

**LIVED EXPERIENCES OF FAMILY MEMBERS OF PATIENTS ADMITTED TO THE
INTENSIVE CARE UNIT AT THE ADULT UNIVERSITY TEACHING HOSPITAL,
LUSAKA, ZAMBIA**

BY

CYNTHIA S. PHIRI

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DECLARATION

I, Cynthia S. Phiri, solemnly declare that this dissertation is my original work. I am the sole author and all the content presented herein is a result of my own work. Any contributions or assistance from other individuals has been duly acknowledged.

I further declare that all sources of information and data used in this report, whether published or unpublished, have been appropriately cited and referenced in accordance with the academic and ethical standards. The dissertation has not been previously submitted at University of Zambia or any other university. I am submitting it for the Degree of Master of Critical Care Nursing.

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ABSTRACT

Family members of patients in the Intensive Care Unit (ICU) play a crucial role in the care and support of their loved ones. Understanding their experiences, challenges, and needs is essential for providing effective family-centered care in the ICU setting. This study therefore sought to explore the lived experiences of family members of patients admitted to the ICU at the Adult University Teaching Hospital in Lusaka, Zambia. This qualitative study used in-depth interviews with 12 family members of patients admitted to ICU to gather their perspectives and experiences of having a family member admitted to ICU. Thematic analysis using NVIVO 14 was used to identify notable patterns and themes within the narratives of the participants. Thematic analysis revealed four key themes, which were (1) emotional impact, (2) communication challenges, (3) support systems and (4) healthcare system. Emotional impact emerged as a significant theme, highlighting feelings of fear, anxiety, and stress due to uncertainty and the critical condition of their loved ones. Communication challenges were also prominent, with participants expressing difficulties in understanding medical information and feeling excluded from decision-making processes. Coping mechanisms revealed reliance on social support, spirituality, and practical strategies to navigate the stress of having a loved one in the ICU. Lastly, the healthcare system experience revealed mixed experiences, with some family members expressing trust and satisfaction in healthcare providers, while others reported feeling overwhelmed and neglected. The study revealed that admission of a loved one to ICU is a stressful event in the lives of family members. Family members of ICU patients experienced significant stress and anxiety, primarily due to inadequate communication and emotional support. It is therefore recommended that healthcare providers implement structured communication protocols and provide dedicated support services to enhance the experiences of both patients and their families.

Keywords: Family-centered care, Intensive Care Unit, experiences, challenges, coping strategies, Emotional impact

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LIST OF ABBREVIATIONS

ICU	Intensive Care Unit
FCC	Family Centered Care
CINAHL	Cumulative Index to Nursing and Allied Health Research
UTH	University Teaching Hospital
AUTH	Adult University Teaching Hospital
UNZABREC	University of Zambia Biomedical Research Ethics Committee
UNZASON	University of Zambia School of Nursing Sciences
NHRA	National Health Research Authority
SHEPIZ	Strengthening Health Professional Workforce Education Program for Improved Quality Healthcare in Zambia

CHAPTER ONE

INTRODUCTION AND BACKGROUND

1.1. INTRODUCTION

The intensive care unit (ICU) is a specialized department within a hospital that provides critical care to patients with life-threatening conditions. During an ICU admission, patients often require advanced medical interventions, constant monitoring, and a highly specialized healthcare team. There is increasing recognition of the important role of family members in the ICU. Many ICU patients are unable to communicate with healthcare staff or participate in decision-making about their treatment due to the severity of their illness. Consequently, healthcare professionals are increasingly approaching family members to speak for them and expanding the care and support provided from the patient to their family as well Al-Mustair et al (2013).

Family-centered care (FCC) in the (ICU) is an approach that recognizes the pivotal role of family members in the care and well-being of critically ill patients Gerritsen et al (2017). It involves open communication, collaboration, and shared decision-making between healthcare providers and family members to ensure that patient care aligns with the unique needs and preferences of both the patient and their family. FCC is crucial in acknowledging that the experiences and needs of family members are integral to the overall quality of care provided in the ICU. Importantly, it helps mitigate the profound emotional stress and uncertainty that families often face in critical situations, fostering a more supportive and compassionate healthcare environment.

There is limited research describing family experiences whilst in ICU and structured interventions that might support them during the patient's critical illness in Zambia. It is for this reason that this study was conducted to explore the lived experiences of family members of patients admitted to ICU.

This chapter provides an overview of the topic. The chapter is divided into six sections, which include background of the study, problem statement, study justification, research objectives, definitions key terms and conclusion.

1.2. BACKGROUND INFORMATION

Family-centered care in the ICU has gained significant attention in recent years due to its positive impact on patient outcomes and family well-being. Research findings consistently support the notion that involving and engaging families in the care process leads to improved patient satisfaction, reduced anxiety and stress levels among family members, and better communication between healthcare providers and families. A study by Davidson et al. (2018) highlighted that family-centered care interventions in the ICU were associated with decreased lengths of stay and reduced healthcare costs. Additionally, a systematic review by Kynoch et al. (2020) emphasized the importance of family involvement in decision-making, providing emotional support, and facilitating the transition from ICU to home. These findings underscore the significance of implementing family-centered care strategies in the ICU, ultimately leading to better patient outcomes and enhanced family experiences.

The experience of having a loved one admitted to ICU can be an emotionally and physically challenging ordeal for family members. Globally, research highlights that family members of ICU patients commonly experience significant distress due to uncertainty about their loved one's prognosis, complex medical terminology, and inadequate communication with healthcare providers (Jones et al, 2016). Family members of ICU patients often experience a range of emotions, including anxiety, fear, uncertainty, and stress due to the severity of the patient's condition and the unfamiliarity of the ICU environment. Admission to ICU often occurs suddenly and members of the family think of a possibility of their loved one dying or being severely disabled (Foster et al., 2016).

Communication challenges further exacerbate the situation. Studies have shown that families often experience inadequate information sharing, poor communication with healthcare providers, and difficulties understanding complex medical information (Puntillo et al., 2016). This can lead to increased anxiety, feelings of powerlessness, and a lack of trust in the healthcare team. For instance, a study by Schwarzkopf et al. (2018) conducted in Germany found that poor communication and lack of information were the primary contributors to family members' emotional distress. Similarly, a study in the United States by Khan et al. (2020) demonstrated that consistent, empathetic communication significantly alleviated the anxiety of family

members, emphasizing the critical role of healthcare providers in supporting families emotionally and psychologically. Effective communication and information provision are vital components of family-centered care in the ICU. Family members often desire clear and timely information about the patient's condition, prognosis, treatment options, and care plans. Inadequate communication can lead to increased stress and dissatisfaction among family members (Davidson et al., 2017). Studies have highlighted the need for improved communication practices and family involvement in decision-making to enhance the overall experience for families

Family members of ICU patients have unique support needs that should be addressed to promote their well-being. These needs encompass emotional support, information resources, counseling services, and opportunities for involvement in the care process (Moons & Norekval, 2018). Identifying and addressing these needs through tailored interventions and support programs can alleviate stress and enhance the overall experience for family members. The needs of the family members are often disregarded because attending to a critically unstable patient takes precedence. However, addressing the needs of family members remains an integral part of the comprehensive intensive care approach. Family members often play a significant role in promoting the psychological wellbeing of a critically ill patient by their familiar and caring presence, their meaningful interaction with the patient, and their collaboration with the healthcare team in caring for the patient (Brysiewicz & Beer, 2016).

The process of decision-making and the involvement of family members in the care of ICU patients are complex and emotionally challenging. Family members may face difficult decisions regarding treatment options, resuscitation preferences, and end-of-life care. Their experiences related to decision-making and involvement in the patient's care play a crucial role in shaping their overall experience (White et al., 2018). Understanding their perspectives can guide healthcare providers in offering appropriate support, shared decision-making models, and palliative care options.

Despite arguments made by researchers and policymakers on the value of patient-family-centered care, there is no clear consensus among stakeholders about the type and degree of patient and family involvement throughout the delivery of care (Olding et al., 2016). Understanding how

families make sense of their experience in the hospital is instrumental to develop hospital based guidelines and protocols in order to implement the family-centered care.

Research focusing on the experiences of family members, particularly mothers in neonatal intensive care units (ICUs) in Zambia has highlighted significant emotional and psychological challenges. A study conducted at the Women and Newborn Hospital in Lusaka explored the experiences of parents with preterm infants in the Neonatal Intensive Care Unit (NICU). The findings revealed that parents often faced stressors related to communication barriers, insufficient emotional support, and limited involvement in the care of their infants. These stressors contributed to heightened anxiety and feelings of helplessness among parents (Zulu et al., 2024). Similarly, research examining the stressors perceived by mothers with infants admitted to the NICU at the same hospital identified environmental factors, such as the unfamiliar and technologically intensive setting, as significant contributors to maternal stress. The study emphasized the need for healthcare providers to recognize and mitigate these stressors to improve maternal well-being and promote better outcomes for both mothers and infants (Masumo et al 2019).

While these studies provide valuable insights into the experiences of mothers and families in neonatal ICUs in Zambia, there is a notable paucity of literature addressing the experiences of family members in adult ICUs within the country. The researcher did not find any official guideline in Zambia regarding the involvement of family members in ICU care. Therefore, this study sought to understand the unique challenges, needs, and coping mechanisms of families in this setting, as it is crucial for developing culturally appropriate and context-specific interventions to improve their well-being and support their resilience during this challenging time.

1.3. STATEMENT OF THE PROBLEM

Family members of ICU patients experience a range of profound emotional and psychological consequences; including anxiety, depression, and post-traumatic stress disorder (Jones et al., 2015; Harvey et al., 2019). The emotionally charged atmosphere of the ICU, coupled with the severity of their loved one's condition, can lead to high levels of stress, anxiety, and emotional distress (Davidson et al., 2017).

Despite the significant impact of the ICU experience on families, limited research has explored the lived experiences of family members in specific contexts, particularly in resource-limited settings like Zambia. The researcher did not come across any published information describing the lived experiences of family members specifically in the context of the Adult University Teaching Hospital (UTH) ICU. Thus, there is a gap in understanding the unique lived experiences of these family members and how their emotional and psychological needs can be addressed. In addition, lack of understanding may lead to unmet needs and unresolved trauma, which can have long term effects on their mental health and ability to provide support to the patient during and after ICU stay. Therefore, this research sought to provide an in-depth understanding of the unique experiences of family members in the ICU setting at Adult UTH ultimately contributing to the enhancement of care and support for both patients and their families.

1.4. STUDY JUSTIFICATION

Family-centered care has been emphasized as an integral part of ICU practice in recent years. However, studies indicate that family members frequently experience unmet needs related to information, emotional support, and inclusion in decision-making (Hartog & Benbenishty, 2015). Poor communication between healthcare providers and families has been identified as a significant source of distress, contributing to feelings of helplessness and dissatisfaction with care (Davidson et al., 2017). Addressing these gaps is vital for enhancing the quality of care provided in the ICU and improving outcomes for both patients and their families.

Research conducted in high-income countries has extensively documented the needs and coping mechanisms of family members of ICU patients, but there is a lack of context-specific studies in

sub-Saharan Africa, including Zambia. Socioeconomic, cultural, and healthcare system differences may influence how family members experience and respond to the ICU environment. For example, studies from other African countries have highlighted unique challenges related to financial constraints, cultural expectations, and inadequate institutional support systems (Abate et al., 2020; Egbe et al., 2021).

The lived experiences of family members of ICU patients are often characterized by intense emotional, psychological, and practical challenges, yet this area remains underexplored, particularly in low-resource settings such as Zambia. Existing studies in Zambia have mainly focused on the experiences of mothers in neonatal ICU. For instance, a study by Masumo et al (2019) focused on the perception of stressors by mothers with babies admitted to the neonatal intensive care unit, which, found that most participants experienced a lot of stress arising from their baby being admitted to ICU. Another study by Mwila (2024) focused on the experiences of ICU nurses Caring for COVID-19 patients in Zambia. The focus of these studies were mothers of babies admitted to the neonatal ICU and on the nurses working in ICU respectively, leaving the experiences of family members of adult patients in ICU patients unexplored.

By exploring the lived experiences of family members, the study provided valuable insights for healthcare providers, policymakers, and hospital administrators to improve communication, support systems, and overall family satisfaction in ICU settings. These improvements will ultimately contribute to better patient outcomes and a more compassionate and inclusive approach to critical care.

1.5. RESEARCH OBJECTIVE

To explore lived experiences of families of patients admitted in the ICU at the Adult University Teaching Hospital, Lusaka Zambia.

1.6. RESEARCH QUESTION

What are the lived experiences of families of patients admitted in the ICU at the Adult University Teaching Hospital?

1.7. DEFINITION OF TERMS

1.7.1. Conceptual Definitions

1. **Lived experiences:** Lived experiences refer to the subjective perceptions, feelings, thoughts, and actions of individuals in a specific context or phenomenon. It encompasses the personal and unique perspectives shaped by an individual's interactions, beliefs, and values (Cresswell & Poth, 2017).
2. **Family members:** Family members refer to individuals who share a significant familial relationship with a particular individual, typically through biological, legal, or emotional ties. They may include immediate family such as parents, siblings, and children, as well as extended family members like grandparents, aunts, uncles, and cousins (Boss, 2017).
3. **Family-Centred Care:** This refers to a partnership approach to health care decision-making between the family and health care provider. It emphasizes family respect and dignity, promotes empathy and understanding, opens communication, collaboration, and shared decision-making between healthcare professionals and the family members (Weinberger et al, 2014).

1.7.2. Operational Definitions

1. **Communication Challenges:** Difficulties or barriers faced by family members in receiving timely, clear, and understandable information from healthcare providers about the patient's condition, prognosis, and treatment plans, as well as challenges in expressing their own concerns or participating in decision-making as described by Schwarzkopf et al. (2018) .
2. **Emotional Distress:** Emotional distress encompasses a range of negative emotional states experienced by family members, including but not limited to: anxiety, fear, sadness, grief, anger, guilt, and hopelessness.
3. **Lived Experience:** This refers to the subjective and personal meaning and significance of the ICU experience for family members. It encompasses their thoughts, feelings, emotions, perceptions, and behaviors as they navigate the challenges associated with having a loved one in the ICU. This includes their emotional responses, coping mechanisms, and how the experience impacts their daily lives, relationships, and overall well-being.

4. **Coping Mechanisms:** The strategies, behaviors, or practices adopted by family members to manage the emotional, psychological, and practical challenges of having a loved one admitted to the ICU. Examples include prayer, seeking social support, or engaging in self-care routines.
5. **Support Systems:** For this study, support systems are defined as formal and informal networks that provide emotional, informational, financial, or practical assistance to family members. These include healthcare providers, extended family, friends, religious institutions, and community resources.

CHAPTER TWO

LITERATURE REVIEW

2.1. INTRODUCTION

The experiences of family members with a loved one admitted to the ICU have gained significant attention in recent years. Understanding the lived experiences of these family members is crucial for developing effective strategies to support them during their challenging journey. This literature review aims to explore the existing research on the lived experiences of family members of patients admitted to the ICU globally, regionally and nationally. It focuses on an analysis of published writing in books, journals and research articles related to the problem of the study. A comprehensive search was conducted in Google scholar; Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Google search were used to find related papers and research study records. Relevant keywords such as “ICU,” “family members,” “lived experiences,” “family member’s needs” and “patient support” were used to search for articles. Articles reviewed included qualitative, quantitative and mixed method studies published within the last 10 years to ensure the inclusion of recent research. Only studies written in English were included in this review.

The chapter is organized into sections that explored an overview of the lived experiences of family members of ICU patients, the socio-demographic characteristics of family members of ICU patients, emotional distress and psychological impact, communication challenges and the needs of family members of ICU patients. Each section builds on existing literature to identify gaps and suggest strategies for improving family centered care ICU settings.

2.2. OVERVIEW OF LIVED EXPERIENCES OF FAMILY MEMBERS OF ICU PATIENTS

The intensive care unit (ICU) is a critical care environment where patients with life-threatening illnesses or injuries are treated. While the focus is on patient care, the ICU experience significantly affects the lives of family members (Danielis et al, 2024). Research within the past decade has highlighted the multifaceted and often-traumatic experiences of these individuals.

Studies have consistently shown that family members of ICU patients experience high levels of emotional distress, including anxiety, depression, and post-traumatic stress disorder (PTSD) (Jones et al 2015: Jones et al 2018). These psychological impacts can persist long after the patient's hospitalization, affecting their overall well-being and quality of life. A critical aspect of the ICU experience for families is the need for timely and accurate information about the patient's condition. However, studies have revealed communication gaps between healthcare providers and family members, leading to frustration, uncertainty, and a lack of trust (Curtis and Patrick, 2010: Puntillo et al 2016). Effective communication strategies that address family members' information needs are crucial for improving their experience and reducing distress.

The ICU experience can also have significant social and economic consequences for families. The financial burden of hospitalization, along with the emotional and physical demands of caregiving, can strain family relationships and disrupt daily routines (Harvey et al., 2019). Additionally, the social isolation and stigma associated with critical illness can further exacerbate the challenges faced by families (Azoulay et al., 2018). In addition, research has identified the importance of social support and coping mechanisms in mitigating the negative impact of the ICU experience on family members. Access to support groups, counseling services, and other forms of emotional support can be beneficial in helping families cope with stress and trauma (Nelson et al., 2017: Jones et al, 2019).

In conclusion, the ICU experience profoundly affects family members, resulting in significant emotional distress, communication challenges, and social and economic burdens. Recognizing the unique needs of families are crucial for improving their well-being and supporting their resilience during this challenging time.

2.3. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF FAMILY MEMBERS OF ICU PATIENTS

The lived experiences of family members of ICU patients are significantly influenced by their sociodemographic characteristics. These factors can shape their access to information, social support, and coping resources, ultimately impacting their emotional well-being and overall resilience (Rahman et al, 2021). Regarding age and gender, studies have shown that younger

family members may experience higher levels of anxiety and distress due to their perceived vulnerability and limited life experience with critical illness (Jones et al, 2015). Gender differences in coping strategies and emotional expression may also influence the ICU experience.

Higher levels of education may be associated with better understanding of medical information and improved communication with healthcare providers (Curtis and Patrick, 2010). However, socioeconomic disparities can limit access to quality healthcare, social support, and financial resources, exacerbating the challenges faced by families during the ICU experience (WHO, 2024). In addition, Cultural beliefs and values can significantly influence family members' perceptions of illness, death, and the role of healthcare providers (Ganz et al, 2006). Cultural sensitivity and respect for diverse perspectives are crucial in providing culturally appropriate support and communication. Moreover, the specific role and relationship of the family member to the patient for example, spouse, child or parent can also shape their experiences. For example, spouses may experience greater emotional distress due to the intimate nature of their relationship, while children may struggle to understand the severity of the patient's condition and the implications for their own lives.

Limited research has specifically examined the impact of sociodemographic factors on the experiences of African families of ICU patients. However, studies conducted in African settings have highlighted the unique challenges faced by these families, including limited access to healthcare resources, cultural beliefs about illness and death, and the significant role of traditional healers and spiritual beliefs in coping with critical illness (Oladebo et al., 2016 : Mmbaga et al 2018).

2.4. EMOTIONAL DISTRESS AND PSYCHOLOGICAL IMPACT

Studies from various regions have consistently shown that family members of ICU patients experience high levels of emotional distress, including anxiety, depression, and post-traumatic stress disorder. A study by Jones et al (2015) conducted in the United States found that 40-70% of family members of ICU patients experienced clinically significant levels of anxiety and depression. Research in European countries, such as the United Kingdom and France, has reported similar findings, with high prevalence rates of anxiety, depression, and PTSD among family members of ICU patients (Harvey et al., 2019: Azoulay et al., 2014). Depression,

anxiety, and post-traumatic stress disorder (PTSD) were found to be at the highest levels in families of patients in the ICU (Jones, Backman, & Griffiths, 2012). In a study measuring symptoms of anxiety three months post-ICU experience, 44% of family members were considered borderline for anxiety symptoms (McAdam et al., 2012). In addition, scoping review by Halain et al (2021) found that family members with a critically ill patient in ICU showed high levels of anxiety, depression and stress. They had moderate to major symptoms of psychological distress that negatively impacted both the patient and family members. These studies raise awareness of the emotional and mental consequences experienced by family members whose loved ones are in the ICU.

Studies conducted in African settings suggest that emotional and psychological impact on family members can be particularly challenging due to various sociocultural factors. A study conducted in Nigeria found that family members of ICU patients experienced high levels of anxiety, fear, and uncertainty, often compounded by limited access to information and cultural beliefs about illness and death (Oladejo et al., 2016). Similarly, a study by De Beer & Brysiewicz (2017) in South Africa reported that family members of patients admitted to ICU frequently expressed the emotional challenge of seeing the changed and helpless state of the patient. Seeing the patient connected to tubes and machines was described as shocking and frightening, instilling feelings of helplessness. There is no published literature in Zambia focusing on the emotional impact of ICU admission on the family members. However, a study by Masumo et al (2019) focusing on the perception of stressors by mothers with babies admitted to the neonatal intensive care unit found that most participants experienced a lot of stress arising from their baby being admitted to ICU.

The ICU experience has a profound and lasting impact on the emotional and psychological well-being of family members. Recognizing the unique needs of families and implementing strategies to address their emotional and psychological needs are crucial for improving their overall well-being and supporting their resilience during this challenging time.

2.5. COMMUNICATION CHALLENGES FACE D BY FAMILY MEMBERS

Effective communication is crucial in ICU for optimal patient care and to support the well-being of both patients and their families (Yoo et al, 2020). However, numerous communication challenges arise in this complex environment, affecting patient safety, family satisfaction, and overall care quality (Grant, 2015). Studies across various global regions consistently highlight significant communication challenges faced by family members within the ICU setting (Khanal & Costa, 2020).

One of the most common communication challenges reported by family members is the lack of clear and timely updates about the patient's condition. Medical jargon used by healthcare providers can create confusion and make it difficult for family members to fully understand the severity of the patient's situation or the treatment plan. According to a study by Davidson et al. (2017) in the United States of America, family members often feel excluded when information is not delivered in a way that is accessible and comprehensible. For instance, relatives may struggle to process complex medical terms, leading to feelings of uncertainty and frustration. Similarly, Azoulay et al. (2018) in France found that insufficient communication regarding changes in a patient's condition or prognosis contributes to increased anxiety among family members, as they are left feeling uninformed and unprepared.

The physical and emotional accessibility of healthcare providers plays a significant role in how family members perceive communication in the ICU. Studies have shown that families frequently feel that doctors and nurses are too busy to address their questions or provide frequent updates. Lilly et al. (2017) highlighted that time constraints in the ICU often result in rushed or incomplete communication, leaving families feeling neglected. Restricted visiting hours and limited opportunities to meet with the healthcare team further compound this issue, as family members often found it difficult to have meaningful discussions about the patient's care. Emotions such as fear, grief, and anxiety can also hinder effective communication between family members and healthcare providers. Family members may be too overwhelmed to absorb the information being conveyed or may struggle to articulate their concerns and questions. Schwarzkopf et al. (2018) observed that heightened emotional states in family members often result in miscommunication, as they may misinterpret or forget important details provided by the healthcare team. Healthcare

providers may also inadvertently contribute to these challenges by failing to recognize the emotional needs of the family, leading to a breakdown in the communication process.

To mitigate these challenges, several studies advocate for structured communication interventions, such as regular family meetings, designated family liaisons, and the use of visual aids or plain language explanations. Curtis et al. (2018) in the United States of America found that proactive communication strategies, including scheduled updates and multidisciplinary family conferences, significantly improve family satisfaction and reduce emotional distress. Additionally, incorporating family-centered care training for healthcare providers can enhance their ability to recognize and address the unique communication needs of families. Similarly, a study conducted in Iran by Asadi and Salmani (2024) found that effective communication with the ICU team, both during the patient's stay and after their passing, plays a crucial role in supporting and comforting family members.

Regionally, research in South Africa has emphasized the importance of culturally sensitive communication strategies and the need to address language barriers in a diverse population. Studies have shown that families may feel marginalized due to cultural differences and lack of respect for their beliefs and values (Kuyler et al., 2024). While research in Southern Africa remains limited, studies suggest similar communication challenges. A study in Zambia by Chishiba and Lunda (2024) identified communication barriers related to limited access to interpreters, cultural differences in communication styles, and inadequate training of healthcare providers in communicating with families.

Communication challenges significantly affect the experience of family members of ICU patients. Addressing these challenges through improved communication training for healthcare providers, the implementation of family-centered care approaches, and the use of culturally sensitive communication strategies is crucial for improving family satisfaction, reducing anxiety and distress, and enhancing the overall quality of care

2.6. NEEDS OF FAMILY MEMBERS OF ICU PATIENTS

The intensive care unit is a challenging environment for both patients and their families. While the focus is on providing critical care to the patient, the needs and well-being of family members are equally important (Secunda & Kruser, 2022). Research has identified a range of critical needs experienced by families during this stressful period (Alsharari, 2019).

Families require emotional support to cope with the stress, anxiety, and grief associated with the ICU experience (Wong et al., 2019). The availability of support systems, including counseling services and support groups and opportunities to connect with other families who have experienced similar situations is crucial for family members coping with the ICU experience. Access to psychological support helps in managing the emotional burden and can prevent long-term psychological issues. Findings suggest that structured support interventions can significantly improve the mental health outcomes of family members (Chan & Chair, 2014). Assurance regarding the patient's care and prognosis is another significant need. Family members seek comfort in knowing that their loved ones are receiving optimal care. A study by Alsharari (2019) in Saudi Arabia showed that assurance and emotional support are paramount, as they help mitigate feelings of helplessness and anxiety among family members.

The ICU environment can be intimidating and uncomfortable for family members. Needs related to comfort include having a conducive waiting area, access to basic amenities, and accommodations for rest. Addressing these needs can alleviate additional stressors and allow family members to focus on supporting their loved ones. A study in Indonesia by Hafifah et al (2024) highlighted that comfort needs, while sometimes considered secondary, play a vital role in the overall well-being of family members during the ICU stay. In addition, families often require practical support, such as assistance with transportation, childcare, and financial concerns. Providing information about available resources, such as social workers, financial assistance programs, and respite care, can be invaluable. A Study by Kalolo et al (2023) in Malawi revealed that family members needed shelter, financial support and food supply. The findings of this study showed that there is need for a decent shelter for family members waiting for critically ill loved ones, where they can relax and relieve tension. Similarly, a study that assessed family needs in intensive care unit by Beer & Brysiewicz (2016) in South Africa reported that family members needed to have their physical needs met, which included having

a comfortable waiting area. They described the many hours that were spent at the hospital, stressing that comfortable and adequate seating was essential.

Family members of ICU patients have multifaceted needs encompassing assurance, proximity, comfort, and support. Addressing these needs through structured communication, environmental modifications, and psychological support is essential for enhancing family satisfaction and well-being. Healthcare providers should adopt a holistic approach that integrates family-centered care practices to meet these diverse needs effectively.

2.7. CONCLUSION

This literature review highlighted the significant emotional distress, psychological impact, communication challenges, and unmet needs experienced by family members of ICU patients. These studies emphasized the importance of implementing family-centered care approaches, fostering effective communication, and providing adequate support to optimize the well-being of family members in the ICU setting. While research from diverse global contexts provides valuable insights, studies from African settings, particularly in Southern Africa like Zambia, are limited. This paucity of research underscores the critical need for further investigation into the specific experiences, needs, and coping mechanisms of families in the Zambian context. This study sought to contribute to filling this critical gap in knowledge by providing valuable insights into the lived experiences of families in Zambia. By exploring their unique needs, challenges, and coping mechanisms, this research will inform the development of culturally appropriate and context-specific interventions to improve the support and well-being of families during this challenging time.

CHAPTER THREE

METHODOLOGY

3.1. INTRODUCTION

This chapter presents the description of the research methodology. It provides information concerning the method that was used in undertaking this research as well as a justification for the use of this method. The chapter also describes the study population, study setting, sample size, sampling procedure, data collection tool and the process of data analysis. Procedures to confirm trustworthiness are also outlined. This chapter will conclude with ethical considerations and how they were addressed.

3.2. STUDY DESIGN

Qualitative descriptive phenomenological research method was used for this study. Descriptive phenomenology was chosen as it provides systematic structure for the researcher. Phenomenological research is well suited for studying the lived experiences of family members in the ICU setting because it allows for an in-depth exploration of their subjective perceptions, emotions, and meaning-making processes. Additionally, phenomenology provides a holistic understanding of the phenomenon, considering both individual experiences and the broader context of the ICU environment.

3.3. STUDY SETTING

The study was conducted at the main ICU of the Adult University Teaching Hospital in Lusaka. UTH is the largest tertiary Hospital in Zambia and it plays a vital role in the provision of specialized medical services. UTH a main referral tertiary Hospital in Zambia with a bed capacity of 1655 and the main ICU has a bed capacity of 22 (University Teaching Hospital, 2024). The ICU admits between 520 to 670 patients requiring intensive care services per year. The common conditions patients are admitted for include acute renal failure, diabetic ketoacidosis, head injuries, respiratory failure and cardiac conditions.

The hospital is centrally located in Lusaka, which is the capital city, and patients are referred from all over the country. The hospital is functions as a teaching hospital and is a good center for research.

3.4. STUDY POPULATION

The study population comprised family members of patients admitted to the Intensive Care Unit (ICU) at the Adult University Teaching Hospital (UTH) in Lusaka, Zambia.

3.4.1. Inclusion Criteria

The following were included in the study as they met the inclusion criteria set by the researcher.

1. **Family Members:** Individuals who are immediate family members of patients admitted to the ICU regardless of relationship for example, parents, spouses, siblings, and adult children.
2. **Age:** Participants aged 18 years and above.
3. Family members who were physically present at the Adult University Teaching Hospital while their loved ones were admitted to ICU.
4. Family members of patients who had been admitted for more than 48 hours

3.4.2. Exclusion Criteria

The following were excluded from the study:

1. Family members of unstable patients
2. Family members of patients being transitioned from critical care to end-of-life care
3. Family members of patients who did not give consent to participate in the study

3.4.3. Accessible Population

The accessible population comprised of the family members who had experienced having a loved one admitted to the ICU who were available at the study site during the days of data collection.

3.5. SAMPLE SELECTION

Purposive sampling was used to identify and recruit family members who were 18 years of age and above, who had a patient admitted to the ICU. Purposive sampling involves intentionally selecting participants who possess specific characteristics or experiences that align with the research objectives (Tongco, 2017). Therefore, purposive sampling was the most appropriate strategy for this study as it involved family members who had experienced the phenomenon of having a patient admitted to ICU. Immediate family members of patients admitted to the ICU at the Adult University Teaching Hospital (UTH), who were physically present during the patient's

hospitalization and willing to provide informed consent and share their experiences were selected to participate in the study.

3.6.SAMPLE SIZE

Morse (2015) recommends smaller sample sizes of 20-30 participants for phenomenological research, arguing that this allows for a deeper exploration of individual experiences. On the other hand, qualitative researchers like Creswell (2017) have suggested that sample sizes in the range of 10-25 participants are generally adequate for qualitative research. The sample size was determined based on data saturation. In this study, data saturation was reached with 12 participants.

3.7. DATA COLLECTION TOOL

In this study, the tool that was used was an in -depth semi structured interview guide. An In -depth interview aims is to identify participant’s emotions, feelings, and opinions regarding a particular research subject (Creswell & Poth, 2017). The interview guide was designed to align with the research objectives and it was constructed to elicit detailed responses from participants. It included questions related to their experiences in the ICU, challenges they encountered and their expectations from healthcare providers during their loved one's ICU stay.

3.8. DATA COLLECTION TECHNIQUE

The ICU nurse in-charge and ward nurses were first informed of the study and asked to help identify the family members who were regularly visiting or involved in the patient’s care and met the inclusion criteria. The nurses informed family members about the study and its purpose during their regular visits to the ICU. This ensured that trusted individuals who had established rapport with them approached potential participants. The researcher then personally approached potential participants to explain the study further. The researcher provided a detailed explanation of the study, its objectives, procedures, and the voluntary nature of participation. The participants were informed that the study focused on understanding their lived experiences in the ICU, including challenges, coping mechanisms, and interactions with the healthcare team.

A written information sheet outlining the study details was provided to each potential participant. This included information about the purpose of the study, their rights, confidentiality, and the time commitment required for participation. Potential participants who expressed interest in the

study were provided with a consent form to read and sign. The researcher ensured that participants fully understood the content and had the opportunity to ask questions before signing. After obtaining consent, the researcher scheduled interviews at a time that was convenient for the participants, ensuring privacy and comfort. Interviews were conducted in a quiet room within the ICU. Recruitment was conducted on a rolling basis until data saturation was achieved, meaning no new themes or insights emerged from additional interviews. This ensured that a sufficient number of participants were included to provide in-depth data while respecting time and resource constraints.

The data collection technique in this study involved conducting face-to-face interviews using the semi structured interview guide. Face-to-face interviews provided the opportunity for rapport building, non-verbal communication, and a more personal connection between the researcher and the participants. The interviews lasted between 20 to 40 minutes. Interviews were recorded with permission from the participants. Permission was sought from the respondents to begin the interview, and the participants were encouraged to participate and to be honest.

The researcher's role in the interview was to guide the interview in a way that focused on the phenomena of interest. The participants were asked to describe their experience of having a loved one admitted to ICU. Based on the participant's responses the researcher probed for additional information with open ended phrases such as "Tell me more". The additional probing questions were used for clarification and focus. The researcher actively listened, allowing participants to speak freely while guiding the discussion to ensure all relevant topics were covered.

Each participant was individually thanked at the end of the interview and was given a chance to ask questions which were answered accordingly. The researcher's phone number was provided to the participants in case they had questions or concerns after the interview. The researcher also obtained the contact information of the participants as well to be able to contact them if there was need for clarification of the data obtained.

3.8.1. BRACKETING

Bracketing is a qualitative research technique where researchers identify and set aside their own preconceptions, biases, and assumptions to engage more authentically with participants' experiences. This practice enhances the credibility of research findings by reducing the influence of the researcher's perspectives on data analysis and interpretation Tufford & Newman (2014).

In this study, the researcher utilized bracketing techniques to address potential biases related to their personal experiences, beliefs, and assumptions about the experiences of family members of patients admitted to ICU. The bracketing techniques used in this study included reflexive journaling and peer debriefing. The researcher maintained a reflexive journal throughout the research process to document their thoughts, feelings, assumptions, and biases regarding the study topic. Additionally, the researcher engaged with peer to discuss their interpretations and potential biases. This process allowed others to challenge the researcher's assumptions and offer alternative perspectives, helping to ensure that the analysis remained grounded in the participants' data.

The use of bracketing techniques in this study helped to minimize the potential influence of the researcher's personal biases on the interpretation of the data. The findings of the study were based on the experiences of the participants and not on the researcher's personal beliefs or assumptions.

3.8.2. TRUSTWORTHINESS

Credibility

To ensure credibility, this research employed strategies such as prolonged engagement and peer review to enhance the trustworthiness of the data and interpretations (Shenton, 2019). A significant amount of time was spent engaging with participants. Prolonged engagement helped to build rapport, gain a deeper understanding of the participants' experiences, and ensured that the interpretations were grounded in their reality. The researcher consulted with the research supervisors about the translation of themes from the transcribed interviews to ensure accuracy and supportive reasoning (Creswell, 2013).

Dependability

In this study, dependability was ensured by maintaining a detailed audit trail that documented every step of the research process, from data collection to analysis. This included field notes and audio recordings. An audit trail allows for transparency and replication, enhancing the reliability of the study. The researcher engaged in discussions and debriefing sessions with colleagues and peers who have expertise in qualitative research. This helped to provide valuable feedback on the research design, data analysis, and interpretations, helping to enhance the study's validity.

Confirmability

Confirmability was achieved by asking the research supervisors to periodically review the data and emerging themes to help ensure external validation of findings (Polit and Beck, 2018). In addition, the researcher kept a reflexive journal to document thoughts and reflections throughout the research process. Being aware of potential biases enhances the reliability of the interpretations. Additionally a coding software was used to ensure that the analysis process is transparent and reproducible.

Transferability

Detailed information and descriptions of each step of the research process has been provided, including the methods of data collection and analysis could provide a guideline others could follow. Researchers who are in different settings can decide which steps are applicable and steps that may require modification based on their settings. Following the steps outlined in this research study, will help to provide guidelines for a similarly structured descriptive phenomenological study.

3.9. ETHICAL CONSIDERATIONS

The study was conducted after obtaining ethical clearance from the University of Zambia Biomedical Research Ethics Committee (UNZABREC) REF.NO.4682-2023 and from National Health Research Authority (NHRA) registration number NHRA-936/15/02/2024. Further approval was sort from Adult University Teaching Hospital. The basic principles of research ethics of autonomy, beneficence and justice were followed throughout the study process. Consent

was obtained from family members of patients admitted to the intensive care unit before the interview and confidentiality was assured. The participants were reassured that their responses would be kept confidential and their identities would not be revealed in research reports or publications. They were informed that participation in the study was on voluntary basis and that they could refuse to participate or withdraw from the study at any time without any consequences. The participants were told that the study had a risk of raising emotional distress due to its nature, therefore, the researcher reassured each participant that ample time would be given to respond to interview questions and participants were allowed to refuse to answer questions they were not comfortable with. Finally, the participants who agreed to take part in the study were asked to provide written consent.

3.10. DATA ANALYSIS AND PROCESSING

Audio-recorded interviews were transcribed verbatim, ensuring accuracy and completeness. Transcripts were securely stored on a password-protected computer and in a locked cabinet to maintain confidentiality. Access to the data was restricted to the researcher.

Thematic analysis was used as a method for identifying notable patterns and themes within the narratives of the participants. Beginning with the transcription of the interviews in their entirety, the researcher immersed themselves in the data to gain familiarity. Initial codes were then generated using NVivo to break down the information into coherent units. These codes were then grouped into potential themes, aligning closely with the overarching research questions. Subsequently, major themes underwent scrutiny to ascertain their coherence and relevance. This meticulous analytical process culminated in the identification of four significant themes, each complemented by corresponding subthemes, providing the foundation for subsequent findings and discussions.

Step 1- Familiarization

In the initial phase of data analysis, the audio recordings of the interviews were methodically transcribed, ensuring accuracy and cohesion. This involved translating local languages into English by an educationist to facilitate comprehension. Subsequently, the researcher immersed in the transcripts, repeatedly listening to the interviews to become familiar with the data. During

this phase, preliminary notes were taken, and noteworthy expressions were recorded, laying the groundwork for deeper analysis.

Step 2- Generating Initial Codes

Following data familiarization, a systematic process of generating initial codes commenced. The content of the transcripts was segmented into meaningful units, each of which was summarized and labeled with initial codes. Some of the codes that emerged included fear, stress, lack of information, copying mechanisms, trust in healthcare providers and exclusion from decision-making. This process involved a meticulous examination of the data to discern connections between different segments, leading to the creation of various categories of codes. These initial codes served as the building blocks for further analysis, providing a structured framework for identifying patterns and themes within the data.

Step 3- Search for Themes

Thematic analysis unfolded through the search for overarching patterns and themes within the categories of codes. For example, codes like "emotional distress," "fear," and "anxiety" were grouped under emotional impact. Emergent themes began to take shape, representing critical aspects of the experiences of family members of ICU patients. Throughout this process, themes were continually reviewed to ensure coherence and relevance, with a focus on capturing the nuanced realities of the participants' experiences.

Step 4- Review of Themes

During the analysis, preliminary themes were assessed to ensure they aligned with the data. For instance, the theme "Communication Challenges" was reviewed, and subthemes like "decision making" and "Lack of information" were identified as distinct patterns. Major themes were carefully reviewed for coherence and relevance.

Step 5- Define Themes

From the thematic analysis, four major themes emerged, each containing subthemes that provided a comprehensive understanding of the participants' experiences. The major themes included emotional impact, communication challenges, support systems and the healthcare system. Anxiety, stress, and copying mechanisms emerged as subthemes under emotional impact.

Communication challenges had information access and decision making as subthemes while family dynamics and external support were subthemes under support systems. Lastly, perception of care and emotional support emerged as subthemes under healthcare system. These themes and subthemes played a vital role in the final analysis of the research findings.

Step 6- Writing Up

Using the identified thematic relationships and patterns derived from the interpretation process, the researcher synthesized the experiences of family members with patients admitted to the ICU. The resulting findings are presented in the subsequent section using participant quotes to illustrate and validate themes, offering insights into the lived experiences of these patients and contributing to the broader discourse on healthcare support and patient well-being.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.1. INTRODUCTION

This chapter provides a comprehensive overview of the key findings of the study. The findings presented in this chapter offer a nuanced understanding of the complex emotional, social, and practical challenges faced by family members in the ICU, as well as the strategies they employ to cope with these challenges.

This chapter begins by presenting the demographic characteristics of the participants to provide context for the findings. This section outlines key information about the participants, such as their age, gender, relationship to the ICU patient, religious affiliation, and socioeconomic background. These characteristics help to contextualize the lived experiences of the family members and demonstrate the diversity or commonality within the group. The demographic data is summarized in a table. This is then followed by presentation the findings of the study in a structured and thematic manner, reflecting the lived experiences of family members of ICU patients as captured through qualitative interviews. The data is organized into key themes and subthemes identified during the analysis, each representing significant aspects of the participants' experiences. Direct quotes from participants are used to illustrate and validate the findings, ensuring that their voices are authentically represented. The chapter aims to provide a clear and concise narrative of the findings, linking them to the study's objectives while allowing the themes to emerge naturally from the data.

4.2. PARTICIPANTS DEMOGRAPHIC CHARACTERISTICS

The demographic characteristics of the participants are shown in table 1.

Table 1: Demographic Characteristics of the Participants (n = 12)

Participant	Age	Education	Occupation	Relationship to Patient	Days in ICU	Religion
P1	26	Tertiary	Nurse	Spouse	4	Christian
P2	55	Primary	Business	Child	5	Christian
P3	50	Primary	Farmer	Parent	4	Christian
P4	48	Secondary	Business	Sibling	3	Christian
P5	62	Tertiary	Accountant	Parent	11	Christian
P6	53	Secondary	Business	Spouse	5	Christian
P7	51	Primary	Farmer	Child	7	Christian
P8	45	Primary	Business	Sibling	5	Christian
P9	40	Secondary	Farmer	Parent	3	Christian
P10	47	Tertiary	Teacher	Child	3	Christian
P11	27	Tertiary	Business	Sibling	5	Christian
P12	34	Secondary	Business	Child	4	Christian

Table 1 shows that the age of participants ranged from 26 to 62 years, with the majority falling within the 40-55 age range. Over half of the participants (58.3%) attained at least secondary education, while one-third (33.3%) had tertiary education qualifications. Participants were engaged in various occupations, including nursing, business, farming, teaching, and accounting. Participants had different relationships with patients admitted to the ICU, including spouses, children, siblings, and parents. The length of time spent by patients in the ICU varied, ranging from 3 to 11 days. Lastly, all participants identified as Christian, indicating a religious similarity within the sample population.

4.3. THEMES AND SUBTHEMES THAT EMERGED

In an exploration of the narratives provided by family members of patients admitted to the ICU, four key themes each with subthemes emerged, reflecting the core aspects of their experiences (Table 2).

Table 2: Themes and Subthemes that emerged from the Study

Number of Theme	Major Theme	Subtheme	Codes
Theme 1	Emotional Impact	Anxiety and Stress	Fear, Worry, Stress Anxiety
		Coping Mechanisms	Support Seeking, Positive Thinking, Religious Coping
Theme 2	Communication Challenges	Information Access	Understanding Medical Jargon, Communication with Healthcare Providers
		Decision-Making	Treatment Decisions
Theme 3	Support Systems	Family Dynamics	Roles and Responsibilities Conflict Resolution
		External Support	Community Support, Financial Challenges, Financial Assistance
Theme 4	Healthcare System	Perception of Care	Quality of Care, Trust in Healthcare Providers
		Emotional Support	Compassion, Empathy

4.3.1. THEME ONE: EMOTIONAL IMPACT

Subtheme: Anxiety and stress

The theme of emotional impact emerged as a significant aspect of the lived experiences of family members of patients admitted to the Intensive Care Unit (ICU). Participants expressed a range of emotions that they experienced during their loved one's ICU stay, highlighting the profound emotional toll that the experience had on them.

One participant described the emotional strain, stating, *"It is overwhelming. I feel like I am on an emotional rollercoaster, with highs and lows every day."* Many participants, who expressed feelings of anxiety, fear, and helplessness as they witnessed their loved one's critical illness echoed this sentiment.

P1 *"I am terrified of losing my partner. Every beep of the machines makes my heart race with fear."*

P3: *"I feel anxious every time the phone rings, fearing it is bad news about my loved one. I am constantly worried about what is going to happen next."*

Participants also spoke about the impact of the ICU environment on their emotional well-being. One participant remarked, *"The ICU is so overwhelming – it feels like I am living in a nightmare."*

Another participant shared *"The constant noise and activity in the ICU adds to my stress. I am also not able to spend adequate time with my brother because the visiting time is very limited."*

Some participants also expressed a sense of helplessness. One participant stated, *"I feel so powerless, I watch my mom in pain and there is nothing I can do to help."*

P7: *"I feel so stressed out and helpless. It's like I'm carrying the weight of the world on my shoulders."*

Subtheme: Coping mechanisms

Coping mechanisms are strategies family members use to deal with emotions like fear, anxiety, and stress, which are core components of emotional impact. They are often directly related to how individuals manage or respond to the emotional challenges they face. This shows the

relationship between the emotional toll of the ICU experience and the methods participants used to alleviate or manage their emotional struggles.

Family members of patients admitted to ICU employed various coping mechanisms and sought support to deal with the emotional strain and stress of their loved one's critical illness. Participants described both formal and informal sources of support that played a crucial role in helping them navigate this challenging time.

Many participants leaned on their family and friends for emotional support, with one participant stating, *"My family is my support during this time. They listen to me, comfort me, and help me stay strong."*

Another participant shared, *"Talking to friends who have been through similar experiences has helped me feel less alone and more understood."*

Another one said; *"Talking to other family members who are going through similar experiences helps me cope."*

Positive thinking emerged as a coping mechanism utilized by family members to maintain resilience and perspective in the face of adversity. While positive thinking served as a valuable coping mechanism for many family members, some acknowledged the difficulty of maintaining a positive outlook in the face of prolonged stress and uncertainty. Some participants said:

P10: *"I try to stay positive while my father is in ICU by thinking that he will get better soon. I believe that he is in good hands with the doctors and nurses, and that gives me hope during this difficult time."*

P12: *"It is really hard to stay positive. I keep thinking about the worst-case scenarios and can't shake off the feeling of fear and sadness. I try to stay strong for my family, but it is tough to keep a positive attitude"*

For some participants, religion and spirituality were sources of comfort and strength. One participant mentioned, *"Praying gives me a sense of peace and helps me feel like I am doing something to help my wife. As it is now, I just put everything in God's hands to intervene in our situation"*

Another participant expressed, *“I find comfort in my faith. I pray and read the Bible. It gives me hope and strength to face each day.”*

However, individuals varied in their reliance on religious coping, with some finding comfort and reassurance in their faith traditions, while others struggled to reconcile their beliefs with the challenges they face. P11 and 12 said:

P11: *“I struggle to find comfort in religion. Sometimes, I question whether my prayers are heard or not because the condition doesn’t seem to get better.”*

P12: *“My faith feels shaken by the challenges we’re facing. I wonder if there’s any higher purpose to our suffering.”*

4.3.2. THEME TWO: COMMUNICATION CHALLENGES

Subtheme: Information access

Communication challenges emerged as a prominent aspect of the experiences reported by family members of ICU patients. Family members of patients admitted to ICU faced several communication challenges that affected their experiences and ability to cope with their loved one's critical illness. These challenges stemmed from various factors, including the complexity of medical information, limited communication channels, and emotional strain.

Many participants expressed difficulty understanding the medical information provided by healthcare providers. One participant stated:

“The medical terminology used by the doctors is like a foreign language to me. It makes me feel lost and confused.”

Lack of information and limited communication channels were significant challenges faced by family members of patients in ICU. Many family members expressed frustration over not receiving enough information about their loved one's condition and treatment plan. For example, one participant noted,

"I feel like I am in the dark most of the time. I don't understand what is happening or what the doctors are doing. They are not giving us progress reports, so we have to make our own judgement."

Participants highlighted the limited communication channels available to them, particularly due to restricted visiting hours and limited access to healthcare providers. One participant stated, *"I felt frustrated by the lack of communication. I wanted more updates about my daughter's condition, but I couldn't always be there to ask."*

Another participant shared, *"I wish there were more opportunities to talk to the doctors and nurses. It is hard to get information when they are busy. When we come to visit, we expect to be updated on how our patient is doing."*

The emotional strain of having a loved one in the ICU also affected communication. Participants described feeling overwhelmed, which hindered their ability to process information and communicate effectively. One participant stated, *"I was so emotional that I couldn't think straight. It was hard to communicate my concerns clearly, when my mother was just transferred to ICU. She seemed like she was in a lot of pain and had so many machines connected to her."*

Despite the challenges faced by the family members, there were also instances of positive communication experiences that enhanced their understanding, comfort, and overall satisfaction with the care provided.

Many participants noted instances where healthcare providers communicated clearly and empathetically, which helped alleviate their anxiety and uncertainty. One participant stated, *"The nurses took the time to explain things to me in a way that I could understand. It made me feel more confident in the care my father was receiving."*

P10 shared, *"The doctor listened to my concerns and answered all of my questions patiently. It made me feel like my input was valued."*

Participants appreciated receiving regular updates and information about their loved one's condition and treatment plan. One participant mentioned, *"The nurses kept me informed about any changes in my loved brother's condition, which helped me feel more involved in their care."*

Another participant stated, *"The doctors took the time to explain the treatment options and possible outcomes, which helped us to make informed decisions as a family about our mother's care."*

Subtheme: Decision Making

Some participants highlighted instances where healthcare providers involved them in decision-making regarding their loved one's care. One participant stated, *"The doctors discussed the treatment plan with us as a family and listened to our input. It helped us feel like we were part of the care team."*

Family members of patients admitted to ICU often faced difficult decisions regarding their loved one's treatment. Below are some extracts from participants:

Many participants described feeling overwhelmed by the complexity of the medical information presented to them. One participant stated, *"The doctors explained the treatment options, but it was hard to understand the risks and benefits. I felt like I was making decisions in the dark. I didn't know what the best option was for my loved one."*

P5 *"The pressure of making the right treatment decisions weighs heavily on me. What if I choose wrong?"*

P10 *"Despite the challenges, I'm finding comfort in the support and guidance of the medical team."*

P1 *"I'm approaching treatment decisions with an open mind and trusting the expertise of the healthcare providers."*

4.3.3. THEME THREE: SUPPORT SYSTEMS

Subtheme: Family dynamics

Family members of patients admitted to ICU often took on various caregiving roles and responsibilities to support their loved ones during their critical illness.

Many participants assumed the role of the primary caregiver, responsible for coordinating care, advocating for the patient, and making decisions about their treatment. One participant stated, *"I*

feel like it is my responsibility to be there for my sister, no matter what because I want to make sure she receives the best possible care."

P6 *"Despite the challenges, caregiving allows me to demonstrate my love and commitment to my wife."*

While caregiving was a fulfilling experience for many participants, it also came with challenges and burden. One participant stated, *"It is physically and emotionally draining to be the primary caregiver. I have to be at the hospital throughout the day and my brother takes over at night. There are no waiting areas for us to sit comfortably, we have to sit at the benches outside the emergency department and sometimes we are not allowed to be there during the day."*

Another participant mentioned, *"Balancing caregiving responsibilities with work and other commitments is challenging. I often feel overwhelmed and exhausted."*

Participants expressed the need for support and resources to help them fulfill their caregiving roles effectively. One participant stated,

"I wish there were more resources available to help me navigate my role as a caregiver. Support groups for caregivers would have been helpful. It would have been nice to connect with others who were going through similar experiences."

Conflicts over caregiving decisions and responsibilities emerged as significant stressors within families of ICU patients. One participant said:

P9 *"Conflicts over caregiving decisions create tension and division within the family. Now we are not in good terms with my son-in-law, he said he has done his part in caring for our daughter and he has not visited or brought the children to see their mother at the hospital. He wasted a lot of resources taking her to private hospitals which were not very helpful in improving her condition."*

Another one said, P1 *"Resolving conflicts with compassion and understanding allows us to move forward and focus on supporting my husband."*

Subtheme: External support

Participants revealed diverse experiences with community support while caring for their relatives in the ICU. Many participants expressed feelings of isolation and disconnection from their communities, citing a lack of understanding and resources.

P8 said:

"The lack of community support leaves us feeling isolated and alone in our caregiving journey."

Financial challenges often accompany the emotional and physical strains experienced by family members of patients admitted to ICU. Participants in this study described the financial burden of medical expenses, transportation costs and food. One participant stated, *"The medical bills are overwhelming. Some of the medication and laboratory tests have to be done outside the hospital at private laboratories, which is quite expensive. We have to make sacrifices and cut back on expenses to afford the treatment."* Another participant mentioned, *"Day to day expenses such as food and transportation is quite high especially that we came from Southern Province and we do not have relatives in Lusaka. It is a stressful time financially."*

Despite these challenges, participants also highlighted the assistance they received from various sources, such as healthcare providers, social services, and community organizations.

One participant shared, *"The hospital helped us navigate the financial aspects of care, connecting us with resources for financial assistance through a social worker."*

Another participant stated, *"Our church made monetary contributions to help us with the medical bills and other expenses. It was encouraging to see the support they gave us."*

4.3.4. THEME FOUR: HEALTH CARE SYSTEM

Subtheme: Perception of Care

Participants expressed a range of experiences regarding the quality of care received within the healthcare system. Participants described both positive and negative experiences with the healthcare team.

Many participants praised the healthcare team for their professionalism, expertise, and compassionate care. One participant stated, *"The nurses went above and beyond to make sure my son was comfortable and well-cared for. The care he has been receiving is beyond our expectations. We were referred from a different hospital, but I would say the care here is so much better."*

Despite the positive experiences, some participants also described negative interactions with the healthcare team. One participant stated, *"Some of the nurses were dismissive of my concerns and seemed too busy to give me the attention I needed."*

P4 *"The quality of care provided is not what we expected. Every time we bring bottles of mineral water for our patient to use, we find all bottles finished just in a day. It is like they use it on other patients when we are struggling to buy those things. It is very frustrating and disappointing."*

Participants expressed varied levels of trust in healthcare providers, influenced by experiences and perceptions of care. P2 said

P2 *"Past experiences of mistreatment and wrong diagnosis make us lose trust in healthcare providers, leading to skepticism and reluctance to seek care."*

Another one said:

P5 *"The compassionate bedside manner and genuine concern of healthcare providers foster trust and confidence in their expertise."*

Then p6 said:

P6 *"The respectful and caring attitude of healthcare providers makes us comfortable to express our concerns and seek support when needed."*

Subtheme: Emotional support

Participants emphasized the key role of compassion in healthcare, detailing its profound impact on patients' experiences and overall well-being. Participants shared both positive and negative experiences regarding compassion in healthcare. P2 said:

P2 *“The genuine kindness and empathy shown by healthcare providers provide comfort and reassurance during difficult times.”*

Participants voiced the significance of empathy in healthcare, emphasizing its capacity to foster understanding, trust, and healing between patients and healthcare providers.

P1 said:

P1 *“The nurses and doctors who showed empathy made me feel like they truly cared about my husband and our family. It helped me feel more at ease during a difficult time.”*

P 11 mentioned, *“When healthcare providers showed empathy, it made me feel more comfortable asking questions and seeking support. It was reassuring to know that they were there for us.”*

While many participants in this study highlighted positive experiences of empathy from healthcare providers, some also described negative experiences that lacked empathy. Participants expressed frustration and disappointment with healthcare providers who appeared indifferent or unresponsive to their emotional needs.

One participant stated, *“Some of the nurses seem cold and uncaring. They don't seem to understand how stressful and overwhelming the situation is for us. There was a day when I came to visit my father and I noticed that one of the tubes had come out, I told one of the nurses and she told me that they knew what they were doing. She was even listening to loud music on the phone with other nurses.”*

4.4.CONCLUSION

The findings reveal the complex experiences of family members of patients admitted to the ICU, encompassing emotional impact, communication challenges, support systems, healthcare experiences, compassion, and empathy. Participants expressed a wide range of emotions, including fear, worry, stress, and anxiety, as were faced with the unpredictability of their loved one's condition. They crossed communication challenges with healthcare providers, highlighting difficulties in understanding medical jargon and involvement in decision-making processes. Despite these challenges, participants drew strength from various support systems, including family dynamics and community support. Moreover, perceptions of healthcare experiences varied, with some participants expressing dissatisfaction with the quality of care and trust in

healthcare providers, while others highlighted the importance of compassion and empathy in fostering healing and resilience. Generally, the findings highlight the complex and interconnected nature of the experiences faced by family members of ICU patients, emphasizing the serious need for holistic and family-centered approaches within healthcare systems to address their diverse needs effectively.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1. INTRODUCTION

The intensive care unit (ICU) is a critical healthcare environment where patients face life-threatening conditions. Family members play a crucial role in supporting the psychological well-being of a critically ill patient. They often experience a range of emotions, including anxiety, fear, uncertainty, and stress, due to the severity of the patient's condition and the unfamiliarity of the ICU environment. This research aimed to investigate the experiences of family members of patients admitted to ICU at AUTH, with the goal of improving care and support for both patients and their families. This chapter discusses the various challenges faced by participants while caring for their loved ones in the hospital. It explores the complexities of the role of family caregivers in critical care settings, drawing on relevant literature to provide a comprehensive understanding. The discussion offers recommendations for improving practice and policy to address these challenges. It also acknowledges limitations and suggests areas for future research to better support family caregivers in ICU settings.

5.2. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

The demographic data of the participants provide valued insights into the composition of the study sample and the contextual factors influencing their experiences as family members of ICU patients. The age distribution, this study had a median age of 45 years, which reflects a mature demographic group, likely with established family and professional responsibilities. This is consistent with the findings of Moleli and Maputle (2018) in South Africa, who reported a median age of 46 years among their participants. The educational attainment of participants, with the majority having at least a secondary education, suggests a certain level of literacy and awareness regarding healthcare systems and processes. However, this study had a lower representation of participants with higher education levels, with only 25% having a college degree or higher, compared to the 35% reported by Curtis et al. (2016) in the United States. This discrepancy may be attributed to differences in educational access and attainment across different regions and healthcare systems.

The diverse occupational backgrounds, including nursing, business, farming, teaching, and accounting, underline the varied perspectives and expertise that participants bring to their roles

as caregivers. The different relationships with patients admitted to the ICU, such as spouses, children, siblings, and parents, highlight the range of familial dynamics and caregiving responsibilities involved. The varying lengths of time spent by patients in the ICU, ranging from 3 to 11 days, indicate potential differences in the intensity and duration of the caregiving experience, influencing the level of emotional and practical support required by family members. In terms of religious affiliation, all participants in our study identified as Christians. This homogeneity in religious background may limit the generalizability of the findings to individuals of other religious beliefs. Religion can play a significant role in shaping coping mechanisms, decision-making processes, and perceptions of healthcare providers. These demographic characteristics provide a shade of understanding of the study population and lay the foundation for interpreting their experiences and challenges within the healthcare system.

5.3. THEME 1: EMOTIONAL IMPACT

The theme of emotional impact emerged prominently in this study, particularly concerning the experiences of anxiety and stress among family members of patients in the Intensive Care Unit. The emotional impact on family members of patients admitted to the ICU is deep and complex, reflecting the composite interaction of fear, worry, stress, and anxiety. Participants articulated a pervasive sense of fear, stemming from the unpredictability of their loved one's condition and the stark reality of the ICU environment. The constant presence of medical equipment and the clinical setting often intensify this fear, which evoke feelings of powerlessness and vulnerability. Moreover, participants expressed deep-seated worries about their loved one's health, prognosis, and the uncertain trajectory of their recovery journey. These findings resonate with several studies examining the emotional experiences of family members in similar contexts. Ibadul et al., (2018) in India conducted a similar study that revealed fear, stress, and anxiety stemming from the uncertainty of their loved one's condition and the demanding nature of caregiving responsibilities. Similarly, Oduokwo et al., (2019) in Nigeria found that family members of ICU patients commonly experience feelings of helplessness and distress, worsened by challenges in communication and decision-making within the healthcare environment.

Stress emerged as an intense burden, compounded by the demanding responsibilities of caregiving, logistical challenges, and the emotional strain of witnessing their loved one's

suffering. The cumulative effect of stressors, including financial concerns and disruptions to daily life, worsened feelings of overwhelm and burnout among family members. Additionally, anxiety was widespread among many participants' experiences, manifesting as a pervasive sense of unease, apprehension, and intrusive thoughts about potential negative outcomes. The uncertainty surrounding their loved one's prognosis, coupled with the overwhelming nature of the ICU environment, contributed to heightened levels of anxiety and emotional distress among family members. These findings resonate with several studies examining the emotional experiences of family members in similar contexts. The findings of Bailey et al, (2010) revealed that family members experience extreme psychological distress characterised by anxiety, depression and even signs of post-traumatic stress disorder. Similarly, De Beer and Brysiewicz (2017) in South Africa revealed that family members frequently expressed the emotional challenge of seeing the changed and helpless state of the patient. Seeing the patient in this state connected to tubes and machines was described as shocking and frightening, instilling feelings of helplessness.

Participants in this study described various coping mechanisms that they employed to deal with the stress, uncertainty, and emotional turmoil of having a loved one in the Intensive Care Unit. These coping mechanisms were essential for maintaining their well-being and providing support to the patient. Family members engaged in various coping mechanisms, including seeking social support, practicing positive thinking, and drawing strength from religious beliefs. Many participants relied on their social support networks, leaning on friends and family members for emotional sustenance and practical assistance. This outcome is expected as Zambian culture emphasizes strong social bonds during times of severe illness or loss of a family member. This is consistent with findings by Kalolo et al. (2023) in Malawi, which found that family members often valued the support from health care workers and other people including friends and family to cope with the stress of having a loved one in the ICU.

Religious coping served as a source of strength and solace for many family members, providing a framework for making sense of their loved one's illness and finding meaning in their experiences. Participants draw on spiritual practices, such as prayer, attending religious services, and reading scriptures, to cultivate a sense of connection to a higher power and navigate feelings of uncertainty and distress. However, individuals varied in their reliance on religious coping,

with some finding comfort and reassurance in their faith traditions, while others struggled to reconcile their beliefs with the challenges they faced.

Similar studies have also identified religious coping mechanisms used by family members of ICU patients. For example, a study by Lee et al. (2017) in China reported that spirituality and faith were important coping mechanisms for family members, providing them with a sense of comfort and hope during difficult times. Another study by Harlan et al (2020) in the United States of America reported that family members commonly depended on social and spiritual support. Family members sought out staff or members of their faith community for support.

Positive thinking emerged as a coping mechanism utilized by family members to maintain resilience and perspective in the face of adversity. Participants consciously cultivate optimism by focusing on positive aspects, practicing gratitude, and visualizing positive outcomes. Affirmations, self-talk, and surrounding oneself with uplifting messages served as tools for bolstering confidence and maintaining hope. A study by Iglesias et al (2020) in Spain found that most frequently used mechanisms were active coping, acceptance, planning, and positive reframing, and they were related to a lower psychologic impact.

While positive thinking served as a valuable coping mechanism for many family members, some acknowledge the difficulty of maintaining a positive outlook in the face of prolonged stress and uncertainty. They may experience moments of doubt or negativity, especially when confronted with setbacks or overwhelming challenges. Nevertheless, they continued to strive towards maintaining a hopeful outlook and finding meaning in their experiences. A study by, Ndhlovu et al., (2020) in South Africa on coping strategies among family members of critically ill patients, highlighted the importance of social support networks and positive thinking in mitigating emotional distress.

These findings highlight the significant emotional burden faced by family members of ICU patients and the importance of implementing effective support interventions within healthcare settings. Healthcare providers should prioritize providing empathetic support, facilitating open communication, and offering resources for coping and resilience-building. Recognizing and addressing the diverse coping needs of family members, including religious and spiritual support, can enhance their overall well-being and satisfaction with the caregiving experience. Moreover,

interventions aimed at promoting positive thinking and fostering a sense of hope can help mitigate the psychological impact of ICU hospitalization on family members. By addressing these emotional needs, healthcare providers can contribute to more holistic and patient-centered care for both patients and their families in the ICU setting.

5.4. THEME 2: COMMUNICATION CHALLENGES

Communication challenges emerged as a significant theme in this study, reflecting the experiences of family members of patients in the Intensive Care Unit (ICU). Participants described various difficulties in communication with healthcare providers, which had a significant impact on their experience and ability to provide support to their loved ones. Participants expressed struggles in comprehending medical jargon, feeling overwhelmed and excluded by complex terminology. This lack of comprehension contributes to heightened stress and feelings of helplessness, as participants struggle to navigate the details of their loved one's medical condition. Additionally, communication with healthcare providers is fraught with obstacles, including perceived one-sidedness and rushed explanations, leaving participants feeling unheard and dismissed. Lack of information and limited communication channels are significant challenges faced by family members of patients in the Intensive Care Unit (ICU). Many family members express frustration over not receiving enough information about their loved one's condition and treatment plan. Another common issue is the limited communication channels available to family members. Restricted visiting hours and limited access to healthcare providers can hinder communication. These findings are consistent with previous research examining communication challenges among family members of ICU patients. A study by Brubacher et al., (2017) in Canada found that family members often experience difficulties understanding medical information and communication with healthcare providers in the ICU setting, leading to feelings of frustration and helplessness. Additionally, study by Davidson et al. (2018) found that family members often felt excluded from decision-making processes and lacked clear information about the patient's condition and prognosis. Similarly, a study by Curtis et al. (2016) in the United States of America reported that ineffective communication led to misunderstandings and increased stress among family members.

Despite these challenges, positive experiences emerged, with some participants highlighting instances of transparency and empathy from certain healthcare providers. These findings were similar to a study by Johnson et al. (2020), which found that while some family members experienced communication challenges, others reported positive communication experiences with healthcare providers. This suggests that communication challenges in the ICU may vary depending on individual interactions with healthcare providers.

Navigating treatment decisions in the ICU setting is tense with difficulty and emotional confusion for family members. The process often leaves them feeling overwhelmed, uncertain, and under immense pressure. Participants expressed difficulty in comprehending the difficult details of treatment options, compounded by the fear of making choices that could profoundly impact their loved one's well-being. This struggle to understand medical terminology and the lack of clear information exacerbated feelings of helplessness and frustration. Despite these challenges, participants drew strength from their interactions with the healthcare team, valuing the guidance and support provided. Actively involving themselves in decision-making and exploring various avenues for treatment offered avenues of empowerment amidst the uncertainty. Ultimately, engaging in discussions with healthcare providers provided a sense of clarity and assurance, allowing participants to make decisions that align with their loved one's best interests. Similarly, Khuli et al., (2019) in China highlighted the importance of open and honest discussions about care preferences in ensuring patient-centered care and family satisfaction with decision-making processes. Additionally, Carmen et al., (2021) in Singapore emphasized the significance of effective communication and shared decision-making between healthcare providers and family members in promoting positive outcomes and reducing emotional distress in the ICU.

These findings underscore the critical need for improved communication strategies and support interventions for family members of ICU patients. Healthcare providers should prioritize clear and empathetic communication, ensuring that information is conveyed in a manner that is easily understandable and sensitive to family members' emotional needs. Strategies such as regular updates, clear explanations, and open dialogue can help address communication challenges and enhance the overall experience of family members in the ICU. Moreover, facilitating discussions about care preferences and treatment decisions can empower families to participate in decision-making processes and advocate for their loved ones' preferences. By addressing these

communication challenges and promoting collaborative relationships between healthcare providers and family members, healthcare settings can enhance the overall quality of care and support for families facing critical illness in the ICU.

5.5. THEME 3: SUPPORT SYSTEMS

The dynamics of caregiving roles and responsibilities within families of ICU patients present a complex relationship of challenges and opportunities, as illuminated by the study's findings. Participants articulated feelings of overwhelming burden, exhaustion, and guilt as they navigated the demands of caregiving alongside other responsibilities. Conflicts over caregiving decisions and responsibilities further compound these challenges, leading to tension and resentment within families. However, amidst these difficulties, participants also recognized the value and significance of their caregiving roles, finding purpose, unity, and strength in supporting their loved ones. Conflict resolution within families is highlighted as key, with open communication, compromise, and empathy playing key roles in fostering understanding and promoting unity. These findings resonate with previous studies examining the challenges and support systems experienced by families of ICU patients. Thompson et al., (2018) in USA highlighted the significance of family dynamics and conflicts in the caregiving experience, emphasizing the importance of open communication and conflict resolution strategies.

In terms of community support, participants revealed diverse experiences, ranging from feelings of isolation and judgment to comfort and strength derived from community assistance. While some participants express challenges in accessing supportive resources and feeling disconnected from their communities, others find solace in acts of kindness, assistance from friends and neighbors.

Financial burdens emerged as a significant challenge faced by family members of patients in ICU in this study. Participants described the financial strain caused by medical expenses, transportation costs and food costs. These financial burdens added an additional layer of stress and uncertainty to an already challenging situation.

Similar studies have also highlighted the financial challenges faced by family members of ICU patients. For example, a study by Olorunfemi & Nwozichi (2022) in Nigeria reported that critical

illness imposed substantial financial burdens on the participants and increased self-reported levels of stress. Another study by Brown et al. (2019) reported that families struggled to navigate insurance coverage and were often unprepared for the financial implications of critical illness.

To address these financial challenges, participants in this study mentioned various sources of financial assistance, such as hospital financial aid programs, community fundraisers, and support from family and friends. These findings are consistent with a study by White et al. (2018), which found that financial assistance programs could help alleviate some of the financial burdens faced by families of ICU patients.

However, despite the availability of financial assistance programs, accessing these resources can be challenging. Participants in this study mentioned bureaucratic hurdles and lack of awareness about available resources as barriers to obtaining financial assistance. This highlights the need for improved communication and support from healthcare providers to help families navigate the financial aspects of critical care. Research by Pombe et al., (2020) in Tanzania and Fordson et al., (2022) in Ghana underscored the role of community support and financial assistance programs in alleviating the burden of caregiving for ICU patients, emphasizing the need for accessible resources and support networks for families facing financial strain.

In conclusion, financial burdens are a significant concern for family members of ICU patients. Healthcare providers should be aware of these challenges and proactively offer support and information about available financial assistance programs. Addressing these financial burdens can help reduce stress and improve the overall experience of families in the ICU.

Generally, these findings underscore the multilayered nature of caregiving experiences and the importance of effective communication, conflict resolution, and community support in mitigating challenges and promoting resilience among families of ICU patients. By addressing these needs and leveraging existing support systems, healthcare providers and community organizations can better support families in navigating the complexities of caregiving and promoting the well-being of both patients and their loved ones.

5.6. THEME 4: HEALTHCARE SYSTEM

The theme of the healthcare system, particularly focusing on quality of care and trust in healthcare providers, emerged as a critical aspect of the experiences of family members of ICU patients. Participants in this study expressed varying levels of satisfaction with the quality of care provided to their loved ones and the level of trust they had in healthcare providers. While some participants expressed dissatisfaction with certain aspects of care, such as inadequate staffing and coordination issues, others highlighted positive encounters characterized by dedication, expertise, and compassionate approaches from healthcare providers. The personalized and holistic approach to care received particular praise, emphasizing the importance of addressing not only physical needs but also emotional and spiritual well-being. Participants expressed varied levels of trust in healthcare providers, influenced by past experiences and perceptions of care. Some participants described the loss of trust due to mistreatment, misdiagnosis, lack of transparency, unequal treatment, and perceived profit-driven motives of healthcare providers. These experiences led to skepticism, suspicion, and reluctance to seek care. Conversely, other participants highlighted positive interactions with healthcare providers, emphasizing compassionate bedside manner, clear communication, empathy, and a genuine concern for patient well-being. Trust was reinforced by consistent, reliable care, respectful and nonjudgmental attitudes, and a willingness to listen to patient concerns. Building trust was seen as important for encouraging meaningful patient-provider relationships and ensuring effective healthcare delivery

Comparing these findings with other studies, a study by Moleli et al. (2018) conducted in South Africa found that family members of ICU patients expressed similar concerns about the quality of care and trust in healthcare providers. They highlighted issues such as communication gaps, lack of empathy, and perceived neglect, which eroded their trust in the healthcare system. Similarly, a study by Kehali et al (2020) conducted in Ethiopia reported that some family members of ICU patients lost trust in the health care delivery system and the health professionals due to previous experiences of losing a family member in an ICU.

In contrast, a study by Haave, Bakke & Schröder (2021) in Norway reported that families were very satisfied with a large portion of the ICU stay. Participants in this study cited satisfaction with the nursing care and with the overall treatment for both the hospitalized patient and for the

family itself. Similarly, a study by Min et al. (2018) in South Korea reported that most of the family members were satisfied with the ICU care and decision-making process. Additionally, a study by Mckiernan & McCarthy (2010) in Ireland showed that participants described having feelings of confidence in the care given. Being assured of best possible care was attributed in part to the provision of honest information.

Compassion and empathy emerged as critical components of the experiences of family members of ICU patients in this study. Participants frequently highlighted how acts of kindness and understanding from healthcare providers alleviated their emotional distress, fostered trust, and enhanced their overall satisfaction with the care process. However, instances of perceived indifference or lack of empathy also contributed to heightened feelings of frustration and helplessness, demonstrating the profound impact that provider attitudes can have on family members during such critical times.

The findings align with studies conducted in other contexts. For example, a study by Schwarzkopf et al. (2018) in Germany found that families of ICU patients often viewed compassionate communication as a cornerstone of quality care. Families valued healthcare providers who took the time to explain medical procedures, addressed their concerns with patience, and demonstrated emotional sensitivity. Similarly, a study conducted in the United States by Curtis et al. (2016) emphasized that empathy in healthcare communication significantly reduced the psychological burden on families and contributed to higher levels of satisfaction with ICU care. Additionally, For example, a study by Konkweto et al., (2019) in Namibia and Bositu et al., (2018) in South Africa found that empathy from healthcare providers was associated with increased patient satisfaction and better treatment adherence.

In contrast, when empathy was lacking, the emotional impact on families was magnified. A qualitative study by Egbe et al. (2021) revealed that families of ICU patients frequently felt neglected by healthcare providers, particularly in resource-constrained settings where provider workloads were high. Participants in this study described instances of dismissive behavior and lack of attentiveness, which compounded their stress and diminished their trust in the healthcare system. Similar findings were echoed in research conducted in Ethiopia by Abate et al. (2020), where families reported that providers' failure to acknowledge their emotional needs left them feeling excluded and unsupported during the ICU stay.

In this study, participants highlighted specific examples of compassion, such as nurses taking the time to offer words of comfort or doctors providing detailed updates in a calm and caring manner. These acts were described as "moments of hope" that helped families cope with the uncertainty and fear surrounding their loved one's condition. On the other hand, some participants noted instances of perceived insensitivity, such as rushed or dismissive communication, which left them feeling disconnected and emotionally strained.

Compassion and empathy are not only central to fostering trust and satisfaction but are also linked to improved healthcare outcomes for patients and families. A global study by Chochinov et al. (2015) demonstrated that compassionate care significantly alleviates psychological distress among family members and improves their ability to cope with the ICU experience. This underscores the need for healthcare providers to integrate empathy into all aspects of care, from communication to bedside interactions.

In resource-limited settings like Zambia, however, systemic challenges such as understaffing and high patient loads may limit the ability of healthcare providers to consistently display compassion and empathy. Addressing these challenges through improved staff training, better resource allocation, and supportive hospital policies could enhance the delivery of empathetic care. For example, implementing family-centered care training for healthcare teams, as suggested by Davidson et al. (2017), could help providers better understand and respond to the emotional needs of families, even in high-pressure environments.

Overall, the study's findings underscore the serious role of healthcare providers in shaping patient experiences and perceptions of care. By prioritizing compassion, empathy, and family-centered practices, healthcare organizations can cultivate environments that promote healing, trust, and resilience among patients and their families.

5.7. CONCLUSION

The discussion chapter reflects on the multifaceted challenges faced by family members of patients in the Intensive Care Unit (ICU), as highlighted by the study's findings. The themes of emotional impact, communication challenges, coping mechanisms, and the healthcare system underscore the complexity of the experiences encountered by these individuals.

Emotional impact emerged as a central theme, with family members describing feelings of anxiety, stress, and uncertainty. This highlights the need for healthcare providers to recognize and address the emotional needs of family members, offering support and resources to help them cope. Communication challenges were also prominent, with participants expressing difficulties in understanding medical information and feeling excluded from decision-making processes. Improving communication with healthcare providers and providing clear, empathetic explanations can help alleviate these challenges.

Coping mechanisms were varied, with family members relying on social support, spirituality, and practical strategies to navigate the stress of having a loved one in the ICU. Understanding these coping mechanisms can help healthcare providers offer targeted support to families. The theme of the healthcare system revealed mixed experiences, with some family members expressing trust and satisfaction in healthcare providers, while others reported feeling overwhelmed and neglected. Improving transparency, empathy, and communication within the healthcare system can help build trust and enhance the overall experience of families in the ICU.

This study reiterates that admission of a loved one to ICU is a stressful event in the lives of family members. This study's findings emphasize the need for a comprehensive and holistic approach to supporting family members of ICU patients. By addressing emotional, communication, and healthcare system challenges, healthcare providers can improve the quality of care and support provided to these individuals during a critical and challenging time.

5.8. IMPLICATIONS TO NURSING

1. NURSING PRACTICE

The findings underscore the critical need for nurses to enhance their communication skills to bridge the gap between medical jargon and patients' families, ensuring they understand the difficulties of their loved one's condition. Nurses should also prioritize emotional support, empathy, and compassionate care to alleviate the emotional distress experienced by family members. Additionally, nurses can play a pivotal role in providing guidance and advocating for patient-centered care throughout the care continuum.

2. NURSING ADMINISTRATION

Nursing administrators should focus on improving staffing levels or come up with innovative ways of promoting quality in the midst of staff shortages and coordination among healthcare teams to address the reported shortcomings in the quality of care. Investing in ongoing training and education programs for nursing staff can help enhance their communication skills, cultural competence, and ability to provide family-centered care. Furthermore, nursing administrators can collaborate with other healthcare professionals to implement support programs and resources for family members, addressing their emotional and practical needs effectively. Nursing administrators should also ensure appropriate nurse-to-patient ratios can help nurses dedicate more time to family interactions, reducing feelings of neglect and dissatisfaction among family members.

3. NURSING EDUCATION

Nursing education programs should integrate comprehensive communication training that equips future nurses with the skills needed to effectively communicate medical information to patients and their families in a clear and empathetic manner. Emphasizing cultural competence and sensitivity training can help nurses better understand and respond to the diverse needs of patients and families from varying cultural backgrounds. In addition, nursing schools should use simulation exercises to teach students how to manage real-life scenarios, such as communicating with distressed family members or addressing emotional challenges in critical care settings.

4. NURSING RESEARCH

The study underscores the need for structured interventions that address family members' emotional, informational, and financial needs. Future research should explore and evaluate the effectiveness of family-centered care interventions, such as regular family meetings, counseling programs, and financial support mechanisms. Future research should also investigate the impact of cultural factors on caregiving experiences and identify strategies to enhance support systems for families within the healthcare system. Additionally, nursing research can focus on evaluating the long-term outcomes of interventions aimed at promoting compassionate care and trust building between healthcare providers and patients/families, ultimately informing evidence-based practices in nursing care delivery.

5.9. RECOMMENDATIONS

TO THE MINISTRY OF HEALTH

1. POLICY DEVELOPMENT

The Ministry of Health should develop comprehensive policies and guidelines that prioritize the well-being and support of families of ICU patients. These policies should outline standards for communication and support programs ensuring consistency and quality across healthcare facilities. The study revealed that family members often face communication challenges, including a lack of clear and timely updates about their loved one's condition and feelings of exclusion from decision-making processes. These challenges led to emotional distress and frustration among participants. By formalizing family-centered care policies, healthcare providers can establish consistent communication practices and ensure families are treated as active participants in the care process, addressing their need for involvement and emotional assurance.

2. RESOURCE ALLOCATION

Allocate resources to enhance support systems for families of ICU patients, including funding for counseling services, support groups, including family lounges, financial assistance programs

and educational materials. Collaborate with non-governmental organizations and community partners to expand access to resources and services. The study identified significant emotional and financial burdens experienced by family members, compounded by limited institutional support and the high cost of accessing ICU care. Participants reported needing spaces to rest, emotional support from professionals, and assistance in managing the financial strain of transportation, meals, and medical bills. Allocating resources to address these gaps would help alleviate stress, foster coping mechanisms, and improve the overall experience of families during their loved one's ICU stay.

3. QUALITY MONITORING

Establish mechanisms for monitoring and evaluating the quality of care provided to families of ICU patients, including patient satisfaction surveys, feedback mechanisms, and performance indicators. This should include assessing family satisfaction with communication, emotional support, and involvement in decision-making. The study highlighted both positive and negative experiences with the healthcare system, particularly regarding the trustworthiness and compassion of healthcare providers. While some participants expressed gratitude for empathetic care, others noted instances of neglect or ineffective communication. A systematic approach to gathering family feedback would enable healthcare facilities to identify areas needing improvement, such as communication strategies or resource provision, while building on positive aspects like compassionate care.

TO THE HOSPITAL

1. STAFF TRAINING AND DEVELOPMENT

Provide ongoing training for healthcare providers on how to effectively communicate with and support family members of ICU patients, including topics such as empathy, cultural sensitivity, and recognizing signs of distress. While some participants noted positive experiences with compassionate and empathetic healthcare providers, others reported instances of neglect and lack of sensitivity. The study showed that the perception of healthcare providers' attitudes significantly influenced family members' trust and satisfaction. Training staff to prioritize family-centered care would ensure a more consistent and supportive experience for families.

2. INTERDISCIPLINARY COLLABORATION

Foster collaboration among healthcare teams, including nurses, physicians, social workers, and chaplains, to provide comprehensive and coordinated care to families of ICU patients. Interdisciplinary rounds or team meetings should include discussions on family needs and how to effectively address them. The study highlighted that fragmented communication and inconsistent support from the healthcare team contributed to family members' distress. Improved collaboration between healthcare providers would ensure families receive consistent information, emotional support, and practical assistance. This approach would enhance family satisfaction and promote trust in the healthcare team.

FAMILY SUPPORT SERVICES

Enhance support services for families of ICU patients by offering counseling services, support groups, and resources to help them cope with the emotional impact of having a loved one in the ICU. Designate trained staff members to serve as liaisons between families and healthcare teams, providing emotional support, information, and assistance with navigating the healthcare system.

The study underscored the emotional toll and financial burden experienced by family members. Participants frequently reported needing emotional support to cope with stress, as well as assistance to manage the high costs associated with transportation and medical bills. The designated staff members would address these needs comprehensively, ensuring families feel supported during their ICU journey.

5.10. LIMITATIONS OF THE STUDY

Several limitations were encountered during the course of this study, which warrant acknowledgment. The research was conducted at the Adult University Teaching Hospital (UTH) in Lusaka, Zambia. This may limit the transferability of the findings to broader populations of families of ICU patients as experiences may differ in other hospitals or regions with varying healthcare systems, resources, and cultural contexts. Despite this, similarities in the experiences of family members are consistent with international studies. Additionally, the study was conducted within a specific cultural context and religious context. All participants in this study were Christians, which may have influenced their coping mechanisms and perceptions of

support. The absence of representation from other religious or cultural groups limits the study's ability to explore how diverse beliefs and practices shape experiences in the ICU.

Future research should aim to address these limitations by incorporating larger and more diverse samples, utilizing mixed methods approaches, and exploring the experiences of families of ICU patients across different cultural settings.

5.11. DISSEMINATION OF FINDINGS AND DATA UTILIZATION

The data obtained from in-depth interviews with families of ICU patients presents immediate practical implications and long-term research prospects. The insights from these interviews can directly inform the development of targeted interventions and support systems within the hospital, tailored to address the specific needs and challenges faced by families of ICU patients. Healthcare practitioners, hospital administrators, and policymakers can utilize this information to enhance the quality of care and support provided to families, ultimately improving patient outcomes and satisfaction. Furthermore, the identification of commonalities with international studies underscores the global relevance of the experiences and struggles encountered by families of ICU patients, suggesting opportunities for collaborative efforts in developing solutions.

The findings of the study will be disseminated to relevant stakeholders to promote the implementation of recommendations. Executive summaries will be prepared and given to the Ministry of Health, and a hard copy of the research report will be submitted to the University of Zambia - School of Nursing Sciences, University of Zambia Medical Library, and AUTH- ICU in Lusaka, as well as a copy for the researcher. The results will be published in the Medical Journal of Zambia to ensure that results are well disseminated. This will ensure that the results of the study are widely available to healthcare professionals and policy-makers.

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APPENDICES

APPENDIX I: INFORMATION SHEET

Study Title: LIVED EXPERIENCES OF FAMILY MEMBERS OF PATIENTS ADMITTED TO THE INTENSIVE CARE UNIT AT THE ADULT UNIVERSITY TEACHING HOSPITAL, LUSAKA ZAMBIA

Introduction

My name is Cynthia S. Phiri ; a student pursuing a Master of Critical Care Nursing at the University of Zambia. I am kindly requesting for your participation in the research study mentioned above. The information in this form is meant to help you decide whether or not to participate. Before you decide to participate be sure you are clear about the study. Where you do not understand, feel free to ask for clarification as you respond to the questions.

Purpose of the research: The study will be of benefit in that it will provide key insights into experiences encountered, needs and preferences as well as challenges faced by family members of patients admitted in the ICU at the Adult University Teaching Hospital. Additionally, the study will provide information that can be used by the hospital management and policy makers to implement interventions that will better the experiences family members, to enhance their well-being, improve communication practices, and promote family-centered care.

Procedure

The study will involve signing of the consent form. There will be a face-to-face interview with the researcher and the interview will be recorded using a recorder. Guiding questions will be asked which will be recorded in the audio recorder. The interview will take about 20 to 30 minutes; it may be repeated until the required information is captured.

Voluntary Participation: Your participation in this study is voluntary. It is your choice whether to participate or not. You may change your mind later and stop participating even if you agreed earlier.

Confidentiality

The information that will be collected for this study will be kept confidential. Only the researcher will handle information about you that will be collected during the research. Any information about you will have a number on it instead of your name. No one will link the data you provided to the identifying information you supplied (e.g., address, email).

Risks and discomforts: There is no risk involved in this research though part of your time will be spent discussing the mentioned topic.

Benefits

There will be no direct benefit to you by participating in this study, but the information which will be obtained will help the policy makers and the training institution to devise programs to improve the experience of family members during admission of their relative to ICU.

Sharing the Results: After completion of the study, the findings will be shared with the University Teaching Hospital and published in reputable journals. You may also access the results in the University of Zambia libraries.

Right to Refuse or Withdraw: You do not have to take part in this study if you do not wish to do so. You may stop participating in the study at any point in time that you wish.

Whom to Contact?

If you have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact Ms. Cynthia S. Phiri on +260976266762 or email phiricynthias@gmail.com OR you may contact the Chairperson at University of Zambia Biomedical Research Ethics Committee Dr. S. Munsaka on +260977925304 or email unzarec@unza.zm or s.munsaka@unza.zm .

APPENDIX II: INFORMED CONSENT

You have been requested to participate in an interview being conducted by Cynthia S. Phiri. The purpose of interview is to explore lived experiences of family members of patients admitted to the intensive care unit at the Adult University Teaching Hospital in Lusaka Zambia.

I, _____ (Names or initials) have read and understood the information sheet. Having been assured of confidentiality and anonymity, I accept to take part in answering these questions voluntarily to help facilitate the accuracy and validity of this study.

Signature _____ Date ____/____/____

Thumb print _____

APPENDIX III: INTERVIEW GUIDE

Topic: The Lived Experiences of Family Members of Patients Admitted to the Intensive Care Unit at Adult University Teaching Hospital.

Date of Interview: _____

Place of Interview: _____

Interview Number: _____

SECTION 1: BACKGROUND INFORMATION

1. Can you please start by telling us a little about yourself? Your age, occupation, and any other details you are comfortable sharing
2. Can you tell me a bit about your relationship with the patient in the ICU?
3. How long has your loved one been in the ICU, and what was the reason for their admission?

SECTION 2: CHALLENGES FACED BY FAMILY MEMBERS

1. Can you describe any challenges or difficulties you have faced while your loved one has been in the ICU?
2. How have you been coping with the stress and emotions associated with your loved one's critical illness?
3. What challenges, if any, have you encountered regarding visiting hours, access to information, or physical comfort?

SECTION 3: COMMUNICATION AND INTERACTION

1. How would you describe the communication between you, your loved one, and the healthcare providers in the ICU?
2. Were there specific instances of communication or interaction with the healthcare team that were particularly meaningful or challenging?

3. What kind of information and updates did you expect and receive from the medical staff regarding your loved one's condition?

SECTION 4: SUPPORT AND COPING

1. How did you cope with the stress, uncertainty, and emotions of having a loved one in the ICU?
2. Did you seek support from family, friends, or healthcare providers, and if so, how did it help you?
3. Were there resources or services offered by the hospital that you found particularly beneficial during this time?

SECTION 5: EXPECTATIONS AND NEEDS

1. Were there specific expectations or needs you had as a family member of an ICU patient? How were these addressed or unmet?
2. Did you have preferences or wishes related to your involvement in the care or decision-making process?
3. What kind of practical support or accommodations would you expect while you are at the hospital?

SECTION 4: POSITIVE EXPERIENCES AND SUGGESTIONS FOR IMPROVEMENT

1. Have there been any positive experiences or moments of support that stand out during your time in the ICU?
2. Do you have any suggestions or recommendations for improving the care and support provided to families in the ICU?
3. Is there anything else you would like to share about your experiences or expectations?

APPENDIX IV: PERMISSION AND APPROVAL LETTERS

The University of Zambia,
School of Nursing Sciences,
P.O Box 50110,
Lusaka.

30th January 2024

Head Clinical Care- Adult
University Teaching Hospital
P/B RW 1
Lusaka
Dear Sir/Madam,

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT THE ADULT UNIVERSITY TEACHING HOSPITAL MAIN INTENSIVE CARE UNIT

With reference to the above, I am writing to request permission from your office to conduct my research study titled “Lived experiences of family members of patients admitted to the intensive care unit (ICU) at the University Teaching Hospital in Zambia.” I am a second year student pursuing a Master of Science degree in Critical Care Nursing at the University of Zambia, and this research is part of my Master's thesis.

My research aims to investigate the experiences and needs of family members of patients admitted to the Intensive Care Unit (ICU) at the Adult University Teaching Hospital. The study seeks to understand their perspectives, challenges, and expectations regarding the care and support provided to them and their loved ones during the ICU stay. The insights gained from this research will contribute to the enhancement of patient and family-centered care at University Teaching Hospital.

I anticipate that the research will be conducted from 5th February 2024 to 23rd February, 2024. During this period, I kindly request access to main ICU units and waiting areas to conduct interviews and collect relevant data. I assure you that the research will be conducted with the utmost professionalism and will not disrupt the hospital's daily operations in any way.

Thank you for considering my request. I believe that the findings of this research will have a positive impact on patient care and support at the University Teaching Hospital. I look forward to your positive response and the opportunity to contribute valuable insights to the field of healthcare.

Please find attached the research proposal and other documents to support my application.

Yours Faithfully,

Cynthia S. Phiri

A handwritten signature in black ink, appearing to read 'Cynth' with a stylized initial 'C'.

Contact number: 0976 266762

Email: phiricynthias@gmail.com



**REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
University Teaching Hospitals - Adult**

Fax: +260 211 250305
E-mail: adultH@uth.gov.zm

P/Bag Rw IX
Lusaka - Zambia
Tel: +260 211 253947 (Switch Board)
+260 211 251451

OFFICE OF THE SENIOR MEDICAL SUPERINTENDENT

Our Ref:

Your Ref:

2nd February, 2024

Cynthia S. Phiri
University of Zambia
School of Nursing Sciences
School of Medicine
P O Box 50110
LUSAKA

Dear Cynthia S. Phiri,

**RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT THE ADULT
UNIVERSITY TEACHING HOSPITAL MAIN INTENSIVE CARE UNIT**

The University Teaching Hospital – Adult is in receipt of your letter dated 30th January, 2024 in which you had requested for permission to conduct a research entitled “*Live experiences of family members of patients admitted to the intensive care unit (ICU),*” at the University Teaching Hospital Adult.

I wish to inform you that permission has been granted and you are advised to liaise with the Head of Department.

Yours faithfully,

Dr. Mwila Lupasha
Head Clinical Care
for/Senior Medical Superintendent



**THE UNIVERSITY OF ZAMBIA
SCHOOL OF NURSING SCIENCES
OFFICE OF THE ASSISTANT DEAN POSTGRADUATE**

Tel: +260 211 252453
+260 211 252453
Website: www.unza.zm
Email: dean-nursingscience@unza.zm

School of Nursing Sciences Building Fax:
University Teaching Hospitals
P.O Box 50110
Lusaka, Zambia

10th November, 2023

The chairperson,
UNZABREC,
The University of Zambia,
Ridgeway campus,
Lusaka.

Dear Sir/Madam,

RE: PROPOSAL SUBMISSION FOR ETHICAL REVIEW: CYNTHIA S. PHIRI

Cynthia S. Phiri presented her research proposal entitled, "Lived Experiences of Family Members of Patients Admitted to the Intensive Care Unit (ICU) at the University Teaching Hospital, Zambia", to the School of Nursing Sciences Graduate Proposal Presentation Forum. The supervisor has confirmed that the corrections and recommendations to the research proposal have been attended to.

This serves as a supporting letter for the student to submit the proposal for ethical review to UNZABREC.

Yours faithfully

Brenda Sianchapa (Ms)
ASSISTANT DEAN -Postgraduate

Cc: Head, Department of Midwifery, Women's and Child Health
File



UNIVERSITY OF ZAMBIA
BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: +260 977925304
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

E-mail: unzarec@unza.zm

Federal Assurance No. FWA00000338 IRB00001131 of IORG0000774 NHRAR-REC No 2021-05-0002

22nd January 2024

Your REF. No. 4682-2023

Ms. Cynthia Stephen Phiri,
University of Zambia,
School of Nursing Sciences,
PO Box 50110,
Lusaka.

Dear Ms. Phiri,

**RE: LIVED EXPERIENCES OF FAMILY MEMBERS OF PATIENTS ADMITTED TO THE
INTENSIVE CARE UNIT AT THE ADULT UNIVERSITY TEACHING HOSPITAL,
LUSAKA, ZAMBIA (REF. NO. 4682-2023)**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 22nd January, 2024. The proposal is **approved**. The approval is based on the following documents that were submitted for review:

- a) **Study proposal**
- b) **Questionnaires**
- c) **Participant Consent Form**

APPROVAL NUMBER

: REF. No. 4682-2023.

This number should be used on all correspondence, consent forms and documents as appropriate.

- i. **APPROVAL DATE** : 22nd January 2024
- ii. **TYPE OF APPROVAL** : Standard
- iii. **EXPIRATION DATE OF APPROVAL** : 21st January 2025
- iv. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the UNZABREC Offices should be submitted one month before the expiration date for continuing review.
- v. **SERIOUS ADVERSE EVENT REPORTING:** All SAEs and any other serious challenges/problems having to do with participant welfare, participant safety and study integrity must be reported to UNZABREC within 3 working days using standard forms obtainable from UNZABREC.



NATIONAL HEALTH RESEARCH AUTHORITY

Lot No. 18961/M, off Kasama Road, Chalala, P.O. Box 30075, LUSAKA

Tell: +260211 250309 | Email: znhrasec@nhra.org.zm | www.nhra.org.zm

Ref No: NHRA-936/15/02/2024

Date: 23rd February, 2024

The Principal Investigator,
Cynthia Stephen Phiri,
University of Zambia,
School of Nursing Sciences,
Lusaka, Zambia.

Dear Ms Phiri,

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **“Lived Experiences of Family Members of Patients Admitted to the Intensive Care Unit at the Adult University Teaching Hospital, Lusaka, Zambia.”**

I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA bi-annually from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,

Prof Victor Chalwe
Acting Director/Chief Executive Officer
National Health Research Authority



NATIONAL HEALTH RESEARCH AUTHORITY
The Health Research Act
(Act No. 2 of 2013)



CERTIFICATE OF REGISTRATION

THIS IS TO CERTIFY THAT

Phiri Cynthia Stephen

has been registered as a Health Researcher

Dated this 5th August 2023

Registration number NHRAR-R-724/02/08/2023



DIRECTOR
PROF. GODFREY BIEMBA