

Understanding the Parental Realities of Caring for Premature Newborns in Rwanda

Olive Mukanshimiyimana¹; Ingabire Clementine²; Mukasine Anne Marie³;
John Peter Ndikubwimana⁴; Louis Ngabonzima⁵; Hakizimana Leonard⁶;
Manishimwe Godeline⁷; Dusabirema Immaculee⁸

¹Main Author: Degree: Master of Science in Nursing (Neonatal)
Neonatal Nurse Clinical Instructor, Partners in Health (Inshuti Mu Buzima – IMB)

²Co-Author: Master of Science in Nursing Education Leadership and Management at University of Rwanda
Director of Nursing and Midwives at Ruhengeri Level Two Teaching Hospital

³Co-Author: Master's in Nursing (Neonatology), Assistant Lecturer,
Ruli Higher Institute of Health (RHIH)

⁴Co-Author: Masters in Counseling Psychology Mount Kenya University of Rwanda,
Research Assistant Consultant, UGHE

⁵Co-Author: Director of Programs, Rwanda NGOs Forum Master's Degree in Project Management

⁶Co-Author: Continuous Quality Improvement Director of Education and Research/ Byumba
Level Two Teaching Hospital

⁷Co-Author: Senior Pediatric Nurse/ CHUB

⁸ Co-Author: Senior Pediatric Nurse/ RLTTH

Publication Date: 2025/11/20

Abstract: Parents of premature newborns admitted to Neonatal Intensive Care Units (NICUs) commonly experience distress, emotional burden, and disruptions in parent-infant bonding. This study explored the lived experiences of parents whose premature newborns were admitted to the Neonatal Unit at the University Teaching Hospital of Butare (UTHB). A qualitative phenomenological approach was used to gain deep insight into parents' perceptions, emotions, and challenges during hospitalization. Ten parents were purposively selected and interviewed through semi-structured interviews. Data were analyzed using Giorgi's phenomenological method. Findings revealed both negative and positive experiences. Negative experiences included stress related to newborn appearance, fear of death, financial constraints, environmental challenges linked to noise, light, and equipment, and loss of parental role. Positive experiences emerged primarily from support provided by healthcare workers, partners, and family members. Understanding these experiences is essential for strengthening family-centered care, improving parental involvement, and enhancing neonatal outcomes. The study recommends structured psychosocial support, improved communication, and enhanced parental engagement in care routines.

Keywords: *Premature Newborn, Neonatal Unit, Parental Experience, Stress, Parental Support, Rwanda.*

How to Cite: Olive Mukanshimiyimana; Ingabire Clementine; Mukasine Anne Marie; John Peter Ndikubwimana; Louis Ngabonzima; Hakizimana Leonard; Manishimwe Godeline; Dusabirema Immaculee (2025). Understanding the Parental Realities of Caring for Premature Newborns in Rwanda. *International Journal of Innovative Science and Research Technology*, 10(11), 981-996. <https://doi.org/10.38124/ijisrt/25nov732>

I. INTRODUCTION

A preterm infant, according to the World Health Organization (WHO, 2015), is any baby born before completing 37 weeks of gestation. The 2015 global action report emphasized that preterm birth remains one of the most urgent public health challenges worldwide, as it is a leading contributor to neonatal illness and death. Globally, prematurity is the primary cause of mortality among children under five, accounting for an estimated 2.7 million deaths, nearly half of which occur in the first 28 days of life (Blencowe et al., 2012; Blencowe et al., 2013). The likelihood of survival among preterm infants strongly depends on gestational age: infants born at 23 weeks face very high mortality rates even with intensive care, while those born at 32 weeks or beyond have significantly better outcomes with appropriate medical support (Lawn, Mongi & Cousens, 2006). For parents, the experience of having a premature infant in an intensive care environment is emotionally overwhelming. Many parents describe a mixture of fear, uncertainty, hope, and emotional exhaustion as they watch their newborns fight for survival (Steyn, 2017). In Rwanda, premature infants account for nearly one-third of neonatal deaths according to the Ministry of Health (MoH, 2014). Admission into a Neonatal Intensive Care Unit (NICU) often disrupts parents' ability to participate in normal parenting roles because the infant's fragility limits the types of care they can safely provide (Russell et al., 2014; Beck et al., 2010).

Research from various settings also shows that parents of premature infants experience high levels of psychological distress, including anxiety, depression, helplessness, fear, and a sense of disconnection from their role as parents (Adama, Bayes & Sundin, 2016; Thon, 2013; Dudek-Shriber, 2004; Hunt, 2011). Because preterm birth is usually sudden, many parents feel unprepared for the experience and uncertain about their baby's chances of survival (Candelori et al., 2015). The physical separation caused by incubators, medical equipment, and prolonged hospital stays can delay bonding, intensify feelings of helplessness, and create emotional distance between parents and their infants (Thon, 2013). Every family entering the NICU brings unique personal, social, and emotional circumstances that influence how they cope. Parents' experiences are shaped by the severity of their infant's condition, the baby's physical appearance, the length of hospitalization, and how medical teams communicate with and support them (Babore, 2015). Although fathers' experiences have been studied less frequently, existing research indicates that they also struggle with emotional turmoil and challenges in adjusting to parenthood during a NICU admission (Candelori et al., 2015; Fegran & Fagermoen, 2008).

One of the most significant hardships for families is the limited opportunity for immediate physical closeness. The fragile health of premature babies and the technical environment of the NICU often delay skin-to-skin contact, yet this contact is known to have profound emotional and developmental benefits for both infants and their parents (Wigert, 2010; Levy, 2015). Parents often rely heavily on the

medical team to guide them, and the constant supervision by staff may make them feel less confident in their ability to care for their own child, sometimes leading to frustration, alienation, or fear of doing something wrong (Fegran, 2008). A study conducted in Iran illustrated how the unfamiliar environment of the NICU can be emotionally painful for mothers. Many described sadness when they saw their infant connected to machines, often interpreting this as a sign of worsening health. A lack of understanding of the equipment sometimes led to fear that the technology could fail, leaving mothers feeling alienated or helpless (Malakouti et al., 2013). Given that numerous studies point to the emotional and psychological burden faced by parents of premature infants ranging from distress and fear to challenges in bonding, this study seeks to explore and understand the lived experiences of parents whose premature newborns are admitted to the Neonatal Unit at UTHB.

➤ Problem Statement

Basing on clinical experience in neonatal unit, basing on informal information received from parents, parents reported that they experience stress when their premature newborns are admitted in neonatal unit leading to poor parental-newborn attachment. In Rwanda thirty three percent (32%) of neonatal deaths are premature babies (Moh, 2014). The study conducted At King Faisal Hospital, Rwanda revealed that parents experienced stress from sight and sound when their infants are cared for in an NICU (Musabirema et al., 2013). Admission of premature newborn in neonatal intensive Care Units presents challenges for the parents on their engagement in parenting occupation leading to stressful situation to them (Beck et al., 2010). Care providers have to be aware of those experiences in order to support parents and to improve the quality of care for premature newborns, while no studies about these issues have been conducted at UTHB. Therefore, the investigator sought to fill this gap by identifying and describing the experiences of parents of premature newborn in neonatal unit at UTHB.

➤ Research Objectives

• Main Objective

To describe the lived experiences of parents with a premature newborn in neonatal unit at UTHB.

• Specific Objectives

- ✓ To describe the positive experiences of parents with a premature newborn in neonatal unit at UTHB
- ✓ To describe the negative experiences of parents with a premature newborn in neonatal unit at UTHB

➤ Research Questions

- ✓ What are the positive experiences of parents with a premature newborn in neonatal unit at UTHB?
- ✓ What are the negative experiences of parents with a premature newborn in neonatal unit at UTHB?

II. REVIEW OF RELATED LITERATURE

➤ Theoretical Literature

A preterm infant is defined by the World Health Organization as a baby born before completing 37 full weeks of gestation (WHO, 2015). Prematurity remains the leading cause of death in the neonatal period, and surviving infants often face immediate and long-term health complications. Babies born too early are at increased risk of respiratory, cardiac, neurological, metabolic, intestinal, hematological, thermoregulation, and immune system problems, as well as later disabilities involving hearing, sight, dental development, learning, and psychological well-being (Hebert, 2014). The neonatal period itself is widely recognized as the most fragile stage of a child's life (Beck et al., 2010). Globally, preterm birth continues to be the primary cause of mortality among children under five. Approximately 2.7 million children die each year from complications linked to prematurity, with nearly half of these deaths occurring within the first month of life. Around one million babies die on the day they are born, and another two million die within the first week (Blencowe et al., 2013). Africa and South Asia together account for about 60% of all preterm births. Rates also vary by income level: in low-income countries, about 12% of infants are born preterm compared with about 9% in high-income countries (WHO, 2015). Socioeconomic inequality within countries also increases the risk, with poorer families being disproportionately affected.

In the United States, one in ten babies is born prematurely, and Black infants experience higher rates of preterm birth compared to white infants. Prematurity also places a heavy economic burden on health systems: the U.S. Institute of Medicine estimated a cost of USD 2.6 billion annually in 2005. In the United Kingdom, approximately 60,000 premature babies are born each year, and survival is closely tied to gestational age. Survival before 23 weeks is nearly zero, while it rises to 15% at 23 weeks, 55% at 24 weeks, and around 80% from 25 weeks onward. Multiples are particularly vulnerable, with about 60% of twins and 90% of triplets born preterm (Barfield, 2015). In Rwanda, the Ministry of Health reported that more than half of all newborn deaths in 2013–2014 (52.6%) were linked to prematurity.

Admission to a neonatal unit is often necessary for preterm infants because they require specialized and continuous monitoring that parents cannot provide at home (Herbst & Maree, 2006). However, the hospitalization creates emotional and practical challenges for families. The infant's fragile condition limits parents' opportunities to carry out their expected caregiving roles, and this interruption may hinder early bonding and attachment (Russell et al., 2014). The physical separation and constant medical interventions associated with Neonatal Intensive Care Unit (NICU) care can be distressing for parents, who often describe feelings of powerlessness, fear, and emotional strain (Al Maghaireh et al., 2016). Nurses play an essential role in reducing this stress by involving parents, explaining procedures, and guiding them in participating in their infant's care. Encouraging parental involvement supports attachment and strengthens

parents' confidence in caring for their child (Gooding et al., 2011).

➤ Historical Development of the Modern NICU

Although physicians began documenting the care of frail newborns as early as the seventeenth century, specialized medical support for premature infants did not become common until the twentieth century (McCann, Kenner & Boykova, 2010). Prior to that, most infants were sent home with little intervention, sometimes accompanied by a nurse. After World War II, hospitals began establishing Special Care Baby Units, the early versions of modern NICUs (Badnjevic et al., 2017).

The introduction of incubators marked a turning point. Early incubators provided heat and humidity, helping stabilize vulnerable infants. Dr. Martin Couney's public demonstrations raised global awareness of their effectiveness, prompting hospitals to adopt the technology. Dr. Julian Hess later advanced incubator design by integrating oxygen delivery, greatly improving survival for premature infants.

During this period, infection control was poorly understood. Many believed that sick infants caught infections mainly from other babies. Dr. Louis Gluck challenged this assumption through studies comparing washed and unwashed infants. His research, involving tens of thousands of newborns, demonstrated that regular handwashing drastically reduced infections. His findings led to major redesigns of neonatal units, emphasizing hygiene, open-room designs for easier monitoring, and broader use of incubators (Badnjevic et al., 2017). These advancements helped shift the survival of premature infants from a rare possibility to a growing expectation.

➤ Lighting Conditions in the NICU

Lighting in the NICU serves various functions, including phototherapy for jaundice and illumination for clinical procedures. However, premature infants have underdeveloped sensory systems, and exposure to bright or continuous lighting can overstimulate them and potentially harm developing organs. The immature retina is particularly vulnerable; excessive light exposure has been associated with risks for retinopathy of prematurity, which can lead to blindness (Wurtman, 2009). Because premature infants are still undergoing rapid developmental changes, environmental factors such as lighting can influence long-term outcomes, including risks of cerebral palsy, sensory impairments, learning challenges, and chronic respiratory problems (Beck et al., 2010).

➤ Noise Effects on Parents

Studies from various countries consistently report that environmental factors in the NICU, especially noise, are major sources of stress for parents. Noise generated by monitors, alarms, and other medical devices frequently contributes to parental distress (Trajkovski et al., 2012; Hunt, 2011). In Rwanda, Musabirema and colleagues examined parents' perceptions of stressors in the NICU and found that excessive sound within the unit was one of the most

distressing aspects of the environment. Other environmental stressors included the overwhelming presence of medical equipment and the unfamiliar, often technical language used by healthcare professionals (Musabirema et al., 2013).

➤ *Effects of Noise on the Infant*

Premature infants are extremely vulnerable, and the NICU exposes them to noise from technological equipment, caregivers, and visiting family members. These sounds are foreign and potentially harmful to the developing brain. Exposure to high noise levels can lead to physiological instability in preterm infants, including increases in heart rate, respiratory effort, and oxygen consumption (Hunt, 2011). NICU staff are therefore encouraged to reduce unnecessary noise by muting alarms when clinically appropriate, speaking softly, and performing procedures in ways that minimize sound (Knutson, 2012).

➤ *Maternal Role Attainment Theory*

Mercer describes maternal role attainment as the process through which a mother bonds with her infant, gains confidence in caregiving skills, and experiences satisfaction and fulfillment in her maternal role (Mercer, 2004). According to Ramona Mercer, this developmental process begins during pregnancy and continues after birth as the mother and infant interact. The model is reciprocal: the mother interprets her role based on the infant's responses, while the infant's behavior is shaped by the mother's emotional and caregiving cues (Husmillo, 2013).

Mercer identifies four stages of maternal role attainment. The second stage, known as the formal stage, begins immediately after birth when mothers start to integrate the newborn into the household and family routines. However, when infants are born prematurely and require prolonged NICU hospitalization, mothers are unable to engage in this stage as expected. The separation and disruption of normal caregiving can increase maternal stress and hinder the development of the maternal role (Howard & Stratton, 2010).

➤ *Empirical Literature*

A systematic review conducted by Obeidat and Bond (2009), which examined 14 qualitative studies, explored parental experiences of having an infant in the NICU. The findings showed that parents commonly experienced depression, anxiety, stress, and a profound sense of losing control. The authors emphasized the need for nursing interventions that promote psychological well-being through family-centered and developmentally supportive care.

Holditch-Davis and colleagues (2011) studied maternal role attainment among 72 medically fragile infants in North Carolina. Their findings showed that components of maternal role attainment—identity, presence, and competence—significantly influenced parenting quality, even after controlling for maternal education and illness severity. Maternal competence was positively associated with responsiveness, while maternal presence was inversely related to participation, particularly in cases involving technological dependence. Mothers with lower competence

and infants with greater medical needs viewed their children as more vulnerable and found it harder to interpret infant cues. The study highlighted the importance of interventions that strengthen maternal role development both during hospitalization and after discharge. Merighi et al. (2011) reported that parents of premature infants experience high levels of depression, anxiety, and Post-Traumatic Stress Disorder (PTSD). These psychological symptoms can persist for up to a year and negatively impact parent–infant interactions. Their findings showed that about one-third of mothers of preterm infants experienced clinically significant anxiety and depressive symptoms one month after birth. The authors noted that only recently have studies begun to examine parents' experiences from a trauma-informed perspective. Gangi and colleagues (2013), in their study of 40 Italian parents of NICU-hospitalized preterm infants, found that preterm birth and NICU hospitalization are often experienced as traumatic events. Altered parental roles and a history of anxiety were strongly linked to the development of PTSD symptoms. The researchers emphasized that early familiarization with the NICU environment and active participation in infant care could improve parental role perception and reduce the risk of PTSD.

Ionio et al. (2016) investigated parental distress among 80 Italian parents of preterm and full-term infants. Their results showed that preterm birth triggered intense emotional reactions and higher levels of stress, anxiety, and negative mood states—particularly among mothers. They also found significant differences between mothers and fathers: mothers often reported greater emotional strain, while fathers expressed more anger and fear. The study concluded that NICUs should implement early supportive interventions to strengthen parent–infant relationships and promote family-centered care from birth onward. Fegran (2008), in a study conducted in Norway, explored mothers' and fathers' experiences of attachment processes in the NICU. Parents described emotional complexity and challenges in forming bonds due to physical separation and limited early contact. The study emphasized that physical proximity is essential for initiating the attachment process.

Castoldi et al. (2015) further demonstrated that preterm birth often leads to negative emotional responses among both mothers and fathers. Mothers tended to show higher levels of stress and traumatic symptoms, while fathers expressed heightened anger, fear, and emotional withdrawal. Poor neonatal health indicators, such as low gestational age and low birth weight, were strongly associated with higher parental distress. The authors stressed the importance of providing emotional and psychological support to parents to help preserve healthy parent–child relationships. A systematic review by Al Maghaireh et al. (2016), which included nine qualitative studies, found that parents experienced significant stress due to their infant's medical condition, disruptions to parental roles, and the NICU environment. These stressors often resulted in negative psychological effects, interruptions to healthy attachment, and a sense of parental role alteration. While numerous studies have examined parental experiences in NICUs, most have focused on parents of critically ill infants rather than specifically on parents of

premature infants. Fewer studies have addressed the unique experiences and stressors faced by parents of preterm babies—an area that remains critical for understanding and improving neonatal and family care.

➤ Conceptual Framework

The conceptual framework of the current study, based on the Parental NICU Distress model proposed by Wereszczak, Miles, and Holditch-Davis (1997).

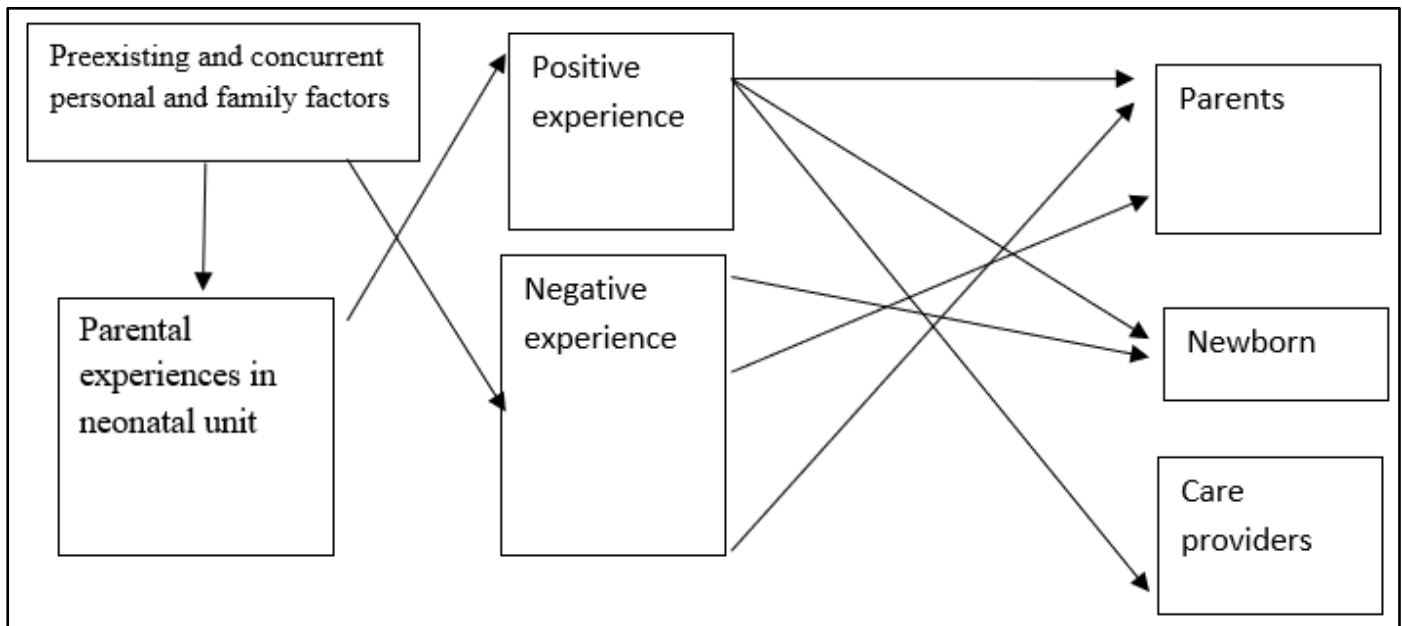


Fig 1 Diagram of Conceptual Framework

The conceptual framework of the current study, based on the preterm parental distress model, proposed by Holditch-Davis and Miles, (1997)

- *There are Six Sources of Stress for Parents of Preterm Infants Admitted in NICU Which are:*

✓ *Pre-Existing and Concurrent Personal and Family Factors:*

These factors give a structure for parental analysis of the NICU experience and may cause stress for parents. Those factors are age, gender, socioeconomic status and financial situation, employment, personality traits, level of social support, and previous experiences about illness and death.

✓ *Parents' Experiences:*

Parents develop their own point of view about NICU environment, some parents may view in a positive way because their infant is getting the care they need, others in the negative way when their infant or staff are not capable of being in touch with their needs (Dudek-shriber, 2004, pp. 517–518).

✓ *Parents:*

The parent-infant relationship is reciprocal in that model, the parent often views him/herself in response to how the infant responds to her/her and the infant responds to the parent based on the infant's sense of the parent's behavior or mood.

✓ *Newborn:*

The severity of the illness becomes a primary source of stress once the infant is born and admitted to the NICU. The

severity of illness of the infants will be one thing which will affect parent's expectation, and they will think more about the negative outcome.

✓ *Loss of the Parental Role:*

When the infant is admitted in the NICU parents consider them as powerless because they lose their parental role to care their newborn. Some of them become spectators because their responsibilities are shifted to care providers.

✓ *Health Care Providers:*

Parents can have stress from the support offered by health care providers especially nurse. Nurses are considered critical in helping parents cope with the infant's illness and encouraging them begins caring for the infant. Through communication nurses can help parents to cope with the NICU experience.

➤ *Critical Review and Research Gap Identification*

Many studies conducted on parental experience focused on parents of ill infants in NICU, not for parents with preterm infants. Other studies done on parental stressors in NICU where results showed that parents experience stress, anxiety, depression, and researchers did not emphasized on needed support for parents of premature newborns. In Rwanda, a study conducted about parent's perceptions of stress in NICU showed that parents are stressed by baby's appearance, noise and light and recommended that it is priority to train NICU staff with the aim of preparing and supporting parents in terms of the sights and sounds in a NICU. In this study, investigator did not emphasize on negative effects of the stress on parental-newborn bonding. At UTHB no study published regarding 'parents' experience of having a

premature newborn in Neonatal Unit and a proper needed intervention for facilitating parental attachment. Therefore this study is helpful for parents who have premature infant in neonatal unit at UTHB, to receive appropriate support, and it is helpful for Neonatal Unit health care providers to improve ways of their intervention needed to parents in order to cope with neonatal environment and to bond with their newborns.

III. RESEARCH METHODS

➤ Study Approach

Qualitative approach was used to describe the parent's experience of having a premature newborn in neonatal unit. Qualitative approach is defined as an approach which involve an interpretative material practices that make the world visible based on realities and viewpoints of participants (Polit & Beck, 2012, p. 487).

➤ Research Design

This study used phenomenological descriptive design to describe parents' experience of having premature newborns in Neonatal Unit. Phenomenological descriptive design fit this study because it helps to understand lived experience of humans and insist on careful description of everyday life (Polit&Beck, 2012, p. 495). This method was chosen for this study because it assisted the researcher to come up with different opinions of parents who have a premature newborn in neonatal unit at UTHB regarding their experience during hospitalization. Therefore, with this design, the researcher explored the phenomenon under study.

➤ Research Setting

According to Burns and Grove, the study field is the place where the research is conducted (Burns & Grove, 2005, p. 341). This study was conducted at the University Teaching Hospital of Butare located in Huye District, Southern Province of Rwanda. UTHB is one of the referral hospitals of the country, with the capacity of 500 beds. UTHB serves many patients include premature newborns that need intensive care. Neonatal Unit of UTHB has 4 rooms, 2 rooms for critically ill newborns including premature newborns, 1room for cribs for recovered newborns, 1 room for Kangaroo care, 1 room for mothers who have the newborn in neonatal Unit.

➤ Study Population

Study Population is the total type of individuals or elements who meet the sampling criteria established by researcher (Burns & Grove, 2005, p. 341). In this study, the study population was all parents who had premature newborn in neonatal unit in Rwanda. The target population is defined as a group of individuals who share some common characteristics that the investigator can be able to identify and conduct a study (Creswell, 2012, p. 142) ;Therefore, the Target population was parents who had a premature newborn in Neonatal Unit at UTHB. Accessible population defined as cases taken from the target population that are present for the researcher at the time of study (Burns & Grove, 2005, p. 341). Accessible population was parents of premature newborn admitted at UTHB at the time of study.

➤ Inclusion Criteria

Inclusion criteria is a list of characteristic that a subject or an element encloses in order to be one of the target population(Burns & Grove, 2005, p. 343). In this study, the inclusion criteria were the parents of the premature newborn admitted to Neonatal Unit at UTHB for one week and above.

➤ Exclusion Criteria

Burns and Grove, describe exclusion criteria as those characteristics that can cause an element to be excluded from target population (Burns & Grove, 2005, p. 343) . The parents who were mentally incompetent, parents who did not consent to participate, family member who assure parental role in Neonatal Unit were excluded in this study.

➤ Sampling Strategy

Sampling strategy is defined as a method or a process used by the researcher to select a subject that represents the studied population (Burns & Grove, 2005, p. 342). Sampling involves the selection of a number of study units from a defined study population (Patton and Cochran, 2002). The subject was who is able to provide most extensive information about the event being studied. A non-probability sampling especially a purposive sampling method was considered in this study because it provides the data required, helps to understand the phenomena of interest ,and it helps to find the cases with rich information for the purpose of the study (Sandelowski, 2000) . It means participants are chosen because they are expected to generate helpful information for the project (Patton and Cochran, 2002).

➤ Sample Size

Qualitative research requires fewer sample than quantitative research ; it is the repetition of information needed which determines the majority of qualitative sample size (Mason, 2010, p. 1–13). During data collection, parents interviewed through semi structured interview. Data was saturated at tenth parent, where the information started to be repetitive, and where was no new information received.

IV. DATA COLLECTION METHODS

➤ Data Collection Instrument

Data collection involves selection of participants and the way of gathering data from them (Gill *et al.*, 2008, pp. 1–6). Instrument is the tool used in research method on which the data is recorded for analysis(Gill *et al.*, 2008, pp. 1–6).

In this study data collection tool was a semi-structured interview which provides valuable information to participants in the qualitative study, and it helps to explore the experience. Interview involve verbal communication between the researcher and the subject as described by(Burns & Grove, 2005); Gill *et al.*, 2008).

A semi-structured interview guide with open questions was used to collect data (Appendix B), the interview questions used in this study to collect data was developed by researcher and validated by experts. The interview guide question was in 2 parts where every part was composed of 5

open questions and each interview session was done between 45 to 60 minutes.

➤ *Data Collection Procedures*

The data was collected at UTHB, the researcher visited the hospital administration and explained to them about the aim of the study through presentation, and then the researcher received the permission to conduct the study from the hospital administration. The researcher also approached the head of pediatrics department and head of the neonatology unit where the patients were admitted and explain them also about the study.

The researcher approached the parents of premature newborns; the researcher introduced herself to them, and explained all information about the study. The researcher made appointment with parents got their written consent. The researcher explained that there was no incentive for participating in the study. Data were collected in the field (UTHB). The day of data collection, the researcher had a good recording instrument, and a positive environment was ensured to facilitate relaxed dialogue. Parents described their experience and the meaning of event through semi structured interview according, the transcription and coding was completed at once, themes and subthemes were developed, and the data analysis was done simultaneously with the data collection. Data saturated at participant ten.

➤ *Data Analysis*

Data analysis is described as a process of synthesis of all data collected, transforming them with an objective of discovering useful and helpful information (Burns & Grove, 2005, p. 565). In qualitative research, the author examines words more than numbers.

The recorded data was transcribed verbatim, then the researcher was immerse in the data by reading the transcribed data carefully and the analysis was done using the Giorgi' phenomenological methodology which help to break down the data , rearrange them into categories that facilitate in interpreting the narrative data within the context of whole text (Polit&Beck, 2012, p. 565). Giorgi' phenomenological methodology has four essential stages followed during data analysis of this study:

- The first step was listening to the recordings several times and catches a general view of parents experience in neonatal unit
- The second step the investigator tried to read the text, and divide it into meaning units and descriptive quotations which was grouped accordingly.
- The third step was to develop and make clarity to the units and move from abstract to concrete information from which the researcher will organize the participants' citation.
- The fourth step the researcher read the concrete units and made sentences that respond the research questions of the study.
- The fifth step, the researcher Identified key quotations to support each theme.

- The Giorgi's step applied to this study as follow.

➤ *Stages of Data Analysis*

The analysis was done using the Giorgi' phenomenological methodology which help to break down the data , rearrange them into categories that facilitate in interpreting the narrative data within the context of whole text (Polit&Beck, 2012, p. 565)

• *The Giorgi's Step Applied to this Study as Follow:*

- ✓ The researcher listened several times the audiotape data and got a global view of parent's experience with premature newborns in neonatal unit, participant interviews was transformed into written form and notable quotes was highlighted.
- ✓ The researcher used to read and to re-read the transcribed text, to compare with the recorded data from each study participant in order to get a sense of the whole, making notes and codes in the margins to identify potentially relevant indicators of the experience of parents.
- ✓ The researcher used to read the transcribed text slowly, breaking it into smaller meaning units and put in the expressive line which will be grouped accordingly (emerging themes)
- ✓ The researcher organized emerging themes according to the study's objectives, develop and make them clear; move from abstract to concrete information.
- ✓ The researcher Identified key quotations to support each theme

➤ *Trustworthiness in Qualitative Data*

The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are "worth paying attention to" (Elo *et al.*, 2014). The investigator assessed trustworthiness through all phases by establishing five alternatives:

Credibility obtained by asking the same question to all participants during interviews and the results were discussed with research supervisor who is experienced in qualitative research techniques. Dependability was established by verbatim transcriptions of data recorded for analysis. Conformability was achieved by interviewing participants separately and the duplications of similar ideas verified that data saturation had been achieved. Transferability was achieved by a dense description of the demographics of the participants and the results of the in-depth interviews supported by direct quotations from participants.

➤ *Ethical Considerations*

Ethical clearance to conduct this study was obtained from CMHS Institutional Review Board (IRB) ethics clearance number CMHS/IRB/065/2017. The investigator also got permission to conduct the research study from UTHB. After obtaining approval letters, the investigator went at the field. The consent form was required before starting data collection; participants were informed about consent form, and sign before participating in this study. To sign consent was a sign of acceptance to participate in this study. Confidentiality was maintained during an interview and

during the discussion between investigator and supervisor; the researcher used codes in the place of participant's names. The parents were also assured by the investigator that they could withdraw at any stage without any consequences to them. All the parents participated voluntarily to the research study.

➤ Data Management

The given data were kept in personal computer with password and were used in analysis. After data analysis the interview schedule guides were kept till the dissemination of the results. After 5 years of study completion, the data will be discarded.

➤ Data Dissemination

Findings were disseminated in the University of Rwanda, College of medicine and health sciences and at CHUB where the study was taken place through the report.

➤ Problems of the Study

Due to lack of enough time and financial problem, it was not easy to carry out this study for the researcher. By hard

working and self-motivation, the situation was managed by the researcher.

➤ Limitation of the Study

In the qualitative study, the findings cannot be generalized (Anderson, 2010). This study was the one on this topic which was conducted in Neonatal Unit at UTHB, the literature review was limited. The Findings were not generalized to other population rather than those this study was conducted within.

V. RESULTS

➤ Demographics Data of Study Participants

All Ten participants in this study were parents whose premature babies were admitted in Neonatal Unit at Unit at UTHB during the time of study. Seven participants were females, three participants were males. They were between 18-41 years of ages. All participants did not have pre-history related to admission in neonatal unit.

Table 1 Participant's Demographic Data

Name	Age	Gender	Marital status	Number of children	Living children	Pre-existing history in neonatal unit	Occupation
Participant 1 (M1)	32	Female	Married	5	5	None	Farmer
Participant 2 (M2)	27	Female	Married	3	3	None	Government's Employee
Participant 3 (M3)	18	Female	Single	1	1	None	Student
Participant 4 (M4)	31	Female	Married	4	3	None	Farmer
Participant 5 (M5)	29	Female	Married	4	4	None	Farmer
Participant 6 (M6)	35	Female	Married	6	4	None	Farmer
Participant 7 (M7)	30	Female	Separated	3	3	None	Government's Employee/
Participant 8 (F1)	41	Male	Married	6	4	None	unemployed
Participant 9 (F2)	38	Male	Married	3	3	None	Private Employee
Participant 10 (F3)	40	Male	Married	4	3	None	Farmer

➤ Positive Experiences of Parents

In this study, 9 emerging themes were extracted from the interviews, 3 sub-themes and at the end 1 main theme, as they are in table 2.

Table 2 Positive of Experiences

Theme	Subtheme	Emerging themes
Support	Care provider's support	Communication Newborn's Care Teaching
	Partners' support	Partners' collaboration Encouragement Sharing system
	Family support	Income generation Spiritual and moral help Relatives' intervention

One theme which is support was identified to explain the positive experience of having a premature newborn in neonatal unit. It has three subthemes which are care providers support, partners' support, and family support.

➤ Support

Parents' positive experience was reflected in the theme of support in which the parents experienced and described how they were supported by care providers as well as the relatives. This theme has three sub-themes which are Care provider support, Partners support, and Family support.

➤ Care Provider Support

While Neonatal Unit care providers provided special care for premature newborn in hospital with an open communication, many parents struggled with limitations in their parental role. Parents' unfamiliar to the environment, caused feelings of anxiety, apprehension and exclusion and limit parents' ability to express their individual needs. Care providers help the parents to be familiar with neonatal unit as seven participants confirmed. Two of them said:

"I don't care my newborn every time because we visit our children only every three hours, are care providers who take care of our newborns and they explain more about neonatal unit environment. When the newborn have a problem, care providers inform us. We always feel free because care providers help us to take care of a our newborns" M4.

"The day that I reached in this service, care providers helped me, explained to me many things and told me that my baby is not able to breastfeed and that I will bring expressed breast milk every three hours. My baby came before and I came after him, they showed me my baby who was in incubator. They helped me a lot. They explained to me that nobody accepted to visit babies except their parents" F1.

➤ Partners Support

Participants reported that they experienced positive things from their partners, because they more helped, encouraged one each other and shared everything in that stressful situation as some of them reported:

"For sure, it is the first time that my husband helped me in bad situation. He helped me from district hospital until

now; he sent the money to use through mobile money. And today we talked and he said "continue to try, don't come back with the baby who has problems. I asked him if I can come back with the baby and he responded 'feel free', 'feel free' when the Nurse asks you something please call me. All those things helped me to release my problems" M2.

"my husband helped me a lot. Even if he doesn't work, he tried to help me. All time that I pass here, he bring the food, he goes to pharmacy to bring medication" M4.

➤ Family Support

During hospitalization of premature newborn, all parents reported that their families supported them financially, physically, morally and spiritually as some of parents said:

"My family helps me! My family members visited us others sent money. There is one who is here to help my wife because sometimes I go at my work, she stay here in my place. And she pass the night here, because me I pass night at home" F3.

"My family came to visit me, and they reassured me! I have only 1 sister. She is married, she has small children, she cannot stay here with me but she sent money to help me during hospitalization. In my family in low they visited us and they reassured and they played for us because one of them is a Pastor" F2.

➤ Negative Experiences of Parents

In this study, 39 emerging themes were extracted from the interviews, 9 sub-themes and at the end 3 main themes, as they are in table 3.

Table 3 Negative of Experiences

Theme	Subtheme	Emerging themes
Stress	Newborn outcome	Newborn appearance Fear of newborn's survival Unknown outcome
	Newborn death	Fear of newborn Death Past experience about newborn death Death for other newborns admitted
	Financial issues	Money Medication Hospitalization
Environmental challenges	Equipments	Fear of incubators Overwhelming of machines Fear of materials
	Sound	Noise from machines Noise from newborns cries Noise from care providers
	Light	Newborn rooms' appearance Newborn harmful death Anxiety related to brightness
Loss of Parental role	Separation	Early Touch Distance Isolation
	Responsibilities	Responsibilities at the hospital home responsibilities Care for other children
	Inadequate Information sharing	Language barrier Inappropriate information Fear of ridicule (laughed)

Three interrelated themes were identified to explain the negative experiences of having a premature newborn in neonatal unit: a) Stress, b) Environmental challenges, c) Loss of parental role.

➤ Stress

Participants reported that an admission of a premature newborn to the neonatal unit put parents in a stressful situation where they have fear of their newborn's life. This theme has three sub-themes which are newborn outcome, newborn death, and financial issues.

➤ Newborn Outcome

Participants showed that during pregnancy, the parents spend much time imagining how the newborn will look like and dreaming about the joys of parenting. But once premature birth occurs, the parents are usually unprepared for such premature event; the parents resulted with stress related to these newborns. parents presented the Distress related to neonatal physical appearance in neonatal units as some participants reported:

"I felt extremely afraid when my baby was admitted in this hospital, I was wondering that he cannot grow up well, because he was attached to many machines and he looked like someone who is not breathing. And I felt more afraid because it was my first time I gave birth to a premature newborn, and I was wondering that he can die" M5.

"Three things worried me after delivering a premature newborn: I first thought of my baby's life because any disease even small one could affect its life or lead to incurable illness. The other feeling is the society's perceptions around me." M4.

➤ Newborn Death

Parents reported that they had fear related to newborns death, they saw some of babies admitted in neonatal unit died, others had a previous experience from their neighbors about newborns death and it was a stressful event for them as some of participants said:

"Many babies died and their parents went home alone, today there in no improvement for my baby, he cannot breastfeed, we use a tube to give him milk and sometimes he vomit. Hum.....We think that he can also die. Doctor explained to us that there is a little chance to survive, because our baby was too small. He was 6 month!" F2.

"No, I was thinking nothing good. Because other babies were getting death every day, it was making me more worried that my baby could be next. So, I was thinking nothing good for sure. I only said 'God, please help me' every day" M3.

➤ Financial Issues

Participants responded that when they have a premature newborn admitted in neonatal unit, they have stress related to money needed to pay for different things such as medications and hospitalization as one parent said:

"The problem I think about at the moment is simply the money that i will pay. Nothing more, because my baby is on oxygen and they told us that oxygen is too expensive. This is now the third consecutive day he was on it. That is what I have been thinking about, how expensive the Oxygen costs, how long I will stay here and I felt sad because I was not able to know why the baby lasted longer on it, as they would ask me to pay a lot of money." M3

Despite mutual insurance facilities parents resulted with financial issues come from how long they asked to deliver medication, hospital structure, and the time spent in the hospital:

"The hospital is too expensive, they tell you to buy medicine, everything requires money, when you don't have it, they cannot help you anything, but when we have money, sometimes we find long queues at the finance unit where we make payments, while we are on under pressure to bring medicine for child health treatment" M5.

➤ Environmental Challenges

This theme with its three subthemes: Equipments, Sounds, and Lights show how participants respond to the physical environment, including the equipments, lights, and noises.

➤ Equipments

Participants described their first impressions of the Neonatal Unit, which is a small room with a lot of machines which makes them sad. They reported that the neonatal unit equipments were new, and to see those equipments were a shock for them. They spoke about the Neonatal Unit environment in general which were overwhelmed with machines and the equipment. Some participants emphasized on these:

"To see an incubator was a big shock to me, you know! To confront with the mixed equipment was a shock. My baby was attached to many machines. I was discouraged to see all those things. There is a small room with a lot of machines, those machine produce the noise during the day and during the night" M7.

"I was angry because my baby was very sick, he had too many machine around him, It was very difficult to inter in that area because of too many machine which are in neonatal unit".

➤ Sounds

All Participants reported that neonatal unit has different noises from machines and from newborns cries. The different alarms make them stressed, and they feel anxious when they are in neonatal unit. All those kinds of noise are a source of stress and fear.

"I looked in to the incubator; there was all kind of noises going on around you. You can't be concentrated because of that noise. It was my first time to be in neonatal unit, all babies cries at the same time, and machines produce a kind of noise. My baby cried but I was not aware who is crying, it was not easy to be there" M3.

"All things I saw here were to me! There is a mix of machines that make some kind of noise. They briefed me that nobody is allowed to visit the child except his parents, but they are not allowed to stay there every time either because of lot of machines" M4.

➤ Lights

Parents were separated from their newborns due to anxiety related to brightness; where newborns had their proper rooms with big lights switched on day and night. Parents reported that they could not sleep:

"It was a death! I touched on incubator and I said that they burn my baby. They give me a bed and I was supposed to bring the expressed breast milk, I felt isolated, like someone who has cardiac attack, who is going to vomit. I found the opportunity to pray and I asked God to switch of those lights for recovering my baby, then I continued to visit him" M3.

➤ Loss of Parental Role

This theme and its three subthemes: separation, responsibilities, and information sharing describe how the parent-newborn relationship is disrupted due to Neonatal Unit care providers as being the primary caregivers.

➤ Separation

Parents were separated from their newborns; they had their proper rooms while premature newborns were in incubators. Parents reports that they could not sleep well because they were separated from their newborns:

"I think the challenge I faced is... you see, when we are here we don't sleep well, we had a problem of accommodation and our newborns are in the other room. You know I was feeling the pain when I was taking the breast milk to the room.

"I thought how my child was struggling to get breast milk and end up feeling hungry, and I was worried that he is going to suffer, the way he would survive without food, and I was so worried" M5.

➤ Responsibilities

At the beginning parents were often spectators; their newborns were supported by Neonatal Unit care providers. Parents lose their role because their responsibilities were shifted to care providers as one of parents said:

"Care providers told us that they are the ones, who feed our newborns with breast milk. Not us. When we arrive there we tell the care provider to come and feed the newborn with our breast milk, then we return outside where we also wash our hands. In general, nobody is allowed to cross in that room the way s/he wants, when we arrive in it we only find Neonatal Unit care providers there" M2.

"I don't have any other person at home, responsibilities increased because I have to be here in the hospital and to be at home to prepare the food for my wife... Every day I feel tired."

➤ Inadequate Information Sharing

Language and cultural barriers were indicated to play a crucial role in the amount of stressors that parents experienced in having a premature newborn in Neonatal Unit, where language and cultural barriers prevented parents from accessing relevant information about their newborns as this participant said:

"Challenge is language barrier where Neonatal Unit care providers use the language in which we don't understand explained for what is going wrong with my child's

health. We do not completely understand what they talk about. I suggest that they can use Kinyarwanda for instance". M7.

Open communication was considered as a fundamental principle to successful parent centered care but it became a major challenge for parents with Neonatal Unit care providers Neonatal Unit care providers don't explain well the newborn's problems for the parents.

"Neonatal Unit care providers themselves told me, 'we are not sure of other problems that your baby have. But she is premature. Because the membranes was prematurely ruptured, we guess that your baby have infection.' M6.

VI. DISCUSSION

➤ Positive Experience of Parents

Considering the conceptual framework of the current study, based on the Parental NICU Distress model as proposed by Holditch-Davis and Miles in 1997, all ten participants of this study had no potential pre existing and concurrent personal and family factors related to prenatal and per natal experience of preterm birth and admission in NICU as pre-existing and concurrent personal and family factors.

Findings showed that parents had positive experience through partner's support, where during this study most partners were closed and helped each other. These are confirmed not only by Rissman and Gerstel that married individuals tend to report less psychological distress in stressful events than the unmarried and the married/stable cohabiting couples also have lower rates of utilization of health care facilities for example admission to hospital (Riessman and Gerstel, 1985). But also Levitt and colleagues (1986) and Coffman and colleagues (1990) found that support from the husband was significantly related to life satisfaction and emotional affect in wives and mothers.

Findings showed that the parents of premature newborns were supported by care providers through open communication and explanations of what is going to the newborn which made them confident to their newborns. Findings of this study are similar to the study conducted in Australia in 2008 by Grant about how nurses can support mother/infant attachment in the neonatal intensive care unit, where the result showed that in the area of mother- infants' attachment nursing, support were found to enhance the mother's maternal role, feelings of closeness, inclusion and confidence. This alleviated mother's anxiety and enhanced their confidence when interacting with their baby (Grant, 2008, p. 79).

➤ Negative Experience of Parents

The findings showed that main challenges in Neonatal Unit at University Teaching Hospital of Butare were manifested in environmental challenges, the appearance and behavior of the premature newborn, the distress from the interruption in assuming the parental role, the dissatisfaction, lack of interactions and communications with Neonatal Unit care providers. The results of this study were similar to

Duker-shriber's results on the study conducted in USA entitled parents stress in NICU for 162 parents, found that parents were stressed by the relationship of baby-parental role area, and regarding how the baby looked and behaved, where equipment and technology were representatives of the criticality of their infants' condition. When combining all of the factors that might impact on stress regarding the sights and sounds (Dudek-shriber, 2004, p. 519). The results showed that participants in this study were stressed by interconnected sights -sounds, physical appearance of the newborn and Neonatal Unit equipments. The results of this study were similar to the results of the study conducted by Carter et al, (2005) about "parental response in NICU" in New Zealand with 447 parents, showed that in a NICU, the baby is exposed to various forms of technology with disturbing sights and sounds. They are attached to many machines that measure heart rate and oxygen levels and these machines are leaved around them. The environment in a NICU could, therefore, become very overwhelming to the baby, and also to the parents. (Carter *et al.*, 2005, p. 112) Along with these issues, parents reported that they often experience difficulties feeling of disruption of the parental role with care giving competencies and communication concerns related to the care of the newborn. Underlining the importance of communication, the high demands placed on health care providers often result in a lack of time to communicate with the parents. This is related to the results of the study conducted on 6 mothers in Sweden by Lindberg and Öhrling, show that having a preterm infant is exhausting event, but most of the situation could be handled with support from the hospital staff, the infant's father and by obtaining knowledge about preterm born infants. Verbal communication between nurses and mothers helped the mothers feel confidence in the nurses and the care they were giving their infants (Lindberg and Öhrling, 2008, p. 468)

In this study findings show that the context of the Neonatal Unit, there was a potential delay in the parent and newborn attachment process, where Parents got distracted from the medical equipment, various forms of technology with disturbing sights and sounds, attached to many machines, around their newborns. Similar to the study done in Israel about the nature of the mother's tie to her infant on 91 mothers resulted that the immediate attachment occurs when the mother's feelings are positive toward the infant. This is more likely to occur if the mother is able to see the infant immediately after birth and when the physical contact occurs between the mother and the infant. It starts to develop early in pregnancy, appears to increase when fetal movements are felt, and intensifies when the infant is born and the parents are able to see, touch and care for their infant (Feldman *et al.*, 1999, p. 936).

Findings show that attachment was a multifaceted parent's experience that required early physical contact of the parents, their newborn in Neonatal Unit environment as showed in his qualitative study conducted in Brazil about Being a father of a premature newborn at neonatal intensive care unit, used twenty two fathers of premature newborns showed that all technological equipment creates a separation of a newborn who can't be held by the father which reduce

physical contact with their parents (Leite *et al.*, 2015, p. 415). Results of this study showed that essential technology in Neonatal Unit equipments with special lights and sounds these entire on newborn, parents become isolated and hesitated to their newborns' life, therefore Neonatal Unit becomes unfavorable environment for parental attachment. These had been also pointed out by Feldman et al; Leite et al ;Arnold where they found that early separation attributable to the infant's bio-medical complications, invasive medical treatments, as well as the anticipated loss of the newborn may result in physical and emotional distance between parents and their preterm newborn leading to poor parental newborn attachment. (Feldman *et al.*, 1999, p. 937, Leite *et al.*, 2015, p. 415, Arnold *et al.*, 2013). In this study, posttraumatic symptoms resulted in Neonatal Unit environment stressors where parents of premature newborn were more likely to experience high levels of distress that included anxiety, depression, and trauma symptoms like sleep and appetite changes, and feelings of anxiety, cardiac attack, heart attack, vomit and tearfulness due to parents' unfamiliar with neonatal environment, the same as Obeidat et al showed in their systematic review done about The Parental Experience of Having an Infant in the NICU that parents of infants admitted to the NICU experience stress, depression, anxiety, and feelings of powerlessness, hopelessness, and alienation within the environment of the NICU (Obeidat, Bond and Callister, 2009, p. 27).

Findings show that parents loose the parental role of being primary caregivers and became spectators due to the birth of a premature newborn and Neonatal Care providers support, the normal attachment process was suddenly interrupted. The pleasing physical contact with the newborn, the anticipated interaction, and the provision of development care were all delayed. These were correlated to the Phenomenological study conducted in Iran by Malakouti et al about mothers experience of having a premature infant in NICU on 20 mothers resulted that, Some mothers believed that although nurses took care of their infant well but they never could fill the place of mother for the infant (Devlin *et al.*, 2008, p. 177). The same view also to the study done in Sweden by Limberg et al on 6 mothers showed that is great importance for mothers to decide how much they wished to be involved in the infant's care. When mothers had to ask for permission to participate in their own infant's care, it resulted in feelings that the infant belonged to the staff. Mothers expressed concerns about whether their role as a mother had been affected by their early experiences of having a preterm infant (Lindberg, 2007, p. 468)

Findings showed that most parents were more helped by Neonatal Unit care providers information and behaviors from the beginning by taking care of their newborns in all needs like breathing, eating, eliminating of waste, immunologic protection including washing hands with water outside then entering the room, wash with hands sanitizer, wearing a yellow dress as well as teaching them how to express breast milk for their newborns and kangaroo care. Through open communication, by letting parents knew what was going on to their newborns, parents gained hope to their newborns safety and became more trustfully in Neonatal Unit

caregivers support. But due to newborn's special needs related to their illnesses where Neonatal Unit's care providers had to be concentrated with newborns themselves as specialists to the newborns illness' treatment, parents became frustrated with that often services. Parents became less trustful in Neonatal Unit care providers as parents visited their newborns every three hours wondering what Neonatal Unit care providers do to their dear newborns in the intervening time when they were not around. Thinking that whether the newborns had problems and they kept it a secret. They always felt worry where they were thinking their newborns could not be taken care as their mother who gave birth to them. These were found in the same point of view to the study conducted in Brazil about being a father of a newborn showed that the health care professional should identify difficulties in the transition to parental hood in order to perform specific intervention, helping them, especially in the case of premature birth and need for hospitalization in NICU. The hospitalization of a premature newborn becomes a crisis for parents filled with emotions. The experiences are diverse and complex. The role of health professionals is critical to minimize the negative feelings experienced by fathers and to help them live the child's birth experience, to have active listening attitudes to demystify fears and regrets, to inform about the usual procedures and involve fathers in the care of the child (Leite *et al.*, 2015, pp. 411–414).

Findings also pointed out that poor communication received from Neonatal Unit care providers about newborns illness, parents resulted in misunderstanding with Neonatal Unit care providers considering the long stay in hospital and their family's interaction. These were related to the study done in Sweden by Limberg showed that family life was affected in many different ways by having an infant born preterm.

Families could not spend time together, which resulted in parents longing for the rest of the family and experiencing a sense of loneliness. When the whole family was at the NICU and the infant's condition was stable, it was important for the family to be together without being disturbed by staff or others. The parents who had children at home described a longing for their older children, stating that it was hard to be away from them. They wanted to be at home yet at the same time they wanted to be with the infant at the NICU (Lindberg, 2007, p. 466). As part of conclusion, since the birth of a premature infant creates a sense of loss, attachment cannot be achieved totally until the parents have resolved their grief reactions and anxieties through Neonatal Unit care provider's support. As Mercer pointed out that Neonatal Unit caregivers are playing an essential role in supporting health to families and children (Mercer, 2004).

VII. SUMMARY OF FINDINGS

This study explored the lived experiences of parents whose premature newborns were admitted to the Neonatal Unit at UTHB. Findings revealed both positive and negative experiences that shaped parental perceptions, emotions, and involvement in newborn care. Positive experiences concentrated around the theme of support, which parents

received from care providers, partners, and family members. Care providers offered clear communication, reassurance, and education on neonatal procedures, while partners and extended family provided emotional, spiritual, and financial support that helped parents cope with distress.

On the other hand, parents also experienced multiple negative challenges. Stress was the most dominant theme, arising from newborn appearance, fear of death, uncertainty about outcomes, and financial burdens related to medication and prolonged hospitalization. Parents also faced environmental challenges, including overwhelming medical equipment, excessive noise, and bright lights, which intensified anxiety. Another significant challenge was loss of parental role, as parents felt separated from their newborns, unable to provide direct care, and highly dependent on nurses. Some parents also faced communication barriers due to language and inadequate explanations regarding their newborns' conditions.

Overall, the study revealed that while support systems strengthened parents' resilience, the NICU environment, limited parental involvement, and emotional burdens negatively influenced parent–infant bonding and parental wellbeing.

VIII. CONCLUSION

This study concludes that having a premature newborn admitted to the Neonatal Unit at UTHB is a deeply emotional and complex experience for parents. The findings demonstrate that while parents valued the essential care and guidance provided by nurses, the hospitalization period remained marked by fear, uncertainty, and psychological distress. The technological and unfamiliar NICU environment intensified parents' worries, particularly regarding the appearance and fragility of their newborns. Fear of death and unpredictable outcomes further contributed to emotional turmoil.

Parents consistently expressed feelings of separation and loss of control, as the neonatal care process required handing over their parental roles to healthcare providers. This shift often resulted in a perceived inability to fulfil expected parental responsibilities, which hindered bonding and confidence. Environmental stressors—such as noise, light, and medical equipment—also contributed to a sense of alienation within the NICU.

Despite these challenges, positive experiences emerged through the support of care providers, partners, and family members. Effective communication, reassurance, and educational guidance played essential roles in helping parents cope. The study ultimately concludes that strengthening family-centered care, improving communication, and increasing parental participation in care are vital for enhancing parental wellbeing, fostering parent–infant attachment, and ensuring better neonatal outcomes.

RECOMMENDATIONS (200 WORDS)

Based on the study findings, several recommendations are proposed to improve parental experiences and neonatal outcomes at UTHB.

First, structured psychosocial support should be integrated into routine neonatal care. Counseling services, emotional support sessions, and peer-support groups can help parents process fear, stress, and anxiety associated with premature birth and hospitalization.

Second, enhanced communication strategies are essential. Care providers should offer consistent, clear, and culturally sensitive explanations about newborn conditions, procedures, and progress. Using simple language, allowing time for questions, and providing written or visual information may reduce confusion. Language barriers should also be addressed to ensure parents fully understand the care process.

Third, greater parental involvement in newborn care is recommended. Encouraging parents to participate in feeding, kangaroo care, and routine caregiving activities can reduce feelings of helplessness and foster attachment. Creating flexible visiting schedules and promoting continuous parental presence would enhance bonding. Fourth, environmental modifications such as minimizing noise, adjusting lighting, and managing equipment alarms can ease stress on both infants and parents. Finally, the hospital administration should consider improving financial support systems, particularly for low-income families, as financial stress emerged as a significant contributor to parental distress. Implementing these recommendations will strengthen family-centered care and improve the overall NICU experience.

ACKNOWLEDGEMENT

I would like to express my sincere gratitude to all parents who generously shared their experiences and made this study possible. My heartfelt appreciation goes to the University Teaching Hospital of Butare for granting permission and providing a supportive environment for data collection. I am deeply thankful to the Neonatal Unit staff for their collaboration throughout the research process. Special thanks to my supervisor for continuous guidance, encouragement, and constructive feedback. I am also grateful to my family and friends for their emotional and moral support. Their understanding and motivation were essential throughout the completion of this work.

REFERENCES

[1]. Adama, E. A., Bayes, S. and Sundin, D. (2016) 'Parents' experiences of caring for preterm infants after discharge from Neonatal Intensive Care Unit: A meta-synthesis of the literature', *Journal of Neonatal Nursing*. Elsevier Ltd, 22(1), pp. 27–51. doi: 10.1016/j.jnn.2015.07.006.

[2]. Alves, E., Amorim, M., Fraga, S., Barros, H. and Silva, S. (2014) 'Parenting roles and knowledge in neonatal intensive care units: protocol of a mixed methods study.', *BMJ open*, 4(7), p. e005941. doi: 10.1136/bmjopen-2014-005941.

[3]. Anderson, C. (2010) 'Presenting and Evaluating Qualitative Research: Strengths and Limitations of Qualitative Research', *American Journal of Pharmaceutical Education*, 74(8), pp. 1–7. doi: 74(8):1-7.

[4]. Arnold, L., Sawyer, A., Rabe, H., Abbott, J. and Gyte, G. (2013) 'Parents' first moments with their very preterm babies: a qualitative study', pp. 1–8. doi: 10.1136/bmjopen-2012-002487.

[5]. Babore, A. (2015) 'The experience of premature birth for fathers: the application of the Clinical Interview for Parents of High-Risk Infants (CLIP) to an Italian sample', 6(September), pp. 1–9. doi: 10.3389/fpsyg.2015.01444.

[6]. Badnjevic, A., Gurbeta, L., Jimenez, E. R. and Iadanza, E. (2017) 'Testing of mechanical ventilators and infant incubators in healthcare institutions', *Technology and Health Care*, 25(2), pp. 237–250. doi: 10.3233/THC-161269.

[7]. Beck, S., Wojdyla, D., Say, L., Betran, A. P., Merialdi, M., Requejo, J. H., Rubens, C., Menon, R. and Van Look, P. F. A. (2010) 'The worldwide incidence of preterm birth: A systematic review of maternal mortality and morbidity', *Bulletin of the World Health Organization*, 88(1), pp. 31–38. doi: 10.2471/BLT.08.062554.

[8]. Blencowe, H., Cousens, S., Chou, D., Oestergaard, M., Say, L., Moller, A.-B., Kinney, M. and Lawn, J. (2013) 'Born too soon: the global epidemiology of 15 million preterm births.', *Reproductive health*, 10 Suppl 1(Suppl 1), p. S2. doi: 10.1186/1742-4755-10-S1-S2.

[9]. Blencowe, H., Cousens, S., Oestergaard, M. Z., Chou, D., Moller, A.-B., Narwal, R., Adler, A., Garcia, C. V., Rohde, S. S., Say, L. and Lawn, J. E. (2012) '15 Million babies born too soon', *Geneva: World Health Organization*, pp. 1–13. Available at: http://www.who.int/pmnch/media/news/2012/preterm_birth_report/en/index.html <http://www.ncbi.nlm.nih.gov/pubmed/15735596> <http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Born+too+soon:+The+Global+Action+Report+on+Preterm+Birth#0> <http://scho>.

[10]. Burns & Grove (2005) 'Practice of Nursing Research', 5, pp. 535–636.

[11]. Camarinha-matos, L. M. and Terminology, B. (2012) 'SCIENTIFIC RESEARCH Unit 2: SCIENTIFIC METHOD', pp. 2009–2012.

[12]. Candelori, C., Trumello, C., Babore, A., Keren, M. and Romanelli, R. (2015) 'The experience of premature birth for fathers: the application of the Clinical Interview for Parents of High-Risk Infants (CLIP) to an Italian sample', *Frontiers in Psychology*, 6(September), pp. 1–9. doi: 10.3389/fpsyg.2015.01444.

[13]. Carter, J. D., Mulder, R. T., Bartram, a F. and Darlow, B. a (2005) 'Infants in a neonatal intensive care unit:

- parental response.’, *Archives of disease in childhood. Fetal and neonatal edition*, 90, pp. F109–F113. doi: 10.1136/adc.2003.031641.
- [14]. Castoldi, F. (2015) ‘Impact of the preterm birth on Mothers and Fathers : an observational single center study Impact of the preterm birth on Mothers and Fathers : an observational single center study’, (April), pp. 1–2.
- [15]. Creswell, J. W. (2012) *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*.
- [16]. Devlin, J. W., Fong, J. J., Howard, E. P., Skrobik, Y., McCoy, N. and Marshall, J. (2008) ‘Intensive Care Unit’, *Critical Care Medicine*, 15(2), pp. 555–565. doi: 10.4037/ajcc2011243.
- [17]. Dudek-shriber, L. (2004) ‘Parental Stress in the Neonatal Intensive Care Unit and the Influence of Parent and Infant Characteristics.pdf’, *The American Journal of Occupational Therapy*, 58(5), pp. 509–520.
- [18]. Elo, S., Kääriäinen, M., Kanste, O. and Pölkki, T. (2014) ‘Qualitative Content Analysis: A Focus on Trustworthiness’. doi: 10.1177/2158244014522633.
- [19]. Fegran, L. (2008) ‘FAMILY AND CARER EXPERIENCE A comparison of mothers’ and fathers’ experiences of the attachment process in a neonatal intensive care unit’, pp. 810–816. doi: 10.1111/j.1365-2702.2007.02125.x.
- [20]. Feldman, R., Weller, A., Leckman, J. F., Kuint, J. and Eidelman, A. I. (1999) ‘The nature of the mother’s tie to her infant: Maternal bonding under conditions of proximity, separation, and potential loss.’, *Journal of child psychology and psychiatry, and allied disciplines*, 40(6), pp. 929–939. doi: 10.1111/1469-7610.00510.
- [21]. Gangi, S., Dente, D., Bacchio, E., Giampietro, S., Terrin, G. and M, D. C. (2013) ‘Posttraumatic Stress Disorder in Parents of Premature Birth Neonates’, *Procedia - Social and Behavioral Sciences*. Elsevier B.V., 82, pp. 882–885. doi: 10.1016/j.sbspro.2013.06.365.
- [22]. Gill, P., Stewart, K., Treasure, E. and Chadwick, B. (2008) ‘Methods of data collection in qualitative research: interviews and focus groups.’, *British dental journal*, 204(6), pp. 291–295. doi: 10.1038/bdj.2008.192.
- [23]. Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L. S., Howse, J. L. and Berns, S. D. (2011) ‘Family Support and Family-Centered Care in the Neonatal Intensive Care Unit: Origins , Advances , Impact’, *YSPEP*. Elsevier Inc., 35(1), pp. 20–28. doi: 10.1053/j.semperi.2010.10.004.
- [24]. Grant, J. (2008) ‘Getting connected : How nurses can support mother / infant attachment in the neonatal intensive care unit’, *Australian Journal of Advanced Nursing*, 27(3), pp. 75–82.
- [25]. Hebert, C. (2014) ‘Premature Birth and the Impact on Family Systems’. Available at: <https://beardocs.baylor.edu:8443/xmlui/handle/2104/8992>.
- [26]. Herbst, A. and Maree, C. (2006) ‘Empowerment of parents in the neonatal intensive care unit by neonatal nurses.’, *Health SA Gesondheid*, 11(3), p. 3–13 11p. doi: 10.4102/hsag.v11i3.232.
- [27]. Holditch-davis, D., Miles, M. S., Burchinal, M. R. and Goldman, D. (2011) ‘Maternal Role Attainment With Medically Fragile Infants : Part 2 . Relationship to the Quality of Parenting’, (December 2010), pp. 35–48. doi: 10.1002/nur.20418.
- [28]. Howard, C. L. and Stratton, J. A. (2010) ‘Maternal Role Attainment - Becoming a Mother’, pp. 1–8.
- [29]. Hunt, K. (2011) ‘The NICU: Environmental effects of the neonatal intensive care unit on infants and caregivers’. Available at: http://opensiuc.lib.siu.edu/cgi/viewcontent.cgi?article=1068&context=gs_rp.
- [30]. Husmillo, M. (2013) ‘Maternal Role Attainment Theory’, *International Journal of Childbirth Education*, 28(2), pp. 46–48. doi: 10.1111/j.1547-5069.1993.tb00791.x.
- [31]. Ionio, C., Colombo, C., Brazzoduro, V., Mascheroni, E., Confalonieri, E., Castoldi, F. and Lista, G. (2016) ‘Mothers and fathers in nicu: The impact of preterm birth on parental distress’, *Europe’s Journal of Psychology*. PsychOpen, a publishing service by Leibniz Institute for Psychology Information (ZPID), Trier, Germany (www.zpid.de), 12(4), pp. 604–621. doi: 10.5964/ejop.v12i4.1093.
- [32]. Knutson, A. J. (2012) ‘Acceptable noise levels for neonates in the neonatal intensive care unit’.
- [33]. Lau, R. and Morse, C. A. (2003) ‘Stress experiences of parents with premature infants in a special care nursery’, *Stress and Health*, 19(2), pp. 69–78. doi: 10.1002/smi.964.
- [34]. Lawn, J., Mongi, P. and Cousens, S. (2006) ‘Africa’s newborns – counting them and making them count’, *Opportunities for Africa’s Newborns*, p. 12.
- [35]. Leite, R., Ferreira, D. S., Christoffel, M. M., Estela, M. and Machado, D. (2015) ‘Being a father of a premature newborn at neonatal intensive care unit: from parenthood to fatherhood’, 19(3), pp. 409–416. doi: 10.5935/1414-8145.20150054.
- [36]. Levy, J. (2015) ‘HHS Public Access’, 42(6), pp. 641–654. doi: 10.1111/1552-6909.12255.Maternal.
- [37]. Lindberg, B. (2007) ‘Fathers’ experiences of having an infant born prematurely’, *Technology*, pp. 1–86. Available at: <http://epubl.luth.se/1402-1757/2007/60/LTU-LIC-0760-SE.pdf>.
- [38]. Lindberg, B. and Öhring, K. (2008) ‘Experiences of having a prematurely born infant from the perspective of mothers in northern Sweden’, 67(5), pp. 461–471.
- [39]. Al Maghaireh, D. F., Abdullah, K. L., Chan, C. M., Piaw, C. Y. and Al Kawafha, M. M. (2016) ‘Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit’, *Journal of Clinical Nursing*, pp. 1–12. doi: 10.1111/jocn.13259.
- [40]. Malakouti, J., Jabraeeli, M., Valizadeh, S. and Babapour, J. (2013) ‘Mothers’ experience of having a preterm infant in the Neonatal Intensive Care Unit , a Phenomenological Study’, 5(4), pp. 172–181.
- [41]. Mason, M. (2010) ‘FORUM: QUALITATIVE SOCIAL RESEARCH SOZIALFORSCHUNG

- Sample Size and Saturation in PhD Studies Using Qualitative Interviews’.
- [42]. McCann, D., Kenner, C. and Boykova, M. (2010) ‘NICU Nursing for the 21st Century’, *NeoReviews*, 11(1), pp. e18–e23. doi: 10.1542/neo.11-1-e18.
- [43]. Mercer, R. T. (2004) ‘Becoming a mother versus maternal role attainment’, pp. 226–232.
- [44]. Merighi, M. A. B., Jesus, M. C. P. de, Santin, K. R. and Oliveira, D. M. de (2011) ‘Caring for newborns in the presence of their parents: the experience of nurses in the neonatal intensive care unit’, *Revista Latino-Americana de Enfermagem*, 19(6), pp. 1398–1404. doi: 10.1590/S0104-11692011000600017.
- [45]. Moh (2014) ‘Health Sector Annual Report’, (July 2013), p. 64.
- [46]. Musabirema, P., Brysiewicz, P., Chipps, J., Africa, S., Africa, S. and Brysiewicz, P. (2013) ‘Parents perceptions of stress in a neonatal intensive care unit in Rwanda’, (Harvey 2010), pp. 1–8. doi: 10.4102/curationis.v38i2.1499.
- [47]. Obeidat, H. M. and Bond, E. A. (2009) ‘The Parental Experience of Having an Infant in the Newborn Intensive Care Unit’, pp. 23–29. doi: 10.1624/105812409X461199.
- [48]. Obeidat, H. M., Bond, E. A. and Callister, L. C. (2009) ‘The parental experience of having an infant in the newborn intensive care unit.’, *The Journal of perinatal education*, 18(3), pp. 23–9. doi: 10.1624/105812409X461199.
- [49]. Patton, M. Q. and Cochran, M. (2002) ‘A Guide to Using Qualitative Research Methodology’.
- [50]. Polit&Beck, et al (2012) ‘Nursing Research Generating and Assessing Evidence for Nursing Practice’, 13(6), p. e29. doi: 10.1016/j.nepr.2013.04.001.
- [51]. Psych, K. S. Bp. M. C. (2009) ‘No Title STRESS AND COPING IN FATHERS FOLLOWING THE BIRTH OF A PRETERM INFANT’, pp. 1–23.
- [52]. Riessman, C. K. and Gerstel, N. (1985) ‘Marital dissolution and health: Do males or females have greater risk?’, *Social Science and Medicine*, 20(6), pp. 627–635. doi: 10.1016/0277-9536(85)90401-0.
- [53]. Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L. and Ayers, S. (2014) ‘Parents’ views on care of their very premature babies in neonatal intensive care units : a qualitative study’, pp. 1–10.
- [54]. Sandelowski, M. (2000) ‘Focus on Research Methods Whatever Happened to Qualitative Description?’, pp. 334–340.
- [55]. Schappin, R., Wijnroks, L., Uniken Venema, M. M. A. T. and Jongmans, M. J. (2013) ‘Rethinking Stress in Parents of Preterm Infants: A Meta-Analysis’, *PLoS ONE*, 8(2). doi: 10.1371/journal.pone.0054992.
- [56]. Steedman, W. K. (2007) ‘Stress Experienced by Parents from the Neonatal Intensive Care Unit’, *Christchurch School of Medicine and Health Sciences*, Master of, p. 104.
- [57]. Steyn, E. (2017) ‘Lived experiences of parents of premature babies in the intensive care unit in a private hospital in Johannesburg, South Africa’.
- [58]. Takrouiri, M. (2003) ‘Intensive Care Unit’, pp. 1–6.
- [59]. Thon, K. N. (2013) ‘Supporting Parents of Premature Infants in the Neonatal Intensive Care Unit : A Manual for Practitioners’, p. 9.
- [60]. Trajkovski, S., Schmied, V., Vickers, M. and Jackson, D. (2012) ‘Neonatal nurses’ perspectives of family-centred care: A qualitative study’, *Journal of Clinical Nursing*, 21(17–18), pp. 2477–2487. doi: 10.1111/j.1365-2702.2012.04138.x.
- [61]. WANDA Barfield, M. (2015) ‘Public Health Strategies to Prevent Preterm Birth | Public Health Grand Rounds | CDC’. Available at: <http://www.cdc.gov/cdcgrandrounds/archives/2015/november2015.htm>.
- [62]. Whittington, C. (2011) ‘Parental perceptions of touch between parents and infants in the neonatal intensive unit.’, *Dissertation Abstracts International Section A: Humanities and Social Sciences*, p. 1095. Available at: http://search.proquest.com/docview/906333794?accountid=14836&nhttp://sfx39uvr.hosted.exlibrisgroup.com/sfx_univr?sid=ProQ:&issn=&volume=&issue=&title=Parental+perceptions+of+touch+between+parents+and+infants+in+the+neonatal+intensive+unit.&page=&date=20.
- [63]. WHO (2015) ‘WHO Recommendations on Interventions to Improve Preterm Birth Outcomes’, WHO, p. 98. Available at: http://www.who.int/reproductivehealth/publications/maternal_perinatal_health/preterm-birth-guideline/en/nhttp://www.ncbi.nlm.nih.gov/pubmed/26447264.
- [64]. Wigert, H. (2010) ‘Parental presence when their child is in neonatal intensive care’, (26). doi: 10.1111/j.1471-6712.2009.00697.x.
- [65]. Wurtman, R. J. (2009) ‘The effects of light on the human body.’, *Scientific American*, 233(1), pp. 69–77. doi: 10.1038/scientificamerican0775-68.