

**EXPERIENCES OF PARENTS OF PRETERM BABIES WITH  
HEALTHCARE STAFF IN THE NEONATAL INTENSIVE CARE UNIT AT  
WOMAN AND NEWBORN HOSPITAL, LUSAKA, ZAMBIA**

**BY**

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REQUIREMENTS FOR THE AWARD OF A DEGREE OF SCIENCE MASTER IN  
NEONATAL NURSING**

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## **DECLARATION**

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

I, further, declare that all sources of information and data used in this report, whether published or unpublished, have been appropriately cited and referenced by the academic and ethical standards.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

Signature \_\_\_\_\_ Date: \_\_\_\_\_

(Candidate)

## ABSTRACT

Hospitalization of a preterm baby presents a significant burden to parents, especially the mother. This study explored the experiences of parents of preterm babies with healthcare staff in the Neonatal Intensive Care Unit (NICU) at the Women and Newborn Hospital (WNH). The study utilized qualitative descriptive phenomenological design with purposive sampling of mothers of preterm babies admitted to the NICU. In-depth interviews were conducted with an interview guide until data saturation was reached at interview 12. The interviews were audio-recorded, transcribed, and analyzed using thematic content analysis. The findings showed parents of preterm babies in the NICU experienced a mix of supportive and challenging interactions with healthcare staff. Key themes included communication, emotional experience, parental involvement, cultural sensitivity, and pre-discharge preparation. Some parents reported receiving clear information and emotional support, while others felt excluded due to rushed explanations and neglect of their emotional needs. Active parental involvement in caregiving improved confidence, while limited engagement led to anxiety and helplessness. Cultural beliefs were not always acknowledged, causing frustration. Additionally, many parents felt underprepared for home care due to inconsistent discharge education. Recommendations include improving communication through clear, and timely updates, providing emotional support with compassion and access to counseling, encouraging parental involvement in care and decision-making, and respecting cultural beliefs through sensitivity training and open dialogue with parents.

***Keywords:*** *Preterm babies, NICU, Experiences, Interpersonal relationship*

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## **LIST OF ABBREVIATIONS**

APA: American Psychological Association

KMC: Kangaroo Mother Care (KMC)

NICU: Neonatal Intensive Care Unit

SDGs: Sustainable Development Goals

WHO: World Health Organization

WNH: Woman and Newborn Hospital

UTH: University Teaching Hospital

## **CHAPTER ONE: INTRODUCTION AND BACKGROUND**

### **1. 1 Introduction**

Parents of preterm babies often face significant emotional and psychological challenges, especially in Neonatal Intensive Care Units (NICUs) (Lasiuk et al., 2021). At the Woman and Newborn Hospital (WNH) in Lusaka, Zambia, these challenges are compounded by the unique healthcare dynamics in a resource-limited setting. Research indicates that the interaction between parents and healthcare staff in NICUs critically affects parental stress levels, coping mechanisms, and overall satisfaction with care (Al Maghaireh et al., 2022). Understanding these experiences can provide valuable insights into improving support systems for parents of preterm infants in Zambia's healthcare facilities. The researcher became inspired to conduct this study after hearing parents complain that they do not receive daily updates about their pre-term newborns and realizing that parents are absent during the medical rounds.

This chapter covers the introduction, background, statement of the problem, justification, research objectives, research question, and conceptual definitions.

### **1.2 Background information**

The World Health Organization (WHO) defines pre-term as babies born alive before 37 weeks of pregnancy are completed (WHO, 2022). Babies born less than 28 weeks are considered extremely pre-term, those born between 28 and 32 weeks are classified as very pre-term, and those born between 32 and 37 weeks of gestation are considered moderate or late pre-term (WHO, 2022). Although various socioeconomic, environmental, dietary, medical, and obstetric factors have been demonstrated to raise the chance of spontaneous pre-term delivery, the exact etiology of preterm birth is unknown (Chawanpaiboon et al., 2019).

Worldwide, pre-term birth is currently the number one cause of death in children under the age of five, and about 15 million babies are born too early each year, accounting for approximately 10% of all live births (WHO, 2022). In the United States, the preterm birth rate was 10.4% (CDC 2022)

and in Europe, preterm birth rates varied by country, ranging from 5.4% to 12%, with an average of 7.3% of all live births (Public Health England, 2020).

Over 60% of pre-term births occur in sub-Saharan Africa (Mochama et al.,2020). The admission of a pre-term baby to a NICU presents a significant burden to parents, especially the mother (Sajadi et al., 2018). The study by Foligno et al., (2020) revealed that stress arising from hospitalization has an eventual effect on the production of breast milk and the establishment of successful breastfeeding among others. It is also a frightening and stressful experience for parents (Apedani, 2019). In addition, parents experience an unfamiliar and particularly distressing and threatening situation, and therefore need support from nurses and physicians (Sankar et al.,2017). Similarly, healthcare professionals need to understand the unique experiences of parents when their neonates are admitted to the NICU because they face significant challenges during the lengthy hospitalization of their pre-term neonates (Yu et al., 2019).

Furthermore, parents of preterm infants often experience significant psychological distress and communication challenges with healthcare providers, largely due to limited involvement in their babies' care (Sajadi, 2018; Lotterman et al., 2019). Although parental presence in the NICU has become more widely accepted, Aijaa (2019) emphasizes the importance of actively involving parents in shared decision-making processes, particularly during medical rounds. Research indicates that parents' anxiety is frequently driven by concerns related to their infants' medical needs, the inability to breastfeed or provide expressed breast milk, restricted visitation policies, and insufficient updates on their infant's clinical progress (Sankar et al., 2017).

In Iran, mothers' top demands include communicating with the hospital personnel regularly, feeling that the staff is caring for the patient, knowing what will happen to the patient, and answering their questions truthfully and honestly (Akbari, 2020). A systematic review in Iran also showed that from the parents' point of view, the need for assurance, awareness, closeness, support, and comfort was the most important need for parents (Akbari, 2020). The need for support is one of the major findings of studies conducted in Iran on the experiences of parents of premature infants admitted to NICU (Alinejad-Naeini, 2020).

It is estimated that 13% of births in Zambia are premature (Zambia Statistics Agency et al., 2019). Zambia shares the disproportionate burden of about 77,600 pre-term births and 6,800 infant deaths

each year due to pre-term birth complications compared to similar settings in sub-Saharan Africa (Castillo et al., 2018). To reduce the risks of death or disability after premature birth, NICU and Special Care Baby Unit environments provide specialized medical care including respiratory support, alternative feeding, and medical interventions to reduce the risk of infections (Taylor, 2022).

Masumo et al., (2021) study in Zambia, revealed that mothers experienced stress and anxiety during the hospitalization of their infants. The study further highlighted that the stress experienced by mothers influences the lactation and bonding between mother and baby (Masumo et al., 2021).

Therefore, healthcare workers must provide adequate support to help parents cope with the stress of infant hospitalization and improve their ability and confidence in caring for their babies (Yu, 2020). Thus, this study aimed to explore parents' experiences of pre-term babies with healthcare staff in the Neonatal Intensive Care Unit at the Woman and Newborn Hospital (WNH).

### **1.3 Statement of the Problem**

The NICU specializes in medical and nursing care for very sick and premature babies (Musengimana, 2017). The Zambian government, Ministry of Health (MoH), and WNH have made efforts aimed at mitigating the challenging experiences of parents with preterm babies in the NICU. These efforts have included the incorporation of emotional support services into neonatal care by offering counselling and involving family members in the care process. Hospitals introduced programs in which counselors or social workers were made accessible to support mothers in coping with the psychological stress of having a preterm baby (Chansa et al., 2021). These emotional and psychological support services have helped mothers manage anxiety and stress, particularly when they were kept informed about their baby's condition, which helped to reduce feelings of isolation (Maimbolwa et al., 2020).

Despite the commendable progress made by MoH and WNH, several challenges persist. One major concern raised by parents was the lack of consistent communication from healthcare providers. Although initiatives were introduced to improve dialogue, some parents still felt inadequately informed, especially during emergencies or complex procedures (Mumba & Tembo, 2021). In addition, a shortage of trained neonatal staff has contributed to excessive workloads, limiting the

ability of staff to offer meaningful emotional support. As a result, interactions sometimes appeared rushed or impersonal, which diminished trust and parental satisfaction (Chanda et al., 2022).

Furthermore, although WNH has made efforts to provide psychosocial support services, their availability remains limited. Some parents reported that counselling services were not consistently communicated or offered, leaving many to navigate the NICU experience without the psychological support needed to cope with stress and uncertainty (Phiri & Banda, 2020). These parents thus need greater support from nurses and medical professionals. It is with this background that the researcher hoped to explore the experiences of parents of pre-term babies with healthcare staff in the NICU at the WNH.

#### **1.4 Study Justification**

Understanding the experiences of parents in the NICU is important, as these encounters profoundly influence parental emotional well-being, bonding with their infants, and overall satisfaction with the care provided (Adama, 2021). Healthcare staff in the NICU play a critical role in communicating with parents, updating them on their baby's clinical state, providing emotional support, and educating them on caring for their preterm infants. The unique circumstances at the WNH, where parents walk a considerable distance to feed their babies every two hours, add a layer of complexity to their experiences (Lorié, 2021; Mutaganzwa, 2018).

The study was also addressing several Sustainable Development Goals (SDGs). It supports SDG 3: Good Health and Well-being by promoting the improvement of neonatal care quality and enhancing the well-being of both infants and their parents through better communication and emotional support in NICUs. It contributes to SDG 5: Gender Equality by addressing the unique emotional burdens often experienced by mothers of preterm babies and advocating for more inclusive and gender-sensitive healthcare practices. Lastly, it supports SDG 17: Partnerships for the Goals by encouraging collaboration between healthcare providers, policymakers, and families to develop more holistic, family-centered approaches in neonatal intensive care.

Acknowledging these insights, the study at WNH sought to explore how parents of preterm babies perceived and experienced their interactions with healthcare staff in the NICU. Gaining insight

into these lived experiences was essential for improving neonatal care quality, strengthening parent-staff relationships, and promoting emotional well-being among parents. It is hoped that the findings of this study will inform healthcare providers, hospital administrators, and policymakers on areas that require improvement to make neonatal care more inclusive, compassionate, and family-centered.

## **1.5 Research questions**

1.5.1 What are the perceptions of parents of pre-term babies with healthcare staff in the NICU at the WNH, Lusaka, Zambia?

1.5.2 What are the interpersonal relationships between healthcare staff and parents nursing pre-term babies in NICU at the WNH, Lusaka, Zambia?

## **1.6 RESEARCH OBJECTIVES**

### **1.6.1 General objective**

To explore the experiences of parents of pre-term babies with healthcare staff in the Neonatal Intensive Care Unit at the Woman and Newborn Hospital, Lusaka, Zambia.

### **1.6.2 Specific Objectives**

1.6.2.1 To explore the perceptions of parents of pre-term babies with healthcare staff in the Neonatal Intensive Care Unit at the Woman and Newborn Hospital, Lusaka, Zambia.

1.6.2.2 To describe the Interpersonal relationships between parents and healthcare staff in the NICU.

## **1.7 Definitions**

### **1.7.1 Conceptual Definition of Terms by Experts/Dictionary**

**Parent:** refers to someone who has a biological or legal relationship with a child and assumes the role of providing physical, emotional, and financial support, as well as guidance and nurturing. (APA Dictionary of Psychology, 2019)

**Pre-term:** refers to the condition of a baby being born before completing the full term of gestation, which is approximately 37 to 42 weeks of pregnancy (WHO, 2018).

**Healthcare staff:** This is anyone who works in a healthcare or social care setting, including healthcare students on clinical placement, frontline healthcare workers, and other healthcare workers not in direct patient contact. (International Labour Organization, 2020)

**Neonatal Intensive Care Unit:** refers to a specialized medical facility within a hospital that provides comprehensive care for newborn infants who are born prematurely or have medical conditions requiring intensive medical attention. (American Academy of Pediatrics, 2012).

**Experiences:** Experiences refers to the subjective perceptions, emotions, and interactions that parents go through while engaging with healthcare staff in the NICU. This includes their emotional responses, expectations, challenges, and overall satisfaction with the care provided to their preterm infants (Schmied et al., 2018).

**Interpersonal Relationship:** An interpersonal relationship is a dynamic connection between parents and healthcare staff, characterized by communication, trust, emotional support, and mutual understanding. In the NICU context, a positive interpersonal relationship involves clear and compassionate communication, collaborative decision-making, and responsiveness to parental concerns (O'Brien et al., 2019).

### **1.7.2 Operational Definition of Terms as Used in this Study**

**Parent:** Mother, or any other designated primary caregiver of a baby born before 37 weeks of gestation and is admitted to the NICU.

**Preterm:** refers to infants born before 37 weeks of gestation and admitted to the NICU for specialized care.

**The neonatal Intensive Care Unit:** refers to the specialized unit at Woman and Newborn Hospital where infants born before 37 weeks of gestation babies receive intensive medical care.

**Healthcare Staff:** these include Nurses, Doctors, Counselors, Social workers, and Nutritionists working in the NICU at Woman and Newborn Hospital who interact with parents of preterm babies.

**Experiences:** refers to the documented and reported interactions, feelings, and challenges that parents of preterm infants encounter while receiving care from healthcare staff in the NICU at Woman and Newborn Hospital.

**Interpersonal Relationship:** refers to the observable and self-reported interactions between parents and healthcare staff in the NICU, focusing on communication effectiveness, emotional support, and mutual engagement.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter focuses on different literature reviewed by other researchers who conducted similar studies related to the experiences of parents of pre-term babies with healthcare staff in the NICU. The main objective of this study is to explore the experiences of parents of preterm babies with healthcare staff in the NICU. In many cases, preterm babies require specialized care in the NICU, where healthcare professionals provide critical support. However, the NICU experience also profoundly affects parents, particularly in their interactions with healthcare providers. Search databases such as PubMed, HINARY, Google Scholar, CINAHL, and Cochrane Library and search terms such as ‘preterm babies’, ‘parents’, ‘experiences’, ‘NICU’, and ‘Healthcare staff’ were used. The chapter, therefore, reviews relevant literature regarding parental perceptions and interpersonal relationships with NICU staff.

#### **2.2 Overview of the Experiences of Parents of Preterm Babies with Healthcare Staff in the NICU**

The admission of a preterm infant to the NICU often presents a profoundly emotional and psychologically challenging experience for parents. Their perceptions and emotional responses are heavily influenced by the nature of their interactions with healthcare staff. The NICU environment characterized by complex medical technologies, unfamiliar routines, and minimal parental participation frequently contributes to feelings of helplessness, anxiety, and emotional vulnerability (Zhang et al., 2021).

The literature emphasized that the quality of communication and support provided by healthcare professionals significantly impacts how parents experience the NICU journey (Craig & Glick, 2021). Parents placed great importance on healthcare workers who demonstrated empathy, transparency, and inclusiveness. Positive experiences are typically linked to compassionate care, open and honest communication, and meaningful parental involvement in decision-making and caregiving (Watson & Healy, 2021). In contrast, negative experiences often arose when parents

perceived a lack of empathy, insufficient information, or are excluded from key decisions, all of which can intensify emotional distress and dissatisfaction with the care provided (Koliouli et al., 2021).

The strength and quality of interpersonal relationships between parents and healthcare providers especially nurses and neonatologists are fundamental to the emotional well-being of parents. When these relationships are based on trust, mutual respect, and emotional support, parents often feel more secure and confident in their infant's care. However, in settings with limited resources, high staff workloads, and systemic inefficiencies, such relationships may be difficult to establish and maintain (Rocha & Silva, 2021).

### **2.3 Socio-Demographic Characteristics of Parents of Preterm Babies**

Socio-demographic factors played a critical role in shaping how parents experience and navigate the NICU environment. Characteristics such as age, gender, marital status, education level, occupation, and cultural or religious background influence parental perceptions, coping strategies, and interactions with healthcare staff (Shorey et al., 2018; Obeidat et al., 2009).

Regarding gender and age, mothers often took on primary caregiving roles and reported higher emotional distress than fathers, particularly younger mothers may have felt underprepared for the challenges of preterm birth (Abeasi & Mufunda, 2020; Kiguli et al., 2015). Marital status affected the level of emotional and practical support available to parents. Those who were married may received more consistent support from partners, while single parents often faced added stress due to limited help and financial strain (Blomqvist et al., 2012; Cleveland & Bonugli, 2014).

Educational background influenced how well parents understood medical information and participated in care. Higher education levels were linked with better communication with healthcare providers and greater confidence in caregiving, while limited education led to misunderstandings and increased anxiety (Franck et al., 2017; Obeidat et al., 2009).

Employment also shaped NICU experiences as parents with unstable employment struggled with transport costs, missed work, or long stays away from home, which reduced their ability to be present and engaged in their baby's care (Flacking et al., 2021).

Additionally, cultural and religious beliefs influenced parental views on preterm birth and medical care. In some settings, preterm birth carried social stigma or was associated with traditional beliefs, affecting parents' willingness to interact with healthcare professionals or accept certain interventions (Mwizerwa et al., 2021).

## **2.4 Parental Perceptions of Healthcare Staff in the NICU**

### **2.4.1 Communication**

A study conducted by Germana (2022) on Communication in a Neonatal Intensive Care Setting in Portugal found that for those who work in the NICU, communication is a critical skill. In another study by Williams et al (2018) on experiences of caring for their preterm neonates from the Neonatal Unit in Ghana, a narrative inquiry study recognized that when caring for their newborns in the NICU, mothers' experiences were frequently centered on communication, and poor communication regarding the continuity of their babies' care adds to feelings of frustration, being alone, abandoned, and burdened with unwelcome responsibilities only makes having a premature baby more painful.

According to many research [Carvalho, (2020), Carvalho (2021), Enke (2017), Sorin (2021)] in Portugal, poor communication affects newborn care negatively and it raises the risk of stress and dissatisfaction in families, burnout in healthcare professionals, and legal concerns with healthcare service delivery. The most common challenges are providing too little information, using too much medical jargon, having nurses rather than doctors give patients clinical information, having parents whose newborns have simpler diseases or are healthier spend less time with doctors, and having clinical observation and physical examinations are done without parents being present.

In a Phenomenological Interpretative Analysis by Dadkhahtehrani, et al (2018) on the Experiences of Fathers with Inpatient Premature Neonates in Iran, fathers' lack of knowledge and awareness of the care process and the outcomes of the premature neonate was one of their top worries, and they emphasized the necessity for learning about the likely consequences of preterm delivery.

In a study entitled “Experiences of Mothers with preterm babies in a low resource setting neonatal intensive care unit” in Kenya by Namusoke, (2020), Participants believed that the medical staff did not adequately explain the baby's condition or allow them an opportunity to ask any questions about the course of treatment. Similarly, another study by Nkosi et al., (2019), highlighted the need for improved communication, emotional support, and shared decision-making to enhance the NICU experience for parents and optimize outcomes for pre-term infants.

#### 2.4.2 Parental Participation

Being actively involved in the newborn's care changes role beliefs which increases confidence and encourages the involvement of fathers in the NICU (Hearn et al, 2020). Although caregivers are present, parental involvement in activities should be strongly encouraged for improved neonatal outcomes (Zauche et al, 2020).

In an observational cohort study by Kim et al (2021) on Caregiver presence and involvement in a Canadian NICU, in Canada, throughout the first week of admission, researchers discovered that caregivers were actively involved in the care of their newborns with the majority of mothers performing skin-to-skin contact, singing/talking/reading, and holding their newborn. Similarly, in studies on the involvement of caregivers in the care of newborns admitted to the NICU by Gonya & Nelin, (2013), Kamphorst et al., (2018) in an observational study in the Netherlands, researchers found that 80% of mothers were involved in the care within the first week of admission, and skin-to-skin contact was performed for close to an hour by mothers and performed the least amount by other caregivers.

A prospective observational cohort study by Kim et al., (2021) on Caregiver's Involvement and Skin-to-Skin Contact in the Neonatal Intensive Care Unit, in an open bay setting of an Eastern Canadian NICU in Canada, found Skin-to-skin contact was less frequently performed compared to holding newborns clothed. Comparing this finding to that of other European research, it was a contradictory study by Raiskila et al., (2017) on Caregivers' presence and involvement. According to Kim et al (2021) in Canada, the NICU nurses' efforts to inform and actively encourage parents to get involved in their newborn's care as soon as they are admitted to the hospital may be the cause of the higher percentage of engagement activities within the first week. The majority of parents in the NICU receive instruction from the medical staff within the first week of admission

as part of the family orientation to the NICU on how to safely hold and care for their infant as well as other tasks like feeding, pumping breastmilk, and changing diapers.

In a phenomenological study by Jerntorp et al. (2020) on the experiences of fathers of pre-term babies in Sweden, the study found that the fathers felt they were active partners with the professionals, who encouraged them to participate actively in care procedures and decision-making. The professionals were helpful, supportive, and accommodating in terms of how much direction and help the fathers required. In another study done by Franck et al. 2017 in the United States of America, a qualitative observational study on Caregiver presence and involvement found that most parents felt they were involved in decision-making. Similarly, a study by Hagen et al. (2019) on fathers' lived experiences of caring for their preterm infant at the neonatal unit and in neonatal home care after the introduction of a parental support program in Norway, discovered that being involved in decision-making and being treated with respect were the most crucial factors for parent satisfaction with NICU treatment.

A systematic review and meta-synthesis of qualitative research aimed at assessing the main functions of parent-provider communication in the NICU and determining what adequate communication entails according to both parents and health professionals in the Netherlands found that a crucial element of Family Integrated Care is enabling parents to exchange information, pose enquiries, and express their thoughts (Lorié et al. 2021). In addition, Family-integrated rounds give parents the chance to develop their confidence in speaking out, expressing questions, and forming bonds of trust with medical professionals. There have been numerous studies on the successful inclusion of parents as partners in medical rounds (Aija 2019, Banerjee 2018).

Furthermore, Lorié et al. (2021) in the Netherlands, demonstrated the need to distinguish between urgent decisions and those that are not. Although parents want to know about urgent decisions and the reasoning behind them, they do not feel the need to be involved before they are carried out, but they do need sufficient information after the fact. Parents do want to be consulted up front when making non-urgent decisions (such as increasing enteral or oral feeding, weaning stages from continuous positive airway pressure (CPAP) use, or scheduling a Magnetic Resonance Imaging (MRI)).

In 2019 study titled "Parental Involvement in the Care of Preterm Infants in a South African Neonatal Intensive Care Unit," Nkosi et al. conducted interviews and focus group discussions with parents to explore their experiences and perceptions of involvement in the care of their preterm infants in a NICU setting in South Africa. The findings emphasized the value parents placed on active participation in their baby's care and the importance of their involvement in the well-being and development of their infants. However, the study also identified challenges including limited physical contact opportunities, communication gaps with healthcare providers, and feelings of powerlessness.

Bogale et al. (2018) conducted a cross-sectional study titled "Parental Involvement in Care of Preterm Infants Admitted to Neonatal Intensive Care Units: A Cross-Sectional Study" in Ethiopia. The study aimed to assess the level of parental involvement in the care of preterm infants in Ethiopian NICUs. Structured interviews with parents were conducted, and standardized tools were utilized to evaluate aspects such as kangaroo care, feeding, and participation in decision-making. The findings revealed varying levels of parental involvement, influenced by socio-cultural beliefs, awareness, and resource accessibility. The study emphasized the importance of promoting parental involvement and highlighted the need for education, information, and support from healthcare providers to enhance parental participation in preterm infant care. The results contribute to the development of interventions and strategies for improving outcomes in Ethiopian NICUs.

A study by Masumo et al 2021 on NICU environmental stressors: towards developing a stress-alleviating model for mothers nursing sick neonates, also concluded that mothers should be involved more in the care of their babies while they are admitted.

### **3.5 Interpersonal Relationships Between Parents and Healthcare Staff**

The interpersonal relationship between parents and NICU staff plays a critical role in the overall parental experience. Such relationships are built on mutual respect, empathy, and collaboration. Studies emphasize the importance of relational continuity, where consistent interaction with the same healthcare professionals fosters familiarity and trust (Hägi-Pedersen et al., 2021).

According to Franck (2017) who conducted a study titled "Family Integrated Care for Pre-term Neonates" in the United States of America, found that parents gave high praise when staff

demonstrated respect, and thoughtfulness and when they addressed babies by name, gave parents up-to-date information about how the baby was while the parents were away, greeted the parents by name, and inquired about their wellbeing.

A study by Babu (2018) in South India on the Practice of Early Initiation of Breastfeeding among Postnatal Mothers in a Tertiary Hospital, found that mothers encounter difficulties when trying to express their breast milk, mothers cited a lack of staff assistance in this regard and reported dealing with harsh language and slow response times from medical staff, which they stated added to the stress of the already challenging scenario of having a premature baby. Similarly, a study done by Pereira (2015) in Brazil, found that mothers meet the challenge of expressing breast milk, referred to mothers as a lack of assistance from staff on how to express.

In a qualitative study done in the United Kingdom by Gallagher et al., (2018) which aimed to explore the experiences of parents of infants admitted to the NICU regarding interaction with healthcare professionals during their infant's critical care, parents stressed the need of providing information in a clear and concise manner, to help them to adequately manage their own expectations of their baby's progress and to make it easier for them participation in discussions about treatment planning. Parents also talked about how secure they felt in their relationships with their regular caregivers because they felt more at ease approaching them with queries to get the information, they required to manage their own expectations of their child's development and be able to participate in discussions with them about treatment and involvement in care.

The study conducted by Ghorbani et al., (2018) in Iran highlighted the experiences of neonatal intensive care unit (NICU) nurses in implementing family-centered care. The findings revealed that nurses faced challenges such as stress and fatigue, which hindered their ability to establish meaningful relationships with parents. The demanding nature of their job and the limited time available often impacted their capacity to provide adequate support and engagement with parents. This aligns with the study by Lindberg and Öhrling (2018) in Northern Sweden, where the importance of receiving kindness and support from the healthcare staff was emphasized by mothers. The presence of a supportive environment reassured mothers that their infants were being well cared for. Conversely, a lack of attentive listening to their thoughts and desires led to feelings of disappointment. These studies collectively underscore the significance of healthcare

professionals in the NICU demonstrating empathy, offering support, and actively engaging with parents to foster a positive and family-centered care environment. By addressing the challenges faced by nurses and prioritizing effective communication and attentiveness to parental needs, healthcare providers can contribute to improved outcomes and experiences for both parents and infants in the NICU setting.

Several studies have explored the experiences of parents in healthcare settings, particularly focusing on how they perceive the treatment of their newborns and themselves by the hospital staff. Notably, Dadkhahtehrani et al., (2018) conducted research in Iran and found that a majority of fathers expressed dissatisfaction with the hospital staff's behavior. They perceived the staff as being careless, indiscreet in their language, and insensitive to the cries of the babies.

In contrast to these findings, Jackson et al. (2016) conducted a study that examined fathers' perspectives on the competence of the staff in an unspecified location. Interestingly, all the fathers in this study expressed confidence in the staff's abilities, which suggests a divergence in the fathers' perceptions compared to the findings of Dadkhahtehrani et al., (2018).

In a study conducted by Williams (2018) in the United States, the focus shifted to mothers' experiences and their interaction with nurses. The findings revealed that numerous mothers expressed stress when they perceived nurses to have a negative attitude or when they believed the nurses were physically rough with their babies during care and procedures. Additionally, many mothers complained about nurses enforcing regulations in ways they considered unkind or hurtful. The study also highlighted mothers' dissatisfaction with rules that they found annoying and felt hindered their ability to care for or spend time with their newborns.

A study by Zimba et al. (2020) highlighted that while some parents reported compassionate and helpful relationships with nurses and midwives, others felt neglected or judged, especially when staff were perceived as too busy or overwhelmed. These relational dynamics underscore the need for structured communication, emotional support systems, and training in interpersonal skills among NICU staff.

## **2.6 Conclusion**

Parents' experiences with healthcare staff in the NICU are significantly impacted by communication and their involvement in caring for their infant. Positive interactions, marked by empathy, openness, and inclusivity, enhance emotional well-being and foster stronger relationships with staff. In contrast, poor communication and exclusion from decision-making create negative experiences and increase stress. Factors such as gender, age, and education influence how parents interact with healthcare professionals.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1. Introduction**

The research methodology, as outlined by Polit & Beck (2021), delineated the designs and procedures utilized by the researcher for the study, while also discussing how the research objectives were attained. This chapter provides detailed insights into the methods employed by the researcher to explore the experiences of parents of preterm babies with healthcare staff in the NICU at the WNH in Lusaka, Zambia. It elaborates on the research design, study settings, study population, selection of participants, inclusion criteria, exclusion criteria, and sample size. Additionally, data collection methods and tools, data management and storage, and ethical considerations were discussed in this chapter. This research aimed to gain an in-depth understanding of the experiences of parents to identify areas for improvement in the delivery of healthcare services in the NICU.

#### **3.2. Study Design**

The study employed a qualitative descriptive phenomenological approach. Phenomenology was regarded not solely as the study of human experience but also as a means to glean insights from others' experiences. Through this design, the researcher aimed to gather detailed and context-specific data that would offer valuable insights into the experiences of parents in the NICU (Neubauer et al., 2019).

#### **3.3. Study setting**

The study was conducted in the NICU of the WNH at the University Teaching Hospitals in Lusaka, Zambia. This facility offered specialist Neonatal Care and served as a tertiary referral hospital. The NICU comprised two sections: The Intensive Care side and the High Care side. The intensive care unit consisted of three rooms. Room one admitted pre-term babies, while room two admitted babies requiring ventilator support. Room three accommodated term babies. Once stabilized, babies were transferred to the High Care side, which comprised High Care One and High Care

Two. High Care One housed pre-term babies awaiting transfer to the Kangaroo Mother Care ward or discharge, while High Care Two was designated for term babies undergoing observations and completion of antibiotic therapy before discharge. Notably, neither section provided accommodation for parents to stay with their babies; hence, parents were only permitted during specified visiting hours. The study was conducted in Intensive Care room one and High Care one to explore the experiences of parents of pre-term babies with healthcare staff in the NICU.

### **3.4 Study population**

The target population comprised parents of pre-term babies admitted to the NICU at the WNBH.

#### **3.4.1 Target Population**

The study population consisted of all parents with preterm babies admitted to the NICU for a minimum of three days.

#### **3.4.2 Accessible Population**

The accessible population included parents of preterm babies who had been admitted to the NICU at WNH for a minimum of three days and were available and willing to participate in the study during the data collection period.

### **3.5 Sampling technique**

A purposive sampling technique was used to recruit information-rich participants who met the inclusion criteria. The purposive sampling process began with defining the inclusion criteria, and the researcher identified eligible parents admitted to the NICU at WNH. Thereafter, the researcher initiated contact by explaining the purpose of the study and ensuring that participation was voluntary and confidential. Parents who agreed to participate were provided with informed consent after having their questions answered. Finally, data was collected through interviews, allowing the researcher to gather in-depth insights into parents' experiences with healthcare staff in the NICU.

### **3.6 Inclusion criteria**

Parents with pre-term babies admitted to the NICU and who had spent a minimum of 3 days in the NICU were included in the study.

### **3.7 Exclusion criteria**

Parents with pre-term babies admitted to the NICU who were sick and unable to come to the NICU were not included in the study.

### **3.8 Sample size**

A total of 12 participants from the study population made up the sample size. This was determined after the 12th participant was interviewed and no new or relevant information emerged, hence signifying data saturation. The sample size was within the range suggested by some researchers, as Creswell (2013) stated that a sample size of 5 to 25 participants is common in phenomenological research. This sample size aligns with findings from other qualitative studies conducted in NICU settings, where data saturation similarly guided the number of interviews. Research by, Hendriks et al. (2020) reached saturation after 12 parent interviews, noting that further data collection no longer contributed new insights. Findings by Orapiriyakul et al. (2017) achieved saturation at 15 interviews with Thai parents, as recurring emotional responses and coping patterns began to surface consistently. Additionally, Lindberg et al. (2017) reported saturation after interviewing 11 fathers of premature infants, as key themes around paternal involvement and stress were thoroughly explored.

### **3.9 Data collection tool**

An in-depth interview was used to allow participants to describe their experiences with the healthcare staff from the time of admission of their preterm babies to their stay on the ward. Prompts were employed to extract further information. With the participant's permission, the interviews were conducted in English or in a language widely spoken in Lusaka (Chinyanja). They were audio-recorded, and detailed field notes were taken during the interview. The in-depth

individual interviews took place in a quiet room within the NICU premises, and each interview lasted approximately 45 minutes. The interviews were transcribed verbatim for data analysis.

### **Trustworthiness and Rigour**

According to Creswell (2014) and Miles, Huberman, and Saldana (2014), ensuring methodological rigour is essential in qualitative research, as the researcher's own perspectives and interpretations are inherently involved in the process. Therefore, it is crucial for the researcher to clearly state their reflexive position and use strategies such as journaling to minimize potential biases. In this study, these approaches were applied to enhance the credibility, dependability, confirmability, and transferability of the findings, consistent with the principles outlined by Shenton (2004). Shenton explains these trustworthy principles as credibility, which is the extent of fairness and authentic show of reality. Credibility was employed in this study by conducting in-depth interviews with participants and taking field notes during each interview to comprehensively understand participants' experiences.

Dependability is the reliability or stability of the data over time and over conditions. Attainment of credibility relies on dependability (Polit & Beck, 2017). This was maintained by ensuring that the same interview guide was used to collect data from participants and that the transcripts were subjected to the same coding and theming process. Also, ensured consistency through clear documentation of the research process, including the research design, data collection methods, and data analysis procedures.

Transferability is the extent to which qualitative findings can be transferable or have applicability in other settings with similar participants (Grove et al., 2015). This was ensured by a detailed detailed descriptions of the research context, participants, and methodology to allow readers to assess the transferability of the findings to other settings or populations.

Finally, Conformability is the objectivity, or the potential for congruence between two or more independent people about the accuracy, relevance, or meaning of the data. Confirmability seeks to submit that the researcher did not invert the data presented but it was the participants' information (Polit & Beck, 2017). The researcher acted as an active listener and facilitator who allowed participants to give detailed information about their experiences. Audio recording of all the words spoken by participants and the researcher during in-depth interviews enabled the researcher to

distinguish the participants' data from the interviewer's words. Data analysed were the words spoken by participants only and the presentation of direct quotations in the findings chapter, thus attaining conformability.

### **3.10. Data Management and Storage**

Data management and storage were crucial aspects of the research study, including the experiences of parents of pre-term babies with healthcare staff in the NICU at WNH in Lusaka, Zambia.

The audio-recorded interviews for this study were verbatim transcribed, and the transcripts were reviewed for accuracy and thoroughness. Subsequently, the transcripts were kept private and secure by being stored on a password-protected computer.

### **3.11 Ethical Considerations**

Ethical approval was sought from the University of Zambia Biomedical Research Ethics Committee (UNZABREC) with reference number 4592-2023, the National Health Research Authority with reference number NHRAR-R-710/28/07/2023, and the Woman and Newborn Hospital (WNBH). Consent was obtained from the participants in the study following a brief explanation of the purpose, procedure, benefits, and risks, of the study. Participants were reassured of the right to withdraw from the study and that no privileges were to be taken away if they decided not to take part while those who were willing to participate were made to sign the consent form. Participants were assured of anonymity and confidentiality of personal information that was shared with the researcher.

### **3.12 Data Analysis and Processing**

Thematic analysis served as the primary approach for discerning significant patterns and themes within the narratives of the participants. After transcribing verbatim interviews and familiarizing with the data, initial codes were generated to segment the information into meaningful units, facilitated by the use of qualitative analysis software. These codes were subsequently organized into potential themes, maintaining alignment with the overarching research questions. Following this, major themes underwent review to ensure coherence and relevance. This comprehensive

analysis process yielded five major themes, each accompanied by corresponding subthemes, forming the basis for subsequent findings and discussions.

### **Step 1: Familiarization with the Data**

The initial step in data analysis involved transcribing the verbatim content of the interviews and reviewing these transcripts. To enhance comprehension, the verbatim transcripts were carefully translated from local languages to English by a skilled translator. This step was integral to ensuring the data's accuracy and cohesiveness. Listening to the original interviews repeatedly allowed for familiarity with the data and enabled the researcher to make preliminary notes and record noteworthy expressions, paving the way for further analysis.

### **Step 2: Generating Initial Codes**

Following data familiarization, the content was divided into meaningful units, which were then summarized and labeled with codes. This process entailed a close examination of the data to identify connections between various codes, leading to the creation of different categories of codes.

### **Step 3: Search for Themes**

Thematic analysis proceeded by identifying overarching patterns and themes within the categories of codes. The researcher combined related codes into cohesive ideas that summarized or closely reflected the data's content. These emergent themes represented critical aspects of the experiences of parents of pre-term babies with healthcare staff in the NICU.

### **Step 4: Review Themes**

During the analysis, preliminary themes were assessed to ensure they aligned with the data. Major themes were carefully reviewed for coherence and relevance.

### **Step 5: Define Themes**

From the thematic analysis, five major themes emerged, each containing subthemes that provided a comprehensive understanding of the experiences of parents of pre-term babies with healthcare staff in the NICU. These themes and subthemes played a vital role in the final analysis of the research findings.

## **Step 6: Writing Up**

Using the identified thematic relationships and patterns derived from the interpretation process, the researcher synthesized the experiences of parents of pre-term babies with healthcare staff in the NICU, shedding light on the complex aspects of their journey and the influences shaping these experiences. The resulting findings are presented in the subsequent section, offering insights into the lived experiences of these individuals and contributing to the broader discourse on neonatal care and healthcare staff interactions.

## CHAPTER FOUR: FINDINGS

### 4.1 Introduction

This chapter presents the findings from the study, which explored the experiences of parents with healthcare staff in the NICU at the WNH in Lusaka, Zambia. The findings were derived from in-depth interviews conducted with 12 parents of preterm babies. The data was analyzed thematically, and five main themes were identified. Each theme is discussed in detail, including subthemes that highlight key aspects of parents' experiences. Verbatim quotes from participants are included to illustrate their perspectives.

### 4.2 Participant Demographic Information

A total of 12 participants took part in the study. Below is a summary of their characteristics presented in the table

**Table 1: Demographic Data for Participants (n = 12)**

<i>Participant</i>	<i>Age</i>	<i>Marital status</i>	<i>Education</i>	<i>Occupation</i>	<i>Relationship to the preterm baby</i>	<i>Religion</i>
<i>P1</i>	20	Single	Grade 9	Nil	Mother	Christian
<i>P2</i>	21	Married	Grade 10	Nil	Mother	Christian
<i>P3</i>	22	Married	Grade 12	Business	Mother	Christian
<i>P4</i>	32	Married	Grade 7	Nil	Mother	Christian
<i>P5</i>	24	Married	Grade 12	Nil	Mother	Christian
<i>P6</i>	37	Married	Grade 7	Nil	Mother	Muslim
<i>P7</i>	35	Married	Grade 12	Business	Mother	Christian
<i>P8</i>	40	Married	Grade 8	Business	Mother	Christian

<i>P9</i>	31	Married	Grade 9	Farmer	Mother	Christian
<i>P10</i>	25	Married	Grade 9	Business	Mother	Christian
<i>P11</i>	19	Single	Grade 12	Nil	Mother	Christian
<i>P12</i>	29	Married	Grade 9	Farmer	Mother	Christian

**Key= P- participant**

The demographic data of the 12 participants reveal a diverse range of characteristics. The ages of participants ranged from 19 to 40 years. The majority of participants were married (83.3%), with only two participants being single (16.7%). Education levels varied, with most participants having completed at least Grade 9 education. In terms of employment, participants were engaged in a variety of roles, including business and farming. Most participants identified their religious affiliation as Christian representing 92% with one participant identified herself as Muslim representing 8%. Additionally, all participants had a direct relationship to the preterm baby, serving as mothers.

#### **4.3 Presentation of the identified themes and subthemes**

After conducting a thorough analysis of participants' narratives, significant themes capturing the essence of their experiences emerged. These themes, along with their corresponding subthemes revealed the experiences encountered by the participants. The table below provides a succinct summary of these identified themes, and subthemes, offering a structured outline of the extensive qualitative data derived from the study.

**Table 2: Themes and sub themes**

<b>MAJOR THEME</b>	<b>SUBTHEME</b>
1. Communication	Clarity Openness and Transparency Approachability and timely updates
2. Emotional Experience	Emotional Support Counselling Compassion
3. Parental Involvement	Parental participation Decision-making
4. Cultural Sensitivity and Respect for Diversity	Cultural beliefs Respect for parental preferences and traditions
5. Pre-Discharge preparation	Discharge planning

#### **4.4 Theme 1: Communication**

Communication was a major factor that influenced parents' experiences in the NICU. Effective communication reduced anxiety, helped parents feel involved, and built trust between them and healthcare staff. However, some parents experienced challenges with unclear explanations, lack of transparency, and delays in receiving updates.

## **Clarity**

Parents appreciated it when nurses and doctors explained medical procedures and their baby's condition in simple, understandable terms. Many noted that when information was delivered clearly, it eased their fears and helped them make informed decisions.

*“The nurses took their time to explain everything in a way that made sense to me. I remember one of the nurses said she was going to check my baby’s sugar levels. Without knowing what sugar levels were, I asked the nurse and she explained everything to me and I understood it.”*  
(P3)

*“When my baby needed a blood transfusion, the doctor explained why it was necessary. He even used a small drawing to show me what happens in the body. That made it easier for me to understand.”* (P5)

However, some parents found explanations to be rushed or unclear, leaving them confused about their baby's condition.

*“There were times I felt like I had to figure things out on my own. Some nurses would just say, ‘your baby is fine’ without explaining much.”* (P6)

## **Openness and Transparency**

Honesty from healthcare staff was highly valued by parents. They wanted to be fully informed about their baby's health, including risks and possible complications.

*“I appreciated when they were sincere about my baby’s condition. Even when things were not going well, I wanted to know the truth.”* (P1)

Some parents, however, felt that they were not always given complete information.

*“At one point, I overheard another mother talking about a test they did on our babies, but no one told me about it. It made me wonder what else I was not being told.”* (P4)

### **Approachability and timely updates**

Parents' experiences were shaped by how approachable and friendly healthcare staff were. Many felt comfortable asking questions when nurses and doctors created a welcoming environment.

*"I never felt like I was disturbing them. Whenever I had a question, they answered me politely. For the Doctors and Nurses, I made a lot of friends with them." (P7)*

However, some parents found certain healthcare staff unapproachable.

*"Some nurses made me feel like I was bothering them whenever I asked something. I started hesitating to ask questions because of that." (P9)*

Receiving regular updates on their baby's condition was important to parents. It reassured them and helped them feel involved in their baby's care.

*"I appreciated that they kept me informed every step of the way. Even when there was no change, they still told me so I would not worry." (P2)*

However, some parents felt left out due to a lack of timely communication.

*"Sometimes, I would go a whole day without knowing if my baby was improving or not. I had to keep asking." (P10)*

### **4.5 Theme 2: Emotional Experience**

The experience of having a preterm baby admitted to the NICU was emotionally overwhelming for many parents. They faced fear, uncertainty, stress, and, at times, feelings of helplessness. The way healthcare staff interacted with them played a significant role in how they coped with these emotions. Parents in this study spoke about the importance of receiving emotional support from nurses and doctors. While some parents felt reassured and comforted by the healthcare staff, others felt ignored or dismissed. The findings under this theme are discussed in three subthemes: availability of emotional support, access to counseling services, and compassionate care from healthcare staff.

## **Emotional Support**

Many parents shared that the emotional support they received from nurses and doctors helped them feel stronger during their NICU journey. Simple words of encouragement, reassuring smiles, and compassionate gestures made a difference in their ability to cope. For some, knowing that the healthcare staff cared about their feelings gave them a sense of hope and strength.

*“The nurses reassured me when I was feeling hopeless. They would tell me, ‘your baby is strong’ and that gave me hope. It made me believe that my child would survive.” (P4)*

*“One nurse used to check on me every time I came to see my baby. She would ask how I was feeling, and sometimes she would even hold my hand when I cried. That meant a lot to me.” (P7)*

However, some parents felt that emotional support was lacking. They observed that while nurses and doctors were attentive to their babies, they rarely checked on how the parents were coping. These parents wished that healthcare staff could recognize that they, too, were struggling emotionally.

*“It felt like they were only focused on the baby. I also needed some reassurance, but no one really asked how I was doing. I would cry alone in the waiting area because I felt they were not paying attention to me.” (P8)*

*“I was going through so much emotionally, but it seemed like nobody noticed. There was no one to talk to, and I had to find my own ways to stay strong.” (P10)*

Some parents also noted that the stress of seeing other babies in critical condition added to their anxiety. They wished healthcare staff would offer more psychological support to help them cope with their fears.

*“Every day, I saw some babies not making it. That scared me so much. I wanted someone to sit with me and just talk, but the nurses were too busy.” (P3)*

## **Counselling**

Counselling services were available at the hospital, but not all parents were aware of this service. Those who managed to access counselling services found them helpful, as they provided a safe space to express their emotions and receive guidance on coping with stress.

*“Talking to a counselor helped me to come to terms with what was happening. It made me feel less lonely. I was able to release some of the fears that I had, bottled up inside.” (P6)*

*“At first, I was hesitant to speak to a counselor, but when I finally did, I felt relieved. She helped me understand that my fears were normal and that I was not failing as a mother.” (P2)*

However, some parents mentioned that they only learned about counselling services from fellow mothers in the NICU, not from healthcare staff. They felt that these services should have been introduced to them earlier.

*“No one told me that I could talk to a counselor. I only found out later from another mother. By then, I had already struggled with anxiety for weeks.” (P11)*

*“I think every parent with a preterm baby should be encouraged to go for counselling. The stress is too much, and not everyone knows how to cope.” (P5)*

For those who did not receive counselling, the lack of emotional support made their experience even harder. They had to rely on their families, other mothers in the NICU, or personal coping mechanisms such as prayer.

*“I survived because of the other mothers. We would sit together and encourage each other. If not for them, I do not know how I would have managed.” (P9)*

*“I turned to prayer because that was the only thing that kept me going. I wish there was someone in the hospital who could have checked on us as parents.” (P12)*

## **Compassion**

Parents deeply appreciated the healthcare staff who showed kindness, patience, and understanding. For them, compassion went beyond medical care it was about feeling seen and valued as a mother or father going through a difficult journey.

*“One nurse always made sure to ask how I was coping. It made me feel like I mattered too, not just my baby.” (P3)*

*“When my baby’s condition worsened, a doctor sat me down and explained everything gently. He did not rush. He made sure I understood and allowed me to ask all my questions. That made a big difference.” (P6)*

Parents also appreciated nurses who reassured them when they felt scared or hopeless. Even a simple gesture like a smile or a few kind words helped them cope.

*“There was a nurse who always told me, ‘we are doing everything we can for your baby, and you are doing your part as a mother.’ That helped me believe that my baby had a chance.” (P1)*

However, not all parents had positive experiences. Some felt that certain nurses and doctors lacked empathy. They described interactions where they felt dismissed, judged, or even scolded for things beyond their control.

*“Some nurses were too harsh. They would talk to me like I was a problem instead of a mother who just worried about her babies.” (P12)*

*“One nurse told me, ‘stop crying, it will not help your baby.’ I felt like she did not understand what I was going through.” (P8)*

For parents already feeling vulnerable, such experiences made the NICU environment more stressful. Some even mentioned that they hesitated to ask questions because they feared how the nurses would respond.

*“I sometimes wanted to ask more questions, but I was scared of being shouted at. Some nurses made me feel like I was bothering them.” (P10)*

These experiences highlight the importance of training healthcare staff on the emotional needs of parents with preterm babies. While many nurses and doctors showed empathy, there were instances where parents felt neglected or misunderstood.

## 4.6 Theme 3: Parental Involvement

Parents expressed a strong desire to be involved in their baby's care while in the NICU. Many saw their participation as essential in bonding with their baby, understanding their condition, and feeling a sense of control during a stressful period. However, the extent to which parents were allowed to take part in their baby's care varied. Some parents described positive experiences where nurses encouraged their involvement, while others felt sidelined by hospital policies or healthcare staff who preferred to handle everything themselves.

### Parental Participation

Some parents were given the opportunity to participate in basic caregiving activities such as feeding, changing diapers, or performing kangaroo care. These small tasks made a significant difference in how parents felt about their role in their baby's recovery.

*“Being able to change my baby's diaper made me feel like I was actually doing something for him. It gave me confidence that I could take care of him when we finally get home.” (P5)*

*“The nurses encouraged me to hold my baby and feed him. At first, I was scared, but they guided me, and I started feeling like a real mother.” (P8)*

However, other parents wished they had been given more opportunities to be involved. Some reported that the nurses handled everything, leaving them feeling helpless and disconnected from their child.

*“I wanted to do more, but the nurses did everything. I felt helpless just watching. I would have loved to at least try feeding my baby or holding him more often.” (P10)*

*“Sometimes I would ask if I could do something, and they would say no, just let us handle him.’ I understood they were doing their job, but I wanted to learn how to care for my baby.” (P7)*

For some parents, limited involvement led to anxiety about whether they would be able to take care of their baby after discharge. They felt that the hospital should have encouraged them to take on more responsibilities gradually.

### Decision-Making

Parents appreciated when healthcare staff involved them in discussions about their baby's care and treatment options. Being consulted helped them feel respected and reassured that their opinions mattered.

*"They explained treatment options and asked what I thought. That made me feel involved. Even though I did not have medical knowledge, it was nice to be asked." (P2)*

*"I was given updates about my baby's progress, and whenever there was a change in treatment, the doctors would sit me down and explain everything before proceeding." (P6)*

However, some parents felt excluded from important decisions regarding their baby's care. They only found out about treatments after they had already been administered. This lack of communication made them feel powerless.

*"I only found out about some decisions after they had already been made, one day I found the nurse had put my baby under some machine with a light. I wish they had at least informed me before doing it." (P7)*

*"One day, I came in and found that my baby had been given a different type of formula milk, and no one had told me in advance. I felt like I was not part of my child's care." (P12)*

For many parents, being actively involved in caregiving and decision-making helped reduce their stress and gave them confidence that they could care for their baby at home after discharge. They called for more efforts from healthcare staff to integrate parents into the care process instead of treating them as mere visitors.

#### **4.7 Theme 4: Cultural Sensitivity and Respect for Diversity**

Parents in the study came from diverse cultural backgrounds, and their beliefs and traditions influenced how they wanted their babies to be cared for in the NICU. Some parents felt that healthcare staff respected their cultural practices, while others felt dismissed when they tried to uphold certain traditions related to childbirth and newborn care.

## **Cultural Beliefs**

For many parents, having their cultural beliefs acknowledged and respected by healthcare staff was an important part of feeling comfortable in the NICU. Some parents had positive experiences where nurses and doctors accommodated their practices without hesitation.

*“The nurses allowed me to pray for my baby before certain procedures. That meant a lot to me. It gave me peace of mind knowing that I had blessed my child in my way.” (P9)*

*“I asked if I could wrap my baby in a cloth that was given to me by my grandmother, and the nurses did not refuse. They understood that it was part of our tradition.” (P6)*

However, other parents reported instances where their beliefs were not considered. Some hospital policies conflicted with traditional practices, and some healthcare workers dismissed parents' requests without explanation.

*“I was told I could not do something for my baby because of hospital rules, even though it was important to me. I understand they have their procedures, but they could have at least explained why.” (P3)*

*“I asked if I could put a small bead on my baby’s wrist, which is part of our tradition for protection, but I was told ‘no’ without much of any explanation. It made me feel like my beliefs did not matter.” (P11)*

Some parents also mentioned that they were hesitant to bring up their cultural practices because they feared judgment from healthcare staff. They wished the hospital had a more open approach to discussing cultural considerations.

*“I did not want to be seen as difficult, so I did not insist on my cultural practices. But deep down, I felt uncomfortable that I had to abandon something that was important to me.” (P5)*

## **Respect for Parental Preferences and Traditions**

Beyond specific cultural rituals, parents also wanted their general preferences regarding their baby’s care to be acknowledged and respected. Some parents found that healthcare staff were willing to listen and adjust care practices to accommodate them.

*“They always asked me if I was comfortable with certain things. That made me feel like my opinion mattered.” (P1)*

However, others felt that their concerns were brushed aside.

*“I tried to tell them that in my culture, we believe that babies born too early should be tattooed in the first week of life for protection from diseases, but the nurse just said, ‘that’s not how we do things here.’” (P4)*

For some parents, not having their cultural background respected made them feel like outsiders in the hospital. They believed that a little more understanding from healthcare staff would have improved their experience.

*“I already felt out of place because my baby was in the NICU. When they dismissed my beliefs, it made me feel even more isolated.” (P10)*

Parents suggested that healthcare staff should receive training on cultural sensitivity to ensure that all families feel valued and respected, regardless of their traditions.

*“I do not expect them to know everything about different cultures, but they should at least ask and try to understand instead of just saying ‘no’ to everything.” (P7)*

#### **4.6 Theme 5: Pre-Discharge Preparation**

Parents emphasized the importance of receiving proper training before discharge so they could confidently care for their fragile infants. Going home meant taking full responsibility for their child’s care, which was both a relief and a source of fear.

##### **Discharge Planning**

Some parents shared that the hospital staff provided them with clear, step-by-step instructions on how to care for their babies at home. Nurses demonstrated essential skills such as bathing, feeding, monitoring the baby’s breathing, and recognizing warning signs that required immediate medical attention. Parents who received thorough training felt much more confident about transitioning to home care.

*“They showed me how to bathe and feed my baby properly. That made me feel ready. At first, I was scared, but after practicing under their supervision, I felt more confident.” (P1)*

*“The nurse took her time teaching me how to handle my baby. She even let me practice under her guidance.” (P3)*

However, not all parents had the same experience. Some felt that the discharge process was rushed, and they did not receive enough time to practice key skills before leaving the hospital. Others wished they had been given written materials or checklists to refer to once they were home.

*“I was nervous about taking my baby home because I was not sure if I was doing things right. They gave me some instructions, but it was all verbal. I wish they had given me something to read later.” (P8)*

Some parents also felt that healthcare staff assumed they knew certain things, which was not always the case.

*“I had never taken care of a baby before. I thought they would go step by step with me, but some things were just mentioned quickly, and I did not get the chance to ask questions.” (P5)*

#### **4.7 Conclusion**

This chapter presented the key findings from the study, highlighting parents’ experiences with healthcare staff in the NICU. Communication, emotional support, involvement in care, cultural sensitivity, and discharge preparation were central themes in their experiences. The next chapter discusses these findings in relation to existing literature.

## **CHAPTER FIVE: DISCUSSION**

### **5.1 Introduction**

This chapter discusses the findings from the study on the experiences of parents of preterm babies with healthcare staff in the NICU at the WNH in Lusaka, Zambia. The discussion is structured according to the five key themes that emerged in Chapter Four: communication, emotional experience, parental involvement, cultural sensitivity and respect for diversity, and pre-discharge preparation. Each section begins by analyzing the study findings, then compares them with similar research conducted in other settings, and finally interprets their significance.

### **5.2 Demographic Characteristics of Participants**

The demographic data of the participants revealed a diverse range of characteristics that influenced their experiences in the NICU. The study included 12 mothers aged between 19 and 40 years, with most of them married (83.3%) and having a minimum educational level of Grade 9. The participants were engaged in different employment, including business and farming, while some were unemployed. Almost all participants identified as Christian, with one participant identifying as Muslim. The findings suggest that marital status and education level played a role in how parents coped with their experiences in the NICU. Married mothers appeared to have more emotional support from their spouses, whereas single mothers expressed feeling overwhelmed and isolated. These findings are consistent with research by Franck et al. (2017), which indicated that parents with limited social support structures often experience greater emotional distress in NICU settings. Similarly, a study by Treyvaud et al. (2019) found that married mothers reported lower stress levels and higher coping capacities compared to single mothers due to the availability of emotional and financial support from their partners. Furthermore, Carter et al. (2020) also emphasized the role of social support, highlighting that single mothers were more likely to report anxiety and depressive symptoms when compared to married mothers in the NICU. Additionally, the study found that mothers with higher education levels were more likely to ask healthcare staff for clarifications regarding their baby's condition, whereas those with lower education levels often relied solely on the information provided without further inquiry. These findings align with research by Hall et al. (2018), which reported that higher maternal education levels correlated with increased health

literacy and active engagement in neonatal care discussions. Similarly, a study by Matvienko-Sikar et al. (2021) demonstrated that mothers with tertiary education were more proactive in seeking explanations and advocating for their infants' needs in the NICU.

However, some studies have presented contrasting findings that maternal education may not always lead to better outcomes in terms of coping or stress levels. In a study by Reyna et al. (2020) found that although higher maternal education levels were linked to increased knowledge, they did not necessarily result in better coping strategies or reduced stress in the NICU. Similarly, Pineda et al. (2019) observed that mothers with lower education levels demonstrated strong engagement with NICU staff when provided with structured support and guidance, highlighting the effectiveness of targeted health literacy interventions in bridging the gap, regardless of educational background.

The significance of these findings lies in the fact that parental stress and coping mechanisms are influenced by both social and educational factors. This highlights the need for NICU healthcare staff to provide tailored communication and emotional support, ensuring that all parents, regardless of their educational background or marital status, receive adequate guidance and encouragement. In resource-limited settings like Zambia, where extended family support is common, integrating family members into the NICU education process could be beneficial in easing parental stress and improving confidence in neonatal care.

### **5.3 Communication**

Effective communication between healthcare staff and parents is crucial in NICU settings, as it directly impacts parental satisfaction, emotional well-being, and engagement in their infant's care. This study found that while some parents expressed satisfaction with the level of communication they received, others voiced frustration over unclear explanations, lack of transparency, and delays in receiving updates. Parents who were provided with clear, timely, and consistent information felt reassured and more involved in their baby's care. They particularly valued healthcare providers who took time to explain medical procedures, used simple language, and provided regular updates on their infant's condition. Conversely, some parents reported feeling excluded from their child's

care, especially when medical staff communicated in a rushed manner or used complex medical jargon that was difficult to understand.

These findings align with previous research conducted in various healthcare settings. A study by Wigert et al. (2019) in Sweden highlighted that parents of preterm babies experienced greater ease and emotional stability when healthcare professionals clearly explained treatment plans and actively invited them to participate in discussions. Similarly, research by Nkosi et al. (2019) in South Africa emphasized the importance of involving parents in medical rounds, as this not only improved their understanding of their child's condition but also reduced anxiety levels. However, a study from Iran by Akbari (2020) revealed that many parents experienced frustration due to inconsistent communication from healthcare staff, an issue that mirrors the challenges reported in the current study.

In light of these findings, it is evident that structured communication strategies could enhance parental satisfaction and involvement in NICU care. One effective approach would be to implement scheduled updates, where parents receive regular, structured briefings on their baby's progress. Healthcare providers could also utilize visual aids such as diagrams, charts, and digital platforms to explain medical conditions and procedures in a more accessible manner. Furthermore, employing simple, non-technical language and encouraging parents to ask questions can bridge communication gaps, particularly in settings where literacy levels vary.

In the Zambian context, where some parents may have limited literacy, additional measures should be considered to facilitate effective communication. For instance, verbal explanations supplemented by culturally relevant visual materials and audio recordings in local languages could improve comprehension. Training healthcare staff in patient-centered communication skills, including active listening and empathy, would also be beneficial. By fostering a culture of open and transparent communication within NICU settings, healthcare institutions can strengthen trust between parents and medical staff, ultimately enhancing parental confidence in their baby's care and promoting better health outcomes.

Overall, improving communication in NICUs requires a multifaceted approach that prioritizes clarity, consistency, and parental involvement. By adopting structured communication practices, healthcare facilities can ensure that parents feel informed, supported, and empowered throughout

their infant's hospitalization. Future research could explore the effectiveness of specific communication interventions in NICU settings, particularly in low-resource environments such as Zambia, to further refine best practices in parental engagement and information sharing.

#### **5.4 Emotional Experience**

The emotional well-being of parents in the NICU was a critical theme in this study. Many participants described the NICU experience as emotionally overwhelming, filled with anxiety, fear, and uncertainty about their baby's survival. Parents who received emotional support from healthcare staff, such as words of encouragement and reassurance, found it easier to cope. However, some parents reported feeling emotionally neglected, as healthcare staff primarily focused on the baby's medical needs while paying little attention to the parents' emotional distress. Counseling services were available, but not all parents were aware of this service, and some only learned about these services through other parents rather than healthcare providers.

Similar trends have been observed in other studies. A study by Flacking et al. (2021) in the United Kingdom found that structured emotional support programs in NICUs helped parents cope better and facilitated stronger parent-infant bonding. In contrast, a Kenyan study by Namusoke (2020) revealed that emotional support was often overlooked, leading to increased parental stress. Research by Yu et al. (2019) also emphasized that parents of preterm babies frequently experience psychological distress, which can be alleviated through structured support mechanisms, including counseling and peer support.

The findings from this study highlight the need for improved emotional support mechanisms in Zambian NICUs. Healthcare staff should be trained to recognize parental distress and provide reassurance where necessary. Additionally, hospitals should ensure that all parents are made aware of available counseling services at the time of their baby's admission. Implementing peer support groups where experienced NICU parents can mentor new parents may also help alleviate emotional distress.

## 5.5 Parental Involvement

Parental involvement in neonatal care is a fundamental aspect of ensuring the well-being of both the infant and the parents. Active participation not only fosters bonding but also equips parents with essential caregiving skills that facilitate a smoother transition from hospital to home care. This study found that while some parents were encouraged to participate in their baby's care such as through feeding, diaper changing, and practicing skin-to-skin contact others felt excluded from these crucial caregiving activities. Parents who were actively involved expressed a greater sense of confidence and preparedness for managing their baby's needs post-discharge. In contrast, those who had limited opportunities to engage in their baby's care described feelings of helplessness, detachment, and anxiety about their ability to care for their baby at home.

The findings of this study are consistent with existing literature. Research conducted by Hearn et al. (2020) in Canada highlighted that early parental involvement in NICU care significantly enhanced parent-infant bonding while reducing parental stress and feelings of uncertainty. Similarly, a South African study by Nkosi et al. (2019) emphasized that integrating parental involvement into NICU policies fostered a stronger sense of partnership between parents and healthcare professionals. This collaborative approach allowed parents to better understand their infant's condition and contribute meaningfully to the care process. However, challenges to parental involvement have also been documented. A study by Masumo et al. (2021) in Zambia found that logistical barriers, including restricted visiting hours, inadequate parental education on neonatal care, and limited space within NICU facilities, often hindered active parental participation. These constraints can create a sense of exclusion, leaving parents unprepared for their baby's discharge.

Given these findings, there is a need for a more structured approach to parental involvement in Zambian NICUs. Healthcare professionals should actively encourage parents to engage in caregiving tasks, providing step-by-step guidance to help build their competence and confidence. NICUs should also consider revising policies to allow more flexible visiting hours and structured training sessions, ensuring that all parents have an opportunity to participate in their baby's care. Additionally, including parents in medical rounds and decision-making discussions can strengthen communication between healthcare providers and families, fostering a more inclusive care environment.

## **5.6 Cultural Sensitivity and Respect for Diversity**

Cultural beliefs and traditions significantly shape parental experiences in the NICU, influencing how parents perceive their baby's care and their interactions with healthcare providers. This study found that while some parents felt their cultural values and traditions were acknowledged and respected, others experienced situations where their beliefs were dismissed or overlooked. Many parents valued healthcare professionals who made efforts to accommodate cultural practices, such as allowing family prayers before medical procedures or recognizing traditional beliefs about infant care. However, some parents felt alienated when their requests were denied without explanation, leading to feelings of frustration and exclusion.

Similar challenges have been documented in other studies. Research by Alinejad-Naeini (2020) in Iran found that parents of hospitalized neonates often wished for more cultural sensitivity from healthcare staff but encountered rigid hospital policies that did not always accommodate their traditions. In Ethiopia, Bogale et al. (2018) emphasized the importance of culturally sensitive care, noting that when healthcare providers disregarded local customs, it contributed to parental distress and reduced trust in medical staff. In Zambia, Masumo et al. (2021) similarly found that many parents struggled when cultural preferences, such as traditional postnatal rituals and dietary practices, were not considered in neonatal care. These findings suggest that a lack of cultural sensitivity can create barriers to effective communication and engagement between healthcare providers and parents.

Addressing these concerns requires a more inclusive approach to neonatal care that respects and integrates cultural diversity while maintaining medical best practices. Healthcare professionals should receive cultural competence training to enhance their understanding of different beliefs and practices, equipping them with the skills to engage with parents in a respectful and inclusive manner. NICUs should also establish guidelines that allow for flexibility in accommodating cultural practices, provided they do not compromise medical safety. For instance, designated spaces for prayer or culturally appropriate communication strategies can help bridge gaps between parents and healthcare providers. Furthermore, fostering an open dialogue where parents feel comfortable discussing their cultural needs can enhance trust and cooperation in neonatal care settings. In the Zambian context, where cultural and spiritual beliefs strongly influence health-

seeking behaviors, it is important for healthcare institutions to create an environment where parents feel their values are acknowledged. Encouraging collaboration between traditional leaders, community health workers, and medical professionals can help ensure that cultural considerations are respected while maintaining the highest standards of neonatal care.

## **5.7 Pre-Discharge Preparation**

The period leading up to discharge was a critical time for parents in this study, as it marked the transition from the highly monitored NICU environment to independent caregiving at home. While some parents felt well-prepared through training provided by healthcare staff, others still had significant anxiety about whether they could adequately care for their baby. For many, the fear of making mistakes, particularly in handling feeding, hygiene, and recognizing signs of complications, added to their stress. Parents who had the opportunity to receive hands-on training, practice essential tasks under the supervision of nurses, and ask questions reported feeling more confident. However, those who received rushed or minimal instruction felt uncertain about how to manage their baby's needs at home.

One of the key concerns among parents was the management of feeding, especially for those whose babies had been on specialized nutritional support in the NICU. Some parents expressed uncertainty about how much milk their baby should consume, how often they should feed, and what signs to look out for if their baby was not feeding well. While some mothers had received clear instructions on how to properly breastfeed or prepare formula, others reported that they had to rely on advice from family members or other mothers, as hospital staff had not provided sufficient guidance. One mother reported that she did not fully understand how to hold her baby in a comfortable position for feeding, leading to difficulties in getting her baby to latch properly.

In addition to feeding, parents worried about how to maintain proper hygiene for their fragile infants. Several mothers mentioned that they were unsure how often to bathe their babies, what temperature the water should be, and whether they needed to use special soaps or lotions. Some reported that nurses had demonstrated how to clean the baby, but for others, this aspect of care had been briefly mentioned without practical instruction. Parents also expressed concern about how to ensure their baby was kept warm, particularly those who lived in homes without reliable electricity

or proper heating. One mother stated that she had been advised to wrap her baby in multiple layers, but when she did so, she noticed the baby was sweating, which made her anxious about whether she was overheating the infant.

Another major concern was how to recognize signs of illness or complications that required urgent medical attention. Parents who received detailed instructions on warning signs, such as difficulty breathing, changes in skin color, or poor feeding, felt more prepared to handle emergencies. However, others mentioned that they were simply told to bring the baby back if they “noticed anything unusual,” which left them feeling unsure about what symptoms were serious enough to require a hospital visit. This uncertainty was particularly troubling for parents who lived far from the hospital and had limited access to transportation.

These findings are consistent with studies conducted in other countries, where parents of preterm infants frequently report feeling overwhelmed when transitioning from hospital to home care. Alderdice et al. (2018) found that in Northern Ireland, many parents struggled to find adequate information on post-discharge care and wished they had received more practical demonstrations before leaving the hospital. Similarly, Flacking et al. (2021) noted that parents in Sweden experienced anxiety about feeding and hygiene, especially when they did not receive step-by-step training in these areas. In low-resource settings, such as Kenya and Uganda, studies by Namusoke et al. (2020) and Musiimenta et al. (2021) highlighted that many parents felt abandoned after discharge due to the lack of structured follow-up programs.

On the contrary, some studies presented different findings regarding the transition from NICU to home. In a study by Alderdice et al. (2018) in Northern Ireland, while acknowledging some parental anxiety, found that many parents felt adequately prepared for discharge. The study highlighted that the mixed feelings some parents experienced were related to general concerns, but not necessarily due to insufficient preparation. Similarly, research by Vance et al. (2019) emphasized that while parents did face challenges, their focus was more on the parent-child role and developing self-efficacy, rather than solely on practical caregiving tasks like feeding and hygiene.

The findings of this study suggest that NICUs in Zambia should adopt a more structured and standardized approach to discharge education. Rather than relying on verbal instructions alone,

healthcare staff should incorporate hands-on demonstrations, where parents can practice essential skills under supervision before taking their baby home. Providing written guidelines, including pictorial instructions for parents with low literacy levels, could also help reinforce learning and serve as a reference after discharge. In addition, follow-up support should be strengthened, either through scheduled phone calls or home visits by community health workers, to ensure that parents feel supported during the initial weeks at home.

Ultimately, ensuring that all parents leave the hospital with the knowledge and confidence to care for their baby is important in improving neonatal outcomes. Babies who receive proper feeding, hygiene, and medical attention in the home environment are more likely to thrive, reducing the risk of complications and readmission. A well-planned discharge process does not just benefit the infant but also reduces parental stress, empowering them to provide the best possible care for their child.

## **5.8 Conclusion**

The findings highlight the need for a holistic, family-centered model of neonatal care emphasizing effective communication, emotional support, active parental involvement, cultural sensitivity, and thorough discharge preparation. Embracing this approach can significantly improve parents' experiences in the NICU, strengthen relationships between parents and healthcare providers, and ultimately lead to better health outcomes both parents and babies in the pre-NICU journey.

## **5.9 Key Findings**

The study's key findings encompass several key aspects of the NICU experience for families. Firstly, effective communication and information sharing by healthcare staff, including clear explanations, visual aids, and regular updates, were instrumental in reducing parental anxiety and fostering understanding. However, challenges arose when information was perceived to be withheld, highlighting the importance of transparency. Secondly, emotional support and empathy from healthcare staff played a significant role in instilling hope and resilience in parents, although barriers to accessing counseling services were noted. Thirdly, parental involvement in care tasks and decision-making empowered parents, but logistical barriers sometimes hindered full

participation. Moreover, creating inclusive environments that respect cultural practices and preferences was essential for fostering trust and partnership with families, although instances of cultural insensitivity were reported. Finally, a smooth transition to home and adequate pre-discharge support were vital for parents, with challenges including feeling overwhelmed by information and difficulties accessing follow-up care and support groups. These findings underscore the complex nature of the NICU experience and the importance of tailored, empathetic care to support families effectively.

## **5.10 Implications to Nursing**

### **Nursing Practice**

The findings of this study underscore the importance of clear and effective communication between healthcare staff and parents in NICU settings. Nurses should prioritize utilizing visual aids and simplified language to enhance parents' understanding of medical information. Regular check-ins with parents to address concerns and provide reassurance are crucial in fostering a supportive environment. Additionally, nurses must demonstrate compassion and cultural sensitivity in their interactions with families, respecting diverse beliefs and practices to promote inclusive care.

### **Nursing Administration**

Nursing administration plays a vital role in supporting effective communication and cultural competence within NICU settings. It is essential to implement policies and protocols that prioritize family-centered care and provide resources for ongoing staff training in communication and cultural competence. By creating a supportive framework and environment, nursing administration can facilitate the delivery of high-quality care that meets the diverse needs of families in the NICU.

### **Nursing Education**

Nursing education programs must integrate modules on effective communication strategies, compassion, and cultural competence into their curricula. By incorporating these essential components, nursing students can be better prepared to provide holistic care in NICU settings. Education programs should emphasize the importance of compassion, communication and cultural

sensitivity in nursing practice, ensuring that future nurses are equipped with the necessary skills to meet the diverse needs of families in the NICU.

## **Nursing Research**

This study highlights the need for further research in several areas related to NICU care and family support. Future nursing research should focus on exploring the long-term impacts of effective communication, emotional support, and cultural competence on parental satisfaction, mental health outcomes, and infant development beyond the NICU stay. Additionally, there is a need for studies examining the effectiveness of interventions aimed at improving communication skills, fostering compassion, and promoting cultural sensitivity among healthcare staff in NICU settings. By advancing nursing research in these areas, we can enhance our understanding of best practices in NICU care and inform the development of evidence-based interventions to better support families throughout their NICU journey.

### **5.11 Recommendations**

#### **Improve Communication**

Healthcare workers should ensure that parents receive clear and simple explanations about their baby's condition and treatment. Updates should be provided regularly to reduce anxiety and keep parents informed. Nurses and doctors should also be trained in effective communication, including being honest and approachable when interacting with parents.

#### **Provide Emotional Support**

Nurses and doctors should acknowledge the emotional struggles of parents with babies in the NICU. They should offer reassurance and check on how parents are coping, not just focus on the baby. Counseling services should be introduced to all parents, and healthcare workers should show empathy through kind words and supportive gestures.

#### **Encourage Parental Involvement**

Parents should be given the chance to participate in caring for their baby, including feeding, diaper changing, and kangaroo care. They should also be consulted before major decisions about their

baby's treatment. Training on baby care should be provided before discharge to build parents' confidence in handling their child at home.

### **Respect Cultural Beliefs and Practices**

Healthcare staff should respect and accommodate parents' cultural practices where possible. They should take time to listen and explain hospital policies clearly when cultural beliefs cannot be followed due to medical reasons. Hospitals should provide training on cultural sensitivity to help staff understand different traditions and beliefs

### **5.12 Limitations of the study**

The study focused solely on the experiences of parents of pre-term babies and healthcare staff within a single NICU setting, potentially limiting the transferability of findings to other healthcare contexts or geographical regions. Furthermore, the study relied on self-reported data from participants, which may be subject to recall bias or social desirability bias.

To address the limitations of the study, diverse participants were sampled from various socio-economic backgrounds, cultural identities, and medical histories within the single NICU setting. Triangulation of data from interviews, surveys, and observations was conducted to validate findings and mitigate biases associated with self-reported data. Reflexivity and member checking were employed throughout the study to ensure the accuracy and credibility of interpretations. Comparison with existing literature from diverse healthcare contexts was performed to contextualize findings, while recommendations for future research advocated for multi-site studies to enhance the transferability of results.

### **5.13 Dissemination of findings**

The findings of the study will be disseminated to relevant stakeholders to promote the implementation of recommendations. The hard copy of the research report will be submitted to the University of Zambia - School of Nursing Sciences, UNZA Medical Library, and Women and Newborn Hospital. The results will be published in at least one peer-reviewed journals to ensure wide accessibility to health care and policymakers.

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## APPENDICES

### APPENDIX I: PARTICIPATION INFORMATION SHEET

**Title:** Experiences of Parents of Pre-term Babies with Healthcare Staff in the Neonatal Intensive Care Unit (NICU) at Woman and Newborn Hospital, Lusaka, Zambia.

#### Introduction

Thank you for your interest in participating in our research study. Before deciding whether to participate, it is important that you have all the necessary information. This information sheet aims to provide you with details about the study's purpose, procedures, potential risks, benefits, and your rights as a participant. Please take the time to read the information carefully, and feel free to ask any questions before making your decision.

#### Researcher Information

**Name of Principal Investigator:** Lucia Zulu, The University of Zambia School of Medicine, Department of Nursing Science, Post Graduate Studies P. O. Box 50110, Lusaka. Phone number +260 979576142. Email: luciaz87@gmail.com.

#### Study Description

##### Purpose

This study aims to explore the experiences of parents of pre-term babies with healthcare staff in NICU at the Woman and Newborn Hospital in Lusaka, Zambia.

##### Procedures

Participation will involve a one-on-one interview with the researcher, lasting approximately 30-45 minutes.

The interview can be conducted in person at a mutually convenient location.

The interview will be audio-recorded to ensure accuracy during the analysis process, but your identity will be kept confidential.

The questions will focus on your experiences, emotions, and perceptions related to the care provided by healthcare staff.

You are free to skip any questions or withdraw from the study at any time without any consequences.

### **Risks and Benefits**

Participating in this study does not pose any known risks. However, discussing past experiences may evoke emotional responses, and support will be provided if needed. No form of monetary compensation will be provided to participants, as the aim of the study is to gather authentic experiences and perspectives to drive meaningful improvements in care practices. By sharing your experiences, you may contribute to improving the quality of care for preterm babies and their families in the future.

### **Confidentiality**

Your participation and any information you provide will be kept strictly confidential.

To ensure anonymity, all identifiable information will be removed during the data analysis process, and pseudonyms will be used.

The audio recordings will be securely stored and only accessible to the research team.

The findings of the study may be reported in academic publications, but no personal identifying information will be included.

### **Voluntary Participation**

Your participation in this study is entirely voluntary.

You have the right to refuse to participate or withdraw from the study at any stage, without providing a reason.

Your decision to participate or decline participation will not affect your current or future relationship with the Woman and Newborn Hospital or any other healthcare providers.

## **Further Information**

If you have any questions, or concerns, or require additional information, please do not hesitate to contact the Principal Investigator. Lucia Zulu, The University of Zambia School of Medicine, Department of Nursing Science, Post Graduate Studies P.O. Box 50110, Lusaka. Phone number +260 979576142. Email: [luciazn87@gmail.com](mailto:luciazn87@gmail.com).

## **Contacts for Queries**

1. Researcher. Lucia Zulu, The University of Zambia School of Medicine, Department of Nursing Science, Post Graduate Studies. P. O. Box 50110, Lusaka. Phone number +260 979576142. Email: [luciazn87@gmail.com](mailto:luciazn87@gmail.com).
2. Ethics Committee. The Chairperson, The University of Zambia, School of Medicine, Biomedical Research Ethics Committee. P. O. Box 50110, Ridgway Campus, Telephone: 260-1-256067, Telegrams: UNZA, LUSAKA, Telex: UNZALU ZA 44370, Fax: + 260-1-250753, E-mail: [unzarec@zamtel.zm](mailto:unzarec@zamtel.zm). LUSAKA, ZAMBIA.
3. The Supervisor. Dr. Dorothy Chanda. The University of Zambia School of Nursing Sciences, Department of Public Health Nursing P. O. Box 50110. Email: [chanda.doro@gmail.com](mailto:chanda.doro@gmail.com)
4. The Co-supervisor. Ms. Brenda Sianchapa. The University of Zambia, School of Nursing Sciences, Department of Midwifery, Women's and Child Health. Email: [brendasianchapa@unza.zm](mailto:brendasianchapa@unza.zm)

## **CHINYAJA VERSION**

### **ZOWONJEZERA 1**

#### **Patsamba Lodziwitsidwa Pazochita**

**Mutu:** Zomwe Makolo Omwe Ali ndi Ana Akhanda Asanakwane Omwe Ali ndi Ogwira Ntchito Zaumoyo ku Neonatal Intensive Care Unit (NICU) ku Women and Newborn Hospital, Lusaka, Zambia.

#### **Mawu oyambira**

Zikomo chifukwa cha chidwi chanu chotenga nawo mbali pa kafukufuku wathu. Musanaganize zoti mutenge nawo mbali, ndikofunikira kuti mukhale ndi zofunikira zonse. Tsamba lazidziwitso

ili likufuna kukupatsirani tsatanetsatane wa cholinga cha phunziroli, njira, zoopsa zomwe zingachitike, maubwino, ndi ufulu wanu monga otenga nawo mbali. Chonde tengani nthawi kuti muwerenge zambiri mosamala, ndikukhala omasuka kufunsa mafunso aliwonse musanapange chisankho.

### **Zambiri Zofufuza**

Dzinalo la Wofufuza Wofunika: Lucia Zulu, University of Zambia School of Medicine, Department of Nursing Science, Post Graduate Study P. O. Box 50110, Lusaka. Nambala yafoni + 260 979576142. Imelo: luciazn87@gmail.com.

### **Kufotokoza kwa Phunziro**

#### **Cholinga**

Phunziroli likufuna kufufuza zomwe makolo a ana asanabadwe ndi ogwira ntchito yazaumoyo ku NICU ku chipatala cha Woman and Newborn ku Lusaka, Zambia.

#### **Njira**

Kutenga nawo mbali kudzaphatikizapo kuyankhulana kamodzi ndi wofufuzayo, komwe kumakhala pafupifupi mphindi 30-45.

Mafunsowo amatha kuchitika payekha pamalo abwino.

Mafunsowo adzajambulidwa kuti atsimikizire kulondola panthawi yowunikira, koma chizindikiritso chanu chidzasungidwa mwachinsinsi.

Mafunso amayang'ana pa zomwe mwakumana nazo, momwe mukumvera, ndi malingaliro okhudzana ndi chisamaliro choperekedwa ndi ogwira ntchito yazaumoyo.

Muli ndi ufulu kudumpha mafunso kapena kusiya kuphunzira nthawi iliyonse popanda zotsatira.

### **Zowopsa ndi Ubwino**

Kutenga nawo mbali phunziroli sikubweretsa ngozi iliyonse. Komabe, kukambirana zomwe zachitika m'mbuyomu kumatha kubweretsa mayankho am'maganizo, ndipo thandizo liperekedwa ngati pakufunika kutero.

Pogawana zomwe mwakumana nazo, mutha kuthandiza kukonza chisamaliro cha ana akhanda ndi mabanja awo mtsogolo.

### **Chinsinsi**

Kutenga nawo mbali ndi chidziwitso chilichonse chomwe mumapereka chidzasungidwa mwachinsinsi.

Kuonetsetsa kuti sizikudziwika, zidziwitso zonse zidzachotsedwa panthawi yowunikira deta, ndipo ma pseudonyms adzagwiritsidwa ntchito.

Zojambulazo zimasungidwa bwino ndipo zimangopezeka ndi gulu lofufuzira.

Zotsatira za phunziroli zitha kufotokozedwa m'mabuku ophunzira, koma palibe chidziwitso chaumwini chomwe chidzaphatikizidwe.

Kutenga mbali mwakufuna

Kutenga nawo mbali pa phunziroli ndikwaufulu.

Muli ndi ufulu wokana kutenga nawo mbali kapena kusiya phunziroli nthawi iliyonse, popanda kupereka chifukwa.

Lingaliro lanu lotenga nawo mbali kapena kukana kutenga nawo mbali sikungakhudze ubale wanu wapano kapena wamtsogolo ndi Chipatala cha Woman ndi Newborn kapena ena onse azaumoyo.

### **Zambiri**

Ngati muli ndi mafunso, kapena nkhawa, kapena mukufuna zina zowonjezera, chonde musazengereze kulumikizana ndi Woyang'anira wamkulu. Lucia Zulu, University of Zambia School of Medicine, Dipatimenti ya Nursing Science, Post Graduate Study P.O. Box 50110, Lusaka. Nambala yafoni + 260 979576142. Imelo: [luciazn87@gmail.com](mailto:luciazn87@gmail.com).

## **MALANGIZO OTHANDIZA**

1. Wofufuza. Lucia Zulu, Yunivesite ya Zambia School of Medicine, Dipatimenti ya Nursing Science, Maphunziro Omaliza Maphunziro P. O. Box 50110, Lusaka. Nambala yafoni + 260 979576142. Imelo: [luciazn87@gmail.com](mailto:luciazn87@gmail.com).

2. Komiti ya Ethics. Wapampando, University of Zambia, School of Medicine, Biomedical Research Ethics Committee. P. O. Box 50110, Ridgway Campus, Telephone: 260-1-256067, Telegrams: UNZA, LUSAKA, Telex: UNZALU ZA 44370, Fax: + 260-1-250753, E-mail: [unazarec@zamtel.zm](mailto:unazarec@zamtel.zm). LUSAKA, ZAMBIA.

3. Woyang'anira. Dr. Dorothy Chanda. University of Zambia School of Medicine, Department of Nursing Science, Post Graduate Study P. O. Bokosi 50110. Imelo: [chanda.doro@gmail.com](mailto:chanda.doro@gmail.com)

4. Woyang'anira. Ms Brenda Sianchapa. University of Zambia, School of Nursing Sciences, Department of Midwifery, Women's and Child Health. Imelo: [brendasianchapa@unza.zm](mailto:brendasianchapa@unza.zm)

## **APPENDIX II: INFORMED CONSENT FORM**

### **Declaration**

I have read (or have had explained to) the information about this study as contained in the participant information sheet. I have had the opportunity to ask questions about the research and any questions I have asked have been answered to my satisfaction.

I now consent voluntarily to participate in this study and understand that I have the right to end the interview at any time if I so wish, and to choose not to answer particular questions that are asked in the study.

My signature below signifies that I am willing to participate in this study

Name (Print): \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Thumbprint: \_\_\_\_\_

## **CHINYAJA VERSION**

### **FOMU YOLIKIRA WODZIWA**

#### **CHILENGEZO**

Ndawerenga (kapena ndidamufotokozero) zambiri za kafukufukuyu monga zili mu pepala lazambiri la ophunzira. Ndakhala ndi mwayi wofunsa mafunso okhudza kafukufukuyu ndipo mafunso aliwonse omwe ndafunsa ayankhidwa mondikhutiritsa.

Tsopano ndikuvomera modzifunira kutenga nawo mbali mu kafukufukuyu ndipo ndikumvetsa kuti ndili ndi ufulu wothetsa kuyankhulana nthawi iliyonse ngati ndikufuna, ndikusankha kusayankha mafunso omwe afunsidwa mu kafukufukuyu.

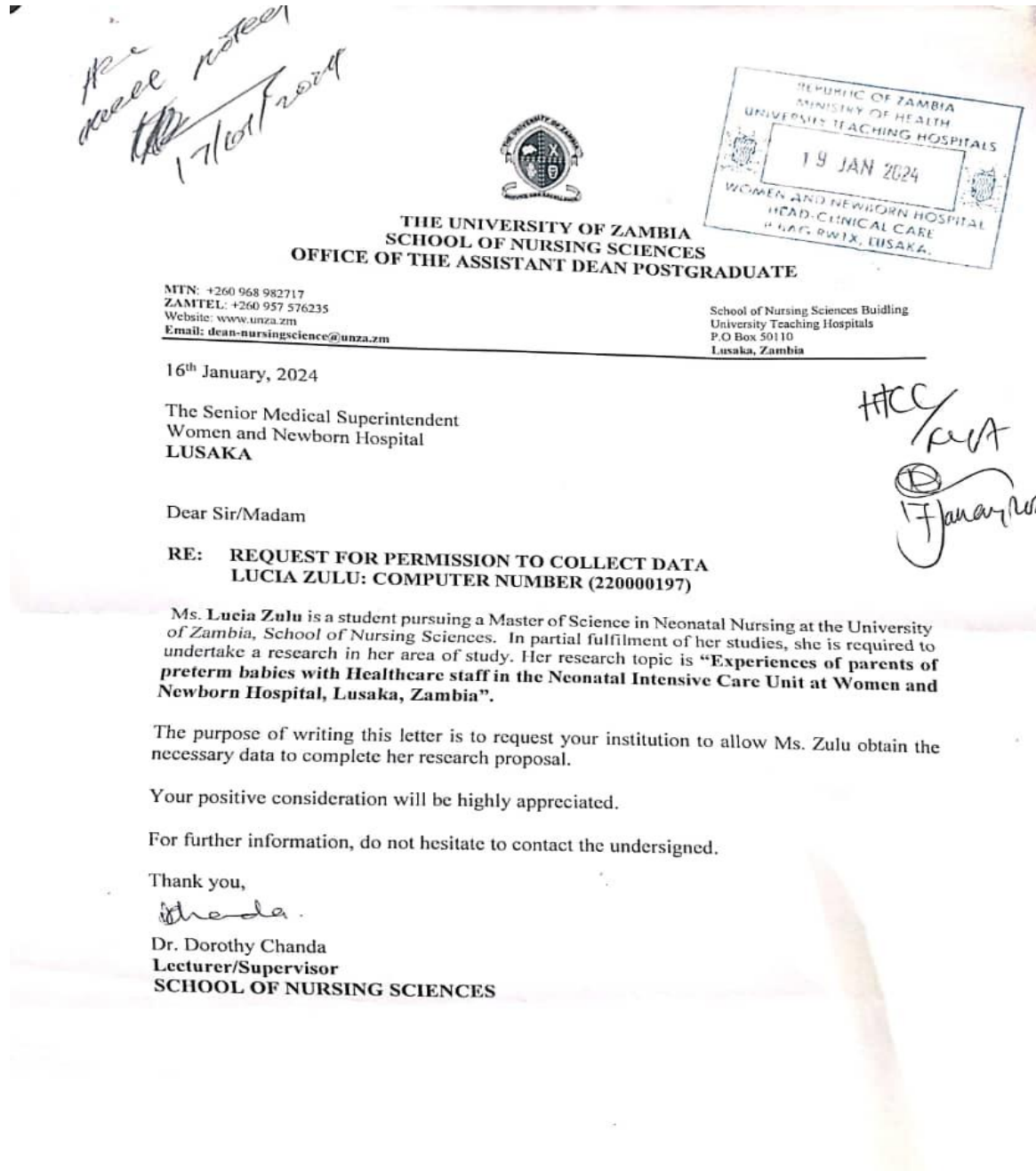
Siginecha yanga pansipa ikuwonetsa kuti ndili wokonzeka kuchita nawo kafukufukuyu:

Dzina: \_\_\_\_\_ Tsiku Lovomereza: \_\_\_\_\_

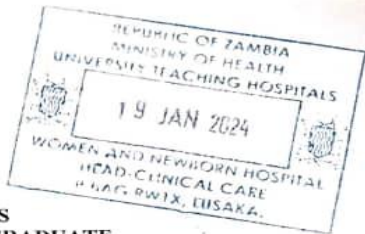
Siginecha ya wophunzira: \_\_\_\_\_

Chizindikiro cha chala chakumanja: \_\_\_\_\_

**APPENDIX III: LETTER FROM THE SCHOOL AND STUDY SITE**



*See  
excel notes  
17/01/2024*



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

MTN: +260 968 982717  
ZAMTEL: +260 957 576235  
Website: www.unza.zm  
Email: dean-nursingscience@unza.zm

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

16<sup>th</sup> January, 2024

The Senior Medical Superintendent  
Women and Newborn Hospital  
LUSAKA

*HCC  
19/1  
17 January 2024*

Dear Sir/Madam

**RE: REQUEST FOR PERMISSION TO COLLECT DATA  
LUCIA ZULU: COMPUTER NUMBER (220000197)**

Ms. Lucia Zulu is a student pursuing a Master of Science in Neonatal Nursing at the University of Zambia, School of Nursing Sciences. In partial fulfilment of her studies, she is required to undertake a research in her area of study. Her research topic is "Experiences of parents of preterm babies with Healthcare staff in the Neonatal Intensive Care Unit at Women and Newborn Hospital, Lusaka, Zambia".

The purpose of writing this letter is to request your institution to allow Ms. Zulu obtain the necessary data to complete her research proposal.

Your positive consideration will be highly appreciated.

For further information, do not hesitate to contact the undersigned.

Thank you,

*Dr. Dorothy Chanda*

**Dr. Dorothy Chanda  
Lecturer/Supervisor  
SCHOOL OF NURSING SCIENCES**

**APPENDIX IV: NATIONAL HEALTH RESEARCH AUTHORITY CERTIFICATE**



# APPENDIX V: UNZABREC APPROVAL LETTER



## UNIVERSITY OF ZAMBIA BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: +260 977925304  
Telegrams: UNZA, LUSAKA  
Telex: UNZALU ZA 44370  
Fax: +260-1-250753  
Federal Assurance No. FWA00000338 IRB00001131 of IORG0000774 NIIRAR-REC No 2021-05-0002

Ridgeway Campus  
P.O. Box 50110  
Lusaka, Zambia  
E-mail: [unzabrec@unza.zm](mailto:unzabrec@unza.zm)

12<sup>th</sup> January 2024

Your REF. No. 4592-2023

Mrs. Lucia Zulu,  
University of Zambia,  
School of Nursing Sciences,  
P.O Box 50110,  
Lusaka.

Dear Mrs. Zulu,

**RE: EXPERIENCES OF PARENTS OF PRETERM BABIES WITH HEALTHCARE STAFF IN THE NEONATAL INTENSIVE CARE UNIT AT WOMAN AND NEWBORN HOSPITAL, LUSAKA, ZAMBIA. (REF. NO. 4592-2023)**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 11<sup>th</sup> January, 2024. The proposal is **approved**. The approval is based on the following documents that were submitted for review:

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

APPROVAL NUMBER

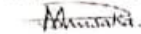
: REF. No. 4592-2023.

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

- i. APPROVAL DATE : 12<sup>th</sup> January 2024
- ii. TYPE OF APPROVAL : Standard
- iii. EXPIRATION DATE OF APPROVAL : 11<sup>th</sup> January 2025
- iv. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the UNZABREC Offices should be submitted one month before the expiration date for continuing review.
- v. **SERIOUS ADVERSE EVENT REPORTING:** All SAEs and any other serious challenges/problems having to do with participant welfare, participant safety and study integrity must be reported to UNZABREC within 3 working days using standard forms obtainable from UNZABREC.

- vi. **MODIFICATIONS:** Prior UNZABREC approval using standard forms obtainable from the UNZABREC Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- vii. **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the UNZABREC using standard forms obtainable from the UNZABREC Offices.
- viii. **NHRA:** You are advised to obtain final study clearance and approval to conduct research in Zambia from the National Health Research Authority (NHRA) before commencing the research project.
- ix. **QUESTIONS:** Please contact the UNZABREC on Telephone No. +260977925304 or by e-mail on [unzabrec@unza.zm](mailto:unzabrec@unza.zm).
- x. **OTHER:** Please be reminded to send in copies of your research findings/results for our records. You are also required to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study. Use the online portal: [unza.rhinno.net](http://unza.rhinno.net) for further submissions.

Yours sincerely,



Prof. Sody Mweetwa Munsaka, BSc., MSc., PhD

**CHAIRPERSON**

Tel: +260977925304

E-mail: [s.munsaka@unza.zm](mailto:s.munsaka@unza.zm)

## APPENDIX VI: INTERVIEW GUIDE

### In-depth interview

**TOPIC: EXPERIENCES OF PARENTS OF PRETERM BABIES WITH HEALTHCARE STAFF IN THE NEONATAL INTENSIVE CARE UNIT AT THE WOMAN AND NEWBORN HOSPITAL, LUSAKA, ZAMBIA.**

Place of Interview: .....

Date of Interview: .....

Name of Interviewer .....

Participant ID: .....

Participant Phone Number: .....

Participant address: .....

### SECTION 1: DEMOGRAPHIC DATA

1. Gender: .....

2. Age: .....

3. Marital status: .....

4. Occupation: .....

5. Religion: .....

6. Relationship to the preterm baby: .....

7. Education Level: .....

#### 1. Introduction

- Can you please tell me a little about yourself and your experience of having a preterm baby at Woman and Newborn Hospital?

- How is your baby doing now?

2. **Initial interactions with healthcare staff:**

- Could you describe your first interactions with the healthcare staff in NICU)? How did they make you feel?
- Did you participate in the Doctors or Nurses rounds?
- Did the healthcare staff provide you with clear information about your baby's condition and the treatment plan? Were you able to understand the information given?

3. **Communication and involvement in care**

- How well did the healthcare staff communicate with you throughout your baby's stay in the NICU? Were they responsive to your questions and concerns?
- Were you encouraged to actively participate in your baby's care and decision-making? Did you feel that your opinions and concerns were valued?

4. **Emotional support provided**

- Did the healthcare staff offer emotional support to you and your family during your baby's stay in the NICU? If so, how?
- Were there any specific instances where you felt the emotional support from the healthcare staff was particularly helpful or lacking?

5. **Information sharing and education**

- How well did the healthcare staff explain your baby's condition, treatment options, and progress during their stay in the NICU? Did they provide information in a clear and understandable manner?
- Did you receive appropriate and sufficient information about caring for your preterm baby and any potential long-term effects related to their prematurity?

6. **Continuity of care**

- Did you experience consistent care from the healthcare staff throughout your baby's stay in the NICU? Were there any challenges in the transition from the NICU to home care?
- Did the healthcare staff provide any follow-up support or written instructions?

7. **Overall experience**

- How would you rate your overall experience with the healthcare staff in the NICU? Can you please elaborate on the reasons for your rating?
- Were there any specific actions or approaches by the healthcare staff that stood out positively or negatively during your time at the NICU?

8. **Closing**

- Is there anything else you would like to share about your experiences with the healthcare staff in the NICU at Woman and Newborn Hospital?
- Thank you for your time and openness in sharing your experiences. Your input is valuable and will contribute to improving the quality of care provided to preterm babies and their families in the future.

## APPENDIX VII: BUDGET

Item	Cost (ZMW)
Transcription Services	3,000
Voice recorder	2500
Translation Services	2,500
Stationary and Supplies	1,000
Travel Expenses	1,000
Data Analysis Software	1,500
National Health Research Authority	1020
Ethics Approval Fee	1,000
Total	<b>13,520</b>

### Budget Justification

The budget allocation outlined in Appendix V provides comprehensive support for key aspects of the research project. Transcription services are essential for converting recorded qualitative data, such as interviews and focus groups, into written form, ensuring accuracy and facilitating thorough analysis. The purchase of a voice recorder enables efficient and reliable recording of interviews, preserving valuable data for later transcription and analysis. Translation services play a crucial role in ensuring that research materials, including consent forms and study instruments, are accessible to participants in their preferred languages, thus enhancing inclusivity and understanding. Stationery and supplies cover essential administrative needs and data collection materials, ensuring smooth operations throughout the research process. Travel expenses are allocated to facilitate fieldwork activities, including participant recruitment and data collection sessions, allowing researchers to reach diverse populations and gather comprehensive data. The allocation for data analysis software provides researchers with the necessary tools to analyze and

interpret collected data accurately and efficiently. Additionally, fees for the National Health Research Authority and ethics approval ensure compliance with regulatory standards, supporting the ethical conduct of the research. Each allocated cost contributes directly to the success and integrity of the research endeavor, ensuring thorough data collection, analysis, and adherence to ethical guidelines.