch the spirit". (P7)

Consider our culture…that is important to us, when we came to the hospital his body was already takes away, we did not have opportunity to perform our [cultural] ritual. (P2).

Culture consists of community and family values, beliefs, traditions and symbols. In providing person-centred EOLC, HCPs should be aware of and acknowledge patients' and families' cultural diversity (Al Mutair, Al Shaer, Al Ghamdi & Al Ghamdi 2018:2). Critically ill patients and their families from culturally diverse backgrounds have a right to receive culturally sensitive care. Accordingly, HCPs should have appropriate knowledge, skills and attributes to respect and effectively respond to the cultural needs of critically ill patients and their families (Friganovic, Bloomer, Northam, Kalauz, Zellinger, Lopez & Fulbrook 2016:82). Saudi families have cultural and spiritual healing beliefs and practices, including faith in God and that God is the ultimate healer, reading of the Qur'an and prayer (Al Mutair, Plummer, Clerehan & O'Brien 2014:137). In Tanzania, Kohi, Obogo and Mselle (2016:7) point out that in African culture, family members and relatives wished to be close to dying loved ones because the last words of the dying are taken very seriously. This could include a blessing or important last wishes and bequests particularly as many people do not have formal written wills. Young and Guo (2020:107) state that cultural competence is learned over time and is a process of inner reflection and awareness, and emphasise the necessity of cultural competence for health care providers and in nursing practice.

4.4.3.2 Spiritual coping

The participants indicated that religion and religious practices were important for spiritual healing of their loved ones. They also stated that they should be allowed to perform religious practices. According to participants,

Accommodate us [family members] to practise our religion… Put a rosary around her [patient] neck or her wrist … [or] just come and rub holy oil on our patient. (P2)

Prayer helps us [family members] as we lay everything in God's hands, we [family] just prayed without touching anything (P3).

During EOLC, relatives and patients commonly experience spiritual distress, which is a disruption of their beliefs and value system (Richardson 2014:156). Spirituality is the way people seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski, Vitillo, Hull & Reller 2014:642). Spiritual care also forms an aspect of EOLC whereby treatment decisions may be based on patients' and families' religious belief system, making a chaplain an integral part (Norlander 2014:8). In addition Gordon (2015:113) emphasises the importance of incorporating spiritual assessment of the patient and family as unmet spiritual needs may result in dissatisfaction with care.

In their study in Ontario, Canada, Holyoke and Stephenson (2017:2) found that spiritual care is necessary for the person dying and also for family members and care providers. Spiritual care is needed to assist and care for 'total pain', namely the physical, psychological, emotional and spiritual dimensions. Spiritual care is embedded throughout the giving of care and attention to the spiritual reduces psychological suffering. HCPs should seek to collaborate with patients and family to ensure that spiritual needs are met (Holyoke & Stephenson 2017:3).

Saudi families have cultural and spiritual healing beliefs and practices, including faith in God and that God is the ultimate healer, reading of the Qur'an and prayer (Al Mutair, Plummer, Clerehan & O'Brien 2014:137). Family members regard spiritual healing beliefs and practices, such as their faith in God, as an integral part of their coping mechanisms. Muslim families believe that it is important to be given the chance and space to practise their spirituality. Religious practices such as prayer should not only be supported but also encouraged in ICU, and opportunities for prayer created (Al Mutair et al 2018:11).

4.4.3.3 Coping strategies

The participants indicated that their main coping strategies when their loved one received EOLC in the HCU were denial, hope and acceptance. Some denied that their loved ones might die, or hoped that their loved ones would not die. Others accepted that their loved ones would die. According to participants,

I wished they [nurses and doctors] would continue to care for her [patient]…as if maybe she would wake up again. (P8)

I hope I would find her opening her eyes today and looking at me. (P8)

It was very hard to accept but with your family around you act brave you try to stay strong especially for the people [family] around you (P1)

Valle and Lohne (2020:2) found that a minor change in the patient's condition could either boost the family's hope or reduce it to a new low. Hope is often used as a coping mechanism when family are faced with a loved one dying in ICU. Hope is temporary, changing from a difficult present to a positive future and uncertain possibilities among family members as they hope for their loved ones' survival (Valle & Lohne 2020:2; McAlearney, Hefner, Sieck & Huerta 2015:464).

Denial is a defence mechanism that refuses to believe a reality or fact of life. The first stage of grief is denial, which helps people to survive the loss (Kübler-Ross & Kessler 2009:7). During denial the world becomes meaningless and people are shocked by the reality.

Acceptance is the fifth stage of grief and means embracing the present, both good and bad, in order to shape the future (Kübler-Ross & Kessler 2009:30). Acceptance is not necessarily a happy or uplifting stage. It means that people have accepted the grief or loss and have come to understand what it means in their life now. For many people, acceptance is the hardest stage. Some are never able to fully accept that their loved one is gone and they are not able to change that (Kübler-Ross & Kessler 2009:30

4.4.3.4 Emotional experiences

The participants stated that their main emotional experiences were anxiety and depression.

The participants indicated feelings of anxiety when their loved ones were admitted in the HCU. According to participants,

Anxiety is the worst because you are unsure if you will find your family member in the unit when you arrive (P7)

All the patients are lying flat, motionless, not talking and next to them there is a lot of machines, and some drips they say it's an alarm. …it more of an anxious environment. (P1)

The ICU is a complex and stressful environment and is associated with significant psychologic morbidity for patients and their families. Many family members experience anxiety after an ICU admission for their loved one, including anxiety, depression and post-traumatic stress symptoms (Beesley, Hopkins, Holt-Lunstad, Wilson, Butler, Kuttler, Orme, Brown & Hirshberg 2018:232).

Brown, Azoulay, Benoit, Butler, Folcarelli et al (2018:1390) emphasise that dignity and respect for both patients and family are interrelated. Disrespect may increase family members' stress and anxiety when loved ones are admitted in the ICU. Family members need information, communication, support, and comfort from HCPs. Family involvement can reduce family members' anxiety (Hetland, McAndrew, Perazzo, Hickman 2018:75).

The participants indicated feelings of depression due to the admission of their loved ones in the HCU. According to participants,

I cannot deal with the situation [EOL] that we are facing...I am so sad…. (P5)

What is happening [EOL] with my sister is very traumatic experience… (P3)

Family members of dying patients suffer psychosocial stresses such as depression (Gordon 2015:59). In a scoping review, Coombs (2015:35) found that during end-of-life care in the ICU, family members frequently experienced anxiety, stress and post-traumatic stress. In Nigeria, Olabisi, Ola, Bolaji, Azeez, Azeez and Olabisi (2020:4) found that family members' depression was influenced by socio-demographic variables like age, income, family relationship and level of education. A study in Turkey found the highest levels of anxiety and depression among the spouses of patients compared to other family members (Köse, Zincircioğlu, Öztürk, Çakmak, Güldoğan, Demir, Şenoglu, Erbay & Gonullu 2016:4). Depression is part of grief, when individuals deal with feelings of hopelessness and inadequacy (McAlearney, Hefner, Sieck & Huerta 2015:472).

4.4.3.5 Psychological healing

The participants indicated a need for psychological healing at the news of their loved one's death and the importance of counselling which could help them to overcome the death of their loved one. According to participants,

Maybe hold regular meeting with the family where not only medical aspects [EOL] are dealt with, but other social aspects (P8)

Having a pastor/counsellor will make it easy for us [family members] to accept that death is inevitable. (P5)

Grief manifests in different ways: emotionally, psychologically, and physically (Norlander 2014:68). Bereavement follow-up needs to be a part of any patient plan of care. As family members are given the news of the death of their loved one, it is important for the HCP to guide the family through the initial loss and help them accept the loss, that could be the beginning of psychological healing (Norlander 2014:71).

4.4.4 Theme 4: Communication

The participants appreciated effective communication and regarded it as an important aspect of EOLC. The participants indicated different experiences of the communication in the HCU. According to participants,

Communication with the doctor to me [family member] was very important at that time. (P4)

The nurses and doctors are concerned about the patients … we [family members] do appreciate the way nurses communicate to us. They [nurses] are patient and show caring. (P5)

Communication is also a key thing to happen in the ward. (P8)

Constant communication to us as the family by nurses and doctors brings out trusting relationships. (P7)

Some participants emphasised a need for early disclosure of the patient’s prognosis and some stressed that HCPs should be mindful of how they communicated with family members. According to participants,

When the patient’s condition is not promising from the word go, family members should be told. Nurses and doctors should readily share information to the relatives and family members. (P5)

The manner in which the news was broken to me really I felt it was unacceptable. I was not given a full clear explanation regarding his [patient] condition. (P4)

Communication is a verbal and nonverbal exchange of ideas, feelings and attitudes to enable common understanding between the sender and the receiver of the message (Wang, Wan, Lin, Zhou & Shang 2018:86). Effective communication is important for safety and quality patient care (Wang et al 2018:82). Communication between nurse and patient is an important component of care that builds therapeutic relationships (Antonacci, Fong, Sumbly, Yi Fan Wang, Doucette & Chevrier 2018:36).

Four categories emerged from Theme 4: Communication, namely access to medical information; honest communication and open communication, and use of language.

4.4.4.1 Access to medical information

The participants expressed a need for medical information to be shared with them and to be kept updated. According to participants,

I was not given a full clear explanation regarding his condition… (P4)

The doctor, you know, he did not tell me anything. I am still empty because I still need to understand what was wrong with her [loved one] … and could not understand what is not making her feel better. (P8)

It is important to discuss the patient's condition and deterioration to help family members understand and make decisions (Anderson, Bloch, Armstrong, Stone & Low 2018:939). Providing family members with constant information about the patient's condition relieves anxiety and stress (Björk, Lindahl & Fridh 2019:534). HCPs should have meetings with patients' families to provide clear medical information with them and make sure that they understand the patients' condition (Imam, Kongsuwan & Nilmanat 2020:4).

4.4.4.2 Honest and open communication

The participants indicated the importance of open communication between HCPs and family members regarding their loved one's condition. According to participants,

They should be truthful about the condition and the treatment the person would be receiving ... and provide updates on his condition on a regular basis. (P1)

Doctors they are the ones who must play a major role through discussions with the relatives, because then we would know everything about the treatment plan. (P3)

Information sharing with us as family members would have benefited us. (P5)

Al Mutair, Al Shaer, Al Ghamdi and Al Ghamdi (2018:7) found that open information was an important part of EOLC, and family members needed and valued frequent updates about the health status and prognosis of their loved ones. In Tanzania, Kohi, Obogo and Mselle (2016:1) found that the admission of a family member in ICU often occurred without warning, which left the family feeling helpless and vulnerable with little knowledge of what was happening and what to expect. HCPs should identify family needs and provide psychological support by having frequent meetings with family members to provide information.

Family members of patients receiving end-of-life care value effective, honest communication about their relatives' prognosis and care (Virdun, Luckett, Davidson & Phillips 2015:777; Imam et al 2020:4). Hajradinovic, Tishelman, Lindqvist and Goliath (2018:11) emphasise that it is important to family members to know what to expect and why, especially in palliative care. Open, honest communication between HCPs, patients, and the patient's family can create trust to defuse tension (Imam et al 2020:4; Akgün, Shamas, Feder, Schulman-Green 2020:344).

The participants referred to honesty and honest communication. According to participants,

During this meeting with doctors and nurses realistic expectations should be laid down. (P7)

We [family members] should get honest and comprehensive information which is shared with us as family members. The doctor did not come up front and say it as it is, that she [patient] was going to die. (P5)

The truth about the patient's condition must be disclosed. Early disclosure about the state the patient is in is important to us [family members]. (P6)

Families of patients in ICU want timely, clear and understandable information about their relative's medical condition, but without leaving room for unrealistic hope (Scott, Thomson & Shepherd 2019:712; Al Mutair, Plummer, Clerehan & O'Brien 2014:140). Family members want honest, true information and do not want false hope (Adams, Anderson, Docherty, Tulsky, Steinhauser & Bailey Jr 2014:411). Isaacson and Minton (2018:12) state that end-of-life communication should be understandable to enable family members to make EOLC decisions and prepare for the dying process.

4.4.4.3 Use of language

The participants indicated that during EOLC it is important that HCPs use plain, simple layman's terms when talking to the family members so that they can understand. According to participants,

We do not understand the terms, so I think it would be better if they use the layman's language. Most of the time we [family members] are just told these things in medical terms, which we do not understand. (P1)

I could not make sense of what the doctor was saying. He said something like "we are doing all in our power to save her life". At that point I got confused. (P5)

Good communication is an essential ingredient of quality care in the ICU and HCPs should continuously share information regarding the patient's condition, treatment plan and prognosis (Fox 2014:94; Matlakala 2015:115). During EOLC conversations HCPs often use language that is unclear to the family members, such as "will likely not recover" and "worsening overall prognosis" (Wentlandt, Toupin, Novosedlik, Le, Zimmermann & Kaya 2018:341). HCPs should speak to family members in simple terminology and avoid ambiguous or insensitive terms or phrases (Norlander 2014:81).

4.5 CONCLUSION

This chapter discussed the data analysis and findings according to the themes and categories that emerged with reference to the literature reviewed. The researcher and HCPs collaborated to analyse the data and identify strategies to improve family members' experience of EOLC in the HCU.

Chapter 5 summarises the findings, briefly describes the limitations of the study, presents strategies to improve family members' experience of EOLC in HCU, and makes recommendations for further study.

CHAPTER 5

FINDINGS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Chapter 4 discussed the data analysis and findings. This chapter briefly describes the findings and limitations of the study, identifies and suggests strategies to enhance families' experience of EOLC, makes recommendations for further research, and presents the researcher's personal reflection on the research journey.

5.2 AIM AND OBJECTIVES

The aim of the study was to identify strategies to improve the end-of-life care experiences of adult family members in the high care unit.
In order to achieve the aim, the objectives were to

- Explore adult family members' experiences of end-of-life care in the high care unit.
- Collaboratively identify strategies that could be implemented by healthcare professionals to enhance family members' experiences of end-of-life care provided.

5.3 FAMILY MEMBERS' EXPERIENCES

The researcher conducted interviews with ten (10) family members. The data was collaboratively analysed by 10 healthcare professionals, namely 3 medical doctors, 6 professional nurses and 1enrolled nurse, and the researcher. Four main themes and related categories and sub-categories emerged from the data. The main theme is concluded and implications for practice and education suggested.

5.3.1 Theme 1: Quality of care

The first theme was quality of care, which included two categories, namely dignity and comfort, and two sub-categories, namely cleanliness and pain free. The study found that the family members perceived that the patients received quality of care at the end of their lives in the HCU. A key responsibility of HCPs is to ensure that patients die with dignity, including in a clean and tidy environment (HCU). Furthermore, it was important for the family members to know that their loved one was pain free and comfortable.

5.3.2 Theme 2: Compassion

Compassion is a cornerstone of quality health care. The family members stated that they wished that the HCPs would show empathy and treat them with kindness, willingness, and loving and caring attitudes. Having a loved one admitted in the HCU is traumatic and stressful for family members so it is important to treat family members with compassion in order to promote healthy relationships between HCPs and family members. Being compassionate increases the satisfaction of HCPs as well as family members.

5.3.3 Theme 3: Support structure

A support structure is important to family members whose loved ones are admitted in the HCU. The participant family members interpreted structural support as HCPs supporting and encouraging them (family members) to practise their culture and spiritual beliefs. HCPs should embrace patients' and families' cultural and spiritual differences. Cultural and spiritual sensitivity forms part of family- and person-centred care in critical care areas like the HCU. The family members experienced different emotions following their loved one's admission in the HCU and needed to adopt strategies that would help them cope with the admission. The family members stressed the importance of psychological healing following the death of a loved one.

It is important to support family members during the time that their loved ones are in the dying phase. The family members viewed HCPs’ support as valuing and respecting their cultural and spiritual practices and beliefs. The admission of a loved one in the ICU has a negative psychological and emotional effect on family members. Supporting family members during EOLC may help meet their cultural, spiritual, psychological and emotional needs. Many family members suffer anxiety and depression following a loved one’s admission in the ICU. HCPs should be culturally and spiritually sensitive when providing EOLC to patients. Accordingly, HCPs should gain skill and competency to become culturally sensitive practitioners. Cultural and spiritual sensitivity forms part of family-centred care in the ICU. Moreover, it is important for family members to receive formal counselling from HCPs and a multidisciplinary team like social workers, psychologists, and a chaplain.

5.3.4 Theme 4: Communication

The family is central to EOLC in the ICU, therefore it is important to know how to communicate with them. Healthcare professionals should use effective communication with relatives at the end-of-life care of their loved one. HCPs must provide accurate, clear, honest information to enable families to make EOL decisions. Communication is an important element in EOLC conversations with family members.

During communication with family members HCPs should be aware of their language when talking to family members. Simple language is important because the family members need to understand and make informed decisions. Open and clear communication prepares the family members for what to expect during the dying process. Honest and effective communication with relatives is associated with family satisfaction. EOL communication remains with the family members long after the death of their loved one.

5.4 STRATEGIES TO ENHANCE FAMILY MEMBERS' EXPERIENCES OF END-OF-LIFE CARE

The HCPs identified strategies to improve family members' experiences of EOLC in the high care unit. The strategies were related to quality of care, compassion, support structure, and communication.

5.4.1 Quality of EOLC to patients

HCPs should provide quality care and manage patients with dignity and ensure the comfort of the patient during EOLC.

- Ensure the patients are pain free at all times, and inform family of pain management schedule.
- Ensure comfort of patient during EOLC
- Give special attention to patient physical appearance and cleanliness of the environment.

5.4.2 Compassion EOLC

Hospital management and HCPs should

- Develop policies that allow flexible or open family visiting times.
- Prepare information leaflets to explain the HCU/ICU environment and how HCPs care for EOL patients and their family members.
- Give family member time during visiting hours to express their fear and answer questions honestly to alleviate fear.
- Display empathy and compassion to family member during this stressful time.

5.4.3 Support structures during EOLC

Hospitals should incorporate in-service training on cultural diversity.

Hospitals and HCPs should

- Encourage and support spiritual practices in the HC unit during EOLC.
- Acknowledge different cultural, spiritual beliefs of their patients and family members
- Provide support services e.g. counsellors, pastors to support family with acceptance and coping strategies.
- Establish support groups for families during and after EOLC

5.4.4 Communication to facilitate ELOC to families

HCPs should

- Encourage and practice open and honest communication with family members and constantly inform family about the patient's condition.
- Have regular family meetings to keep family updated and answer questions.
- Use general, layman's terms when talking to family members.
- Give honest and realistic outcomes to family members

5.5 RECOMMENDATIONS

Based on the findings and their implications, the researcher makes the following recommendations for practice, education and management, and further research.

5.5.1 Practice

The HCU and HCPs should

- Adopt a family-centred approach during EOLC
- Should regard compassionate care as a cornerstone when supporting family members during EOLC of their loved ones.
- Ensure that patients are kept pain free
- Provide culturally and spiritually sensitive health care to patients and their families
- Allow family members to practise their cultural and spiritual practices when their loved ones receive EOLC in the HCU.

- Continuous involvement of the family members can improve their experiences in the ICU
- Encourage and facilitate continuous professional development to enable HCPs to communicate effectively with family members.
- Provide honest, clear information to avoid false hope, and have regular meetings with family members to give ongoing information so family understand developments.

5.5.2 Education

Medical and nursing education should include the following:

- Undergraduate curricula for nursing and medical students should include EOLC for both patients and their families.
- HCPs should be trained in how to comfort family members, show compassion to family members, and counsel family members whose loved ones are at the end of life.
- Nursing and medical students should be taught soft skills to assist them providing comfort to family members during the EOLC of their loved ones.
- Cultural and spiritual diversity should form part of formal training in undergraduate nursing and medical programmes.
- Ongoing in-service training should be provided on culture and spirituality in hospitals.

5.5.3 Further research

Further research should be conducted on the following topics:

- An exploration of development programmes for HCPs to render quality EOLC to patients and their families
- PCPs' perceptions of providing compassionate EOLC for patients and family members
- An exploration of HCPs' cultural and spiritual beliefs during EOLC
- Nurses' perceptions of barriers and facilitators to providing quality EOLC in the HCU to patients and family members

5.6 LIMITATIONS

The study was limited to ten (10) family members of patients who received end-of-life care in the HCU of one provincial hospital in Gauteng, therefore the results cannot be generalised. Studies with more participants in bigger hospitals in other provinces might provide similar or different findings.

5.7 PERSONAL REFLECTION

At the outset, I felt lost and unsure whether I had done the right thing in enrolling for a master’s degree. Over the three years of study, I discovered and embarked on a journey of personal and professional growth. The opportunity of researching within critical care nursing practice provided fulfilment. During data collection from family members, I found it very difficult because of the emotions evoked during interviews. In fact, I even regretted choosing the topic and research method. Some family members had very raw emotions and others changed their minds on the dates of the interviews, saying that it would not bring their loved ones back.

The Covid pandemic made the third year of my studies very trying. It was a tough and difficult year as one of the front liners. A new way of life had to be adopted and by the grace of God I managed to fight the pandemic without being infected, that is grace at its best. The support from my supervisors and family pulled me through. At the end of this study, I feel I have grown in nursing and research, and wish to continue studying for a doctoral degree.

5.8 CONCLUSION

This chapter concluded the study, briefly described the findings and limitations of the study, presented the strategies to enhance family members’ EOLC experiences, and made recommendations for further research.

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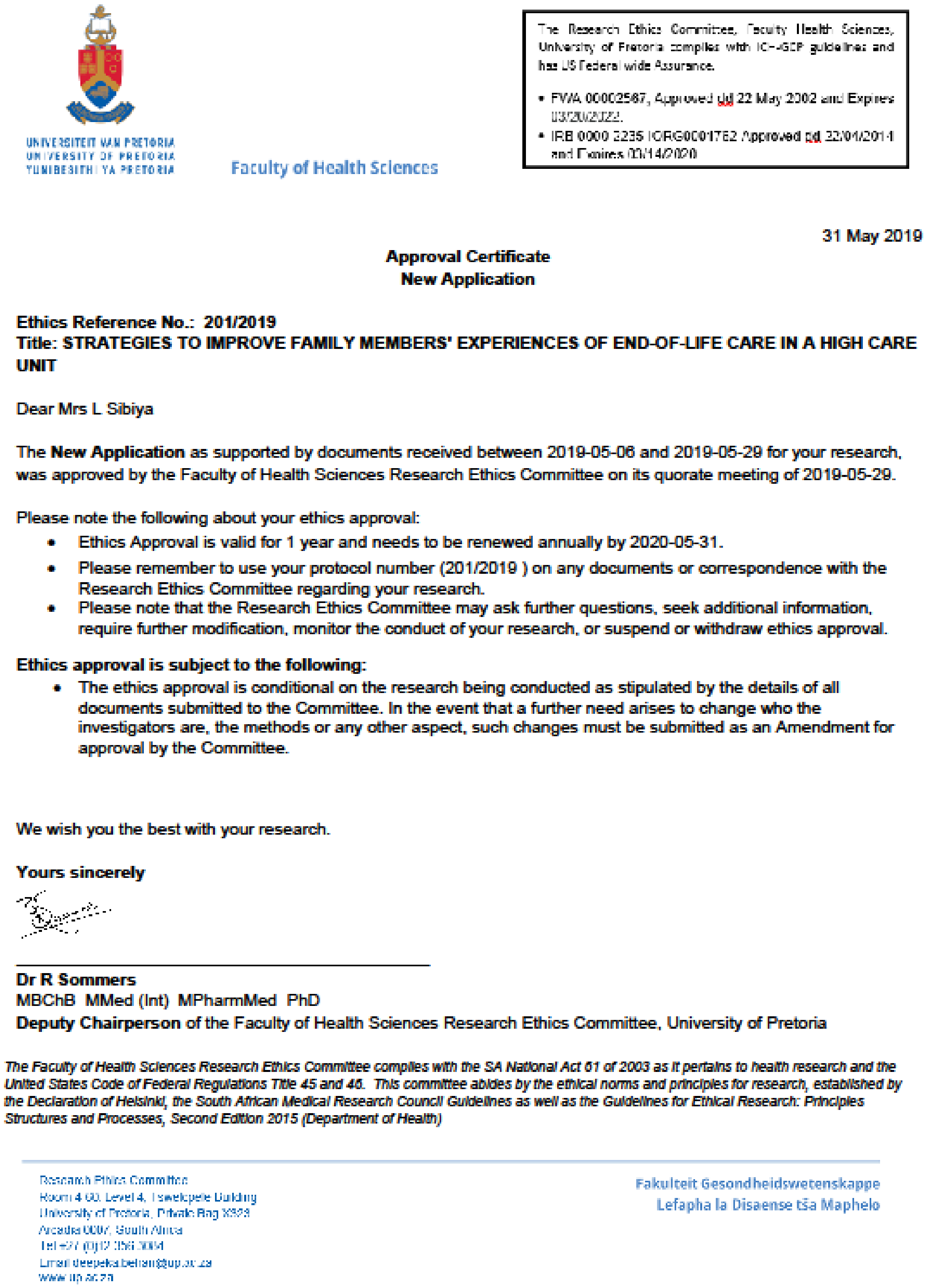
ANNEXURE A1

UP ETHICS APPROVAL



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020

31 May 2019

Approval Certificate
New Application

Ethics Reference No.: 201/2019
Title: STRATEGIES TO IMPROVE FAMILY MEMBERS' EXPERIENCES OF END-OF-LIFE CARE IN A HIGH CARE UNIT

Dear Mrs L Sibiya

The **New Application** as supported by documents received between 2019-05-06 and 2019-05-29 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 2019-05-29.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2020-05-31.
- Please remember to use your protocol number (201/2019) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers
MBChB MMed (Int) MPharmMed PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

Research Ethics Committee
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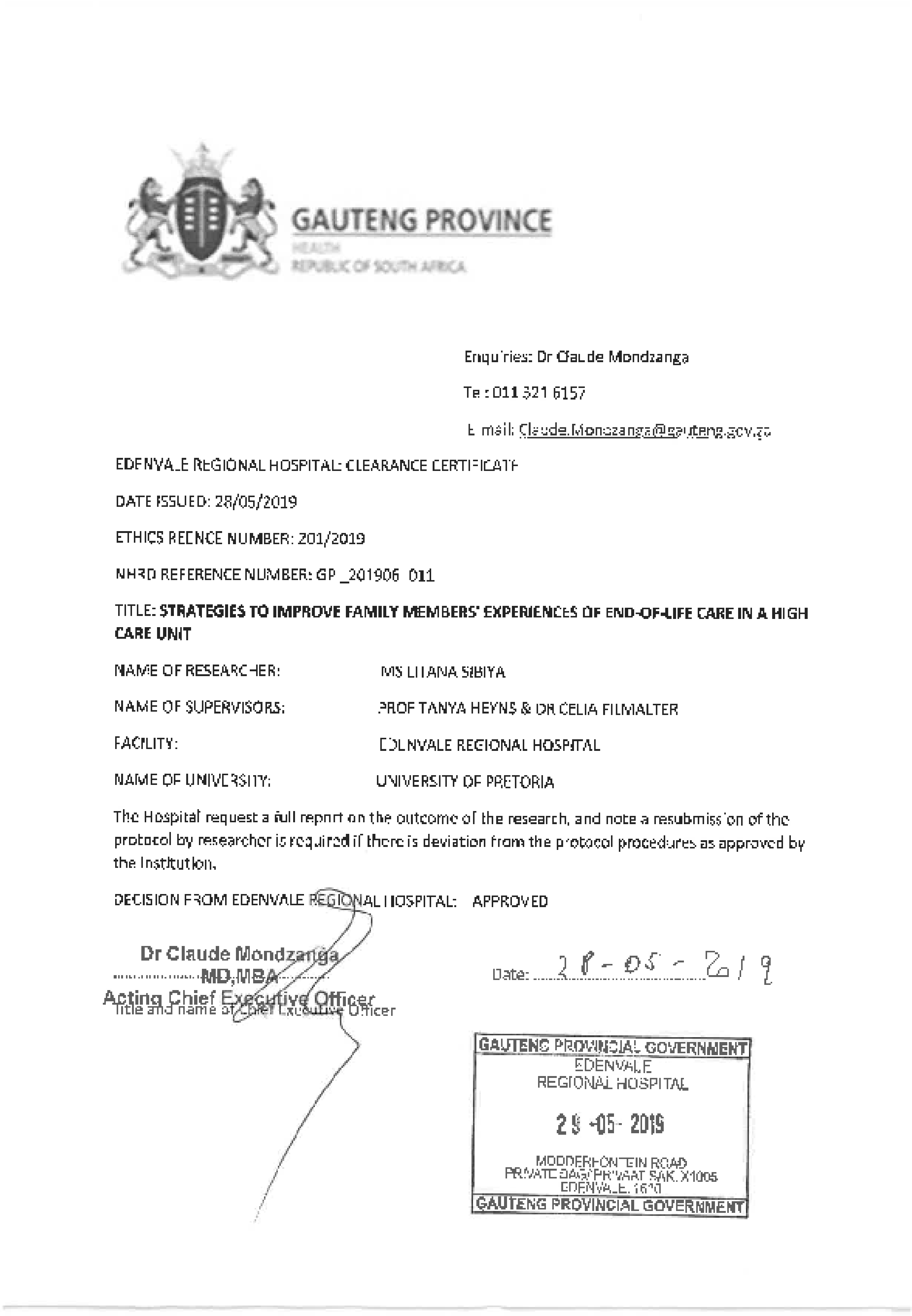
Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

ANNEXURE A2

THE HOSPITAL ETHICS APPROVAL



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr Claude Mondzanga

Tel: 011 321 6157

E-mail: Claude.Mondzanga@gauteng.gov.za

EDENVALE REGIONAL HOSPITAL: CLEARANCE CERTIFICATE

DATE ISSUED: 28/05/2019

ETHICS REFNCE NUMBER: 201/2019

NHRD REFERENCE NUMBER: GP _201906 011

TITLE: **STRATEGIES TO IMPROVE FAMILY MEMBERS' EXPERIENCES OF END-OF-LIFE CARE IN A HIGH CARE UNIT**

NAME OF RESEARCHER:	MS LITANA SIBIYA
NAME OF SUPERVISORS:	PROF TANYA HEYNS & DR CELIA FILMALTER
FACILITY:	EDENVALE REGIONAL HOSPITAL
NAME OF UNIVERSITY:	UNIVERSITY OF PRETORIA

The Hospital request a full report on the outcome of the research, and note a resubmission of the protocol by researcher is required if there is deviation from the protocol procedures as approved by the Institution.

DECISION FROM EDENVALE REGIONAL HOSPITAL: APPROVED

Dr Claude Mondzanga
MD,MBA
Acting Chief Executive Officer
Title and name of Chief Executive Officer

Date: 28-05-2019

GAUTENG PROVINCIAL GOVERNMENT
EDENVALE
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PRIVATE BAG/PRIVAAT SAK X1005
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ANNEXURE B1

PARTICIPANT INFORMATION LEAFLET – FAMILY MEMBERS

PARTICIPANT INFORMATION LEAFLET AND INFORMED CONSENT

ADULT FAMILY MEMBERS

STUDY TITLE: STRATEGIES TO IMPROVE THE FAMILY MEMEBERS EXPERIENCE OF END OF LIFE CARE IN HIGH CARE UNIT

Principal Investigator: Litana Sibiya

Institution: University of Pretoria

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers 0824756727

After hours: 0824756727

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Day	**Month**	**ear**		**Time**

Dear Participant,

Date of consent procedure _____./______./______

1) INTRODUCTION

I would like to invite you to participate in a research study. The information leaflet will help you decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of the study is to identify and explore strategies to improve the end-of-life experiences of family members in the high care unit. You as a participant are an important source of information.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

The researcher will be asking you questions during face-face interview. With your permission, the interview will be audio recorded. The interview will range between 30 and 45 minutes and the interview will take place at the hospitals' debriefing room away from the high care unit. The audio record will be kept for 15 years by the department of Health Science of the University of Pretoria.

- The researcher will ask the questions: How did you experience the process of end of life care rendered in the high care unit to your loved one?
- What would you recommend as absolutely important to ensure good end of life care in the high care unit?
- What are your wishes for future family members of patients receiving end of life care in the high care unit.

4) RISK AND DISCOMFORT INVOLVED

There are no risks involved in taking part in the study. However, there may be a possibility of feeling uncomfortable and feeling distraught due the questions that I am going to ask which may remind you of unpleasant memories. Feel free to ask to stop at any given time then continue when calm or ready to continue. You also have a choice of not answering. If you wish support I will also have a psychologist on standby.

5) POSSIBLE BENEFITS OF THIS STUDY

There will be no direct benefit to you from participating in this study. Your participation will enable me and you in understanding the experiences of family members whose loved ones are being given end of life care. The study will help in quality improvement in patient care in high care unit. There will be strategies drawn up to improve family member's experience of end of life care in high care unit.

6) I UNDERSTAND THAT IF I DO NOT WANT TO PARTICIPATE IN THIS STUDY, I WILL NOT BE VICTIMISED

Your participation is completely voluntary. You may refuse to participate or stop at any time during the study without giving any reason.

7) I MAY AT ANYTIME WITHDRAW FROM THE STUDY

Your withdrawal will not affect you in any way.

8) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol will be submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval have been granted by that committee [201/2019]. The study will be structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding doctors in biomedical research involving human/subjects. A copy of the ethics approval letter may be obtained from the investigator should you wish to review it.

9) INFORMATION

If you have any questions about your participation in the research process, you should contact the researcher Litana Sibiya at the daytime and night-time numbers supplied at the beginning of this document.

Alternatively, you can contact any of my supervisors:

Prof Tanya Heyns	at 0832873929
Prof. Isabel Coetzee	071158904
Dr Celia Filmalter	0829575458.

10) CONFIDENTIALITY

All data collected during this study will be regarded as confidential. Your name as well as the names of other participants will not be reported on. Results will be published or presented in such a fashion that all participants remain unidentifiable.

11) CONSENT TO PARTICIPATE IN THIS STUDY

I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I understand that if I do not participate I will not be victimised. I hereby volunteer to take part in this study.

CONTACT DETAILS OF PSYCHOLOGIST

The researcher is of the opinion that wherever the interview might be the cause of emotional distress to the participant, participant welfare will in every case take priority over the needs of the research study. There will be a psychologist on standby during the interview. Zinakekele counsellors will be approached to provide counselling during and after the interview should you require counselling. The debriefing room where interview will be taking place there will be a phone and you will be helped to contact Zinakekele. You will be given Zinakekele business in order to contact them anytime the need arises.

The psychologist will be asked to provide you with counselling should you require counselling services.

Zinakekele counsellors 0800611169.

I have received a signed copy of this informed consent agreement.

____________________________ ______________________

Participant name Date

____________________________ ______________________

Participant signature Date

____________________________ ______________________

Investigator’s name Date

____________________________ ______________________

Investigator’s signature Date

____________________________ ______________________

Witness name Date

____________________________ ______________________

Witness signature Date

ANNEXURE B2

EXAMPLE OF TRANSCRIBED INTERVIEW

Interviewee: Participant 1

Interviewer: L Sibiya

Date of interview: 25/8/19 16:00

Location of interview: Debriefing room

List of acronyms: P=participant, R=researcher

R: Good afternoon and how are you mam?

P: I'm good thanks and yourself?

R: Thanks for coming to meet me my name is Litana Sibiya as I explained through our telephonic first encounter uhh that we as a hospital we are trying to embark on quality care improvement strategy, in all patients who were admitted or who are in high care in our hospital. Uhh on the day we spoke I heard you say you a student?

P: Yes

R: You are studying, what are you studying by the way?

P: I'm studying software engineering

R: Ok where?

P: At uhh a private institution called Bonjion campus.

R: That's nice is your studies so far?

P: Hmm so far is great and well luckily is my final year.

R: Wow, that's great I wish I can also say the same that also my studies are going well, but anyway thank you for coming it's through you that I'll be able to say that my studies is also going well. Laughing.

R: Ok. Uhh prior now to we start I want us to clarify some few information uhh which are a content of ehh patient information leaflet.

P: Ok

R: I want to ehh stress on the information of confidentiality, whatever we will be discussing now today is strictly confidential. The interview ehh in terms of data collected now your name won’t be there, it would be interpreted in such a way that nobody can identify who is talking or ehh whatever you have said and remember as I explained before that I said the results would be published unanimously in a fashion that you will remain unidentifiable. Okay another thing mam I would like to request remember that I did say the interviews will be recorded I just want to verify if you are still comfortable with us going ehh forward while I am recording this conversation that we are having. Thank you very much for your consent and then ehh for your information your information you must that there is a psychologist on standby, which is available should you feel emotional or distraught you can stop me at any time and also I can even identify so that we call the lady to intercede or intervene when you feel you are distraught or emotional about the whole interview process. Okay the interview you would be do much more of talking and I’ll listen, wherever I have queries or clarity seeking question then I will ask you, okay and remember now because of you want to better the service of patient care which we are rendering in our institution, whatever that I’m asking you there’s is no wrong or right answer. Just feel free to talk anything that you feel is relevant to the question that I am asking. Alright before we start are you still comfortable for us to go thru as you have consertered before, okay thank you very much uhh can you please tell me mam how was your experience in the process that ehh end of life care that was rendered by high care unit in our institution to your loved one while he still was admitted until his passing.

P: Ehh it was a very strange environment nothing new but also nothing usual but it was very quiet and all the machines was bipping at the time. Ehm the life support machine was on him which made it more ehh uncomfortable to be around that environment, ehh the environment was very very formal which made it more like of an anxious environment. Because you are with a person who does not speak and the only thing that you can hear within that environment is the machines so you feel alone in a way that’s why it makes you feel scared. Ja also in my way I wouldn’t have my uncle be in that position it would have been better to have him at home.

R: Why is that can you care to elaborate why specifically you would whished for him to be at home?

P: I think at home it would have been easier cos we would see him on a daily basis and we would be able to spend more time with him before his last days.

R: Okay I do understand. I see, all right I do understand.

R: Anything more that you can tell me about the experience as a whole?

P: The experiences as a whole uhhm with my uncle he's always been part of our lives and he's has always been a family man, so him dying or leaving us rather was a painful experience and left a gap.

R: I'm sorry for interrupting you, it left a cap in terms of what, and how did he leave the gap?

P: He stayed with our grandmother so basically, he was taking care of our grandmother. So with him passing on we would have to adjust our living condition because we cannot leave an old women alone. So one of us has to step in from where he left off. The situation was very stressful especially ahh knowing that he is in that state and the doctor had said that he has tried his best and cannot do anything about it ,is very stressful to wait for that specific moment where you get called and told that this person is no more. Ehh looking at ehh how he use to take care of my granny in terms of finances, it will be a drastic change in our family because he use to do everything for our granny so now it is a thing that we have to split the responsibilities as ehh family members in terms of financial responsibilities and all kind of responsibilities.

R: And then how was the interaction throughout his stay in the High care unit with health care providers?

P: Ehh the daily visits were essential to our family, although we had nurses around reassuring us his condition and if it was improving or not. The nurses were also there to encourage us because usually when you walk into a hospital the first person you see is a nurse, and you will ask the nurse did he eat today, how is his condition? They would always reassure us that he is well fed, he has taken a bath he's ok, he's fine. And they would also encourage us to speak to him like speak to him giving him encourages words, although it was a one way communication we would speak to him but he wouldn't respond. But the nurses would encourage us to speak to him more.

Ohh yes and with the communication it not easy when doctor brakes the news to the family. He broke to news to us to say that uhhm he has tried his best, and at that point there was nothing else he can do he has tried almost everything.

R: Ok on that level when the news were broken to you as family members ehh what transpired, how it made you feel on than particular moment when the doctor spoken to you about this?

P: It was very hard to accept but with your family around you act brave you try to stay strong especially for the people around you, but once I got home and I was alone it hit me that I might not see this person again I might not ever speak to my uncle again because to me he was like my friend. We would speak about anything and he was a man full of jokes so for me to accept that I cannot laugh at one of his jokes anymore it was a tremendous experience because……… Ja okay (silent).

R: Okay I see that he was a good man and again sorry for your loss that you had lost him and he passed on. Is there anything that you would add on the experiences throughout his stay in the high care unit that you feel is something worth sharing with me?

P: Uhm, the doctors honestly that is what I appreciated more than anything. Unlike having our hopes very high he was honest for the get go that my uncle’s condition was like this and this is what he has done. But at that point he couldn’t do anything more, which we also accepted as a family that now that everything is in God’s hands.

R: So now when you have to, after your acceptance that it is in God’s hands what have happened, what went through your mind as a family member having to to uhh wait what happened at that particular time?

P: During our waiting process it was very hard because now. We are in a position where we know that there is nothing that he can do now everything is in God’s hands. So for us going to the hospital on a daily basis is us hoping every day that he is still alive, although he would not respond but we would still talk to him telling him that we love him making sure that at least he gets those positive words so it was …. Pausing a very difficult time.

R: I am sure it was a difficult time for a families to go through that process hay?

P: Yes.

R: Now I am going to move over to the other question is what would you recommend very very and absolutely important to ensure that end of life care given in the high care unit it’s held high, meaning what is that you feel that this is important to recommend so that the future families members coming that we ensure that we do?

P: I would really recommend pastoral services in the high care.

R: Why specifically?

P: Because in most case we get to hospital and we find our love one on machines, we never understand why and how. So leaving your love one in that state it’s never easy and it’s never in a comfortable and positive way, so I think it would be best if you get ehhm spiritual weather is spiritual or professional help in a way talk to a pastor or priest as you are about to leave, or pray about this situation just get that burden off you. Because it not healthy driving in that state all the way and all you think about is that person that you have left in that hospital bed.

R: o Ja I see I am sorry

P: Another thing is the day to day discussion with the doctors. I would for my experience I would have appreciated if we had seen the doctor on a daily basis, to rather hear the news from the doctor himself because uhhm nurses cannot tell us all that he doctor has performed on the person. So I would recommend that doctors try I know doctors can be very busy, but try to see the family members of the patient more often and give us regular progress.

R: Updates?

P: Yes

R: Okay I see that any other thing that you would like to add or recommend the health care professionals can do to enhance the experiences?

P: Honestly and truthfulness about the condition and the treatment the person would be receiving. Most of the time we are just told these thing in medical terms which we do not understand as people, people only in the medical field would understand but we as everyday people we don't understand and ehhm we would also like to understand why this specific thing is given to a patient, unlike we get there no we gave him medication we did this we did that. I think it would be much better if we understood why this specific thing was given to him and also the update on the conditions on a regular unlike we had been in where person has been in the hospital for two weeks and the only update we had was from the first week that person had been admitted.

R: Okay that make sense and then what would be your future wishes to the family members receiving end of life care in high care unit? What would you wish that you know if this can be done it would improve the experience of family members that we as a hospital can implement so that our quality of care can be improved.

P: I would like to start flexibility of visiting hours.

R: Okay why specifically?

P: Usually visiting hours are only for an hour, hence I mentioned before that I would appreciated it that he was at home because we get to spend more time with our love one before they pass on. The visiting hours are not flexible they are limited and we would like to spend time with our love one and even assist getting to hospital and making sure that I bath my love one, I make sure he eats all those process would be appreciated. Also we usually don't understand the process are of withdrawing of the life support machine we usually just agree but we don't fully understand what is what.

R: So would you care to elaborate on the processes when they withdraw, what is it that you would like to see happening?

P: I would really like to understand at which point and which level do you do the withdrawal of the life support machine.

R: It makes sense what you saying.

P: And ehhm going back to the doctors making time for family members, like I said before that would be appreciated because when we leave our loved ones in the hospital we leave them in the doctor’s hands. So we’d like regular updates and all those we would really appreciate them as family members of patients.

R: Ok, ok I do get it.

P: And with the languages that ehhm our doctors and nurses use, sometimes we do not understand. We do not understand the terms, so I think it would be better if they use the layman language.

R: Yes

P: Because that would be much better or if there is a word that is within the medical term can they at least elaborate and make us understand what it really means because sometimes you are stressed you do not even have time to ask what does this means you just agree to everything they say.

R: OK, all right is there anything that you would uhh like to add that you feel is important for me to know uhh during this interview?

P: No

R: Okay is there anything that you would like to ask me?

P: About?

R: Anything

P: Uhhm with the nurses in the high care are they not allowed to disclose the information

R: Okay Yes can disclose information up to a certain level, ehh remember nurses yes they are independent practioners but doctors they are the once who can elaborate more. Ehh they can, the nurses can only disclose up to within their competency level or their knowledge. You understand?

P: Yes

R: Anything you feel you're not answered fully on then the doctor can always come and explain further, but then they can be able to explain within their competency level what they know about the condition and anything.

P: Well then I think it would be my wish for nurses, because they are available all the time. To disclose this other information to us, because is not always that we go to hospital and we find the doctor it's is very rare sometimes never. So I think it would be better if nurses were able to communicate with us as family members of patients, and disclose information that they cannot.

R: Ok

P: Yes

R: All right thank you very much for coming over mam, once again ehh definitely whatever we have shared through our interviews ehh we will strive to draw or improve our service in terms of whatever level that you have shared to us. Then ehh there will be strategies that will be identified to improve quality care in our institution as a whole.

P: Ok

R: Thank you very much for your time have a lovely journey back home, thank you very much appreciated.

P: Thank you very much.

ANNEXURE C1

WORKSHOP INVITATION

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

Navrae / Enquiries:

Private Bag X323 ARCADIA 0007 Pretoria – Republic of South Africa

Web: https://www.up.ac.za Tel: (012) 354-2125 Fax: (012) 354-1490

☎ : (012) 354-2125

🖷 : (012) 354-1490

💻 :tanya.heyns@up.ac.za

Dear healthcare professionals

As healthcare professionals working in the High Care Unit, you are invited to an event:

Let's listen to our peoples' voice

Aim	Identify strategies to improve the end-of-life care experiences of family members in the High Care Unit.
Date	12th March 2020
Time	08:00 to 11:00
Venue	Edenvale Hospital ground floor boardroom
Researcher	Litana Sibiya +27 824756727 litana.sibiya@gauteng.gov.za

Programme

Timeframe	Activities
08:00 to 08:20	Getting acquainted
08:20 to 08:30	Opening
08:30 to 09:30	Sharing patient’s family member’s experiences
09:30 to 10:15	Strategies to improve the family member’s experience of end of life care in high care unit
10:15 to 10:30	Break
10:30 to 11:00	Way forward
11:00 to 11:30	Closing

Please R.S.V.P. before the 10 March 2020. Your participation, collaboration and valuable inputs is of high importance.

Regards

Litana Sibiya

ANNEXURE C2

PARTICIPANT INFORMATION LEAFLET – HEALTHCARE PROFESSIONALS

PARTICIPANT INFORMATION LEAFLET AND INFORMED CONSENT

HEALTHCARE PROFESSIONALS

STUDY TITLE:: STRATEGIES TO IMPROVE THE FAMILY MEMEBERS EXPERIENCE OF END OF LIFE CARE IN HIGH CARE UNIT

Principal Investigators: Litana Sibiya

Institution: University of Pretoria

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers 0824756727

After hours: 0824756727

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Date	**Month**	**Year**

Time

Dear Colleague,

Date of consent procedure _____./______./______

1) INTRODUCTION

I would like to invite healthcare professionals that work in high care unit to take part in this study. The information leaflet will help you decide if you would like to participate. Before you agree you should fully understand what is involved. Please note that no remuneration will be provided for participation in this research study.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of the study is to identify strategies to improve the end-of-life care experiences of family members in the high care unit.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

Once you have decided to participate, you will be invited to actively participate in a data analysis workshop at _12 March 2020 on Thursday which will take up approximately four hours (09:00 to 13:00) of your time and include:

The researcher will ask you to collaborate work with the analysis of the data obtained from the adult family members who have provided the researcher with information their experiences in the high care unit when their loved ones died. You will be asked to collaboratively identify strategies to improve end-of-life care in the high care unit, based on reflections from feedback from the family members.

4) RISK AND DISCOMFORT INVOLVED

There are no risks involved in taking part in the study. However, there may be a possibility of feeling uncomfortable and feeling distraught due the feedback from family members which may remind you of unpleasant memories. Feel free to ask to stop at any given time then continue when comfortable and ready. You also have a choice of not answering

5) POSSIBLE BENEFITS OF THIS STUDY

There will be no direct benefit to you from participating in this study. Your participation will enable me and you in understanding the experiences of adult family members whose loved ones are being given end of life care. The study may help in quality improvement in the care families when their loved ones are at the end-of-life care in high care unit. The identified strategies drawn up may be implemented in your unit to improve family member's experience of end of life care in high care unit.

6) I understand that if I do not want to participate in this study, I will not be victimised in the high care unit and it will not influence my performance management

Your participation is completely voluntary. You may refuse to participate or stop at any time during the study without giving any reason.

7) I may at any time withdraw from the study

8) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol will be submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria have granted ethics approval for the study [201/2019]. The study will be structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding doctors in biomedical research involving human/subjects. A copy of the ethics approval letter may be obtained from the investigator should you wish to review it.

9) INFORMATION AD CONTACT PERSON

If you have any questions about your participation in the research process, you should contact the researcher Litana Sibiya at the daytime and night-time numbers supplied at the beginning of this document.

Alternatively, you can contact any of my supervisors:

Prof Tanya Heyns	0832873929
Prof. Isabel Coetzee	071158904
Dr Celia Filmalter	0829575458.

10) CONFIDENTIALITY

All information collected during this study will be regarded as confidential. Your name as well as the names of other participants will not be reported on. Research reports and articles will not any information that may identify you as a participant. Information will not be disclosed to any third party without your written permission.

11) COMPENSATION

This study is completely voluntary and there is not compensation for your participation.

CONTACT DETAILS OF PSYCHOLOGITS

The psychologist will be asked to provide you with counselling should you require counselling services.

Zinakekele counsellors 0800611169.

CONSENT TO PARTICIPATE IN THIS STUDY.

I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate I will not be victimized. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

___________________________ ______________________

Participant name Date

___________________________ ______________________

Participant signature Date

___________________________ ______________________

Witness name Date

___________________________ ______________________

Witness signature Date

___________________________ ______________________

Investigator’s name Date

___________________________ ______________________

Investigator’s signature Date

ANNEXURE D

DECLARATION FROM THE EDITOR

Cell/Mobile: 073-782-3923

53 Glover Avenue
Doringkloof
0157 Centurion

6 June 2021

TO WHOM IT MAY CONCERN

I hereby certify that I have edited Litana Sibiya’s Master’s dissertation, **Strategies to improve family members’ experience of end-of-life care in a high care unit**, for language and content.

IM Cooper

Iauma M Cooper

192-290-4