

**LIVED EXPERIENCES OF PARENTS WITH NEONATES NURSED ON
MECHANICAL VENTILATORS IN THE NEONATAL INTENSIVE CARE UNIT AT
THE UNIVERSITY TEACHING HOSPITAL LUSAKA, ZAMBIA**

BY

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MASTER OF SCIENCE IN NEONATAL NURSING**

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DECLARATION

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I further declare that all sources of information and data used in this report, whether published or unpublished, have been appropriately cited and referenced in accordance with the academic and ethical standards.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 Science in Neonatal Nursing.

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ABSTRACT

The admission of a neonate requiring mechanical ventilation represents one of the most stressful experiences parents can face in the Neonatal Intensive Care Unit. In resource-limited settings, these challenges are often intensified by contextual factors including infrastructure limitations and cultural considerations. Understanding parents' lived experiences is crucial for developing appropriate support systems and improving family-centered care practices. A descriptive phenomenological study was conducted to explore lived experiences of parents with neonates on mechanical ventilation in the Neonatal Intensive Care Unit at the University Teaching Hospital, Lusaka, Zambia. Through purposive sampling and in-depth interviews, ten parents (six mothers and four fathers) shared their journey of navigating the complexities of having a critically ill neonate requiring ventilator support. Thematic analysis using NVIVO 14 was used to identify notable patterns and themes within the narratives of the participants. Thematic analysis revealed five key themes, which were emotional and psychological impact, communication challenges, coping strategies and support systems, environmental and structural challenges and inadequate professional support. The study participants represented diverse backgrounds in age, education, and distance from the hospital, providing rich perspectives on the experience. Study results revealed parents experienced profound emotional and psychological impacts including initial shock, persistent anxiety, and disrupted bonding patterns, while facing significant communication barriers within the technical NICU environment. Parents developed various coping mechanisms, predominantly religious practices and peer support networks, though they encountered substantial environmental and resource challenges including infrastructure limitations, financial strains, and difficulties balancing presence with family responsibilities. The cultural dynamics and limited formal support systems, particularly regarding psychological services, highlighted critical gaps in addressing parents' comprehensive needs during their journey. The study emphasizes the need for developing culturally sensitive family support frameworks, enhancing multilingual communication protocols, and improving infrastructure to better support parents through their challenging journey. These findings provide crucial insights for healthcare providers and administrators working to enhance family-centered care practices within resource-limited settings.

Keywords: *mechanical ventilation, parental experiences, psychological impact, cultural sensitivity, NICU support, resource-limited settings, family-centered care.*

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LIST OF ABBREVIATIONS

CINAHL	Cumulative Index to Nursing and Allied Health Research
HIE	Hypoxic Ischemic Encephalopathy
ICU	Intensive Care Unit
JRMO	Junior Resident Medical Officer
LBW	Low Birth Weight
NHRA	National Health Research Authority
NICU	Neonatal Intensive Care Unit
NNP	Neonatal Nurse Practitioner
PPHN	Persistent Pulmonary Hypertension of the Newborn
RDS	Respiratory Distress Syndrome
SHEPIZ	Strengthening Health Professional Workforce Education Program for Improved Quality Healthcare in Zambia
SRMO	Senior Resident Medical Officer
UTH	University Teaching Hospital
UNZA	University of Zambia
UNZABREC	University of Zambia Biomedical Research Ethics Committee
WHO	World Health Organization

CHAPTER ONE

1.0 Introduction

Parents of neonates on mechanical ventilators share their valuable insights on the challenges and emotions they face. This study explores the emotional, psychological, and practical aspects that parents encounter while navigating the complexities of having a newborn on mechanical ventilation in the University Teaching Hospital (UTH) Neonatal Intensive Care Unit (NICU) in Lusaka, Zambia. This chapter provides an overview of the topic. The process of decision-making and the involvement of parents in the care of NICU is complex and emotionally challenging. Parents 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. The chapter is divided into six sections, which include background of the study, problem statement, study justification, research objectives, definitions key terms and conclusion.

The Neonatal Intensive Care Unit (NICU) provides specialized care for premature and critically ill new-borns in a controlled, sterile environment. Within this setting, mechanical ventilation serves as a crucial life-saving intervention, providing respiratory support through artificially controlled breathing for neonates experiencing respiratory distress or compromised lung function (Shakur et al., 2021; Frank et al., 2017). Mechanical ventilators deliver precise mixtures of air and oxygen, supporting infants with conditions including respiratory distress syndrome, bronchopulmonary dysplasia, and congenital heart disease (WHO, 2019). Common factors necessitating ventilation include premature birth, underdeveloped lungs, respiratory infections and congenital anomalies (Smith et al., 2020). Healthcare professionals initiate ventilation based on clinical indicators including respiratory distress severity, blood gas values, and overall condition.

While ventilation can improve oxygenation and resolve respiratory distress, it may also present complications such as lung injury or infections (WHO, 2019). The psychological impact on parents navigating this complex medical journey remains understudied. Parents experience significant

stress, anxiety, and emotional turmoil, compounded by unfamiliar medical environments and limited infant interaction (Masumo et al., 2019). At UTH Lusaka, these challenges intensify within a resource-limited setting characterized by infrastructure constraints and healthcare personnel shortages (Chisala et al., 2018). The emotional journey of parents becomes particularly challenging against this backdrop of systemic limitations (Mwamba et al., 2018). While medical aspects of mechanical ventilation are well-documented, significant gaps exist in understanding parents' psychological and emotional experiences (WHO, 2020; Johnson et al., 2019).

1.1 Background

Medical, economic, cultural and societal factors on parents in Africa places enormous pressure on how they perceive their responsibility when their neonate is in Intensive Care Unit (Nyabvudzi, Muchena, & Chikoko, 2020). Mothers are expected to bond easily with their neonate and begin to provide care. This can create emotional strain due to societal judgement and personal feelings of inadequacy especially if their infant is hospitalised in NICU (Nyaloko et al., 2024). This situation is compounded by lack of adequate resources in that financial burdens restrict support systems thereby influencing coping mechanisms among parents.

Parents from limited resource settings face challenges including lack of transportation to and from the hospital and their capacity to prolong their visit to the hospital is reduced due to lack of financial resources. In addition, there are instances where institutions also lack or have limited support mechanism for parents caring for their neonate requiring critical care. However, a study by Chipeta, Mulenga, and Zulu (2024), observes that informal support networks play an important role in reducing the financial burden that arises as a result of taking care of a hospitalised neonate.

The above factors exacerbate the emotional and psychological distress experienced by parents nursing infants hospitalised at NICUs. This scenario calls for the need to have a robust approach that can address these factors.

This study, therefore, explores parents' first-hand experiences at UTH-NICU Lusaka, examining their emotional challenges and logistical difficulties in balancing family responsibilities while supporting a ventilated neonate. This investigation addresses critical gaps in understanding parental experiences within resource-limited NICU settings.

1.2 Statement of the problem

In the NICU of the UTH in Lusaka, Zambia, parents of neonates requiring mechanical ventilation face a pressing issue. The neonatal care environment, characterized by a high-tech setting and the fragility of their infants, presents parents, particularly mothers, with a unique set of emotional and practical challenges. A study by Li et al., (2024) observes that the NICU experience of neonates affects parents' mental health, causing various problems, such as anxiety, depression, and post-traumatic stress disorder (PTSD), and the psychological pain of the parents tends to persist after discharge. While the medical aspects of mechanical ventilation are well-documented, there is a significant gap in understanding and addressing the psychological and emotional distress experienced by these parents in this specific context (Kabila et al., 2015).

In this setting, parents' experiences are compounded by the unfamiliar and highly technical NICU surroundings, adding to their emotional and logistical burdens. Despite a growing recognition of the importance of psychosocial support in NICUs, the precise challenges faced by parents, particularly in Lusaka, Zambia, remain poorly understood.

A study using the Hospital Anxiety and Depression Scale investigated 100 parents in the NICU and found that 64 % and 23 % of the parents reported mild anxiety and depression symptoms, respectively (Li et al, 2024). The consequences of unaddressed emotional and practical challenges among parents of neonates requiring mechanical ventilation in the NICU can have profound effects. These may include elevated stress, guilt, anxiety, and sadness due to the neonates' uncertain health prognosis Nyaloko et al., (2024). Furthermore, the emotional well-being of parents directly influences their ability to actively engage in their neonate's care, make well-informed decisions, and promote their child's overall development. Failure to address these challenges may lead to long-term psychological difficulties for both parents and their neonates.

Efforts to address this issue have mainly focused on medical interventions and technical aspects, leaving the emotional and psychological well-being of parents relatively unexplored. If this gap persists, parents may continue to navigate this wild journey without adequate support, potentially leading to heightened stress levels, emotional strain, and even potential negative effects on the infant's development. Thus, a comprehensive investigation into the lived experiences of parents facing these circumstances is essential to inform targeted interventions, refine healthcare practices,

and establish a robust support framework that encompasses the holistic well-being of both the neonate and their family.

1.3 Justification

The justification for conducting this research is that studies documented significant gaps in understanding parents' experiences with neonates on mechanical ventilation at UTH Lusaka. Similar studies by Muchimba et al. (2020) revealed heightened parental stress and anxiety in the NICU, while Cobby et al. (2019) demonstrated mental health impacts of prolonged hospitalization. Brent et al. (2018) established the importance of parent-infant bonding despite clinical complexities. However, these studies do not address the specific issues regarding parental experiences with mechanical ventilation in resource-limited settings in the context of emotional, psychological, and practical challenges. This is despite the potential benefits for stakeholders that may arise from such a study.

Healthcare providers may benefit by gaining understanding of the experiences of parents during hospitalisation of their neonates. This may inform appropriate support systems and evidence based decision making. Policy makers can benefit from the valuable insights of the study that may inform policy decisions and improve practice. Researchers and educators may gain access to information needed for refining approaches to neonatal care education and practice. Ultimately, the study can benefit society as a whole by improving the supportive environment for neonatal health, family well-being and clinical outcomes.

1.4 Research Objectives

1.4.1 General Objective

The overarching goal of this research was to explore the lived experiences of parents with neonates undergoing care on mechanical ventilators in the Neonatal Intensive Care Unit (NICU) at the University Teaching Hospital (UTH) in Lusaka, Zambia.

1.4.2 Specific Objectives

1. To describe the emotional and psychological experience of parents whose neonates are undergoing mechanical ventilation in the NICU at UTH Lusaka, Zambia.
2. To explore the challenges faced by parents navigating the care of their neonates on mechanical ventilation in the NICU at UTH Lusaka, Zambia.

3. To identify the coping strategies and support system utilized by parents with neonates on mechanical ventilators, in the NICU at UTH Lusaka, Zambia.

1.5 Research Questions

1. What is the emotional and psychological experience on parents with neonates undergoing mechanical ventilation in the NICU at UTH Lusaka, Zambia?
2. What are the challenges faced by parents navigating the care of their neonates on mechanical ventilation in the NICU at UTH Lusaka, Zambia?
3. What are the coping strategies and support system utilized by parents with neonates on mechanical ventilators, in the NICU at UTH Lusaka, Zambia?

1.6 Conceptual Definitions

1. **Parent:** The biological mother or father of a neonate who holds primary responsibility for the child's care and medical decision-making, particularly in the context of neonatal intensive care. This includes direct involvement in the neonate's care, emotional support, and healthcare decisions while working in partnership with medical providers (WHO, 2022; American Academy of Pediatrics, 2024).
2. **Neonates:** Refers to newborn infants within the first 28 days of life, often known as the "neonatal period" (WHO, 2019).
3. **Mechanical Ventilation:** A medical intervention that involves the use of a machine known as a ventilator to assist or replace a neonate's natural breathing process. It delivers oxygen-rich air and facilitates the exchange of gases within the neonate's lungs (Gelvier, 2017).
4. **Lived Experiences:** The subjective perceptions, feelings, emotions, and insights of individuals, in this context, parents, as they navigate the challenges and circumstances associated with having a neonate on mechanical ventilation (Haggins, 2020).
5. **Neonatal Intensive Care Unit (NICU):** A specialized medical unit within a hospital that provides intensive medical care to critically ill neonates, often involving premature infants or those with complex medical conditions (WHO, 2019).
6. **Emotional Challenges:** The psychological and affective difficulties faced by parents, including stress, anxiety, grief, guilt, and other emotional responses, as they cope with the medical condition of their neonate (Andrew, 2014).

7. **Family-Centered Care:** An approach to healthcare that recognizes the significance of involving and supporting family members, including parents, in the care and decision-making process of their neonates while in the NICU. This approach aims to acknowledge and address the emotional and practical needs of both neonates and their families (WHO, 2019).
8. **Support Mechanisms:** Various resources, interventions, and strategies, both formal and informal, are designed to address the emotional, psychological, and practical needs of parents and families with neonates on mechanical ventilation in the NICU. These mechanisms aim to aid and guidance for parents during their neonate's medical journey (Daimon, 2018).

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

The literature review is an important component of proposal writing since it aids in setting the study within the body of already existing knowledge. The literature review, which highlights the findings of other researchers, is scrutinized in this chapter. In this literature review, the researcher summarizes the lived experiences of parents with neonates nursed on mechanical ventilators. Search databases such as PubMed, HINARY, Google Scholar, CINAHL, and Cochrane Library were used. The chapter is organized into sections that explore an overview of parents with neonates nursed on mechanical ventilators, experiences of parents with neonates nursed on mechanical ventilators in NICU and a conclusion. Each section builds on existing literature to identify gaps and suggest strategies for improving experiences of mothers in NICU settings.

2.1. Overview of Parents with Neonates Nursed on Mechanical Ventilators

Parents traversing the journey of caring for neonates reliant on mechanical ventilators within the Neonatal Intensive Care Unit (NICU) embark on a distinctive and emotionally charged odyssey (Maghaireh, 2018). The introduction of mechanical ventilation into the care regimen of neonates brings forth a spectrum of emotions for parents, encompassing anxiety, worry, hope, and determination (Franck, 2017). Witnessing their delicate newborns intricately connected to tubes and monitors elicits a complex amalgamation of fear and resilience (Franck, 2017). Within this context, parents find themselves navigating the delicate balance between the eagerness to actively participate in their neonate's care and the necessity to entrust medical professionals with their specialized expertise (Williams, 2020). This equilibrium is intricate, as parent's grapple with the unfamiliarity of the medical environment while ardently desiring optimal care for their neonates.

The NICU environment introduces another layer of complexity to this already challenging situation. The constant beeping of machines, the intricate language of medical professionals, and the presence of other critically ill neonates collectively contribute to an overwhelming atmosphere (Williams, 2020). Practical challenges further compound the emotional strain experienced by parents, including issues such as transportation, financial burdens, and the labyrinthine nature of navigating the healthcare system (Gennaro, 2019). These challenges not only exacerbate the

emotional toll but also add a layer of practical hurdles for parents already grappling with the intricate care demands of neonates on mechanical ventilation.

In this intricate landscape, parents often forge profound connections with the healthcare professionals responsible for the well-being of their neonates. These connections extend beyond the realm of medical expertise, encompassing emotional support and guidance (Gennaro, 2019). The relationships formed with the medical team play a pivotal role in shaping parents' experiences. A compassionate and communicative medical team can alleviate some of the stress and uncertainty inherent in such challenging circumstances, offering a support system that extends beyond the immediate medical care provided to neonates.

The provided literature review emphasizes the critical nature of the challenges faced by parents of neonates requiring mechanical ventilation in the NICU at the University Teaching Hospital (UTH) in Lusaka, Zambia. It delineates the emotionally charged and logistically intricate landscape encountered by these parents, aligning with the identified problem statement. The literature underscores the unique emotional and psychological burdens faced by parents, echoing the need to understand and address the specific distress experienced in this context. The study aims to bridge the gap highlighted in the literature by delving deeply into the lived experiences of these parents, seeking to elucidate the emotional, psychological, and practical challenges they encounter. By focusing on these aspects, the research aims to provide empirical evidence that can inform targeted interventions and policies. The study's objectives are directly aligned with the highlighted gaps in the literature, aiming to explore the emotional and psychological impacts, communication challenges, coping mechanisms, and support systems available to these parents in the NICU at UTH Lusaka, Zambia. Ultimately, this investigation intends to contribute to the refinement of healthcare practices and the establishment of comprehensive support frameworks that cater to the holistic well-being of both the neonates and their families within this specific context.

2.2 Experiences of Parents with Neonates Nursed On Mechanical Ventilators in NICU

The experiences of parents with neonates requiring mechanical ventilation in the Neonatal Intensive Care Unit (NICU) have garnered significant attention globally, as evidenced by various studies that offer valuable insights into the challenges and dynamics faced by these parents. Kaur et al. (2017) conducted a qualitative study in India titled "Parental Experiences of Neonatal

Intensive Care Unit," involving 40 parents. The study illuminated that parent expressed a spectrum of emotions, including emotional confusion, vulnerability, and apprehension while navigating the complex NICU environment. These findings resonate with the qualitative research conducted by Gray et al. (2019) in the United Kingdom, titled "Parental Experiences of Having an Infant in a Neonatal Intensive Care Unit." With a participant pool of 60, the study highlighted parental stress, fear, and the paramount importance of clear communication with healthcare professionals. Collectively, these studies underscore the critical need for comprehensive support systems tailored to the unique challenges faced by parents in the NICU.

Rao et al. (2021) contributed insights through a comparative study in India, focusing on distinctions in parental decision-making processes and information access between urban and rural NICU settings. 300 parents were engaged, and the research identified unique challenges and decision-making dynamics influenced by geographical contexts. Similarly, Van der Linden (2022) conducted a facility-level analysis across multiple NICUs in Europe, involving 500 parents, to assess variations in NICU environments and their impact on parental mental health outcomes. The research demonstrated significant associations between NICU environmental factors and diverse parental mental health outcomes, emphasizing the pivotal role of institutional considerations in shaping the overall parental experience in NICUs.

Andersson (2022) undertook a cross-cultural qualitative analysis in Sweden and Saudi Arabia, exploring the cultural dimensions shaping coping mechanisms among parents in the NICU. With an extensive participant pool of 80 parents, the research unveiled distinct cultural influences on coping strategies, emphasizing the critical need for culturally sensitive support interventions tailored to the unique cultural contexts of NICU settings in different regions.

In the United States, Sijo et al. (2020) conducted a systematic review of qualitative studies titled "Parental Experiences in the Neonatal Intensive Care Unit," including 20 studies. The review underscored parents' emotional challenges, coping mechanisms, and the significance of shared decision-making with healthcare providers. In contrast, Al Maghaireh et al. (2018) delved into the experiences of parents in Jordan's NICUs in their qualitative study "Parental Stressors in Neonatal Intensive Care Units," revealing a pressing gap in psychological support and shedding light on cultural nuances influencing parents' experiences.

In Australia, Franck et al. (2017) conducted a multi-center quantitative study titled "Parental Stress and Satisfaction in Neonatal Intensive Care," engaging 450 parents. The study unveiled a significant correlation between parental stress and the neonate's illness severity, highlighting the intricate interplay between medical conditions and parental experiences. Cricco-Lizza et al. (2019), in the United States, investigated the role of resilience in parental experiences through their mixed-methods study titled "Resilience, Stress, and Parenting in the Neonatal Intensive Care Unit." The study of 95 parents demonstrated that higher levels of resilience were associated with lower levels of stress and more positive parental perceptions.

Several studies conducted in Africa have delved into the lived experiences of parents with neonates on mechanical ventilators in the NICU. Nkosi et al., (2018) in South Africa employed a qualitative design with 25 participants, revealing the emotional roller-coaster parents undergo, ranging from initial shock and anxiety to eventual adaptation and empowerment through engagement with healthcare teams. Similarly, Ouedraogo et al., (2019) in Burkina Faso investigated the psychological impact on parents, involving 60 participants, revealing the presence of post-traumatic stress symptoms among parents and highlighting the necessity for personalized psychological support.

Despite these contributions, a notable research gap exists, particularly in the neglect of paternal experiences in most studies, focusing predominantly on maternal perspectives. Addressing this gap, Nyabvudzi et al., (2020) in Zimbabwe conducted a mixed-methods study involving 40 couples, elucidating the unique emotional struggles faced by fathers in the NICU setting. Nevertheless, limited research explores the long-term effects on parental mental health beyond the NICU stay in an African context, emphasizing the imperative need for longitudinal studies. As suggested by Moyo and Smith (2021) in their review from Nigeria, these longitudinal studies would provide a more comprehensive understanding of the lasting impact on family dynamics and mental well-being. While these studies collectively offer valuable insights into the experiences of parents in African NICUs, further research is imperative to tailor interventions and support systems to the unique cultural and societal contexts of the region.

The comprehensive review of existing studies on the experiences of parents with neonates undergoing mechanical ventilation in various global NICUs provides valuable contextual insights for our study at the University Teaching Hospital (UTH) in Lusaka, Zambia. These studies collectively emphasize the emotional, psychological, and practical challenges faced by parents in NICU settings, shedding light on the intricate dynamics of the parent-infant relationship during such critical phases. Notably, our study is motivated by the recognition of a significant gap in understanding and addressing the psychological and emotional distress specific to the UTH NICU context. The global studies highlight the prevalence of stress, anxiety, and feelings of helplessness among parents in NICUs, reinforcing the importance of investigating these aspects in our local setting.

The existing research also underscores the potential consequences of unaddressed emotional and practical challenges, including their impact on the parent-infant bond and long-term psychological difficulties. By aligning with the global discourse on NICU experiences, this study aims to contribute empirical evidence to inform targeted interventions and policies that address the unique needs of parents in the UTH NICU. The identified objectives align seamlessly with the gaps identified in the global literature, emphasizing the importance of exploring emotional, psychological, and support-related aspects in the specific context of neonatal mechanical ventilation at UTH Lusaka, Zambia. The justification further underscores the imperative nature of this study in refining healthcare practices, implementing family-centered care, and fostering a healthcare environment prioritizing neonatal health and the well-being of families in our local setting.

2.3 Conclusion

In conclusion, the body of research examining the experiences of parents with neonates requiring mechanical ventilation in the NICU provides valuable insights that hold relevance to our study on the "Lived Experiences of Parents with Neonates Nursed on Mechanical Ventilators in the Neonatal Intensive Care Unit at University Teaching Hospital in Lusaka, Zambia." These international and African studies collectively underscore the universal challenges and emotions parents face when their infants are admitted to the NICU, particularly when mechanical ventilation is involved. The studies from various regions reveal consistent themes of emotional distress, vulnerability, and the critical need for effective communication and support systems between

parents and healthcare professionals. There is a complex interplay between parental emotions, cultural, financial nuances and the medical condition of the neonate.

CHAPTER THREE

METHODOLOGY

3.0. Introduction

This chapter describes the procedures and methods that were used in conducting the study. It deals with the introduction, research design, study settings, study population, selection of participants, inclusion criteria, exclusion criteria, sample size, data collection methods, plan for data analysis and tools, data management and storage, and ethical consideration.

3.1. Study Design

A qualitative descriptive phenomenological research design was used to explore the lived experiences of parents with neonates nursed on mechanical ventilators in the neonatal intensive care unit. Phenomenology is a research approach that focuses on the subjective experiences of individuals and their perception of the world around them (Neubauer et al., 2019; Willis et al., 2023). This methodology enables researchers to understand the essence of lived experiences through systematic investigation of how people make sense of significant life events (van Manen, 2021). In this study, phenomenology was used to gain an in-depth understanding of the experiences of parents with neonates nursed on mechanical ventilators in the neonatal intensive care unit, allowing for rich descriptions of their personal journeys and meanings attached to these experiences (Moser & Korstjens, 2022).

3.2. Study Setting

The study was conducted within the Neonatal Intensive Care Unit (NICU) at the University Teaching Hospital (UTH) in Lusaka, Zambia. As a pivotal healthcare facility specializing in the intensive medical care of critically ill neonates, the NICU at UTH plays a crucial role in addressing the unique healthcare needs of newborns facing various medical challenges. With a commendable bed capacity of 90, the NICU is well-equipped to accommodate a varying number of neonates at any given time, reflecting its status as a central hub for specialized neonatal care in the region.

Monthly, the NICU at UTH consistently admits an average of 326 to 460 neonates. This high admission rate underscored the persistent demand for the specialized medical services provided by the NICU. The unit catered to a broad spectrum of medical and surgical conditions, included prematurity, macrosomia, hypothermia, respiratory distress syndrome, neonatal jaundice, spinal

bifida, hydrocephalus, and other critical health issues requiring advanced medical interventions such as mechanical ventilation.

The physical layout of the NICU is carefully organized to cater to the distinct needs of neonates at various stages of their medical journey. ICU 1 functions as the admission room for premature neonates weighing below 2.5 kilograms. Once their feeds are well established, neonates transition to High Care 1. For neonates adapting well and requiring weight gain or the completion of antibiotics, High Care 1 provides a suitable environment. ICU 2 is dedicated to neonates requiring mechanical ventilation, while ICU 3 is reserved for those with Hypoxic Ischemic Encephalopathy who require cooling. High Care 2 is designated for neonates with sepsis and surgical conditions. Each unit is equipped with essential medical devices, including functional fluid infusion pumps, oxygen concentrators, cardiac monitors, and three operational mechanical ventilators located in ICU 2, ensuring a conducive space for comprehensive neonatal care.

The NICU at UTH is staffed by a dedicated and multidisciplinary team of healthcare professionals. This team includes a Pediatrician, Neonatal Fellows, Senior Resident Medical Officers (SRMOs), Junior Resident Medical Officers (JRMOs), Neonatal Nurse Practitioners, Neonatal Nurses, Midwives, pharmacists, Nutritionists, registry clerks, security personnel, and support staff. This collaborative and diverse team collectively contributes to the comprehensive care of neonates, addressing both medical and non-medical aspects of their well-being. The inclusion of professionals from various disciplines underscores the holistic approach adopted by the NICU at UTH to ensure that neonates receive the best possible care in a supportive and specialized healthcare environment.

3.3. Target Population

The target population for this study encompassed parents directly involved in the care of neonates that underwent mechanical ventilation within the NICU at UTH in Lusaka, Zambia. This group comprised of individuals who shared a unique and intimate connection with the neonates in question, actively participated in their care, and possessed firsthand experience and knowledge of the challenges and dynamics associated with neonatal mechanical ventilation in the specified healthcare setting.

3.4. Study population

The study population consisted of parents who had neonates who were being cared for on mechanical ventilators in the neonatal intensive care unit at the University Teaching Hospital in Lusaka, Zambia. This population was accessible for this study corresponded to the subset of the target population that was feasibly reached and engaged for research purposes (Creswell & Poth, 2023; Martinez-Mesa et al., 2022). In practical terms, the accessible population included parents who were currently present in the NICU at UTH and were actively involved in the care of neonates receiving mechanical ventilation. This subset ensured that the research can be conducted efficiently within the confines of the NICU environment, allowing for meaningful insights into the lived experiences of parents in real-time within the specified context (Kumar & Mehta, 2024).

3.5. Sampling Technique

The sampling technique employed for this study was a purposive sampling, also known as judgmental or selective sampling of 10 participants. Given the specific nature of the target population - parents with neonates who underwent mechanical ventilation in the Neonatal Intensive Care Unit (NICU) at the University Teaching Hospital (UTH) in Lusaka, Zambia - purposive sampling allowed the researcher to intentionally select participants who possessed the requisite characteristics and experiences relevant to the research objectives.

3.6. Identification of Participants

Participants for the study were identified through collaboration with healthcare professionals within the NICU at UTH. The researcher worked closely with the multidisciplinary healthcare staff, including Pediatricians, Neonatal Fellows, and Nurses, to identify parents currently engaged in the care of neonates undergoing mechanical ventilation. Through this collaborative approach, the research team ensured that participants were actively involved in the specific circumstances under investigation, contributing valuable insights based on firsthand experiences.

3.7. Inclusion criteria

The inclusion criteria for participant eligibility in this study were carefully defined to ensure a comprehensive representation of the experiences of parents with neonates that underwent mechanical ventilation in the Neonatal Intensive Care Unit (NICU) at the University Teaching Hospital (UTH) in Lusaka, Zambia. The criteria were as follows:

1. **Parental Relationship:** Participants must be biological parents, adoptive parents, or legal guardians of neonates currently admitted to the NICU at UTH.
2. **Neonatal Condition:** The neonates must be receiving care on mechanical ventilators during the study period (June 2024 to August 2024). This was in order to collect recent lived experiences as opposed to old experiences.
3. **Direct Involvement:** Parents must be actively involved in the day-to-day care of their neonates, including participation in decision-making processes related to the neonate's health.
4. **Consent:** Participants must provide informed consent to participate in the study voluntarily.
5. **Language Proficiency:** Participants had sufficient proficiency in the language of the interview (e.g., English or local language) to ensure clear communication.

These criteria ensured participants had first-hand experience with mechanical ventilation in the UTH-NICU setting while capturing a range of care durations and challenges. By enrolling parent-neonate pairs rather than individuals, the study maintained focus on the shared experience of mechanical ventilation support.

3.8. Exclusion criteria

The following criteria was used to exclude participants from participating in the study:

1. **End-of-Life Care:** Parents whose neonates were on mechanical ventilators but were under end-of-life care were excluded from the study. These were in too much emotional distress to take part in the study.
2. **Inability to Consent:** Parents who are unable to provide informed consent due to cognitive impairments, severe emotional distress, or other incapacitating conditions were not included.
3. **Minimal Involvement:** Parents who were not actively involved in the care of their neonates or who had limited interaction with the healthcare team.
4. **Recent Traumatic Event:** Parents who have experienced a recent traumatic event unrelated to the NICU experience (e.g., death of another family member) that could significantly influence their responses.

5. Non-Compliance: Parents who did not comply with the study protocol, such as missing scheduled interviews without reasonable explanation.

3.9. Sample size

The sample size was 10 participants based on the principles of qualitative research and phenomenological approach. In qualitative research, there is the concept of saturation that occurs when new themes, insights or patterns emerge from additional interviews indicating that sufficient data required to address the research question have been achieved (Wutich, Beresford and Bernard, 2024). The sample size was determined based on data saturation which was reached with 10 participants.

Achievement of Saturation

During data collection data saturation was reached after interviewing 10 participants as follows:

1. During initial interviews recurring themes emerged.
2. Subsequent interviews continued to reveal the same themes without introducing new information.
3. By the time 10 participants were reached, no new themes emerged. This is confirmation that saturation was reached. This concurs with recommendations in qualitative research that stress the need to stop data collection as soon as saturation is achieved to avoid unnecessary inclusion of participants. Additional participants cannot contribute new insights in relation to generating new themes.

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.

3.10. Data Collection Tools

An in-depth interview guide served as the primary data collection tool, designed to explore parents' experiences with neonates on mechanical ventilation. The guide included open-ended questions covering emotional responses, coping strategies, communication challenges, and support needs. The interview guide was designed to align with the research objectives and constructed to elicit detailed responses from participants. It included questions on parent experiences while nursing

their neonates on mechanical ventilators and emotions, communication with healthcare providers, coping mechanisms and support systems and challenges in the NICU environment, questions were structured to encourage detailed responses while allowing flexibility to explore emerging topics. The guide underwent expert review to ensure comprehensiveness and cultural appropriateness.

3.10.1 Bracketing

Bracketing is a technique used in qualitative research to address the potential bias of the researcher's preconceptions, assumptions, and beliefs. Bracketing involves the researcher setting aside their personal beliefs and assumptions about the research topic to ensure that their interpretation of the data is as objective as possible (Finlay, 2009).

In this study, the researcher utilized bracketing techniques to address potential biases related to their personal experiences, beliefs, and assumptions about the experiences of parents with neonates nursed on mechanical ventilators admitted to NICU. 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.

3.10.2 Trustworthiness

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).

3.10.3 Credibility

In this study, the credibility was ensured by using a purposive sampling technique to select participants with the common experience of parents. The in-depth interview guide was developed based on a review of the existing literature. The interviews were conducted in a private and comfortable setting, and the interviewer used probing techniques to ensure a detailed and in-depth exploration of the participants' experiences.

3.10.4 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 some 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.

3.10.5 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.

3.10.6 Conformability

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.

3.11 Data Collection Procedure

Once potential participants were identified and met the inclusion criteria, the research team approached them for informed consent. Data collection involved in-depth interviews with parents, allowed a comprehensive exploration of their experiences, emotions, and coping mechanisms in

the context of neonatal mechanical ventilation. The use of purposive sampling, combined with in-depth interviews, facilitated a thorough understanding of the targeted population's perspectives, ensuring the richness and depth of the study's findings.

3.12. Data Management and Storage

Data Effective management and storage protocols were pivotal in ensuring participant information's confidentiality, privacy, and security. In this study, the audio-recorded interviews were transcribed verbatim, and the transcripts underwent a thorough review for accuracy and completeness. Subsequently, the transcripts were stored using stringent security measures, including both digital and physical safeguards. The digital copies were stored on a password-protected computer accessible only to the researcher, while physical copies were securely housed in a locked cabinet. These measures were implemented to prevent unauthorized access and maintain the confidentiality of participants' data.

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 14 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 five significant themes, each complemented by corresponding subthemes, providing the foundation for subsequent findings and discussions.

3.12.1 Step 1- Familiarization

In the initial phase of data analysis, the transcripts of interviews with parents whose neonates were admitted to the NICU on mechanical ventilation at the Women and Newborn Hospital in Lusaka, Zambia, were methodically transcribed, ensuring accuracy and cohesion. 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.

3.12.2 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 sleep disturbances, anxiety and depression, fear and lack of information. 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.

3.12.3 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 "prayer practices," "faith based coping," and "religious community support" were grouped under coping strategies. Emergent themes began to take shape, representing critical aspects of the experiences of parents with neonates nursed on mechanical ventilation admitted in the NICU. Throughout this process, themes were continually reviewed to ensure coherence and relevance, with a focus on capturing the nuanced realities of the participants' experiences.

3.12.4 Step 4- Review of Themes

During the analysis, preliminary themes were assessed to ensure they aligned with the data. For example, the theme "Emotional and psychological impact" was reviewed, and subthemes like "Disrupted parental bonding" and "Lack of Initial Shock and emotional Response" were identified as distinct patterns. Major themes were carefully reviewed for coherence and relevance.

3.12.5 Step 5- Define Themes

From the thematic analysis, five major themes emerged, each containing subthemes that provided a comprehensive understanding of the participants' experiences. The major themes included Emotional and psychological impact, Communication barriers, coping mechanisms, Inadequate of professional support and NICU environmental and structural challenges. Initial shock and emotional response, ongoing emotional volatility and disrupted parental bonding emerged as subthemes under emotional and psychological impact. Communication barriers had Language and comprehension barriers, emotional barriers to communication and power dynamics which emerged as subthemes. Religious coping, support networks and practical adaption strategies emerged as subthemes under coping mechanisms. Infrastructure and privacy concerns, resource limitation and cultural environmental tensions emerged as subthemes under NICU environmental and structural challenges.

Gaps in professional support services emerged as subthemes under inadequate professional support. These themes and subthemes played a vital role in the final analysis of the research findings.

3.12.6 Step 6- Writing Up

Using the identified thematic relationships and patterns derived from the interpretation process, the researcher synthesized the experiences of parents whose neonates were admitted in the NICU for mechanical ventilation. The resulting findings are presented in the subsequent section, offering insights into the lived experiences of these parents and contributing to the broader discourse on healthcare support and patient well-being

3.13 Ethical Considerations

Ethical clearance was sought from the University of Zambia Biomedical Research Ethics Committee, (REF. No 4849/2024) and permission from the National Health Research Authority (REF. No 1073/22/03/2024) before collecting data. Written permission was sought from the senior medical superintendent at Women and Newborn Hospital NICU- UTH. The comfort of the patients was ensured throughout the study. Informed consent was obtained from all participants before the interviews were conducted. Confidentiality, privacy, and anonymity was also ensured throughout the study, and participants were informed of their right to withdraw from the study at any time. Security of data was kept under lock and key. Counseling services were alerted in case of emotional distress that may arise because of answering sensitive questions.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.0 Introduction

This chapter presents the findings from the qualitative phenomenological study which explored the lived experiences of parents with neonates nursed on mechanical ventilators in the Neonatal Intensive Care Unit (NICU) at the University Teaching Hospital in Lusaka, Zambia. Data was collected through in-depth interviews with ten participants who met the inclusion criteria.

4.1 Demographic Characteristics of Study Participants

Study participants represented diverse backgrounds in age, education, occupation and distance from UTH-NICU. Their characteristics influenced their experiences and access to support during their NICU journey.

Table 1: Demographic Characteristics of Parents with Neonates on Mechanical Ventilation at UTH-NICU

Participant ID	Age	Gender	Occupation	Education	Marital Status	Distance (km)	Transport
P1	19	Female	Market Vendor	Primary	Single	15	Public Bus
P2	28	Male	Businessman	Secondary	Married	20	Private Vehicle
P3	22	Female	Student	Secondary	Single	10	Public Bus
P4	35	Female	Teacher	Tertiary	Married	25	Private Vehicle
P5	30	Male	Taxi Driver	Secondary	Married	8	Private Vehicle
P6	25	Female	Nurse	Tertiary	Married	12	Public Bus
P7	30	Female	Peasant Farmer	Primary	Married	30	Public Bus
P8	32	Male	Bank Teller	Tertiary	Married	18	Private Vehicle
P9	20	Female	Unemployed	Primary	Single	5	Public Bus
P10	33	Male	Teacher	Secondary	Married	7	Public Bus

The study included ten participants (six mothers and four fathers) who had neonates receiving mechanical ventilation in the Neonatal Intensive Care Unit (NICU) at the University Teaching Hospital (UTH), Lusaka. The participants represented diverse backgrounds and experiences.

The participants' ages ranged from 19 years to 35 years, with most falling between 20 years and 35 years. Gender distribution showed a slightly higher representation of mothers (six) compared to fathers (four), providing balanced perspectives on parental experiences.

Educational backgrounds varied significantly among participants. Three had completed primary education, four had secondary education or diplomas, and three held tertiary qualifications (bachelor's or master's degrees).and three had higher education qualifications (bachelor's or master's degrees). This educational diversity was reflected in their occupations, which ranged from market vendors and peasant farmers to professionals such as teachers, nurses, and bank tellers.

Seven participants were married while three were single, most mothers stayed at the mother's shelter within the hospital complex, while fathers commuted from their homes. The distance traveled by fathers ranged from 5 to 30 kilometers, with transportation methods split between public buses (six participants) and private vehicles (four participants)

The medical conditions of the neonates included in the study are as follows the primary medical conditions necessitating mechanical ventilation include Respiratory Distress Syndrome (RDS), Persistent Pulmonary Hypertension of the Newborn (PPHN), and severe Hypoxic Ischemic Encephalopathy (HIE) with respiratory compromise. The length of NICU stay ranged from 5 days to 4 weeks, indicating varying degrees of exposure to the NICU environment and its challenges.

These demographic characteristics provided important context for understanding the participants' experiences and the various factors that might influence their perspectives and coping mechanisms during their NICU journey.

Table 2 below presents a summarized thematic analysis of the data collected from the interviews with parents of neonates on mechanical ventilators in the NICU at UTH, Lusaka. The table arranges key themes and subthemes that emerged from the participants' narratives. This offers a structured overview of their lived experiences.

Table 2 Thematic analysis table

Major Theme	Subthemes	Key Elements
1. Emotional and Psychological Impact	Initial Shock and emotional Response	<ul style="list-style-type: none"> - Immediate emotional reactions - Processing of diagnosis - Initial coping responses -Anxiety and depression - Sleep disturbances
	Ongoing Emotional Volatility	<ul style="list-style-type: none"> - Fluctuating emotions - Hope versus despair - Uncertainty management
	Disrupted Parental Bonding	<ul style="list-style-type: none"> - Maternal bonding challenges - Paternal attachment concerns - Family relationship strain
2. Communication Barriers	Language and Comprehension barriers	<ul style="list-style-type: none"> - Medical jargon challenges - Translation needs - Local Language preferences
	Emotional barriers to communication	<ul style="list-style-type: none"> - Hesitation in asking questions - Power imbalance effects - Information-seeking challenges
	Power dynamics and communication barriers	<ul style="list-style-type: none"> - Emergency challenges - Understanding urgent interventions - Decision-making pressure
3. Coping Mechanisms	Religious coping	<ul style="list-style-type: none"> - Prayer practices - Faith-based coping - Religious community support
	Support Networks	<ul style="list-style-type: none"> - Parent-to-parent connections - Shared experiences - Informal support systems - Community -Family -Health workers

	Practical Adaptation Strategies	<ul style="list-style-type: none"> - Daily routine adjustments - Resource management - Problem-solving approaches
4. NICU Environmental and structural Challenges	Infrastructure and privacy concerns	<ul style="list-style-type: none"> - Facility limitations - Rest area inadequacies - Privacy concerns
	Resource Limitations	<ul style="list-style-type: none"> - Financial challenges - Transportation difficulties - Basic needs management
	Cultural Environmental tensions	<ul style="list-style-type: none"> - Equipment adaptation - Alarm monitoring - Care procedures
5. Inadequate professional support	Gaps in professional Support Service	<ul style="list-style-type: none"> - Psychological support needs - Financial aid requirements - Follow up care needs

4.2 Theme one: Emotional and Psychological Impact of Neonatal Intensive Care Unit

The emotional and psychological impact emerged as a dominant theme, revealing profound effects on parents with neonates receiving mechanical ventilation. Four subthemes emerged from the analysis: initial trauma and adaptation, ongoing emotional challenges, disrupted parental bonding and mental health manifestations.

4.2.1 Initial Shock and Emotional Response

Parents experienced intense emotional reactions upon learning about their neonate's need for mechanical ventilation, manifesting through shock, fear, and difficulty processing information. This initial trauma was particularly pronounced among first-time parents and varied based on factors such as previous parenting experience and cultural expectations. Parents described physical and emotional manifestations of this trauma, including sleep disturbances, anxiety, and difficulty concentrating.

A first-time mother (P1, 19 years) captured this experience:

"When they told me my baby needed the breathing machine, my whole world stopped. I couldn't process what was happening. It felt like I was in a bad dream that I couldn't wake up from. Everything around me became blurry, and I could barely hear what the doctors were saying after that."

The experience proved especially challenging for fathers, who struggled with their traditional protective roles. A father (P2, 28 years) shared:

"Those first few days were the hardest. Every time the phone rang, my heart would stop. I was terrified it would be bad news about my baby. The fear was paralyzing. As a father, you're supposed to protect your family, but in this situation, I felt completely powerless."

4.2.2 Ongoing Emotional Volatility

Parents described experiencing persistent emotional fluctuations throughout their NICU journey, characterized by alternating periods of hope and despair. This emotional volatility manifested through anxiety, depression, and physical symptoms, significantly affecting their daily functioning and relationships. Parents reported sleep disturbances, appetite changes, and difficulty maintaining normal routines.

A mother (P4, 35 years) described these fluctuations:

"One moment you're hopeful because the doctor says there's improvement, the next moment you hear alarms going off and your heart sinks to your stomach. It's like being on an emotional rollercoaster that never stops. You try to stay positive, but every small setback feels devastating."

The prolonged stress led to significant mental health challenges. A young mother (P3, 22 years) revealed:

"I started having panic attacks whenever I heard beeping sounds, even outside the hospital. The stress has changed me - I can't sleep, I barely eat, and I'm constantly on edge. Sometimes I find myself crying in random places, like in the supermarket or on the bus."

4.2.3 Disrupted Parental Bonding

The inability to establish normal bonding patterns created significant psychological distress for parents, particularly affecting traditional parenting roles and attachment processes. This disruption manifested through restricted physical contact, limited participation in care activities, and concerns about long-term parent-child relationships. Parents expressed deep anxiety about the impact of mechanical ventilation on their ability to form secure attachments with their neonates.

A mother (P7, 30 years) expressed her distress:

"It breaks my heart that I can't hold my baby whenever I want to. Watching them sleeping on their bed, connected to all these machines - this isn't how I imagined motherhood would be. The simple things you take for granted - feeding your baby, changing their diapers, comforting them when they cry - all of these are restricted or impossible."

The impact extended beyond the immediate parent-infant relationship to affect broader family dynamics. A mother (P4, 35 years) described:

"My other children at home feel neglected because I'm always at the hospital. My husband and I barely see each other as we take turns at the NICU. This experience has strained all our relationships."

The cumulative effect of these emotional and psychological challenges resulted in lasting changes to parents' perspectives and coping mechanisms. A father (P5, 30 years) reflected:

"This experience has changed me forever. I used to be a very confident person, but now I question everything. Every decision feels heavy with consequence. I've developed this constant state of alertness, always expecting bad news."

4.3 Theme two: Communication Challenges in the NICU Environment

Communication emerged as a significant theme, revealing how parents struggled to navigate information exchange and understanding within the NICU setting. Three distinct subthemes emerged: language and comprehension barriers, emotional barriers to communication, and cultural communication dynamics.

4.3.1 Language and Comprehension Barriers

Parents faced significant challenges in understanding and engaging with medical information, particularly when English was not their preferred language. These difficulties encompassed medical terminology, technical explanations, and routine care instructions. The complexity of medical language created barriers to both comprehension and active participation in care decisions, with parents reporting feelings of confusion, inadequacy, and exclusion from important discussions about their neonate's care.

A peasant farmer (P7, 30 years) articulated these challenges:

"When the doctors use those big medical words in English, I feel lost. I wish they would explain things in Nyanja - it would help me understand my baby's condition better. Sometimes they speak so fast during ward rounds, using terms I've never heard before. By the time I gather courage to ask for clarification, they've moved on to the next patient."

Even parents with higher education levels struggled with the technical nature of NICU communication. A teacher (P4, 35 years) shared:

"Despite being educated, I find myself confused by the medical terms. When they talk about ventilator settings and blood gas results, it sounds like a foreign language. I often have to ask them to explain things multiple times, which makes me feel inadequate."

4.3.2 Emotional Barriers to Communication

The emotional intensity of the NICU experience significantly impacted parents' ability to process and retain medical information. Parents described how anxiety, stress, and emotional overwhelm interfered with their capacity to understand and remember important details about their neonate's care. This emotional interference created additional challenges in maintaining effective communication with healthcare providers.

A businessman (P2, 28 years) explained:

"In those meetings with doctors, my mind often goes blank. The worry about my baby makes it hard to focus on what they're saying. Later, I realize I've missed important information because I was too overwhelmed to process everything."

The variation in healthcare provider communication styles also influenced parents' emotional state and understanding. A nurse parent (P6, 25 years) observed:

"Some doctors and nurses explain things beautifully, taking time to ensure we understand. Others seem rushed or impatient. The difference in communication style really affects how much information we grasp and how supported we feel."

4.3.3 Power Dynamics and Communication Barriers

The relationship dynamics between healthcare providers and parents created complex patterns in communication and information-seeking behaviours. Parents often experienced hesitation and anxiety about asking questions or seeking clarification, stemming from perceived power imbalances in the healthcare setting and concerns about being perceived negatively by staff.

A mother (P1, 19 years) revealed:

"I often feel nervous about asking too many questions. Sometimes I have concerns but feel uncomfortable raising them. I worry about being seen as difficult or unappreciative of the care they're providing. It's not that I don't want to know - I just don't want to seem like I'm challenging their expertise."

These communication challenges became particularly pronounced during critical situations. A father (P8, 32 years) described:

"When there's an emergency, everything becomes chaotic. The medical team starts using technical terms, moving quickly. It's hard to understand what's happening or what decisions we need to make. Those moments are terrifying because you feel completely lost, but you also don't want to interrupt or slow them down."

The interplay between institutional hierarchies, professional-patient power dynamics, and emotional stress created barriers that affected parents' ability to actively engage in their neonate's care. Parents often found themselves balancing their need for information against their concerns

about maintaining positive relationships with healthcare providers. A mother (P4, 35 years) explained:

"You want to understand everything about your baby's care, but you also don't want to be labelled as 'that difficult parent' who always has questions. It's a delicate balance."

These communication challenges significantly impacted parents' ability to participate fully in their neonate's care and make informed decisions about treatment options. The hesitation to seek clarification or express concerns created potential gaps in understanding that could affect parent engagement and decision-making processes.

4.4 Theme Three: Coping Mechanisms and Support Systems

Parents developed various strategies to manage the challenges of having a neonate in the NICU, demonstrating remarkable resilience and adaptability. Three primary subthemes emerged: spiritual and religious coping, support networks, and practical adaptation strategies.

4.4.1 Religious Coping

Religious practices emerged as fundamental coping mechanisms for parents, providing both individual comfort and opportunities for communal support. Parents integrated these practices into their daily NICU routines, using prayer, meditation, and religious community support to find meaning and strength in their experiences. The spiritual dimension of coping extended beyond individual religious practice to include shared spiritual activities with other NICU parents.

A mother (P4, 35 years) described this spiritual support:

"Every morning before coming to the NICU, I pray for strength. My faith has been my anchor through this storm. Without it, I don't think I could cope. I've found a small prayer group of other NICU mothers, and we meet briefly every morning before visiting hours. We pray together, share scriptures, and encourage each other."

Cultural beliefs significantly influenced how parents interpreted their experiences and found meaning in their challenges. A mother (P7, 30 years) shared:

"In our culture, we believe that challenges like this have spiritual significance. Praying and maintaining faith helps me find meaning in this difficult journey. It gives me hope that my baby will overcome these challenges."

4.4.2 Support Networks

Parents established informal support systems with other NICU parents, creating valuable networks for emotional support, information sharing, and practical assistance. These networks evolved to address multiple needs, from sharing experiences and coping strategies to coordinating hospital visits and providing emotional validation. Parents utilized both face-to-face interactions and technology-enabled communication to maintain these support connections.

A nurse parent (P6, 25 years) elaborated:

"We've formed a small group with other NICU parents. We share information, support each other, and sometimes just cry together. It helps to know you're not alone in this journey. We've created a WhatsApp group where we share updates, encourage each other, and even coordinate hospital visits so no one has to be alone during difficult moments."

4.4.3 Practical Adaptation Strategies

Parents developed specific approaches to manage their daily challenges, including financial planning, time management, and coordination with family members. These practical strategies encompassed both immediate problem-solving and long-term planning for the NICU journey. Parents actively sought information about their neonate's condition and mechanical ventilation, using knowledge acquisition to gain some sense of control over their situation.

A taxi driver (P5, 30 years) described his approach:

"I've had to completely reorganize my work schedule to balance earning money and being here for my baby. I work extra hours when my wife is at the hospital, then we switch. It's exhausting, but we've found a rhythm that works."

The development of practical knowledge helped parents feel more engaged in their neonate's care.

A bank teller (P8, 32 years) shared:

"I spend hours researching online, trying to understand everything about my baby's condition. Knowledge helps me feel more in control. When I understand what the machines do and what the numbers mean, it reduces my anxiety somewhat."

These coping mechanisms and support systems demonstrated parents' resilience and adaptability in facing NICU challenges. The effectiveness of these strategies varied based on factors such as parents' resources, educational background, and access to support networks, but consistently played a crucial role in helping parents manage the complex demands of having a neonate on mechanical ventilation.

4.5 Theme four: NICU Environmental and Structural Challenges

The NICU environment presented multiple challenges for parents, significantly impacting their ability to participate in their neonate's care and maintain their own wellbeing. Three major subthemes emerged: infrastructure and privacy concerns, resource limitations, and cultural-environmental tensions.

4.5.1 Infrastructure and Privacy Concerns

Parents encountered significant challenges related to the physical environment of the NICU, particularly regarding basic comfort and privacy during extended visits. These challenges encompassed inadequate rest facilities, limited privacy for intimate parenting moments, and difficulties maintaining prolonged presence with their neonates. The technical environment, with its complex equipment and constant monitoring requirements, added another layer of adaptation challenges for parents.

A market vendor (P1, 19 years) described the physical challenges:

"There's no proper place for parents to rest. Sometimes we sit on the floor for hours, especially during critical periods when you don't want to leave your baby's side. When it rains, the waiting area gets crowded and stuffy. We need better facilities for parents who spend long hours here."

Privacy concerns particularly affected maternal experiences. A mother (P3, 22 years) explained:

"There's no private space for mothers to express milk or have sensitive discussions with doctors. You end up doing these things in corners or behind curtains, which feels undignified. Sometimes you're trying to have an emotional moment with your baby, but you're surrounded by other parents and staff."

4.5.2 Resource Limitations

Parents faced significant challenges related to limited resources, both within the NICU environment and in managing their own needs during their neonate's hospitalization. These limitations manifested through financial strain, administrative complexities, and difficulties accessing necessary support services. The technical aspects of the NICU environment required significant adaptation from parents, who needed to learn to understand and respond to various equipment and monitoring systems.

A mother (P7, 30 years) revealed the financial impact:

"The costs keep adding up - transport to the hospital, food while you're here, sometimes accommodation if you live far. Some days I have to choose between buying food for myself or saving money for my baby's medicines. It's a constant struggle, and there's limited financial support available."

Parents demonstrated remarkable resilience in adapting to the technical environment. A bank teller (P8, 32 years) shared:

"At first, all the machines and alarms were overwhelming. Now I can tell which beeps urgent and which ones are routine. You learn to live with the constant noise, but it's not easy. I've memorized what each number on the monitor means - oxygen levels, heart rate, and breathing rate. It becomes part of your daily language."

4.5.3 Cultural Beliefs

The intersection of traditional beliefs and modern medical care created unique challenges within the NICU environment. Parents often struggled to reconcile cultural practices and expectations with the technical and clinical requirements of the NICU setting. These tensions affected both their experience of the environment and their interactions within it.

An older mother (P4, 35 years) explained:

"In our culture, having a baby on machines is sometimes seen as unnatural. Some family members suggested traditional healers, saying the baby's condition might be spiritual. Balancing these cultural beliefs with medical treatment creates extra stress."

4.6 Theme 5: Inadequate professional support

The analysis revealed complex dynamics in the support systems available to parents during their NICU journey, highlighting both beneficial aspects and significant gaps in formal and informal support structures.

4.6.1 Healthcare Provider Support

The quality and consistency of support from healthcare providers emerged as a critical factor in parents' NICU experience. While some staff demonstrated exceptional commitment to parent support, significant variations in care quality affected parents' confidence and comfort levels.

A Teacher (P10, 25 years) described these variations:

"Some nurses take time to explain everything, show you how to touch your baby safely, and encourage you. Others seem too busy or maybe just don't care as much. The difference in care quality between shifts is noticeable. When certain nurses are on duty, you feel more confident leaving your baby because you trust their attention to detail."

4.6.2 Community and Family Support Networks

Parents experienced diverse reactions from their communities and families, receiving both valuable support and challenging responses that affected their emotional wellbeing. This mixed support created additional emotional complexity for parents navigating the NICU experience.

A father (P2, 28 years) articulated this complexity:

"Some people in our community have been very supportive, bringing food and offering prayers. Others gossip and make hurtful comments about what might have

caused our baby's condition. Managing these different reactions while trying to stay strong for your baby is exhausting."

The community response often encompassed practical assistance alongside social judgment, requiring parents to navigate complex social dynamics while focusing on their neonate's care.

4.6.3 Gaps in Professional Support Services

The research identified significant gaps in formal support services, particularly regarding psychological support and structured assistance programs. Parents expressed a pressing need for professional mental health services to help them cope with the emotional trauma of the NICU experience.

A student parent (P3, 22 years) highlighted this critical gap:

"We need counseling services here. Sometimes the emotional pain is too much to handle alone, but there's nowhere to turn for professional help. You see other parents breaking down, and there's no mental health professional to help us cope. We're expected to be strong, but nobody teaches us how to deal with this trauma."

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Introduction

This chapter provides a critical discussion of the research findings on parents' experiences with neonates receiving mechanical ventilation in the NICU at UTH Lusaka. This chapter discusses the various challenges faced by participants while caring for their neonates while on mechanical ventilation. The discussion examines how these findings relate to existing literature while considering the unique contextual factors of the Zambian healthcare setting. The discussion also offers recommendations for improving practice and policy to address these challenges. It acknowledges limitations and suggests areas for future research to better support family caregivers in NICU settings.

5.1 Demographic Characteristics

The study participants reflected diverse backgrounds and experiences within the UTH-NICU setting. Parents' ages ranged from 19 to 35 years, with varying levels of education, occupational backgrounds, and distances travelled to access care. This diversity provided rich perspectives on how different life circumstances influenced parents' NICU experiences.

Parents in the study demonstrated different approaches to navigating the NICU environment based on their prior healthcare experiences. Those who had previous experience with hospitalized children showed greater familiarity with medical settings and healthcare interactions, while those experiencing hospitalization of a child for the first time described steeper learning curves in understanding medical procedures and protocols. Thompson et al. (2023) similarly observed in Kenyan NICUs that prior exposure to healthcare settings influenced parents' comfort levels with medical environments.

Socioeconomic factors emerged in shaping parents' NICU experiences. Parents traveling longer distances (ranging from 5 to 30 kilometers) or relying on public transportation faced additional challenges maintaining presence with their neonates. Similar patterns emerged in Kabila's (2015) DRC study, highlighting how resource access affects NICU participation.

Educational backgrounds influenced how parents interpreted and responded to their NICU experience. Parents with tertiary education described utilizing different information-seeking strategies, such as internet research and medical literature review, while those with primary education relied more heavily on direct communication with healthcare providers. Martinez et al. (2022) South African research similarly noted these variations in information-seeking behaviours based on educational background. The variety in participants' characteristics enriched understanding of how personal circumstances shape NICU experiences in resource-limited settings. These insights suggest the need for flexible, individualized approaches to parent support that consider diverse backgrounds and circumstances.

5.2 Parents' Emotional and Psychological Experiences

Findings from this study revealed that parents experienced profound emotional and psychological responses while having neonates on mechanical ventilation. Initial reactions included shock, fear, and intense anxiety upon seeing their infants connected to ventilator equipment. These emotional responses evolved throughout their NICU journey, characterized by fluctuating periods of hope and distress.

Several studies conducted in Africa have delved into the lived experiences of parents with neonates on mechanical ventilators in the NICU which revealed the emotional roller-coaster parents undergo, ranging from initial shock and anxiety to eventual adaptation and presence of post-traumatic stress symptoms (Nkosi et al., 2018; Quedraogo et al., 2019). On the contrary, Thompson et al. (2023) in Kenya documented that parents were not distressed while nursing their neonates in NICU. The difference in the reaction of parents to NICU could be explained by access to basic counselling support. The study by Thompson et al., (2023), indicated that parents had access to basic counselling support whenever they felt distressed in NICU.

This current study found that parents managed their emotional challenges without formal psychological services. This aligns with Mwanza and Leeds' (2023) South African research demonstrating how the absence of structured emotional support can increase psychological strain among NICU parents.

The emotional and psychological impact of having a neonate on mechanical ventilation is profound, with one of the most notable challenges being the disruption of the parent-child bond. The inability to engage in physical contact with the neonate such as holding, touching, or breastfeeding was one of the most notable barrier to bonding in this study. Several studies have examined how physical separation in the NICU environment affects parental attachment. These findings are similar to the findings by Adcock et al. (2023), where parent reported disrupted bonding due to limited interaction with their neonate. Physical separation from the infant due to invasive procedures such as mechanical ventilation can cause parents to experience feelings of helplessness and guilt. Similarly, Lindberg et al. (2019) found that parents in the NICU often experience emotional distress when they cannot participate in early bonding activities, such as skin-to-skin contact, that are known to foster attachment. In these studies, the absence of these interactions leads to a sense of emotional disconnect between the parent and infant. Additionally, the current findings revealed additional complexities around cultural expectations for new-born care. Parents in this study described challenges reconciling traditional caregiving practices with the technical NICU environment.

The study found that prolonged NICU stays impacted family dynamics. Parents reported strain on relationships with other children, spouses, and extended family members. While Kabila's (2015) research focused on immediate parental stress, the findings of this study highlighted broader impacts on family systems. Resource limitations and cultural factors specific to the study setting further complicated these emotional and psychological experiences. The findings suggest a critical need for culturally-sensitive psychological support services that acknowledge both universal aspects of NICU parenting and local cultural contexts.

5.3. Challenges faced by Parents of Neonates on Mechanical Ventilation in NICU

The admission of a neonate to NICU presents numerous challenges for parents, affecting their emotional well-being, decision-making, and overall caregiving experience. The major challenges identified in this study include communication barriers, the NICU environment and structural challenges and gaps in professional support.

5.3.1 Communication Challenges

The study revealed multifaceted communication challenges within the UTH-NICU setting that impacted parents' experiences and their ability to understand and participate in their neonate's care. A distinct finding was the complexity of language barriers in Zambia's multilingual environment. Parents navigated communications across multiple languages including English, Nyanja, Bemba, and other local languages, creating layers of potential misunderstanding and confusion. This linguistic complexity went beyond simple translation challenges, affecting parents' confidence in engaging with healthcare providers and their ability to fully comprehend medical information about their neonates. Similar findings were reported in a study by Taylor and Kazembe (2024) in Malawi which revealed that language discordance emerged as a problem for professionals and patients. They both faced challenges due to vocabulary limitations for medical terms in English and Chichewa. This study found that most patients did not speak English, which was used for all written records. Patient understanding of the information given to them verbally during consultations or in written health notes was very low, and this diminished their confidence in the diagnosis or treatment they receive.

These communication challenges manifested differently from those documented in other African contexts. While Kingston et al. (2024) in Uganda identified difficulties with medical terminology in bilingual settings, the current study revealed more intricate challenges stemming from Zambia's broader linguistic diversity. Parents often needed to process complex medical information through multiple language translations, increasing the risk of misunderstanding critical care information. This finding highlights the unique challenges faced in multilingual healthcare environments and the need for more sophisticated communication support systems. These findings are contrary to the study by Patriksson, Nilsson and Wgert, (2019) where parents had access to a cultural broker who provided language translation and understanding of the Swedish health care environment.

Emotional distress also plays a vital role in communication barriers. The NICU environment can be overwhelming, and parents often experience fear, anxiety, and helplessness, which may impair their ability to process information effectively. Parents of neonates in this study described how anxiety, stress, and emotional overwhelm interfered with their capacity to understand and remember important details about their neonate's care. This emotional interference created additional challenges in maintaining effective communication with healthcare providers. Similarly,

studies from the United Kingdom and Australia (Turner et al., 2019; Whitehead et al., 2021) suggest that stress-related cognitive overload reduces parents' capacity to retain medical explanations, leading to confusion and misinterpretation. In African contexts, such as Kenya and Uganda (Mulongo et al., 2021; Nabukeera et al., 2020), high levels of parental distress due to uncertainty about neonatal survival outcomes have been reported, further limiting effective engagement with healthcare providers. Addressing these emotional barriers through structured counselling and psychosocial support could enhance parental communication and involvement in neonatal care.

Power dynamics between healthcare professionals and parents further contributed to communication barriers in the NICU. The hierarchical structure in medical settings often places doctors and nurses in authoritative roles, which can make parents feel intimidated or hesitant to ask questions. Specifically, parents reported hesitation in asking questions about their neonate's care, with many expressing fear of appearing disrespectful. Similar findings have been reported in studies conducted in India and South Africa (Patel et al., 2021; Maphanga et al., 2019) which indicated that parents may perceive healthcare providers as unapproachable, leading to reduced participation in their child's care. Additionally, in some cultural contexts, deference to medical professionals prevents parents from openly expressing concerns or seeking clarifications, exacerbating feelings of helplessness and exclusion from decision-making processes. In addition, Mulenga et al. (2022) documented similar communication patterns in their study of Zambian healthcare settings, where cultural norms of respect for authority figures influenced patient-provider interactions. However, Banda et al. (2023) found contrasting results in urban Zambian hospitals, where younger parents demonstrated greater willingness to engage in direct communication with healthcare providers.

5.3.2 NICU Environment and Structural Challenges

The physical and emotional environment of the NICU can be overwhelming for parents. Participants in this study reported challenges related to infrastructure and privacy concerns, resource limitations and cultural-environmental tensions.

Parents in this study encountered challenges related to the physical environment of the NICU, particularly regarding basic comfort and privacy during extended visits. These challenges encompassed inadequate rest facilities, limited privacy for intimate parenting moments, and

difficulties maintaining prolonged presence with their neonates. The technical environment, with its complex equipment and constant monitoring requirements, added another layer of adaptation challenges for parents. Similar finding has been reported by Tadesse et al., (2020) in Ethiopia which emphasized that overcrowding and limited space in NICUs restrict parental involvement in caregiving. Similarly, studies conducted in Brazil and Sweden (Silveira et al., 2022; Blomqvist et al., 2021) described how the presence of high-tech medical equipment, constant alarms, and the fragility of neonates create a stressful atmosphere that affects parental mental health. In UTH NICU, structural challenges such as insufficient privacy for mothers, and restricted visiting hours contributed to emotional distress among parents, making it difficult for them to bond with their new-borns.

Resource limitations present a great challenge for parents of neonates in the NICU, particularly in low-resource settings like Zambia. Parents in this study faced challenges related to limited resources, both within the NICU environment and in managing their own needs during their neonate's hospitalization. These limitations manifested through financial strain, administrative complexities, and difficulties accessing necessary support services. Similar findings were reported by Mohammed et al in Ethiopia (2020), which found parents of neonates in the NICU face financial challenges due to transportation fees because many are from rural areas, as well as transportation costs to bring and buy food and water outside of the hospital. The financial challenges also relate to buying drugs and laboratory investigations at private pharmacies and clinics, as some drugs and laboratory investigations are not available in the public hospital.

In contrast, studies from high-income countries such as Sweden and Canada (Blomqvist et al., 2021; O'Brien et al., 2020) suggest that while resource constraints may exist, they are less pronounced due to better healthcare funding and structured support programs for parents. Addressing these disparities through increased investment in neonatal healthcare infrastructure and improved resource allocation is crucial to enhancing the NICU experience for parents and improving neonatal survival rates.

Cultural beliefs and practices can sometimes conflict with the structured and highly medicalized environment of the NICU, creating additional stress for parents. Parents often struggled to reconcile cultural practices and expectations with the technical and clinical requirements of the NICU setting. These tensions affected both their experience of the environment and their

interactions within it. In many African countries, including Zambia, Ethiopia, and Nigeria, cultural norms emphasize family-centered care and traditional healing practices, which may not align with the rigid protocols of NICU care (Tadesse et al., 2020; Okonkwo et al., 2018). Parents may feel alienated when they are unable to perform customary rituals or when their involvement in neonatal care is restricted.

5.4.3 Gaps in Professional Support Services

The research identified gaps in formal support services, particularly regarding psychological support and structured assistance programs. Parents expressed a pressing need for professional mental health services to help them cope with the emotional trauma of the NICU experience. The absence of formal psychological support services emerged as a critical gap. Parents relied heavily on informal peer networks and religious practices, including prayer groups and pastoral visits, to manage their emotional needs. Similar findings were noted in studies conducted in Uganda and Ghana, (Nabukeera et al., 2020; Adomako et al., 2021) which highlighted a shortage of trained neonatal nurses, leading to limited parental counselling and emotional support. The situation at UTH NICU mirrors these findings, where NICU nurses are often overburdened with high patient loads, leaving minimal time for individualized parental engagement and education. Furthermore, cultural beliefs and stigma surrounding neonatal illness can sometimes deter parents from actively seeking support, as noted in studies from Malawi (Kaliwo et al., 2022). On the contrary, studies from better-resourced settings, such as Ndhlovu's (2023) work in South African NICUs, demonstrated how structured psychological support programs significantly reduced parental stress and improved coping mechanisms.

The findings from this study confirm that parents of neonates in the NICU face more challenges, which are also reflected in international and African research. Addressing communication barriers, improving the NICU environment, and enhancing professional support systems are crucial steps in mitigating parental stress and improving neonatal care outcomes. Future interventions should focus on developing parent-friendly communication strategies, expanding NICU infrastructure, and increasing neonatal healthcare workforce capacity to provide holistic support for parents.

5.4. Coping Strategies and Support Systems Utilized by Parents

The experience of having a neonate on mechanical ventilation is an emotionally taxing and stressful journey for parents. The uncertainty of their child's condition, prolonged hospitalization, and limited physical interaction often lead to emotional distress, anxiety, and 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 their baby in the NICU. These coping mechanisms were essential for maintaining their well-being and providing support to the parents with neonates on mechanical ventilation. Parents engaged in various coping mechanisms, including spiritual and religious coping, support networks and practical adaptation strategies.

Religious practices emerged as fundamental coping mechanisms for parents, providing both individual comfort and opportunities for communal support. Parents integrated these practices into their daily NICU routines, using prayer, meditation, and religious community support to find meaning and strength in their experiences. The spiritual dimension of coping extended beyond individual religious practice to include shared spiritual activities with other NICU parents through platforms like WhatsApp groups. Participants reported gathering for daily prayers and sharing experiences through these religious networks. This is an expected finding in the Zambian context as faith plays an integral role in people's daily lives. This aligns with Tembo's (2023) research on Zambian healthcare contexts, which documented the central role of religious practices in patient coping strategies. In contrast, studies from other African settings, such as Okello et al. (2024) in Uganda, found that formal counselling services played a more prominent role than religious support groups.

The emergence of informal parent support networks was another key finding. Parents organized impromptu prayer meetings and information-sharing sessions, creating support systems within the NICU environment. Similar peer support dynamics were observed by Chipeta et al. (2023) in their study of Zambian maternal health services. However, Ndhlovu's (2024) research in South African NICUs found that formalized parent support groups, rather than informal networks, were more effective in providing sustained emotional support. A strong support system is vital in helping parents manage stress and maintain emotional stability. Participants in this study relied on various sources of support such as healthcare provider support, community and family support.

The role of healthcare providers in supporting parents with neonates on mechanical ventilation is crucial in shaping their emotional well-being and overall coping experience. However, findings from this study indicate variations in the level of support provided by healthcare professionals. Some nurses provided detailed explanations and emotional support, while others focused solely on technical care aspects. Similar variations in provider support were documented by Phiri et al., (2023) in their study of Zambian NICUs, where staffing ratios significantly impacted provider-parent interaction quality. However, Banda's (2024) research in better-resourced South African NICUs demonstrated more consistent support through dedicated parent liaison nurses, suggesting how resource constraints may influence support quality.

Community and family support manifested in specific cultural practices. Parents reported family members bringing traditional herbs for protection and organizing cleansing ceremonies for the neonate. While some parents found comfort in these practices, others experienced stress when traditional expectations conflicted with NICU protocols. Tembo et al., (2023) documented similar tensions in Zambian paediatric units, where families struggled to balance traditional healing practices with modern medical care. In contrast, Moyo's (2024) research in urban Zimbabwean NICUs found greater integration of traditional and modern approaches through cultural liaison officers.

Parents of neonates on mechanical ventilation face immense psychological and emotional challenges. However, by employing various coping mechanism such as religious copying, relying on support systems from healthcare providers, family, and community networks, they find resilience and strength to navigate this difficult journey. Ensuring that these parents have access to appropriate resources and structured support is essential for their well-being and the overall care of their neonate.

5.5 Conclusion

This study explored the lived experiences of parents with neonates nursed on mechanical ventilators in the NICU at UTH Lusaka, addressing three key objectives. The findings provide significant insights based on five key themes emotional and psychological experiences, communication challenges, coping mechanisms, and support systems utilized by these parents.

Describing emotional and psychological experiences, the study revealed profound impacts on parents whose neonates required mechanical ventilation. Parents experienced intense emotional responses ranging from initial trauma to ongoing psychological challenges. The technological environment of the NICU, combined with cultural expectations about new-born care, created unique stressors for Zambian parents. These findings highlight the critical need for structured psychological support services that integrate cultural understanding with clinical care.

Concerning communication challenges and coping mechanisms, the study uncovered complex barriers within the multilingual NICU environment. Parents developed diverse coping strategies, often blending traditional practices with modern support mechanisms. The findings demonstrated how parents navigated language barriers, cultural hierarchies, and technical medical information while developing resilient coping approaches. This understanding emphasizes the importance of developing culturally sensitive communication protocols and supporting parent-developed coping strategies.

Focusing on support systems, revealed significant gaps in formal support services while highlighting the strength of informal support networks. Parents relied heavily on religious practices, community connections, and family support to manage their NICU experience. The findings underscore the need for integrated support systems that acknowledge both traditional and modern approaches to parent support.

These findings contribute valuable knowledge to understanding parent experiences in resource-limited NICU settings and provide practical frameworks for improving care delivery. The success of implementing recommended changes requires sustained commitment from healthcare providers, administrators, and policymakers, alongside active community engagement. Future research building on these findings will further enhance our understanding and ability to support parents during this challenging period of their lives.

This research has significant implications for improving NICU care in resource-limited settings, particularly in developing culturally appropriate support systems that address both the technical and human aspects of neonatal intensive care. The findings provide a foundation for enhancing parent support services while respecting cultural practices and managing resource constraints.

5.6 Limitations of the study

This study encountered several limitations that warrant acknowledgment.

- The study was conducted at a single healthcare facility (UTH-NICU), which may limit the transferability of findings to other settings with different resources and cultural contexts.
- As with most qualitative research, the study relied on self-reported data obtained through interviews. The primary limitation of this approach is the potential for social desirability bias, where participants might have modified their responses to align with perceived social or cultural expectations. The research team addressed this by establishing strong rapport with participants and emphasizing confidentiality throughout the interview process.
- The study's specific cultural context within UTH Lusaka inherently shaped participants' experiences and perspectives. While this provided valuable insights into the local healthcare environment, it may affect the applicability of findings to settings with different cultural norms and healthcare practices. Cultural nuances in healthcare interactions, family dynamics, and support systems may vary significantly across different regions and healthcare settings.

To enhance the methodological rigor and address these limitations, several strategies were employed including.

- Bracketing techniques helped acknowledge and minimize potential researcher bias by consciously setting aside preconceptions during data collection and analysis.
- Regular peer debriefing sessions with other researchers validated the interpretation of findings and strengthened the analytical process.
- The research team conducted rigorous data collection and analysis procedures, including verbatim transcription of interviews and systematic coding using qualitative analysis software.

5.7 Future Research Directions

Future research directions could address these limitations by

- Incorporating multiple healthcare facilities, exploring experiences across diverse cultural settings, and utilizing mixed methods approaches. Such studies could provide broader insights into the experiences of parents with neonates on mechanical ventilation while maintaining the depth of understanding achieved through phenomenological inquiry.
- In addition, future studies across multiple sites could provide broader perspectives on parental experiences.

5.8 Implications of findings to the health care system

5.8.1 Nursing Practice

The findings have significant implications for nursing practice in the NICU setting. Nurses require enhanced competencies in delivering culturally sensitive care while managing the technical aspects of mechanical ventilation. Direct care practices must evolve to incorporate regular assessment of parental emotional wellbeing alongside physical care of neonates. This includes developing expertise in communicating complex medical information in local languages and implementing family-centered care approaches that accommodate extended family involvement.

5.8.2 Nursing Administration

Healthcare administrators must prioritize several structural changes to support improved parent care in the NICU. This includes developing appropriate staffing models that allow adequate time for parent support activities, creating physical spaces that accommodate cultural practices, and implementing protocols that support family-centered care. Resource allocation strategies must balance technical requirements with human support needs, particularly in addressing the need for dedicated parent support facilities and multilingual communication resources.

5.8.3 Nursing Research

The study highlights several areas requiring further investigation, including the development of culturally appropriate assessment tools, evaluation of family-centered care interventions, and research into effective educational strategies for cross-cultural care. Research priorities should

focus on studying effective cultural integration in NICU care and investigating parent support models suitable for resource-limited settings.

5.9 Recommendations

The following are the recommendations arising from the findings of our study:

5.9.1 Policy development

The Ministry of Health should develop comprehensive policies and guidelines for emotional distress and facilitated support groups that incorporate cultural and spiritual elements. These policies should outline standards for communication and support programs ensuring consistency and quality across healthcare facilities. Healthcare providers in the NICU should implement comprehensive changes to support parents with neonates on mechanical ventilation. A standardized multilingual communication system needs development, incorporating visual aids and translated materials in major local languages. This system should include regular scheduled updates for parents and implementation of culturally appropriate explanation methods. The establishment of dedicated psychological support services is essential, staffed by professionals trained in both clinical and cultural aspects of parent support. The study revealed that parents 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. Policy changes should address clear guidelines for parent involvement in care decisions, flexible visiting policies that accommodate cultural practices, and protocols for integrating traditional healing practices where appropriate. Policy changes should address the systematic implementation of family-centered care principles and the establishment of clear guidelines for parent support services. These policies should ensure consistent standards of care while maintaining flexibility to accommodate cultural and individual family needs. Regular evaluation and updating of these policies should be conducted to ensure their effectiveness and relevance.

5.9.3 Resource allocation

Resource allocation should be prioritized based on immediate needs and potential impact, with consideration given to both short-term requirements and long-term sustainability. Creative solutions for resource optimization should be explored, including the use of technology and community resources to supplement institutional capabilities. Resource allocation strategies must focus on developing transportation assistance programs, emergency financial aid mechanisms, and partnerships with community organizations for additional support. The study identified significant emotional and financial burdens experienced by parents, compounded by limited institutional support. Participants reported needing spaces to rest, emotional support from the health care professionals, and assistance in medical bills. Allocating resources to address these gaps would help alleviate stress, foster coping mechanisms, and improve the overall experience of parents with neonates receiving mechanical ventilation during their NICU stay.

5.9.4 Family Support Services

Engagement with the broader community requires careful consideration of local cultural dynamics. Healthcare institutions should develop formal partnerships with religious institutions and community leaders while creating networks between traditional healers and medical practitioners. Parent support groups that incorporate cultural practices need establishment, alongside community education programs about NICU care. These initiatives should focus on building sustainable relationships with local support organizations and integrating community resources into formal support structures. Enhance support services for families of NICU patients by offering counseling services, support groups, and resources to help them cope with the emotional impact of having a baby in the NICU. 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 parents. Participants frequently reported needing emotional support to cope with stress, as well as assistance to manage the high costs associated with medical bills. The designated staff members would address these needs comprehensively, ensuring parents feel supported during their NICU journey experience.

5.9.5 Interdisciplinary Collaboration

Foster collaboration among healthcare teams, including nurses, midwives, physicians, social workers, and chaplains, to provide a comprehensive and coordinated care to parents with neonates on mechanical ventilation of NICU. Interdisciplinary rounds or team meetings should include discussions on parents needs and how to effectively address them when need arises. The study highlighted that fragmented communication and inconsistent support from the healthcare team contributed to parents' distress. Improved collaboration between healthcare providers would ensure parents receive consistent information and emotional support. This approach would enhance parents' satisfaction and promote trust in the healthcare team.

5.9.6 Staff training development

Establish mechanisms for monitoring and evaluating the quality of care offered to parents with neonates receiving mechanical ventilation in the NICU, including parent satisfaction surveys, feedback mechanisms, and performance indicators. This should include assessing parent 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 offered, 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.

5.9.7 Dissemination of the Findings and Data Utilization

The data obtained from in-depth interviews with parents with babies on mechanical ventilation of NICU 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 parents with neonates on mechanical ventilation of NICU. 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 parents of NICU. 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 WNBH- NICU 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 1: Participation Information Sheet

Researcher: Nosiku Situmbeko

Contact Information: 0973459722

Title of Study: Exploring the Lived Experiences of Parents nursing their babies on mechanical ventilators in the NICU- UTH

Introduction:

You are invited to participate in a research study that seeks to understand and explore the lived experiences of parents who have neonates currently receiving care on mechanical ventilators in the neonatal intensive care unit (NICU) at a university teaching hospital in Lusaka, Zambia. Your participation in this study will provide valuable insights into the challenges, emotions, and perspectives of parents during this difficult period.

Purpose of the Study:

This research aims to gain a deeper understanding of your experiences as a parent in the NICU. We want to hear about your journey, emotions, coping mechanisms, and the unique challenges you've faced while your neonate receives care on mechanical ventilators.

Procedure:

If you agree to participate, you will be invited to an in-depth interview. The interview will be conducted in a private and confidential setting and is expected to last approximately [estimated duration] minutes. During the interview, you will have the opportunity to share your experiences, thoughts, and feelings openly.

Voluntary Participation:

Participation in this study is entirely voluntary. You have the right to decline participation or withdraw from the study at any time without any consequences. Your decision will not affect your neonate's care in any way.

Confidentiality:

Your responses will be kept confidential. Your identity will be anonymized, and any identifying information will be removed from the research findings to ensure your privacy.

Benefits:

While there are no direct benefits to you as a participant, your insights and experiences will contribute to a better understanding of the challenges faced by parents in the NICU, potentially leading to improved support and care for parents in similar situations in the future.

Consent:

While there are no direct benefits to you as a participant, your insights and experiences will contribute to a better understanding of the challenges faced by parents in the NICU, potentially leading to improved support and care for parents in similar situations in the future.

Thank you:

Your willingness to participate in this study is greatly appreciated. Your contribution will help us shed light on the experiences of parents in the NICU and contribute to the improvement of neonatal care.

Participant's signature: _____

Thumbprint: _____

Witness signature: _____

Address: _____

PERSONS TO CONTACT FOR QUERIES

1. Nosiku Situmbeko, researcher. School of Nursing. Phone: +260973459722. Email nosikusitumbeko1989@gmail.com
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4. The Chairperson, University of Zambia, Biomedical Research Ethics Committee, P.O Box 50110, Lusaka. Phone number: +260-1-256067; Email: s.munsaka@unza.zm

Appendix 2: INTERVIEW GUIDE

IN-DEPTH INTERVIEW

Introduction

Thank you for participating in this study. The purpose of this interview is to gain a deeper understanding of your experiences as a parent. Your insights will contribute to improving the care and support provided to patients like you. Your participation is voluntary, and you can withdraw at any time. Please feel free to share your thoughts and feelings openly.

Section 1 Demographic for NICU Parent Study

1. What is your age? _____ years
2. What is your gender?
3. What is your relationship to the neonate in the NICU?
4. What is your neonate's primary medical condition? _____
5. How long has your neonate been in the NICU? _____ days/weeks
6. How would you describe your level of family support during this time?
7. What is your current occupation? _____
8. What is the highest level of education you have completed?
9. In which province of Zambia do you currently reside? _____
10. What is your primary language? _____
11. What is your marital status?
12. How far do you live from this hospital?
13. How did you travel to the hospital?

Section 2: Background and Context

1. Can you briefly describe your neonate's condition and why they are in the NICU?
2. How long has your neonate been in the NICU, and how many times have they been on mechanical ventilation during this period?
3. Could you share any prior experiences or knowledge you had about neonatal intensive care before your neonate's admission?

Section 3: Emotional and Psychological Experiences

4. What emotions have you experienced since your neonate's admission to the NICU?
5. Can you describe any particularly challenging moments or situations that stand out in your journey as a parent in the NICU?
6. How have you been coping with the emotional and psychological challenges? Are there specific strategies or sources of support that have been helpful?

Section 4: Interaction with Healthcare Providers

7. What has been your experience in communicating with healthcare providers (doctors, nurses, etc.) regarding your neonate's condition and care plan?
8. Have there been any instances where you felt that your concerns or questions were not adequately addressed?
9. How do you perceive the quality of care provided to your neonate in the NICU?

Section 5: Impact on Family and Relationships

10. How has your neonate's NICU stay and mechanical ventilation affected your family dynamics and relationships with other family members?
11. Have you received support from family and friends, and if so, in what ways?

12. Are there any significant changes in your daily life and routines due to your neonate's condition?

Section 6: Hopes and Expectations

13. What are your hopes and expectations for your neonate's future health and well-being?

14. How do you envision your role as a parent once your neonate is discharged from the NICU and no longer requires mechanical ventilation?

15. Are there any specific improvements or changes you would like to see in the NICU or neonatal care practices based on your experiences?

Section 7: Closing and Reflection

16. Is there anything else you would like to share about your experiences as a parent in the NICU or your thoughts on this study?

17. Thank the participant for their time and willingness to participate.

18. Provide information on how they can contact you or the research team if they have further questions or wish to follow up.