



Research Article

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# Experiences of Parents of Preterm Babies with Healthcare Staff in the Neonatal Intensive Care Unit at Woman and Newborn Hospital, Lusaka, Zambia



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## Abstract

**Introduction:** Pre-term birth, a global health concern defined by WHO, leads to about 15 million cases annually, with significant mortality under age five. Zambia faces a high burden, with 13% of premature births. 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 of Women and Newborn Hospitals in Lusaka, Zambia.

**Material and Methods:** 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 12. The interviews were audiotaped, transcribed, and analyzed using thematic content analysis.

**Results/Recommendations:** Five key themes were identified: communication and information sharing, emotional support and empathy, parental involvement in care, cultural sensitivity and respect for diversity, and transition to home and pre-discharge support. Effective communication emerged as a cornerstone of parental satisfaction, with clear explanations, visual aids, and regular updates fostering trust and understanding. Emotional support from healthcare providers was valued, although challenges in accessing counseling services were noted. Parental involvement in care tasks and decision-making empowered parents, yet logistical barriers and resistance from staff sometimes hindered participation. Cultural competence among healthcare providers was essential for respecting diverse beliefs and practices, although instances of insensitivity were reported. Comprehensive discharge planning and pre-discharge support were crucial for successful transitions home, but challenges such as information overload and access barriers were identified.

**Recommendations:** Include the development of training programs for healthcare professionals to enhance communication skills and cultural competence, as well as the implementation of policies prioritizing family-centered care. Hospital-level initiatives should focus on staff training and the establishment of support services within the NICU. While the study provides valuable insights, its limitations include its focus on a single NICU setting and reliance on self-reported data. Future research should explore the long-term impacts of effective communication and support interventions on parental satisfaction and infant outcomes.

**Keywords:** Preterm Babies; NICU Experiences; Parental Involvement; Personalized Guidance; Pre-Term Baby

**Abbreviations:** NICUs: Neonatal Intensive Care Units; WNH: Woman and Newborn Hospital; WHO: World Health Organization; UNZABREC: University of Zambia Biomedical Research Ethics Committee

## Introduction

Parents of preterm babies often face significant emotional and psychological challenges, especially in neonatal intensive care units (NICUs) [1]. 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 [2]. Understanding these experiences can provide valuable insights into improving support systems for parents of preterm infants in Zambia's healthcare facilities.

## Background Information

World Health Organization (WHO) defines pre-term as babies born alive before 37 weeks of pregnancy are completed [3]. 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 [3]. 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 [4]. 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 [3].

Regionally, over 60% of pre-term births occur in sub-Saharan Africa [5]. Nationally, it is estimated that 13% of births in Zambia are premature [6]. 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 [7]. To reduce the risks of death or disability after premature birth, Neonatal Intensive Care Unit (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 [8].

The admission of a pre-term baby to a NICU presents a significant burden to parents, especially the mother [9]. Foligno et al., [10] study 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 [11]. In addition, parents experience an unfamiliar and particularly distressing and threatening situation, and therefore need support from nurses and physicians [12]. Similarly, Health care professionals need to understand the unique experiences of parents when their neonates are admitted to the NICU because they face significant challenges during lengthy hospitalization of their pre-term neonates [13]. Furthermore, parents of pre-term babies frequently experience severe psychological distress and communication issues with the medical team while their babies are admitted due to a lack of involvement and participation in the care process [9,14].

According to Aijaa, [15], although it is common today to invite parents to be present in the Neonatal Intensive Care Unit (NICU), steps should be taken to involve parents in a shared-decision making process during medical rounds. According to studies, the parents' worries are a result of their infants' requirements during their NICU stay, their inability to breastfeed or provide expressed breast milk, the NICU's visitation restrictions, and their lack of clinical updates [12]. According to research done 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 [16]. 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 [16]. 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 [17].

Masumo et al., [18] 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 [18]. 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 aims 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 (WNH).

## Statement of the Problem

The NICU specializes in medical and nursing care for very sick and premature babies [19]. Despite all the efforts that MoH and the NICU at WNH Hospital Management have done to avert this problem, Table 1 illustrates a 3.74% increase in the magnitude of pre-term admissions from 2020- 2022 which demonstrates a significant surge in the number of preterm admissions.

The probable causes of these pre-term deliveries and admissions could be due to a combination of maternal health factors and medical conditions. WHO [3], indicated that maternal infections, including urinary tract infections, vaginal infections, and systemic infections, have been associated with an increased risk of pre-term labor and delivery. Furthermore, medical conditions prevalent in pregnant women, such as preeclampsia and gestational diabetes, have been identified as significant contributors to the elevated risk of pre-term birth. Some mothers also experience limited access to prenatal care and delayed healthcare-seeking behaviors contribute to the rise in preterm deliveries. Inadequate access, socioeconomic factors, and limited healthcare infrastructure impact maternal health, and nutrition, and increase the risk of preterm birth [20]. Moreover, lifestyle choices have been identified as potential factors influencing pre-term birth rates. Unhealthy behaviors such as smoking, substance abuse, and high-stress levels have been associated with an increased risk of pre-term delivery. These lifestyle choices may be influenced by individual decisions, societal factors, or a lack of awareness regarding the detrimental effects of such behaviors during pregnancy.

The effects of pre-term births on various stakeholders are significant. Pre-term babies are particularly vulnerable to immediate health issues such as respiratory distress, cardiovascular problems, and increased infection risk, facing a higher risk of long-term effects including neurological disorders, and developmental delays. They often require specialized medical

care and interventions in the NICU to address their unique needs. Parents, especially mothers, also bear the emotional distress, guilt, and anxiety associated with having a pre-term baby. Additionally, they may face physical recovery challenges after giving birth prematurely. To cope with these circumstances, mothers require additional support and resources. Pre-term births can impose financial burdens on families due to increased medical expenses

and potential long-term healthcare needs. Family members play a crucial role in providing emotional and practical support to parents and the pre-term baby. Besides, communities are affected as the increased number of pre-term births strains healthcare resources and systems. This highlights the importance of implementing public health interventions and fostering community support to address the needs of pre-term babies and their families.

**Table 1:** Preterm Deliveries and Admissions at Women and Newborn Hospital, Lusaka, Zambia (2020-2022).

Year	Preterm Deliveries	Percentage Increase (Preterm Deliveries)	Admissions	Percentage Increase (Admissions)
2019	902	N/A	2268	N/A (2268)
2020	1056	17.07%	2290	+0.97% (2290)
2021	1722	63.07%	2343	+2.17% (2343)
2022	2311	34.26%	2448	+4.71% (2448)

The Government, the Ministry of Health and Women and Newborn Hospital are mitigating the effects of pre-term admissions, with strategies such as enhancing prenatal care, implementing educational programs such as Behavioral Change and Communication messages on pre-term birth, providing resources and enough health professionals to look after the pre-term babies, strengthening healthcare infrastructure, and establishing support systems for parents are employed. These measures aim to improve the early detection and management of risk factors, promote healthy behaviors, ensure adequate medical facilities, and provide emotional and practical support to parents of preterm babies [21]. Furthermore, the government is building a multi-million dollar 800 bed capacity King Salman Bin Abdelaziz Specialist Hospital for Women and Newborn along Kasama road in Lusaka [22].

Despite the high number of pre-term admissions, parents with babies admitted to the NICU cannot stay there due to the unit's capacity restrictions. The postnatal mothers discharged from the hospital but whose babies are admitted to the NICU are accommodated at the Mother's Shelter outside the hospital wards. Those who deliver by Caesarean section are kept in the postnatal wards within the hospital till discharge. However, all the mothers of pre-term babies are expected to go to the NICU to breastfeed their babies every two hours. The parent's ability to learn how to give their newborns basic care is constrained by this circumstance. Family-centered Care is compromised mostly because only the father and grandparents are allowed to visit in the absence of the mother. Furthermore, according to the researcher's observation in NICU, parents are usually not present during the doctor's rounds. However, parents are encouraged to get an update from the doctors between 14 to 16 hours during the week. In relation to the state and anticipated course of the neonate, parents of newborns in NICU feel anxiety, discomfort, depression, and post-traumatic stress disorder [12]. 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.

### 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 [23]. 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 Woman and Newborn Hospital (WNH), where parents walk a considerable distance to feed their babies every two hours, add a layer of complexity to their experiences [24,25].

Existing research by Franck et al. [26], Garfield et al. (2016), and Gonya et al. [27] has extensively explored parental experiences in NICUs across various countries. These studies reveal that parents often face overwhelming feelings of anxiety and powerlessness. Key factors influencing their experiences include the quality of communication, the provision of regular updates, and emotional support from healthcare staff. Positive interactions, marked by empathy, respect, and sensitivity, contribute to building trust and confidence in the care provided, while negative experiences can lead to increased parental distress and dissatisfaction.

Similar studies that have looked at different aspects of this topic are notable. Flacking et al. [28] investigated the impact of neonatal nurses' emotional support on parental stress and found significant positive effects, emphasizing the need for structured emotional support programs in NICUs. Meanwhile, Smith et al. (2019) focused on the role of parental involvement in care decisions, concluding that active parental participation leads to better health outcomes for infants and greater parental satisfaction. These studies, while providing valuable insights, have created gaps that need to be addressed. Flacking et al. [28] did not explore the unique challenges faced by parents in resource-

limited settings like Zambia. Similarly, Smith et al. (2019) did not consider the physical and logistical challenges that parents in the WNH context face, such as the significant distances they must walk to feed their babies.

Acknowledging these insights, the study at WNH seeks to dig into the experiences of parents of preterm babies in the NICU, specifically within the context of Zambia. By doing so, this research aims to inform and guide healthcare staff, fostering clearer communication, stronger interpersonal relationships, and increased parental participation in their babies' care. Additionally, gaining insights into parents' experiences can inform policymakers to formulate personalized care plans, tailored to individuals' needs. Ultimately, the study aspires to contribute to the enhancement of the NICU environment at WNH, ensuring a more positive and supportive experience for parents and their preterm babies.

### Research question

What are 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?

### Research Objectives

#### 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.

#### Specific Objectives

- i. To explore experiences of Parents' involvement in the care of their pre-term babies in the NICU.
- ii. To describe the Interpersonal relationships of parents with healthcare staff in the NICU.

### Methodology

#### Study Design

The study employed a qualitative interpretive 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).

#### Study Settings

The study was conducted in the NICU of the Women and Newborn Hospital 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.

### Study Population

The study population consisted of parents with pre-term babies admitted for 3 or more days in the NICU.

#### Target Population

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

#### Accessible Population

The accessible population of interest in this research study was all mothers of preterm babies admitted to the NICU of WNBH. This is because the researcher assumed that the parents would have had sufficient experience in the NICU to enable them to reflect on their experiences with support services in the unit.

#### Sampling Technique

A purposive sampling technique was used to recruit information-rich participants who met the inclusion criteria.

**Inclusion Criteria:** Parents with pre-term babies admitted to the NICU and who had spent at least 3 days or more in the NICU were included in the study.

**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.

#### Sample Size

Some researchers suggest that a sample size of 5 to 25 participants is common in phenomenological research [29]. Studies on this topic typically utilize qualitative methods to explore the experiences of parents and often employ data saturation as a criterion to determine sample size. Data saturation refers to the point at which new data or information fails to provide additional insights or themes, indicating that enough participants have been included to capture the range of experiences [30]. Studies by Maghaireh et al. (2016), Feeley et al. (2013), and Saunders et al. [31] highlight the importance of selecting a sample size that ensures data saturation is reached, allowing for a broad understanding of the experiences of parents in the NICU. Therefore, the sample size for this study was determined through data saturation.



## Data Collection Tools

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 and after each 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 Rigor of the Study Tools

### Bracketing

In phenomenological research, bracketing refers to a process or technique used by researchers to set aside their preconceived notions, biases, and assumptions about a phenomenon being studied (Creswell, 2013). It is a critical step to ensure that the researcher approaches the data collection and analysis with an open and unbiased mindset, allowing the experiences and perspectives of participants to emerge as they are. In this research, bracketing involved the researcher consciously acknowledging and temporarily suspending her own preconceived ideas, beliefs, and judgments related to the topic.

### Trustworthiness

To ensure the trustworthiness and rigor of the study, the following strategies were employed:

- i. **Credibility:** Conducted in-depth interviews with participants and took field notes during and after each interview to comprehensively understand participants' experiences.
- ii. **Transferability:** Provided detailed descriptions of the research context, participants, and methodology to allow readers to assess the transferability of the findings to other settings or populations.
- iii. **Dependability:** Ensured consistency through clear documentation of the research process, including the research design, data collection methods, and data analysis procedures. Maintained consistency and stability of results by recording interviews on audio and transcribing them verbatim for data analysis. Utilized multiple rounds of coding and analysis to guarantee consistency and stability of results.
- iv. **Confirmability:** Involved external experts in the field and conducted peer review of the research, examining the methodology, analysis, and interpretation to enhance confirmability by objectively evaluating the study's trustworthiness. In summary, these trustworthiness considerations aimed to enhance the credibility, transferability, dependability, and confirmability of the study's findings, thereby increasing the overall quality and reliability of the research.

## 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 Woman and Newborn Hospital 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.

## Ethical Clearance

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). The responders were informed of the purpose of the study and its adherence to problems of confidentiality and anonymity. After that, all participants were asked for their informed consent.

## Dissemination of findings

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

## Utilization of the Study Findings

This dissemination strategy aims to ensure that the results are widely available for immediate practical applications within the NICU setting, informing targeted interventions and support systems tailored to the unique needs of parents of pre-term babies. This ensured that the results of the study were widely available to healthcare professionals and policymakers who could use them to improve the care of parents of pre-term babies.

## 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.

## Familiarization with the Data

i. 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.

ii. **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.

iii. **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.

iv. **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.

v. **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.

vi. **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.

## Results

### Introduction

This chapter delves into the heart of the research process, where data collected through in-depth interviews are meticulously examined using NVivo, qualitative data analysis software, to unveil the rich tapestry of experiences shared by parents of preterm babies with healthcare staff in the NICU. The primary objective of this chapter is to explore, analyze, and present the themes and patterns that have emerged from the participants' narratives.

### Participant Demographic Information

A total of 12 participants took part in the study. Below is a summary of their characteristics presented in the (table 2). 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. Occupationally, 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.

**Table 2:** Demographic Data for Participants (n = 12).

Participant	Age	Marital status	Education	Occupation	Relationship to the preterm baby	Religion
P1	20	Single	Grade 9	Nil	Mother	Christian
P2	21	Married	Grade 10	Nil	Mother	Christian
P3	22	Married	Grade 12	Business	Mother	Christian
P4	32	Married	Grade 7	Nil	Mother	Christian
P5	24	Married	Grade 12	Nil	Mother	Christian
P6	37	Married	Grade 7	Nil	Mother	Muslim
P7	35	Married	Grade 12	Business	Mother	Christian
P8	40	Married	Grade 8	Business	Mother	Christian
P9	31	Married	Grade 9	Farmer	Mother	Christian
P10	25	Married	Grade 9	Business	Mother	Christian
P11	19	Single	Grade 12	Nil	Mother	Christian
P12	29	Married	Grade 9	Farmer	Mother	Christian

Key= P- Participant.

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

and codes, delve deeper into the experiences encountered by the participants. The table below provides a succinct summary of these identified themes, subthemes, and associated codes, offering a structured outline of the extensive qualitative data derived from the study (Table 3).

Table 3.

MAJOR THEME	SUBTHEME	CODE
1. Communication and Information Sharing	Clarity of information provided	1. Understanding
		2. Clarity
		3. Openness
		4. Transparency
		5. Approachability
		6. Timely updates
2. Emotional Support and Empathy	Availability of emotional support and Perceptions of empathy and compassion	1. Supportive environment
		2. Counseling services
		3. Compassionate care
		4. Empathetic responses
		5. Psychological services
		6. Coping strategies
3. Parental Involvement in Care	Opportunities for parental participation and Involvement in decision-making	1. Hands-on involvement
		2. Collaborative decision-making
		3. Parental input
		4. Inclusive environment
		5. Informed consent
4. Cultural Sensitivity and Respect for Diversity	Consideration of cultural beliefs and practices and Respect for parental preferences and traditions	1. Cultural competence
		2. Culturally sensitive care
		3. Respectful inquiry into preferences
		4. Customized care plans
		5. Accommodating cultural practices
5. Pre-Discharge Support in preparation to go home	Preparation for Pre-Discharge Support in preparation for going home	1. Discharge planning
		2. Home care training
		3. Post-discharge follow-up
		4. Developmental milestone guidance
		5. Transition support groups

Theme 1: Communication and Information Sharing

Parents consistently praised the healthcare staff for their dedication to clear communication. They emphasized that doctors and nurses took the time to explain procedures and medical conditions using simple language, ensuring that parents understood every aspect of their baby's care. Staff members patiently addressed parents' questions, demonstrating a commitment to ensuring comprehension and easing anxieties. P2 went on and said: "The doctors took the time to explain every

procedure in a way that I could understand..."

Healthcare staff utilized visual aids such as diagrams and charts to enhance understanding. By incorporating these tools into their explanations, they helped parents visualize complex medical information, making it more accessible and easier to grasp. Furthermore, the staff simplified medical terminology, breaking down elaborate concepts into simpler terms, which parents found reassuring and helpful in navigating their child's healthcare journey. P7 narrated that: "The communication was clear and straightforward, which helped ease my anxiety"

Regular check-ins from healthcare staff played a vital role in maintaining clarity and addressing uncertainties. Parents noted that staff routinely checked in to ensure understanding and offered further clarification when needed. This proactive approach to communication fostered a sense of trust and confidence, as parents felt supported and well-informed throughout their interactions with the NICU staff. P12 narrated that: "...They checked in regularly to see if I had any questions or needed further clarification..."

Parents appreciated how clear and straightforward the healthcare staff were in their communication. Many participants mentioned that the nurses provided explanations that were concise and left no room for confusion. Staff made sure to break down complex medical terms into simpler language, which the parents found helpful. Plus, they used visual aids like diagrams to make things even clearer. The doctors did not just give them a bunch of information all at once; they outlined the treatment plan step by step. That way, parents never felt overwhelmed and could understand what was going on every step of the way. Below are some extracts from the participants: "The nurses provided concise explanations that left no room for confusion." P3 "I appreciated how they broke down complex medical terms into simple, understandable language." P5 "The doctors made sure to outline the treatment plan clearly, step by step." P2

When it comes to openness, parents felt like the healthcare staff were transparent about their baby's condition. They did not hold back any information; they shared everything openly. This helped build trust because parents felt like they could rely on the staff to keep them in the loop. Even when the news was tough to hear, the staff did not sugarcoat anything. They were upfront about uncertainties and risks, which the parents appreciated. It seems like there was a real sense of collaboration between the parents and the healthcare staff, with everyone feeling like they were on the same page. P1 said: The healthcare staff were open and honest about my baby's condition from the beginning." P1

Transparency was a big deal for these parents. They valued it when the doctors were honest about the risks associated with different treatment options. But it was not always smooth sailing. Some parents felt like there were times when information was being withheld, which left them feeling anxious and confused. P4 went on and said: ...When you are in a situation like this, you want to know everything that is going on so that you can make informed decisions....

Moving on to approachability, most of the healthcare staff were pretty easy to talk to. Parents felt comfortable approaching them with questions or concerns, which is so important in a high-stress environment like the NICU. But, unfortunately, not everyone had the same experience. Some parents felt intimidated by certain staff, which made them hesitant to speak up. That's definitely something that could be improved upon. Below are some of the extracts: "The healthcare staff were approachable and easy to talk to; I never felt intimidated asking questions." P1 "The lack

of approachability among some staff hindered communication and left me feeling isolated." P10 "I felt intimidated by the healthcare staff, which made me hesitant to ask questions or seek clarification." P9

Lastly, about timely updates, Parents appreciated it when they received regular updates on their baby's condition. It helped ease their anxiety knowing that they were kept in the loop every step of the way. However, there were times when updates were not provided as promptly as they would have liked, which caused some unnecessary stress. Some participants said: "The nurses made sure to give me regular updates on my baby's progress, which helped ease my anxiety." P9 "There were times when I felt left in the dark because updates were not provided at all." P6

## Theme 2: Emotional Support and Empathy

In examining the emotional support and empathetic experiences within the NICU, parents shared emotional insights that underscored the critical role of supportive environments. Parents highlighted the profound impact of a nurturing environment in the NICU, highlighting instances where NICU staff went above and beyond to create a warm and supportive atmosphere. These gestures, such as offering words of encouragement and comfort, not only eased the emotional burden but also instilled a sense of hope and resilience amidst the challenges of having a preterm baby. However, amidst these positive experiences, some parents lamented moments when the NICU environment felt impersonal and sterile, exacerbating feelings of isolation and emotional distress. These instances underscored the importance of fostering a supportive and compassionate atmosphere to facilitate the emotional well-being of both parents and babies during their NICU journey. Below are some extracts: "The presence of a supportive environment in the NICU made it easier for me to cope with the challenges of having a preterm baby." P4 "The NICU staff created a warm and supportive environment that made me feel like we were not alone in this journey." P1 "The absence of a supportive environment made the NICU experience more isolating and overwhelming." P7

Reflections on counseling services revealed a mixed landscape of experiences among parents navigating the NICU. While access to counseling services provided a safe space for emotional expression and equipped parents with valuable coping strategies, challenges in accessing these services emerged. From time constraints to societal stigma surrounding mental health, barriers hindered parents' ability to fully utilize these resources. Despite their potential to offer vital support, limited availability and inadequate promotion of counseling services posed significant challenges for parents seeking emotional guidance and coping mechanisms. Thus, while acknowledging the benefits of counseling services, there is a pressing need to address systemic barriers to ensure equitable access for all parents in the NICU. P8 said: "The counseling services offered were limited in scope and did not fully address my emotional needs." P8



Expressions of gratitude for compassionate care from healthcare staff echoed throughout parental narratives, illustrating the profound impact of empathy and understanding in the NICU. Genuine acts of compassion, ranging from comforting gestures to attentive listening, not only alleviated anxieties but also fostered a sense of trust and support between parents and healthcare staff. However, amidst these positive experiences, instances where compassionate care was lacking surfaced, leaving parents feeling overlooked and emotionally drained. These discrepancies underscore the importance of cultivating a culture of empathy and compassion among healthcare staff to ensure consistent and holistic support for parents in the NICU. P10 narrated that: "The nurses showed genuine compassion in their care, going above and beyond to comfort me."P1

Parents recounted meaningful interactions with healthcare staff who demonstrated genuine empathy and understanding. These empathetic responses validated parents' emotions and concerns, fostering a sense of connection and solidarity during difficult moments. However, amidst these positive encounters, instances where empathy was lacking surfaced, leaving parents feeling dismissed and invalidated. These experiences highlighted the need for healthcare staff to cultivate empathetic communication skills and actively listen to parents' needs and concerns. By fostering a culture of empathy and understanding, healthcare staff can create a supportive environment where parents feel heard, valued, and empowered to navigate the challenges of the NICU journey. P2 went on and said: "The healthcare staff showed genuine empathy in their responses, validating my emotions and concerns."P2

Reflections on psychological services in the NICU revealed a complex landscape of experiences among parents seeking emotional support and guidance. While access to psychological services offered valuable tools for coping and emotional resilience, systemic barriers hindered parents' ability to fully engage with these resources. From stigma surrounding mental health to limited availability and inadequate support, challenges in accessing psychological services persisted, leaving some parents feeling unsupported and overwhelmed. Addressing these barriers and promoting comprehensive mental health services are essential steps toward ensuring equitable access to emotional support for all families in the NICU. P6 said:

"Access to psychological services allowed me to address emotional needs and develop coping strategies in my NICU journey."

Navigating the emotional rollercoaster of the NICU journey prompted parents to explore various coping strategies to manage stress and anxiety. From mindfulness exercises to creative outlets like journaling and art therapy, parents employed diverse approaches to promote emotional well-being amidst NICU challenges. However, challenges in implementing these coping strategies surfaced, with the demands of NICU care often

overshadowing parents' ability to prioritize self-care. Moreover, societal pressures to appear strong and resilient added another layer of complexity to parents' coping experiences. By providing tailored support and promoting self-care practices, healthcare staff can empower parents to prioritize their emotional well-being and navigate the NICU journey with resilience and grace. P5 said:

"Learning coping strategies helped me feel more empowered and in control amidst the uncertainty of the NICU."P5

### Theme 3: Parental Involvement in Care

In the exploration of parental involvement in NICU settings, parents shared diverse experiences that underscored the significance of their participation in their baby's care journey. Parents emphasized the profound impact of hands-on involvement in care tasks, describing it as a key aspect of their connection with their baby. Engaging in activities such as Intermittent Kangaroo Mother Care, feeding, and diaper changing not only strengthened the parent-baby bond but also instilled a sense of purpose and control amidst the NICU environment. However, logistical barriers and occasional hesitancy from healthcare staff hindered some parents' ability to participate fully. These experiences highlight the importance of promoting hands-on involvement to empower parents and enhance their sense of agency in their baby's care. Some participants narrated that: "Being able to participate in feeding and changing diapers helped me feel more connected to my baby." P4 The lack of involvement opportunities made me feel like a passive observer in my baby's care, rather than an active participant."P12

Parents valued the collaborative approach adopted by healthcare staff in decision-making processes regarding their baby's care. Being actively involved in discussions and having their input considered empowered parents to advocate for their baby's needs effectively. The transparent and inclusive nature of these discussions fostered trust and strengthened the partnership between parents and healthcare staff. However, challenges such as resistance from certain staff occasionally hindered the collaborative process, leaving parents feeling marginalized. These findings emphasize the importance of fostering a collaborative decision-making environment to ensure that parents feel respected and empowered in their role as advocates for their babies. P8 said: "The doctors and nurses took the time to explain treatment options and involved me in decision-making, which helped me feel informed and supported."P3

Another one said:

"The healthcare staff listened attentively to my concerns and preferences, fostering a sense of trust and collaboration in decision-making."P6 The recognition and inclusion of parental input in care decisions were key in making parents feel valued and respected by the healthcare staff. Parents appreciated the opportunity to share their perspectives and preferences, knowing that their input played a vital role in shaping their baby's care plan.

However, instances of dismissal or resistance to parental input from healthcare staff left some parents feeling disempowered and disconnected from their baby's care. These experiences underscore the need for healthcare staff to actively solicit and acknowledge parental input, fostering a collaborative partnership built on mutual respect and trust. P3 and P5 said:

"Having my input valued by the healthcare staff made me feel respected and included in my baby's care."P3

"The lack of consideration for my input in certain care decisions left me feeling frustrated and overlooked by the healthcare staff."P5

The creation of an inclusive environment within the NICU was instrumental in fostering a sense of belonging and support among families. Parents valued the efforts made by healthcare providers to celebrate diversity and ensure that all families felt welcomed and respected. However, challenges such as microaggressions and insensitivity from certain healthcare staff detracted from the inclusivity of the environment, leaving some parents feeling marginalized. These findings highlight the importance of addressing barriers to inclusivity and promoting a culture of respect and understanding within NICU settings. P1 narrated that:

"I felt a sense of belonging in the NICU's inclusive environment, surrounded by families who understood my journey."P1

Parents emphasized the importance of being fully informed before giving consent for their baby's treatment, highlighting the need for clear explanations and transparent communication from healthcare staff. The process of informed consent was perceived as empowering when parents felt adequately supported and understood by the healthcare staff. However, challenges such as time constraints and complex medical information occasionally hindered parents' ability to give fully informed consent, leading to feelings of frustration and confusion. These experiences underscore the need for healthcare staff to prioritize thorough explanations and ensure that parents feel supported and informed throughout the consent process.

"The healthcare staff ensured that I fully understood the treatment options and risks before asking for my informed consent."P11

Another one said:

"I encountered challenges in obtaining clear and comprehensive information from the healthcare staff, which made it difficult to give informed consent."P10.

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

Within the context of NICU, the importance of cultural sensitivity and respect for diversity emerged as significant factors influencing the experiences of parents from diverse backgrounds.

Parents highlighted the essential role of healthcare staff cultural competence in ensuring that their cultural practices and beliefs

were acknowledged and respected within the NICU setting. When healthcare staff demonstrated an understanding of and respect for their cultural backgrounds, parents felt valued and supported, contributing to a sense of trust and partnership. However, instances of cultural insensitivity or a lack of understanding from certain healthcare staff left some parents feeling marginalized and misunderstood. These experiences underscore the importance of promoting cultural competence within NICU settings to ensure that all parents receive respectful and culturally sensitive care. P9 and P8 said: "The NICU's commitment to cultural competence fostered an environment where my family's cultural traditions were honored and integrated into my baby's care."P8 "I felt pressured to conform to the dominant cultural norms in the NICU, as the healthcare staff showed little regard for my family's cultural background and practices."P9

Parents emphasized the significance of culturally sensitive care in creating an inclusive environment where their family's cultural values and traditions were honored and integrated into their baby's care plan. When healthcare staff demonstrated sensitivity to their cultural backgrounds, parents felt more comfortable and confident in advocating for their baby's needs. However, challenges such as superficial attempts at cultural sensitivity or resistance from healthcare staff hindered some parents' ability to fully engage with the care provided. These findings highlight the importance of fostering an environment where cultural diversity is respected and celebrated, ensuring that all parents feel valued and supported in the NICU. P11 said: "The healthcare staff's cultural sensitivity allowed them to communicate effectively with me, ensuring that my cultural needs were understood and met."P11

The respectful inquiry into parents' preferences played a crucial role in empowering parents to actively participate in decision-making and advocate for their baby's needs. When healthcare staff took the time to listen to and consider their preferences, parents felt heard and respected, contributing to a sense of partnership and collaboration. However, experiences of dismissal or disregard for parental preferences left some parents feeling disempowered and frustrated. These findings underscore the importance of fostering open communication and mutual respect between healthcare staff and families, ensuring that all voices are heard and valued in the decision-making process. P6 narrated that: "I appreciated the healthcare staffs' efforts to engage me in meaningful conversations about my preferences, which strengthened my trust in their expertise."P6

The development of customized care plans tailored to each family's unique needs and preferences was instrumental in enhancing parents' sense of control and agency in their baby's care. When healthcare staff demonstrated attention to detail and flexibility in adapting care plans, parents felt supported and reassured, contributing to a positive experience in the NICU. However, challenges such as a lack of transparency or resistance from healthcare staff hindered some parents' ability to fully engage with the care provided. These findings highlight the importance

of individualized approaches to care planning, ensuring that each parents' specific needs and preferences are considered and respected. Below are some extracts from participants: "The healthcare staff's commitment to creating customized care plans empowered me to take an active role in our baby's care and well-being." P1 "I encountered resistance from certain healthcare providers when I tried to request modifications to the care plan, which hindered my ability to advocate for my baby's best interests." P12 "Despite assurances of customized care plans, I felt that my specific needs and preferences were not adequately considered in my baby's treatment." P4

The accommodation of parents' cultural practices with respect and understanding played a crucial role in fostering a supportive and inclusive environment within the NICU. When healthcare staff demonstrated a willingness to adapt care routines to align with cultural beliefs, parents felt more connected and supported, mitigating the stress of being in an unfamiliar environment. However, experiences of resistance or tokenistic attempts at accommodation left some parents feeling overlooked and misunderstood. These findings underscore the importance of promoting cultural inclusivity within NICU settings, ensuring that all parents feel respected and valued for their cultural heritage and practices. P3 said:

"I appreciated the flexibility of the healthcare staff in adapting care routines to align with my cultural beliefs and preferences." P3

### Theme 5: Pre-Discharge Support in Preparation to go Home

The transition from the NICU to home represents a critical phase for parents, and the provision of adequate support and resources during this period greatly influences their experience and confidence in caring for their baby post-discharge.

Parents highlighted the significance of thorough discharge planning in preparing them for the transition home with their baby. When healthcare staff provided clear communication, personalized guidance, and coordinated community resources, parents felt equipped and confident in managing their baby's care pre-discharge. However, challenges such as feeling overwhelmed by information or difficulties accessing necessary resources hindered some parents' ability to navigate pre-discharge care effectively. These findings emphasize the importance of comprehensive discharge planning to ensure a smooth and successful transition for parents from the hospital to home. P2 said: "Experiencing comprehensive pre-discharge planning in the NICU has given me peace of mind knowing that I have a roadmap for managing my baby's health and development after leaving the hospital." P2

The provision of comprehensive home care training was instrumental in empowering parents with the skills and confidence needed to care for their baby's medical needs at home. When healthcare staff offered hands-on training sessions such as

how to express breast milk, clear instructions, and personalized support, parents felt prepared and competent in managing their baby's care independently. However, challenges such as feeling rushed or encountering difficulties in applying learned skills in real-life situations left some parents feeling unprepared and anxious. These findings underscore the importance of tailored and supportive home care training to ensure that parents feel confident and capable of providing quality care for their baby pre-discharge. P7 narrated that: "The healthcare staff took the time to address my questions and concerns during home care training, providing reassurance and guidance as I prepared for the transition to Kangaroo Mother Care ward and home." P7

Regular follow-up appointments and communication from the healthcare staff provided valuable guidance and reassurance to parents as they adjusted to caring for their baby at home. When healthcare staff demonstrated a proactive and personalized approach to follow-up care, parents felt supported and reassured in their caregiving journey. However, challenges such as insufficient support or difficulty accessing follow-up appointments left some parents feeling isolated and uncertain. These findings highlight the importance of ongoing support and communication from healthcare staff to ensure that parents feel supported and empowered in managing their baby's care post-discharge. P10 stated that: "Despite assurances of post-discharge follow-up, I felt that the support provided was insufficient and inconsistent, leaving me feeling isolated and overwhelmed." P10

Guidance on developmental milestones played a crucial role in empowering parents to monitor their baby's growth and development at home. When healthcare staff offered practical tips, age-appropriate activities, and personalized recommendations, parents felt confident in supporting their baby's development. However, challenges such as feeling overwhelmed by information or difficulties implementing recommendations in real-life situations hindered some parents' ability to effectively support their baby's development. These findings underscore the importance of clear and practical guidance on developmental milestones to ensure that families feel equipped and informed in promoting their baby's growth and learning pre-discharge. P8 went on and said: "The healthcare staff took the time to discuss age-appropriate activities and interventions during developmental milestone guidance sessions, fostering my baby's growth and learning." P8

Participation in transition support groups provided parents with a sense of community, emotional support, and practical advice as they navigated the challenges of transitioning home with their baby. When facilitated effectively and inclusive of diverse perspectives, transition support groups fostered empowerment, resilience, and solidarity among parents. However, challenges such as limited availability or lack of relevance to specific parents' needs hindered some parents' ability to access and benefit from support groups. These findings highlight the importance of well-structured, diverse, and accessible transition support groups to

ensure that parents feel connected, supported, and empowered in their transition home with their baby. P4 said: "I appreciated the opportunity to share my challenges and successes with fellow parents in transition support groups, which offered valued emotional support and encouragement."P4.

## Conclusion

In conclusion, the findings of this study highlight the critical importance of effective communication, emotional support, parental involvement in care, cultural sensitivity, and comprehensive pre-discharge support in optimizing the experiences of parents with preterm babies in the NICU. Clear communication and compassionate care from healthcare staff fostered trust and empowerment among parents, while opportunities for active involvement and collaborative decision-making strengthened their sense of agency. Moreover, the recognition and accommodation of cultural diversity, coupled with tailored pre-discharge support, were instrumental in ensuring a smooth transition to Kangaroo Mother Care Ward and home and promoting the well-being of both parents and babies. These insights emphasize the need for healthcare systems to prioritize holistic and family-centered approaches to NICU care, ultimately enhancing outcomes and satisfaction for all stakeholders involved.

## Discussion

### Introduction

This chapter discusses the key findings of the study whose aim was to explore the experiences of parents of pre-term babies with healthcare staff at Women and New-born Hospitals in Lusaka, Zambia. The discussion revolves around several key themes and insights that have emerged from the in-depth interviews of the parents and the study's findings draw comparisons with previous studies discussed in the literature review. Through the voices and experiences of the parents themselves, a deeper understanding that characterizes their voices is gained. The discussion is structured around the research question and it draws on relevant literature to provide a broader understanding of the results. The chapter concludes with recommendations and limitation

### Demographic Characteristics

The demographic data of the 12 participants in this study depict a diverse cohort with varying ages, marital statuses, education levels, occupations, and religious affiliations. The participants' ages ranged from 19 to 40, with the majority being married (83.3%). Education levels varied, with most having completed at least Grade 9 education. Occupationally, participants were engaged in diverse roles, including business and farming. Notably, majority of participants identified as Christian while the minority as Muslim and all had a direct relationship with the pre-term baby, primarily as mothers. This diversity enriches the study's findings, providing a complex perspective on the experiences of parents of pre-term babies and healthcare staff in the NICU.

### Theme 1: Communication and Information Sharing

The findings regarding communication and information sharing in the NICU shed light on the complex dynamics between healthcare staff and parents, underscoring the fundamental role of effective communication in supporting families through challenging circumstances. Participants consistently praised the dedication of healthcare staff in ensuring clear and accessible communication, emphasizing the importance of comprehensible explanations, regular updates, and transparency in fostering trust and confidence.

One participant highlighted the clarity of communication, stating, "The doctors took the time to explain every procedure in a way that I could understand." This sentiment echoes the importance of healthcare staff taking the time to ensure that medical information is conveyed in a manner accessible to parents. Furthermore, another participant emphasized the impact of regular check-ins, stating, "...They checked in regularly to see if I had any questions or needed further clarification..." This proactive approach to communication not only fosters a sense of trust but also ensures that parents feel supported and well-informed throughout their interactions with the NICU staff.

These aligns with Arockiasamy et al. [32] similarly highlighted the significance of clear communication and regular updates in promoting parental satisfaction and involvement in the NICU care process. The study by Treherne et al. [33] resonated these sentiments, emphasizing the importance of transparency and approachability in healthcare providers to facilitate effective communication and support parental well-being. Moreover, Russel et al. [34] emphasized the need for consistent information-sharing practices and identified barriers to communication in the NICU environment.

These findings collectively underscore the importance of proactive and transparent communication practices in the NICU, not only in providing essential medical information but also in addressing emotional needs and promoting parental involvement in the care of their pre-term infants. However, challenges such as variations in staff approachability and delays in providing updates highlight areas for improvement to ensure that all families receive the necessary support and information throughout their NICU journey. Enhancing communication practices in the NICU can contribute to improved parental satisfaction, increased confidence in healthcare staff, and ultimately better outcomes for pre-term babies and their families. Therefore, ongoing efforts to address communication barriers and implement evidence-based communication strategies are essential in optimizing care delivery in the NICU setting.

### Theme 2: Emotional Support and Empathy

The exploration of emotional support and empathetic experiences within the NICU revealed a nuanced landscape shaped by the interactions between parents and healthcare



staff, underscoring the significance of supportive environments in navigating the challenges of pre-term birth. Participants highlighted the profound impact of a nurturing NICU environment, where acts of compassion and encouragement from healthcare staff provided solace and hope amidst adversity.

One participant expressed gratitude for the supportive environment, stating, "The NICU staff created a warm and supportive environment that made me feel like am not alone in this journey." This sentiment emphasizes the importance of fostering a sense of community and support within the NICU, which can significantly impact parental well-being. Furthermore, reflections on counseling services illuminated both the benefits and barriers encountered by parents seeking emotional support. A participant shared their experience, stating, "The counseling services offered were limited in scope and did not fully address my emotional needs." This highlights the challenges faced by parents in accessing comprehensive mental health support, underscoring the need to address systemic barriers to ensure equitable access for all NICU families.

Expressions of gratitude for empathetic care from healthcare staff echoed throughout parental narratives, highlighting the profound impact of understanding and empathy in fostering trust and connection. Another participant emphasized the importance of empathetic responses, stating, "The healthcare staff showed genuine empathy in their responses, validating my emotions and concerns." These quotes emphasize the crucial role of empathetic communication in supporting parents through the emotional challenges of the NICU journey.

The findings resonate with existing literature on the importance of supportive environments in healthcare settings. Research by Smith et al. (2018) similarly emphasizes the significant impact of compassionate care from healthcare staff in promoting well-being and resilience among patients and their families. Furthermore, studies by Johnson et al. (2019) and Lee et al. [35] highlight the challenges faced by families in accessing comprehensive mental health support, underscoring the need to address systemic barriers to ensure equitable access for all NICU families. In contrast to parental experiences, healthcare staff perspectives on providing emotional support in the NICU may reveal additional insights into the challenges and facilitators of empathetic care delivery. Interviews with NICU nurses and physicians could provide valuable perspectives on the barriers they face in delivering emotional support, such as time constraints or training gaps, as well as their strategies for overcoming these challenges. Comparing parental narratives with healthcare staff perspectives can offer a holistic understanding of the dynamics of emotional support within the NICU environment. Reflections on psychological services revealed a complex landscape of experiences, with systemic barriers hindering access to comprehensive mental health support. Addressing these barriers is essential to ensuring that all NICU families have access to the emotional support they need.

### Theme 3: Parental Involvement in Care

Examining parental involvement in NICU settings reveals a complex landscape, showcasing both the benefits and challenges associated with active participation in their baby's care journey. Participants emphasized the profound impact of hands-on involvement in care tasks, describing it as instrumental in fostering a strong bond with their baby and providing a sense of purpose amidst the NICU environment.

One participant highlighted the significance of hands-on involvement, expressing, "Being able to participate in feeding and changing diapers helped me feel more connected to my baby." This sentiment underscores the importance of promoting parental involvement to enhance the parent-baby bond during the NICU stay.

Furthermore, a collaborative approach to decision-making regarding their baby's care was highly valued by parents, as it empowered them to advocate effectively and strengthened the partnership between parents and healthcare staff. Another participant shared their experience, stating, "The doctors and nurses took the time to explain treatment options and involved me in decision-making, which helped me feel informed and supported." This emphasizes the importance of fostering collaborative partnerships between parents and healthcare staff to ensure that parents feel respected and empowered in their role as advocates for their babies.

However, challenges such as resistance from certain staff members occasionally hindered this process, underscoring the need for fostering a collaborative decision-making environment to ensure parents feel respected and empowered. Another participant emphasized the importance of recognition and inclusion of parental input in care decisions, stating, "Having my input valued by the healthcare staff made me feel respected and included in my baby's care." This highlights the necessity for healthcare staff to actively seek and acknowledge parental input to foster a collaborative partnership built on mutual respect and trust. Creating an inclusive environment within the NICU played a pivotal role in fostering a sense of belonging and support among parents. However, challenges such as microaggressions detracted from inclusivity, emphasizing the need for addressing barriers and promoting a culture of respect and understanding within the NICU.

Finally, ensuring that parents are fully informed before giving consent for their baby's treatment is paramount. While the process of informed consent was perceived as empowering when parents felt adequately supported and understood, challenges such as time constraints and complex medical information occasionally hindered this process, emphasizing the need for thorough explanations and support from healthcare staff.

In comparison with existing literature, studies by Chansa et al. [36], Verle et al. [37], and Amek et al. [38] similarly

underscored the importance of parental involvement in NICU care, emphasizing its role in fostering parent-baby bonding and enhancing parental empowerment. Additionally, research by Perte et al. [39] highlighted the challenges associated with healthcare staff resistance to parental involvement, echoing the need for fostering collaborative partnerships between parents and healthcare staff. These findings underscore the importance of promoting parental involvement, fostering collaborative decision-making environments, and ensuring inclusive and respectful care practices within NICU settings to effectively support families through their care journey.

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

Parents underscored the crucial role of healthcare providers' cultural competence in ensuring that their cultural practices and beliefs were acknowledged and respected within the NICU setting. When healthcare teams demonstrated understanding and respect for their cultural backgrounds, parents felt valued and supported, contributing to a sense of trust and partnership. Conversely, instances of cultural insensitivity or a lack of understanding left some families feeling marginalized and misunderstood. These experiences highlight the importance of promoting cultural competence within NICU settings to ensure that all families receive respectful and culturally sensitive care.

Culturally sensitive care was emphasized as critical in creating an inclusive environment where families' cultural values and traditions were honored and integrated into their baby's care plan. A participant stressed the NICU's commitment to cultural competence highlighting, "The NICU's commitment to cultural competence fostered an environment where my family's cultural traditions were honored and integrated into my baby's care". Challenges such as superficial attempts at cultural sensitivity or resistance from healthcare staff hindered some families' ability to fully engage with the care provided, underscoring the need for fostering an environment where cultural diversity is respected and celebrated.

Respectful inquiry into families' preferences empowered parents to actively participate in decision-making and advocate for their baby's needs. When healthcare staff considered their preferences, parents felt heard and respected, contributing to a sense of partnership and collaboration. However, experiences of dismissal or disregard for parental preferences left some families feeling disempowered and frustrated, highlighting the importance of fostering open communication and mutual respect. The development of customized care plans tailored to each family's unique needs and preferences enhanced parents' sense of control and agency. Challenges such as a lack of transparency or resistance from healthcare staff hindered some families' ability to fully engage, emphasizing the importance of individualized approaches to care planning.

Accommodating families' cultural practices with respect and understanding fostered a supportive and inclusive environment within the NICU. When healthcare staff demonstrated a

willingness to adapt care routines to align with cultural beliefs, parents felt more connected and supported. Another participant appreciated the flexibility of the healthcare staff "I appreciated the flexibility of the healthcare staff in adapting care routines to align with my cultural beliefs and preferences" However, experiences of resistance or tokenistic attempts at accommodation left some families feeling overlooked, highlighting the importance of promoting cultural inclusivity.

These findings with existing literature, studies by Rodriguez et al. [40], Lee et al. [35], and Jones et al. [41] similarly emphasized the importance of cultural sensitivity and respect for diversity in NICU care. Collectively, these findings underscore the need for healthcare staff to prioritize cultural competence and inclusivity to ensure that all families receive respectful and supportive care tailored to their unique cultural backgrounds and preferences.

#### Theme 5: Pre-Discharge Support in Preparation to go Home

Thorough discharge planning emerged as decisive in preparing families for the transition home. When healthcare staff provided clear communication, personalized guidance, and coordinated community resources, parents felt equipped and confident. However, challenges such as feeling overwhelmed or difficulty accessing necessary resources hindered some parents' ability to navigate pre-discharge care effectively.

Comprehensive home care training was instrumental in empowering parents with the skills and confidence needed to care for their babies at home. One participant stated, "Experiencing comprehensive pre-discharge planning in the NICU has given me peace of mind knowing that I have a roadmap for managing my baby's health and development after leaving the hospital". Challenges such as feeling rushed or difficulties in applying learned skills left some parents feeling unprepared and anxious, emphasizing the need for tailored and supportive training. Pre-discharge follow-up and communication provided valuable guidance and reassurance to families. Challenges such as insufficient support or difficulty accessing appointments left some families feeling isolated and uncertain, highlighting the importance of ongoing support.

Guidance on developmental milestones played an important role in empowering parents to monitor their baby's growth and development at home. Another participant highlighted, "The healthcare staff took the time to discuss age-appropriate activities and interventions during developmental milestone guidance sessions, fostering my baby's growth and learning". Challenges such as feeling overwhelmed or difficulty implementing recommendations hindered some families' ability to effectively support their baby's development, emphasizing the need for clear and practical guidance. Participation in transition support groups provided parents with a sense of community, emotional support, and practical advice. Challenges such as limited availability or lack of relevance hindered some parents' ability to access and benefit from support groups, highlighting the importance of well-

structured, diverse, and accessible groups.

In comparison, studies by Wami et al. [42], Shapa et al. [43], and Adeboye et al. [44] similarly emphasized the importance of comprehensive discharge planning, home care training, pre-discharge support, guidance on developmental milestones, and participation in support groups for successful transitions from the NICU to home. Collectively, these findings underscore the need for healthcare staff to prioritize holistic and tailored support to ensure that families feel empowered and supported throughout the transition process.

## Conclusion

In conclusion, the findings underline the critical importance of comprehensive support and personalized resources for families transitioning from the NICU to home care. Clear communication, personalized guidance, and ongoing support play essential roles in empowering parents, fostering confidence, and enhancing their ability to navigate the complexities of caring for their pre-term baby post-discharge. By addressing the identified challenges and prioritizing holistic support strategies, healthcare staff can facilitate smoother transitions, promote positive caregiving experiences, and ultimately improve outcomes for both parents and babies in the pre-NICU journey.

## 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.

## What is New in the Study

The study brings several new insights into the NICU experience, particularly regarding the nuanced dynamics of communication, emotional support, parental involvement, cultural sensitivity, and pre-discharge care. It sheds light on the effectiveness of visual

aids and simplified medical terminology in facilitating parental understanding, as well as the key role of proactive communication and regular check-ins in reducing parental anxiety. Additionally, the study emphasizes the significance of genuine empathy and transparent communication in fostering trust between healthcare staff and parents, contributing to a supportive NICU environment. Furthermore, it highlights the importance of cultural competence in healthcare delivery, advocating for the acknowledgment and integration of diverse cultural practices and beliefs to ensure inclusive care. Moreover, the study underscores the necessity of comprehensive discharge planning and tailored home care training to empower parents in caring for their baby post-discharge, addressing potential challenges such as information overload and access to follow-up support. The study contributes valuable insights that can inform and enhance the provision of family-centered care in NICU settings.

## 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 empathy 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, empathy building, 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 empathetic 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 empathy, 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.

## Recommendations

### To the Ministry of Health

Firstly, there should be an allocation of funding towards the development and implementation of training programs tailored for healthcare professionals working within NICU settings. These programs should prioritize the enhancement of communication skills, empathy, and cultural sensitivity to better support families during their NICU journey. Secondly, the Ministry should spearhead the development of policies that prioritize family-centered care practices within NICU settings. These policies should ensure that healthcare staff actively involve parents in decision-making processes and deliver culturally sensitive care to meet the diverse needs of families.

### To the Hospital Management

At the hospital level, recommendations center on staff training and the development of support services. Staff training sessions should be implemented regularly, focusing on enhancing communication skills, providing emotional support, and promoting cultural competence among healthcare staff in the NICU. This will ensure that staff can effectively meet the diverse needs of families and provide them with the necessary support throughout their NICU journey. Additionally, the hospital should establish support services such as counseling and transition support groups within the NICU. These services will offer families emotional support and guidance during their time in the NICU and facilitate a smoother transition home for both parents and babies.

## Study limitation

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 [45-80].

## 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: luciazn87@gmail.com.

## Study Description

- i. **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.
- ii. **Procedures**
  - a. Participation will involve a one-on-one interview with the researcher, lasting approximately 30-45 minutes.
  - b. The interview can be conducted in person at a mutually convenient location.
  - c. The interview will be audio-recorded to ensure accuracy during the analysis process, but your identity will be kept confidential.
  - d. The questions will focus on your experiences, emotions, and perceptions related to the care provided by healthcare staff.
  - e. 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

- i. Your participation and any information you provide will be kept strictly confidential.
- ii. To ensure anonymity, all identifiable information will be removed during the data analysis process, and pseudonyms will be used.
- iii. The audio recordings will be securely stored and only accessible to the research team.
- iv. The findings of the study may be reported in academic publications, but no personal identifying information will be included.

## Voluntary Participation

- i. Your participation in this study is entirely voluntary.
- ii. You have the right to refuse to participate or withdraw from the study at any stage, without providing a reason.
- iii. 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: luciaz87@gmail.com.

## 14.8. Contacts for Queries

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- iv. 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

## 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: .....

## 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?

## 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?

## 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?

## 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?

## 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?

### 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?

### 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?

### 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.

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