SOCIO-ECONOMIC AND PSYCHOLOGICAL CHALLENGES EXPERIENCED BY CAREGIVERS OF BABIES ADMITTED AT PRINCESS MARINA HOSPITAL NEONATAL INTENSIVE CARE UNIT GABORONE, BOTSWANA

By

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Declaration

I, Boineelo Ketshabathupa, hereby declare that the work presented in this study for the Master of Science Degree in Neonatal Nursing has not been presented either in wholly or part for any other Degree and is not being submitted for any other Degree.

Signed: _____Date: _____

Candidate

Abstract

The Neonatal Intensive Care Unit (NICU) has been denoted as a place of uncertainty, fear, anxiety and sorrow as the experience of having a baby admitted to the NICU is seldom unexpected, traumatic and demanding. Previous studies have discovered that families of NICU infants often experience various challenges following the birth of a baby requiring specialised care. Limited information is available in Botswana about the challenges encountered by caregivers during the period of NICU hospitalisation, as few local studies conducted mostly focused on difficulties faced by families of premature neonates. This study aimed to assess the socio-economic and psychological challenges experienced by caregivers of babies admitted to Princess Marina Hospital NICU, and explored their coping strategies. A descriptive phenomenological study design was used to assess those challenges. In-depth interviews with ten mothers of babies admitted, 5 fathers and 2 grandmothers were conducted in private rooms within the postnatal ward and others at their homes, who were not accessible at the study site (4 fathers and 1 grandmother). Purposive sampling with data saturation determined the sample size. 17 interviews were recorded and transcribed verbatim. Thematic analysis was conducted to identify themes in the data and 8 themes were extracted which included: the challenges of caregiving in the face of adversity, the struggles of caregivers amidst isolation and limited support, emotional and religious displacement in healthcare settings, cultural expectations and responsibilities of fathers in healthcare context, financial struggles and access to basic needs, healthcare staffing and service quality in neonatal care, the psychological struggles of caregivers amidst separation, stress and systemic challenges, as well as coping strategies. Findings revealed that the socio-economic and psychological challenges experienced by caregivers are complex and vary per family. Caregivers experiences were impacted by a range of factors including their proximity to the facility, the nature of their family relationships and support systems as well as their financial circumstances amongst others. Consequently, some facility issues exacerbated the challenges incurred by NICU caregivers and hence formed the most significant component of the study findings. The provision of social and emotional support can act in the best interest of not only caregivers but also lead to improved health outcomes for neonates. Measures including staffing consideration, incorporating FCC and regular training of staff are also mandatory to achieve sustainable and satisfactory neonatal care. Keywords: Neonatal Intensive Care Unit, Caregivers, Challenges, Healthcare Professionals, Experiences, Psychological, Social, Economic.

Dedication

I dedicate this study to my husband Mr Solly Kabo Ketshabathupa, my three children Tsoseletso, Motlodiwa and Omogolo Ketshabathupa. My mother Annah Motlhoki and my siblings for being supportive throughout my academic years as well as taking care of my children in my absence.

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List of Abbreviations

NICU	Neonatal Intensive Care Unit
PMH	Princess Marina Hospital
FCC	Family Centered Care
WHO	World Health Organization
PTSD	Post Traumatic Stress Disorder
UNZA	University of Zambia
UNZABREC	University of Zambia Biomedical Research and Ethics Committee
GPPF	Graduate Proposal Presentation Forum
NHRA	National Health Research Authority
NHS	National Health Service
SWD	Social Work Department
HCP	Healthcare Professional

CHAPTER ONE

1.1 Introduction

The NICU can be a place of fear and uncertainity, with very ill infants, intimidating technology and inconsistent communication from various medical staff, making it hard for parents to understand their baby's prognosis (Haward, Lantos and Janvier, (2020). The feature of the NICU often takes a psychological toll, and it is a complex experience for families (Riskin et al., 2022). Many parents who have had children in the NICU suffer from post-traumatic stress disorder, anxiety, depression and prolonged grief, whereas others develop resilience by adapting constructively to traumatic experiences (Malouf et al., 2021).

Green and Little, (2019) attest that the birth of a high-risk infant can cause intense emotional stress for families who may turn to religion or spirituality for support, even though the crisis can challenge their spiritual beliefs, and at the same time, it can also lead to spiritual growth and a deeper, more resilient faith.

Bry and Wigert (2019) emphasise that the stress of having a child hospitalised at the NICU has been well-established in research, among the major sources of stress and anxiety for parents are fear of their child's health, alteration in their parental role, the infant's behaviour and the highly technical NICU environment. Furthermore, they proclaim that it is not uncommon for parents in the NICU to experience severe enough stress to meet diagnostic criteria for acute stress disorder or post-traumatic stress disorder.

The mandate of this study, was to explore the socio-economic and psychological challenges experienced by caregivers of babies admitted at Princess Marina Hospital Neonatal Intensive Care Unit Gaborone, Botswana.

1.2 Background

The Neonatal Intensive Care Unit (NICU), is a hospital unit designed for the care of high-risk newborns aged between 0 and 28 days, who need highly trained healthcare professionals for the provision of intensive and specialised therapeutic care (Duate et al., 2020). Most premature and full-term newborns with particular need of care such as congenital anomaly, sepsis, maternal

diabetes, hypertension and necrotizing enterocolitis require hospitalisation in the NICU (Negarandeu et al., 2021).

The findings of the study conducted by William et al., (2018) highlight that the theme of NICU, physical environment and regulations encompasses everything from the physical characteristics of the NICU (i.e. medical machines and devices, alarms, hectic interactions with medical staff, distressed families) to the rules of the NICU and the manner in which they were enforced. The study supplements that, it became apparent through participant comments that explanations of medical equipment, their purpose and the meaning behind alarms and alerts helped greatly to relieve maternal stress (William et al., 2018)

In the NICU, parents need emotional and practical support during infant hospitalisation, friends and families of parents may constitute the most significant providers of this support, but few studies are available on when and how important others can be present and be involved in neonatal care (Flacking et al., 2022). Previous studies reveal that mothers experience a moderate level of stress and anxiety during hospitalisation of their newborn (Negarandeu et al., 2021). The impact of preterm birth and subsequent hospitalisation to NICU on maternal mental health is significant, and mothers are at an increased risk of postpartum depression, anxiety and post-traumatic stress disorder (Bieleninik et al., 2021).

Mothers are likely to experience social isolation due to prolonged hospital stays and limited family involvement in the NICU (Abukari and Schmollgruber, 2024). Cultural norms in Botswana assign significant roles to extended family members, particularly grandmothers in newborn care, including the naming ceremonies and daily caregiving tasks, hence NICU policies that restrict family access hinder these traditional practices, causing emotional distress among mothers who value familial participation in their infants early life (Nyaloko et al., 2024).

Findings of the study conducted by Lambiase et al., (2023) found that NICU hospitalisation significantly affects families financially, particularly those with infants facing adverse outcomes like premature birth. The study revealed that 36.1 percent of mothers and 20.5 percent of fathers had to leave their jobs, while 9.8 percent of parents were fired during the hospitalisation period.

In Botswana however, limited studies have been done concerning the difficulties experienced by caregivers of newborn babies admitted to NICU, hence the predicament of NICU families

during the time of admission remains unknown. Therefore, this study aimed to explore the socio-economic and psychological challenges experienced by caregivers of babies admitted at Princess Marina Hospital Neonatal Intensive Care Unit in Gaborone, Botswana.

1. 3 Statement of the Problem

Babies who are sick or born prematurely may need specialist care in the neonatal unit, however, this can be extremely distressing for parents as they are separated from their baby in an unfamiliar and overwhelming environment (Veenendaal, et. al., 2022). In 56 studies that involved more than 6000 mothers and their significant others globally, findings reveal that around 2 in 5 parents had anxiety (42 percent) or post-traumatic stress disorders (PTSD) 40 percent (McKeown et al., 2023). The findings of these studies highlight the importance of implementing globally standardised maternal screening for PTSD to identify parents at risk of distress following NICU experience.

Despite the aggravating affirmation of the NICU environment as a contributing factor to PTSD of caregivers of babies admitted to NICU, the rates at which this outcome occurs in Botswana are not well understood, and there is no evidence that the research population benefits from the psychological and social services available in the facilities. The researcher anticipate that psychological health screening and support will become a mandatory service, for caregivers whose babies are admitted to NICU through the conduct of this study.

A study conducted by Ncube, Barlow and Mayers, (2016) in Botswana, revealed that reduced access to NICU has been identified as a key barrier to fathers and other caregivers direct involvement in infant care. Additionally, the cultural beliefs and practices, negative perceptions held by the communities regarding the role of fathers in the care of infants, and the extent to which clinicians allow involvement of families in NICU, were found to represent a barrier to family engagement. However, its impact to caregivers remains unknown.

Guidelines for the successful implementation of family-centered care (FCC), are not available for the NICU, and little information is known about the provision of counsel and collaboration opportunities between healthcare professionals and families, hence the NICUs remain the most secluded units in Botswana facilities. Without structured FCC and counselling opportunities,

caregivers may experience heightened anxiety, fear and helplessness when separated from their newborns in the NICU. A lack of collaboration and clear communication between healthcare professionals and families can lead to misunderstandings, dissatisfaction with care and reduced trust in healthcare system. Furthermore, in the absence of formal guidelines, there is a higher risk that care approaches may not consider the cultural and social context of caregivers, which is crucial in diverse communities like those in Botswana. Therefore, the requisite to carry out this study to ensure timely and exceptional psycho-social support that expedites family welfare and collaboration.

Lambiase et al., (2023) describe the financial burden, as typically one's perceptions of the financial strain i.e. subjective pressures and economic challenges. According to Lokshmanan et al., (2022), several studies highlighted the financial burden experienced by families during NICU hospitalisation, however, its annotation is not clear. To the researcher's knowledge, hardly any studies examined the economic insults experienced by families of NICU graduate infants during hospitalisation in Botswana. The absence of economic data has the potential to limit the development of targeted social support programs and families may face significant hidden costs without recognition or assistance, pushing some into deeper poverty. To address these gaps, the mandate of this study was also to explore the direct and indirect costs as well as perceived financial burden of caregivers during NICU hospitalisation.

1.4 Justification

Understanding and addressing the socio-economic and psychological necessities of caregivers of neonates admitted to NICU; is important not only to ease the mother's distress during hospitalisation. It can also add to the best possible long-term outcome, for the infant and the caregivers at large. The World Health Organization (2018) outlines that, strengthening parents' skills and competencies in caring for their small, sick or high-risk infant reduces stress, anxiety and benefits the newborns' weight gain and neurodevelopmental progress.

Limited studies in Botswana have been conducted concerning the experiences of caregivers with infants in the NICU, and few studies executed, are centered on the experiences of mothers with very fragile or premature babies, but remain silent concerning the socioeconomic and psychological challenges experienced by overall NICU caregivers. The study explored the social,

economic and psychological challenges experienced by caregivers of NICU families during hospitalisation and identified their coping strategies during this difficult time with the aim of attaining improved neonatal healthcare outcomes.

The results of this study will further aid in preserving the good mental health status of caregivers by deducing strategies to strengthen and implement holistic care approaches that include the family at large (family centered care). Furthermore, the promotion of mutually beneficial partnerships among caregivers, and healthcare providers to support healthcare planning, delivery and evaluation as emphasised by the World Health Organization, (2018) will be fulfilled.

The significance of incorporating other health care departments like psychology and social services in providing holistic care to caregivers of babies in the NICU will be enhanced, hence become mandatory services provided in the NICU. Additionally, the findings of this study will help policymakers and stakeholders in reviewing policies and protocols that govern neonatal care in Botswana health facilities.

1.5 Research Objectives

1.5.1 General Objective

To explore the socio-economic and psychological challenges experienced by caregivers of babies admitted to the Neonatal Intensive Care Unit at Princess Marina Hospital in Gaborone, Botswana.

1.5.2 Specific Objectives

The specific objectives are:

1. To explore the socio-economic challenges experienced by caregivers of babies admitted to NICU at PMH.
2. To explore the psychological challenges experienced by caregivers of babies admitted to NICU at PMH.
3. To identify the coping strategies used by caregivers when their babies are admitted at PMH Neonatal Intensive Care Unit.

1.6 Research Question

1. What are the socio-economic and psychological challenges experienced by caregivers of babies admitted at Princess Marina Hospital Neonatal Intensive Care Unit?

2. What coping strategies do caregivers use when experiencing socio-economic and psychological challenges when their babies are admitted to NICU at PMH?

1.7 Conceptual Definitions

The key terms used in this study were conceptually defined as follows;

Neonate: A newborn infant, or a neonate is a child under 28 days of age (World Health Organization, 2023).

Neonatal Unit: a part or unit within hospitals that provides care for newborn babies between the ages of 0-28 days who are sick or born prematurely (before 37 weeks of gestation), i.e. with a medical condition that needs treatment, or at low birth weight (World Health Organization, 2018).

Neonatal Intensive Care Unit (NICU): Neonatal Intensive Care Unit, is the unit that provides care and specialised therapeutic care for complicated newborns, including premature and full-term newborns with a particular need of care. (Negarandeh et al., 2021).

Socio-economic: the relationship or position of an individual or group, which is determined by a combination of social and economic factors such as income, amount and the type of education, type of prestige of occupation, place of residence and in some societies or ethnic origin or religious background (Vocabulary.Com Dictionary, 2024).

Psychological: affecting or arising in the mind; related to the mental and emotional state of a person and it incorporates ways of thinking, perceiving, feeling and acting (Lahey, 2021).

Family-Centered Care (FCC): An approach to health care that emphasises respective collaborative partnerships between healthcare professionals and families of sick patients to meet their physical, emotional, social and developmental needs (Abukari et al., 2022).

Caregiver: A person who cares for people who need assistance taking care of themselves, examples include children, the elderly or patients who have chronic illnesses or are disabled. A caregiver may be a health professional, family member, friend, social worker, or clergy member. They may give care at home, hospital or other healthcare setting (National Cancer Institute Dictionary, 2019).

Challenges: the situation of being faced with something that needs great mental or physical effort to be done successfully and therefore tests a person's ability, stepping outside the comfort zone and taking on a new and difficult situation that requires determination (Cambridge Dictionary, 2021).

Experiences: Dieumegard et al., (2019) define experiences as an ongoing process that is known from within, they are active, passive, holistic and situated in a complex temporality and partly pre-reflective.

1.8 Operational Definitions

The key terms used in this study are defined as follows;

Neonate: A newborn infant or a neonate is a baby under 28 days of age.

Neonatal Unit: a part or unit within hospitals that provide care for newborn babies between the ages of 0-28 days who are sick or born prematurely (before 37 weeks of gestation) as defined also by World Health Organization, i.e. both sick and needs medical treatment or born with a low birth weight.

Neonatal Intensive Care Unit (NICU): a specialised unit within the hospitals that has specialist medical staff and equipment to care for premature and sick newborn babies. Another common feature of a NICU is specialised personnel who are trained to manage and take care of small and sick neonates.

Socio-economic: In this context, this entails the combination of social and economic factors that impact on daily lives of cargivers during hospitalisation. These can be income level, education, occupation, social class, access to resources or even living conditions. In some communities, the originality of an individual and religious background forms part of the socio-economic definition.

Psychological: Pertains to mental functions and processes, including cognition, emotion, perception and behaviour often studied to understand mental health and wellbeing.

Family-Centered Care (FCC): In this context, family-centered care is defined as hospital care that perceives relatives or caregivers as vital components of neonatal care. It goes to the extent of caregivers being allowed to take part in decision making and practically being there for both the mother and the neonate admitted to the Neonatal Intensive Care Unit.

Caregiver: In this context, refers to the mother admitted with the baby, the grandmother and the father who were rendering support to the mother by ensuring that her daily needs were met during the period of hospitalisation.

Challenges: Challenges can be defined as set of factors or problems that individuals or group of people encounter in various aspects of life. Life challenging situations that leads to emotional turmoil, and can positively or negatively impact an individual's life style in one way or the other.

Experiences: For the interest of this study, experiences refer to the subjective acumens, senses or apprehensions as well as sentiments or reactions narrated by mothers and their caregivers when having a neonate admitted to Neonatal Intensive Care Unit.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

In this chapter, the views or relevant information of previously conducted peer-reviewed or scholarly journals from electronic databases, textbooks and search engines like Google Scholar, Science Direct and PubMed; that are similar or related in content to the researcher's study were reviewed and critically analysed to identify gaps of knowledge, and exposing other crucial aspects that have always been omitted. This eventually helped in facilitating an understanding of the socio-economic and psychological challenges surrounding caregivers of babies admitted to the Princess Marina Hospital Neonatal Intensive Care Unit. However, it is worth noting that most literature consulted, has been conducted globally or regionally due to few studies conducted in Botswana concerning the phenomenon being researched.

2.2 Psychological Challenges

Parents of NICU babies experience high levels of stress, depression, anxiety and posttraumatic stress disorders (Erdei and Liu, 2020). Tasquit and Dil (2022),also attest that parents who experience stress are more likely to have disturbed social relationships and mood swings. Further parental stress can also affect the development of babies (Ganguly et al., 2020). The above studies support the claim that NICU parents are at an increased risk of psychological disorders due to the emotional trauma of having a critically ill newborn. The broader social effects, such as disturbed relationships and mood swings which are often overlooked in clinical care are highlighted. However, the above study findings lack nuance in various areas as it tends to generalise all NICU caregivers without acknowledging variability in individual responses to stressful situation during admission. Furthermore, while the findings implies a direct causal relationship betweeen parental stress and infant development, this relationship is likely caused by several contextual factors including socio-economic status and the availability of early intervention program (Maharlouei, et al., 2020) which were not explored in these studies, the more reasons why this study needs to be conducted to extapolate further the phenomenon of this study.

Stefana et al., (2021) denote the preterm birth and subsequent admission of a high-risk child to the neonatal intensive care unit (NICU); as a critical event for both mothers and fathers even in the absence of medical risk and injuries for the infant. Indeed, several studies have shown that parents of these infants experience high levels of psychological distress, with high fatigue, sleep disruption and reduced general wellbeing (Tasquit and Dil, 2022). During the prenatal and postpartum periods, mothers' and fathers' emotional states are significantly correlated and parental mental health affects self-efficacy and influences the quality of both parent-infant interaction and parent-infant attachment (Kiviruusu et. al, 2020). The authors'characterisation of the preterm birth and the subsequent admission of a high-risk neonate as a critical event for parents even in the absence of a direct medical condition, is a significant challenge that broadens the NICU caregiver trauma. However, there is need to strengthen the assertation by further acknowledging the protective factors and intervention opportunities which are not extrapolated in the above studies. Hence exploring the coping strategies employed by caregivers during NICU hospitalisation, remains a preliminary measure to ensure effective neonatal healthcare outcomes.

In a study conducted by Gibson et al., (2021) in which they explored the experiences of mothers in a neonatal unit and their use of the babble app; their findings largely suggest that mothers find managing their expectations and developing a sense of their motherhood particularly challenging in the context of the neonatal unit. Strong connections with family and staff and the importance of clear communication were identified as essential, in helping mothers manage throughout the admission. Mothers in the same study, emphasised the importance of information and utilised a variety of information-seeking styles, aligning with their individual needs. The babble app was seen by users as an essential adjunct to personally delivered information in the context of supportive relationships; and as a way to enhance relationships with other family members and friends through the sharing of information. However, while mobile apps have the potential to improve the burden of challenges experienced by NICU caregivers, digital access inequalities are still persistent (Jani et al., 2022). Caregivers with low socio-economic status in middle and low income countries like Botswana, may face challenges such as limited smartphone ownership, poor and unaffordable network connectivity or even low digital literacy (Muthelo et al., 2023). Without addressing these barriers, the mobile apps maybe unequally distributed, potentially reinforcing rather than reducing health disparities. The researcher as a means of addressing the

potential gap that can be brought by the suggested use of mobile apps find it essential for healthcare professionals to recognise the role of their relationships with parents, consider the individual needs and experiences of parents, and develop targeted support informed by the above perspectives and the empirical evidence that will be revealed by conducting this study to bringforth better supportive measures for caregivers.

Wang et al., (2021) also conducted a study reviewing the mother's experiences in the NICU and implications for clinical practice. They concluded that the NICU is not conducive to the formation of a mother-child bond, but a healthy bond can nevertheless be accomplished with the help of dedicated nursing staff who consider and commit to altering standard NICU nursing practice. The researchers provides a useful insight into the challenges of bonding in the NICU and the potential role of nursing staff in mitigating these challenges. However, several key elements are lacking when discussing support for the general NICU caregivers. The finding exclusively refers to mothers' experiences, ommiting the role of fathers and other caregivers (e.g grandparents), whose mental health and involvement are also critical to the neonate development and caregiver adjustment. Hence a more inclusive approach would acknowledge the challenges experienced by all caregivers . Furthermore, while the role of nursing staff is emphasised and very significant, the attestation fails to mention the contribution of other healthcare professionals such as psychologists and social workers amongst others. This gap can only be addressed by exploring the general social, economic and psychological challenges faced by NICU caregivers during the period of hospitalisation and understanding the impact of multidisciplinary collaboration to address emotional and practical needs of caregivers. Effective family centred care, involves collaboration among healthcare professionals including physicians, social workers and mental health specialists to address the diverse needs of NICU families (Shannon et al., 2024).

Ncube, Barlow and Mayers, (2016) in their attempt to explore the lived experiences of mothers with preterm infants, assert that mothers were shocked by the sudden birth of a preterm infant and found the neonatal environment intimidating. The study further reveals that the circumstances surrounding the preterm birth, increase the mothers' fear and anxiety leading to a delayed development of a relationship between mothers and their infants. Support from staff,

other mothers in the neonatal unit and family members according to Ncube, Barlow and Mayers, (2016) enabled the mothers to overcome their fears and developed an emotional connection with their infants. Additionally, the study outlines that on-going supportive communication with the mothers by healthcare professionals, promotes the mothers confidence and competence in caring for their preterm infants, which in turn promotes mother-infant attachment. Therefore the outcome of this study, captivate a need to explore further and include other mothers in the NICU, not only those with premature babies but also mothers of babies with different conditions, as their experiences might not be the same.

Stefana et al., (2021) study had two aims which were to explore fathers' experiences of supporting their partners and their relationship with their partners during their preterm infant's stay in the NICU, and to assess whether different profiles of the fathers' partnership experience could be identified from their interviews and eventually associated with any characteristics of the fathers and or their partners. The results were very compelling and added to the still scant literature on fathers' experiences during their preterm infants' hospitalisation in NICU. However, their findings were from one level III NICU located in Northern Italy and focused on a specific population (i.e., preterm infants in typical Italian nuclear families); hence these findings might not be generalisable to other settings or populations. By focusing only on fathers, the study misses the broader perspective of caregivers including grandparents, single mothers or non traditional family units that are potentially facing unique socio-economic challenges. Furthermore, the study does not highlight the parternal coping strategies nor address financial pressures that come with NICU admission e.g medical costs, transport expenses, loss of income from time off work or even the responsibility of caring for other children. The impact of the above mentioned challenges remains unknown in the context of tswana NICU families hence empirical evidence will be significant to help in mitigating challenges experienced by caregivers in a local context.

Several studies concede parenting in the NICU, as an agonising trek. In their study, Haward, Lantos and Janvier, (2020) attest that parents struggle to build intimacy with their children amid complex emotions and medical uncertainties, with the need to rapidly adapt their vision of parenthood to the realities of intensive care. This concept is also essential for parents of infants

in the NICU according to the above pronounced researchers, although they acknowledge the complexity of their path. It is worth noting that the researchers wrote as clinicians who were also families in the NICU. They suggest that parents with babies in the NICU, need to hear and internalise three important messages that overlap but are each important: that they are parents, not bad parents, but very good parents. Moreover, they offer practical suggestions to NICU clinicians that they believe will help NICU parents cope while their infants are in the NICU and afterward.

Valuable recommendations are made by Haward, Lantos and Janvier, (2020) as noted above, more especially that they depict true and felt emotions as experienced clinicians, who have vast knowledge, experience and understanding of the NICU environment, and at the same time had to take care of their high-risk neonates. However, they focused only on the psychological experiences of mothers. There is a need for further exploration into the social and economic circumstances of the mothers, as they (socio-economic challenges), can make it difficult for mothers to cope and not necessarily the baby's condition i.e. lack of social support and finances can be independent variables that aggravate the mother's psychological status. The clinicians might have gone through the emotional challenges of having a baby admitted to the NICU, but their socio-economic circumstances somehow might have helped them to cope better than those who are disadvantaged in the area, hence the study has its own limitations including elite biasness.

Klawetter, Cetin and Nicolaidis, (2022) acclaim that though NICUs generally share key elements, units are diverse and vary in size, level of acuity, environmental design, and service delivery structure. The presence of discrepancies, and geographically different catchment areas, further complicate the delivery of parent mental health support. Variability in service delivery structures implies that mental health and social support services are not uniformly available across all NICUs. Hence caregivers in low resourced units are likely to lack access to psychological counselling and social work support amongst others. Black, American Indian, Alaska Native, Hispanic families and families with low socio-economic positions are over-represented in the NICU in the above study. Additionally, most NICUs are located in cities but provide care for infants whose families may live in suburban and more distant rural areas, hence

rural or marginalised populations may be more affected by cultural barriers and lower health literacy compounding stress and limiting their ability to advocate for themselves. Conducting the study exploring the socio-economic and psychological challenges experienced by NICU caregivers, will add to the body of knowledge and acknowledging the gaps not addressed by previous studies. Furthermore, addressing these challenges might require NICU policy reforms that considers not only the infants' immediate clinical care, but also the financial stressors and emotional needs of caregivers shaped by geographical and socio-economic status.

Hearn, Clarkson and Day, (2019) submit that fathers are usually torn between work and family responsibilities, as the weight of social norms and expectations compel them to provide financially for their family; while also managing role identity expectations as a member of the family. The findings of the study, highlight fathers experiencing a conflict between the demand of work and the expectations of being emotionally and physically present within the family unit. This is intensified in the NICU setting where the enviromental stressors and the condition of the baby increase emotional strain. The authors further highlight that fathers feel more comfortable in the role of a financial provider, rather than in their role as NICU fathers, and reportedly feel that the NICU staff focus more on the mother of the infant, thus making them feel excluded. Social norms and values have historically constructed the father as the head of the family and the provider, and many have internalised this role, feeling a strong obligation to fulfill it, even at the expense of their emotional presence even during vital family moments like a baby's hospitalisation (Trivedi and Bose, (2018); Bitalo, Piotrowski and Naudé (2024). Even though this is a well known attestation, unfortunatly, there is no local empirical evidence that speaks to the above challenge incured by fathers. In general, there is a need for a more inclusive approach in the NICU, that actively acknowledges and supports paternal involvement hence the need to conduct the study encompassing the social, economic and psychological challenges experienced by general NICU caregivers to mitigate these challenges.

The responses of the fathers from the study above, are a clear indication that there is a lot that needs to be executed to incorporate fathers in neonatal care. Their significance in improving the wellbeing of the mother and the baby during NICU admission remains unexplored, hence they are not equipped with enough information on their importance during this crucial period.

Moreover, previous studies intended to explore fathers' experiences in the NICU resulted in analysing some needs while other necessities were omitted. It is necessary to take into consideration that these studies were mostly conducted outside Botswana where practices, structures, settings and community influence may be different.

In their study on parenting self-efficacy in fathers of medically complex infants, Vance, Costa and Brandon, (2021) also offer clinical implications for fathers who have an infant with complex care needs. They conclude that fathers' self-efficacy scores were consistently at or below the clinical risk range indicating low confidence in their parental role. The study provides a valuable insight into the under researched area of parenting self efficacy among fathers of medically complex neonates, addressing an important gap in neonatal and paternal mental health literature. One of the study's major contributions is its emphasis on clinical implications as it draws attention to consistently low self efficacy scores observed in fathers, suggesting a heightened risk of psychological distress and challenges in adjusting to the parental role under stressful medical circumstances.

However, a significant limitation lies in the lack of qualitative depth regarding fathers' lived experiences. While the study quantifies self efficacy, it does not sufficiently explore the specific challenges or unmet needs of fathers during NICU admission. This is a critical ommision as contextual factors such as work responsibilities, emotional support systems, and gender norms could play a pivotal role in shaping paternal confidence and engagement. Therefore, it would be beneficial to conduct a study that include fathers and capture their voices , contextual pressures and personal narratives to better inform supportive clinical practices.

2.3 Socio-Economic Challenges

Namasuke et al., (2021) study findings revealed that when a baby is born, there are expected expenditures that many new mothers will prepare for, however, it is hard and expensive to envisage preparing for a preterm baby who has uniquely expensive needs in terms of time, care and emotions. The study further highlights that many mothers were worried about how they would meet their financial obligations to the baby and those that they were taking care of before they delivered the preterm baby. Mothers were faced with financial challenges as they looked

after their preterm babies. These challenges were worse in financially constrained populations in a low-resource setting.

A key strength of Namasuke et al. (2021) study is its recognition that while most mothers anticipate standard postnatal expenses, preterm births introduce an unplanned and overwhelming financial strain due to the specialised and extended care these infants require. This insight is especially valuable as it brings attention to a frequently overlooked dimension of neonatal care; the socio-economic toll on mothers. The study also appropriately situates these challenges within the broader context of economic inequality, noting that mothers in financial constrained populations just like in Botswana, incur disproportionate financial burden thereby highlighting how preterm births can exacerbate existing vulnerabilities and potentially trap caregivers in cycles of poverty and stress. However, while the study identifies the financial stressors and emotional implications, it appears to focus predominantly on the outcomes. A limitation is the lack of analysis on coping strategies, social support systems or policy responses that might alleviate these financial insults. Additionally, while the study reveals mothers' experiences, it has missed an opportunity to explore how family dynamics, community influence and fathers involvement play a role in managing these financial and caregiving challenges. Therefore, there is a need for greater inclusion of social support and exploring holistically interventions to support caregivers more effectively.

Namiiro et al., (2023) also proclaim that literature on care and economic implications following preterm birth is scarce, and the available information is mainly from the developed countries. The authors further highlight that the data available, is mostly on direct costs of preterm delivery which are health care related and focused on the health care providers' perceptions, while the indirect cost of care has no monetary value tagged to it because it is hard to measure and thus unpriced. This implies that findings may not be generalisable or relevant to others countries with different healthcare systems, economic structures or social support networks. The scarcity of research available on the subject, suggests a need for more comprehensive studies like the present study especially in low and middle income countries like Botswana where data is even more sparse. Additionally, the direct costs of preterm care are relatively easy to quantify and often based on billing or healthcare charges while unfortunatly, there is neglect of indirect costs

like loss of parental income due to caregiving, long term developmental support or even transportation which are largely unmeasured, but have the potential for long term significant impact on caregivers.

In another study conducted in Ethiopia, findings revealed that Ethiopian NICU parents faced financial challenges due to transportation fees because many are from rural areas while the NICUs were located in cities and big villages. Additional costs were encountered when the need arosed to bring food, and water outside of the hospital, buying drugs and paying for laboratory investigations at private pharmacies and clinics, as some drugs and laboratory investigations were not available in the public hospital (Yassin, Legesse and Hailu, 2023). The study highlights the need for out-of-pocket necessities including food and water during NICU hospitalisation. The situation is further exacerbated by the inadequacy of public healthcare facilities where essential drugs and diagnostic services are often unavailable, forcing families to seek expensive alternatives in private pharmacies and laboratories.

Despite the widespread acknowledgment that there is a financial burden incurred by caregivers during NICU hospitalisation, hardly any studies exist that have unearthed the nonmedical expenses or even further, the classification of expenses sustained by NICU caregivers in Botswana. The lack of data specific to Botswana implies that policymakers lack the necessary evidence to develop supportive interventions or financial protection mechanisms for affected caregivers. This gap underscores the importance and relevance of the current study which aims to explore the expenses borne by NICU caregivers, hence contributing to a more comprehensive understanding of the economic impact of NICU hospitalisation and can inform policy development and healthcare planning to better support vulnerable caregivers.

2.4 Cultural Factors

In Botswana, the common setting is that traditionally the mother is the primary caregiver during confinement, while relatives have very limited access (Ncube, Barlow and Mayers, 2016). In their study, Rempel et al., (2019) outline that in most Tswana cultures, botsetsi (confinement) involves the presence of an older female who cares for the newborn and supports the new mother (motsetsi) to heal and rest during the first weeks or months of the baby's life. The baby's maternal grandmother is usually expected to take care of motsetsi in the case of the first baby. For subsequent babies of a married couple, the baby's paternal grandmother is expected to take

charge. Mother and baby are either moved to the grandmother's home or the grandmother comes to stay with the new parents. Sometimes this means that the father has to move out of the bedroom or the house to give way to the grandmother. The power of culture is so strong that even healthcare professionals are not fully accepting of fathers playing roles traditionally considered feminine (Rempel et al., 2019). Traditionally, caregiving and nurturing have been seen as feminine roles, and despite the evolving of family structures these practices still persist. Notably, previous local studies have remained largely silent on this subject, failing to explore how cultural perceptions impact the involvement of fathers in neonatal care during the period of hospitalisation. This silence points to a significant gap in local research and underlines the urgent need for more inclusive studies that address the evolving roles of fathers in caregiving.

The researcher has noted that despite increasing evidence of the significant role fathers play in neonatal care, cultural norms and beliefs continue to hinder efforts to improve health outcomes particularly for infants in the NICU.. The effects of these traditional customs on NICU caregivers remain poorly understood . Many communities lack adequate information, and while some are resistant to change, others are not necessarily uninterested, but are instead constrained by the absence of tangible, locally grounded evidence that promotes informed neonatal healthcare practices over long standing cultural beliefs.

2.5 Religious Factors

Berlsford and Doheny, (2022) purport that the birth of a child is often accompanied by elation and celebration, but when a birth results in admittance to the Neonatal Intensive Care Unit, the typical emotions of joy and celebration may be tampered by feelings of anxiety and fear. Parents with a religious and spiritual worldview may find that their faith and spiritual lens are important aspects of coping with their NICU experience. Genstler et al., (2022) study findings revealed that many sentinel articles on spiritual care were published several decades ago, leaving many wondering if the results from those studies are still applicable, given the values and cultural shifts in society. Furthermore, most of these studies do not elucidate to what extent religion and spirituality help NICU caregivers cope with circumstances surrounding NICU admission, hence a prerequisite for more studies to annotate how this area can be strengthened and successfully implemented for families during this difficult period.

A study involving 101 NICU parents found that acceptance, emotional support, active coping, positive reframing and planning were frequently used coping mechanisms (Huenink and Porterfield, 2017) . The study reveals the above as the strategies that were commonly used as coping mechanisms for NICU parents. However, the study mentions only a few coping strategies. The demographic, cultural or socio-economic factors that could impact coping are not mentioned. Caregivers' strategies may differ based on background, support systems or even mental health history, and the impact of the mentioned coping mechanisms on parental wellbeing is also not discussed.

2.6 Conclusion

From most literature reviewed, caregivers' socio-economic and psychological challenges remain under study yet are crucial aspects. The majority of studies globally focused on the experiences and emotional challenges of mothers with babies in the NICU, especially those with vulnerable or babies born with low birth weight or prematurity.

However, other caregivers also feel the reality and even have their share in the emotional turmoil and challenges of the NICU experience (Aubel, 2020). Hilary, (2022) contemplates that grandmothers, for example, are often invisible during the birth of a high-risk baby and the NICU restrictions can create an imbalance of whether they are or not significant. Hence was the need for this study to be conducted to uncover the perspectives of different caregivers concerning the challenges they faced during the NICU admission, thereby improving the outcome of the babies admitted to NICU and their families.

Understanding the perceptions and experiences of caregivers is vital in implementing effective FCC, as it provides insight into their needs, expectations and challenges. Although studies are emerging on the experiences of these significant family members, usually samples of them are not from diverse socio-economic, racial, or ethnic communities or populations which leads to the findings of the studies not being generalisable, hence limiting the execution of the recommendations in NICUs of low socio-economic and developing countries like Botswana.

Furthermore, even though the need and benefits of establishing and implementing family centered care approach in the NICUs have long been established by previous studies and World

Health Organization (WHO), there seems to be no change in the clinical area as NICUs remain highly restricted areas in Botswana, the models of care that involve families in the care of NICU infants are unclear and the benefit of FCC in NICU remains misunderstood.

Some of the challenges in promoting family centered care have been linked to the long standing practices and beliefs established during the early establishment of NICUs. The mandate of this study was also to establish a better and more tolerable NICU environment that will enhance improved health outcomes for babies and their caregivers.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

A research methodology is an implementation of steps and procedures for collecting data, analysing and interpreting data collected during the conduct of the study (Willie, 2024).The purpose of this chapter is to outline and justify the research design that was employed in this study i.e. descriptive phenomenological study design. Descriptive in the sense that the researcher took the phenomena (socio-economic and psychological challenges experienced by caregivers in the NICU); uncovered relatively unknown experiences of the study participants and even found meaning attached to those experiences. This chapter comprises the study design, study setting, study population, sampling method, data collection tool, data collection technique, data analysis, data storage and management as well as ethical considerations.

3.2 Study Design

The study utilised the descriptive phenomenological study design, using in-depth interviews and observations to explore socio-economic and psychological challenges experienced by caregivers of neonates in the NICU at Princess Marina Hospital.

3.3 Study Setting

The study setting was the Princess Marina Hospital Neonatal Intensive Care Unit, one of the two national referral hospitals, consisting of the largest neonatal intensive care setting in the Southern region of Botswana. This NICU receives the high-risk and sick neonates referred from the labour ward and operation theatre in PMH as well as external or from home and all local clinics and surrounding district hospitals in the Southern District of Botswana, which is its catchment area. It is a 39 bed unit, consisting of six intensive care unit (ICU) beds, ten beds for premature infants, six beds for feeder-grower neonates and 13 beds for full term infants. The unit functions above the required capacity half (50 percent) of the time .This NICU receives total admissions of approximately 1200 per year (Gezmu et al., 2020). The hospital was chosen as a research site since it is a high volume government run health facility in Botswana serving all patients regardless of their socio-economic status.

However, due to their different circumstances, some participants/caregivers were followed to their respective homes where interviews were conducted.

3.4 Study Population

The study population represents the entire group of interest meeting study criteria (William, 2024). The study population involved mothers whose babies were admitted to the Neonatal Intensive Care Unit at Princess Marina Hospital. The study also incorporated significant family members, i.e. grandmothers, aunts and fathers, who were at the forefront of rendering support to the mothers during the period of hospitalisation.

3.5 Target Population

A target population as defined by Willie (2024) is a specific sub-group within the population that possesses the qualities or experiences of interest to the study. The target population for this study were caregivers that is, the mothers, fathers of the baby, grandmothers, aunts or anyone significant who had a mutual relationship with the mother, taking care of the mother and the baby by ensuring that all their daily needs were met during the period of hospitalisation at Princess Marina Hospital Neonatal Intensive Care Unit.

3.6 Accessible Population

The accessible population for this study was the equivalence of the target population mentioned above, which was practically accessed during the time of conducting the study. This comprised the mother or father of the neonate admitted to PMH Neonatal Intensive Care Unit and grandmothers who came during stipulated visiting times as per the hospital protocol. Some were followed to their respective homes where interviews were conducted.

3.7 Sampling Technique

The study employed purposive sampling of caregivers of babies admitted to the Princess Marina Hospital NICU. Purposive sampling, according to Campbell et.al., (2020) enables the researcher to better match the sample to the aims and objectives of the research, thus improving the study's rigor and the trustworthiness of the data and the results.

3.8 Identification of Participants

Access to the study participants was negotiated with the head of unit and on-duty staff within Princess Marina Hospital NICU and the postnatal ward where mothers were lodging. Mothers were consulted for the involvement of their caregivers, i.e. when they expected them to visit and phone call appointments were made with five of them, four fathers and a grandmother, who were not accessible at the study site during the time of data collection. Hence interviews were conducted at their homes in places that incorporated Tlokweng, Mogoditshane and Tsolamosese.

3.9 Sample Size Determination

The sample size was based on data saturation. The concept of saturation is one of the most important aspects of qualitative research and it is a criterion for stopping data collection, hence an indicator of whether a sample is sufficient for the phenomenon under study (Rahimi and Khatooni, 2024). Since the purposive concept was executed as a sampling technique, the participants were selected based on their capability to provide rich, textured information relevant to the phenomenon under study, as annotated by Vasileiou, et al., (2018), making sample size determination using saturation sensible. Hence saturation was a determining factor for sample size in this study.

3.10 Data Collection Technique

The study was conducted between a period of July and early August 2024. Two assistants, one a final year Bcs Nursing student and the other a graduate, both previously trained and experienced in conducting research, were engaged to assist with data collection.The interviews were conducted in quiet and private rooms within the postnatal unit and others at participants' homes. 15 interviews were conducted in Setswana while two in English language. Individual in-depth interviews were used to unveil the experiences of caregivers when their babies were admitted to Neonatal Intensive Care Unit. Rutledge and Hogg, (2020) attest that this strategy is significant for obtaining detailed information that sheds light on caregivers' perspectives, experiences, feelings, and the derived meaning of the phenomenon of study. Hence in-depth interviews were employed.

Rapport, a relationship that is built on mutual interest, support, and understanding, (Horsfall et al., 2021) was established as a way of easing anxiety and building trusting relationships between the researchers and participants. The study's mandate was elaborated during the recruitment period to the participants, who were assisted with signing the informed consent before the interviews. Copies of the information sheet and signed consent forms were also given to each participant for future reference and inquiries. 17 interviews were tape recorded and field notes were also written. Reflective notes were captured to further aid in data analysis during interviews which lasted between 12 and 32 minutes. Verbal and non-verbal prompts were contemplated during observation. The typical observation focused on a distinct behavioural feature portrayed by participants' such as smiling, crying, laughing and even accent articulation**.** Data was collected until all significant insights were exhausted and no new information emerged.

3.11 Inclusion Criteria

Mothers who met the following criteria were included in the study; 18 years old and above. The age of majority or threshold of adulthood in Botswana is 18 years, at which point a person can assume full legal capacity according to the law (Government Gazette Extraordinary, 2020). Mothers of babies who had been admitted for at least seven days and above, with the assumption that they had an exposure to NICU long enough to narrate their true experiences, stable or babies who were initially sick but had improved in due course, first time mothers. Caregivers (fathers and grandmothers) who were staying with the mother or rendering support during hospitalisation.

3.12 Exclusion Criteria

Sick mothers, those whose babies were re-admitted to the unit following discharge, and mothers who delivered at home or before arrival at the health facility. Mothers of babies with newborns on end-of-life care and severe congenital anomalies that were not compatible with life were also excluded from the study as they may had needs that were very specific to their situation.

3.13 Data Collection Tool

The data collection tool used was an in-depth questionnaire (Appendix III), structured according to the phenomenon of interest, and was used to assess the socio-economic and psychological

challenges experienced by caregivers when their babies were admitted to Neonatal Intensive Care Unit, at Princess Marina Hospital Gaborone, Botswana. The in-depth interview guide consisted of primarily open ended questions that were structured by the principal investigator, taking into consideration the qualitative nature of the study, and included topics on the social, economic and psychological challenges that caregivers might have experienced. The questions were structured in English, translated to the native Setswana language and back translated to English by a bilingual, sworn and accredited translator (see Appendix VI).

Different sets of questions (along with their probes) were structured for mothers and other caregivers respectively, since their experiences would be different. The interviews for example, commenced with the question followed by probes:

"Can you describe your baby's condition and recount the reasons why he/she is admitted to the NICU?

- What are your perceptions or experiences of having a baby admitted to the Neonatal Intensive Care Unit?
- Can you narrate your feelings when you were shown your baby immediately after delivery? Have you encountered any change of feelings since then?

The probe questions encouraged the participants to elaborate more on the phenomenon under study, and the researchers were not limited by the scripted probes and hence had a chance to probe further and by repeating the participants 'words' to confirm if they meant what was captured or documented. More clarification was sought whenever the researchers felt there was more to what the participants were conveying i.e. in case of any trails singled out in the conversation. Robinson, (2023) proclaimed that probing achieves access to the extra level of detail and depth via verbal prompts to clarify, elaborate, illustrate or explain a prior answer to an interview question that the participant has already given. Therefore by employing the use of probes, a lot of insights were obtained that were significant for answering the study questions.

3.14 Pilot Testing

Pilot testing of the study tool was conducted at Scottish Livingstone Hospital Neonatal Unit, Molepolole Botswana. The piloting was repeated at the study facility where the first participants interviewed were excluded from the study. The number of participants can vary from 2- 5 or can be above 20 as well, depending on the complexity of the topic under investigation, level of expertise, time and resources available to the researcher (Ayesha and Khan, 2020). Therefore, a total of four participants were recruited for pilot testing of the study tool. The tool was revised following the pre-test as responses to some of the questions were repetitive, leading to saturating within the first few responses. Consequently, some questions were merged and others removed from the questionnaire. Ayesha and Khan, (2020); Majid et al., (2017) attest that pilot testing helps the researcher especially novice researcher to have some practice in interviewing and to be able to refine the final road map for the main study.

3.15 Bracketing

Throughout the conduct of this study, bracketing was guardedly enforced. This process ensures that the researcher temporarily suspended his/her own beliefs, biases and subjective interpretations. Additionally, this further guarantee that the participants' beliefs and the research material are not obscured or distorted by the researcher's inclinations or biases (Dörfler and Stierand, 2020). Thomas and Sohn, (2023) encourage the researchers to maintain notes from ongoing reflection sessions, which should be incorporated into the ongoing journals until the conclusion of the research. The researchers documented their ongoing insights about data and continued self discovery. This left some room for reassessment and addressing any apparent prejudice. The documents were treated as part of the audit trail giving account of how decisions were made during the study. The study also involved a peer review process and scientific analysis of findings that reinforced the trustworthiness of the study. A literature review was conducted post data collection and analysis, and an audit trail was also carried out by supervisors.

3.16 Trustworthiness of the Study

The aim of investigating the trustworthiness of this qualitative research was to ensure that the study expressed the experiences of the participants exactly as they were relayed. Lincolin and Guba's 1985 trustworthiness criteria was applied to ensure the rigour of the study. This comprised the study's credibility, transferability, dependability, and conformability.

3.16.1 Credibility

Credibility means that the data collected is accurate or representative of the phenomenon under study (Applied Doctoral Centre, 2024). Different participants with diverse attributes concerning age, race, gender, marital status, level of education, and religion were included in the study.

Prolonged engagement with the data was executed instituting a virtuous rapport that enhanced trust with participants. A semi-structured interview was steered by interview questions along with constant observations which were employed to obtain in-depth data. Peer debriefing with co-researchers during data analysis to confirm findings by presenting to them and receiving their comments to improve the data quality also was implemented. Several sources of information, including peer-reviewed journals, books, and search sites were consulted and utilised for guidance. McKenna, (2022) attests that peer review involving external review of audit trail activities and the use of multiple sources of data to facilitate triangulation are also recognised means for managing rigor and expected processes reported by researchers.

3.16.2 Transferability

To reinforce the study's transferability, the study design, data collection, interpretation processes and detailed depictions of the study are clearly outlined. A comprehensive audit trail that can provide a guide for conducting further related studies by other researchers was also executed. Therefore, providing rich descriptions of experiences as narrated by participants, and a purposive sampling technique enhances the transferability of the study.

3.16.3 Dependability

Peer debriefing, audit trial and listening to the audio recordings of the interviews, both verbal and non-verbal data, were verbatim transcribed and saved appropriately to cross check the whole process of the study and maintain the consistency of the interpretations. Furthermore, to reduce preconceived personal bias, the whole process of the research, data collection, data analysis, and reporting of the findings were done using scientific procedures.

3.16.4 Confirmability

Confirmability of qualitative data is assured when data are checked and rechecked throughout data collection and analysis, to ensure the possibility of the results being replicated by others. This was guaranteed by a clear coding schema that identified the codes and patterns identified in analyses (Dissertation Centre, 2024). Peer debriefing, member checking, and reflexive journaling were also ensured.

3.17 Data Management and Storage

Permission from participants was sought for audio recordings that were captured. Listening to the recordings was ensured and notes were written down. Transcription of keywords, phrases and statements was done as recordings were repeatedly played. To avoid instances of forgetting some information during the interview process, the researchers also took observational field notes to retain the data gathered. All data was verbatim encrypted and is stored safely in a pass worded computer and lockable cupboard (for field notes, consent forms and in-depth interview scripts) and will be retained for at least two years after the completion of the study.

3.18 Data Processing and Analysis

The conducted interviews were verbatim transcribed immediately after the interviews were conducted to single out errors when the interviews were still ongoing. Translation to English for interviews conducted in Setswana language was done, and checked for precision by colleagues fluent in both languages. McMullin, (2023) attest that transcripts are vital for assisting the

researchers to systematically organise and manage the data, making it easier to search for specific themes, patterns or even keywords and speeding up the data analysis process.

Cues such as laughter, pauses, or emotional expressions were noted to provide valuable context and insight into the participant's experiences and perspectives. Findings were analysed using thematic analysis. The steps of thematic analysis outlined by Braun and Clarke (2019) involve identifying and reporting patterns in a data set, which are then interpreted for their inherent meaning (Liebenberg et al., 2020; Xu and Zammit, 2020) were utilised. The patterns were found based on understanding the meaning of keywords used by the participants. Further utilisation of NVivo 14 software also assisted in data arrangement. The following steps outlined and elaborated by Naeem et al., (2023) were followed:

Step 1: Transcription, Familiarisation with the data and selection of quotations

The transcription of data was effected and the researcher became conversant with it by repeatedly going through it i.e. re-reading the data to make sense or meaning out of it. Notes on general thoughts concerning each interview were made pertaining to the research questions:

What are the socio-economic and psychological challenges experienced by caregivers of babies admitted to PMH Neonatal Intensive Care Unit? What coping strategies do caregivers use when having babies admitted to the PMH NICU?

The researcher conducted an in-depth analysis of the content to discern preliminary themes and key data segments. Selection of codes that gave meaning and competently represent varied diverse points and patterns relevant to the research objectives was also done.

Step 2: Selecting Keywords

Cross examination of the data from all the interviews was executed. Recurring patterns, terms, or keywords that seemed significant to the phenomenon under study were picked. The keywords encapsulated participants' true perceptions and experiences (Kiger and Varpio, 2020).

Step 3: Coding

Naeem et al., (2023) highlight data coding, short phrases or words commonly known as codes are assigned to segments of data that represent the data's core message, significance or theme. Considering the codes created, they were scrutinised, and those fitting together were grouped into a single unit using different colours. This step assisted by simplifying the complex data and identifying elements related to the research questions.

Step 4: Development of Themes

Theme development involves organizing codes into meaningful groups to identify patterns and relationships, thereby offering insights into the research question as described by Naeem et al., 2023; Kiger and Varpio, (2020) was the next step followed. The researcher diverted from a comprehensive analysis of codes and categories and formulated more meaningful interpretations by creating themes that were descriptive and giving insight to the phenomenon under study.

The outcome of the data analysis was a comprehensive illustrative abstract that precisely reflect the meaning participants ascribed to their lived experiences.

3.19 Ethical Considerations

Ethical approvals to conduct the study were obtained from the National Health Research Authority, approval number NRHA1192/17/05/2024, the University of Zambia Biomedical Research Ethics Committee (UNZABREC) REF. No. 5152-2024, the Ministry of Health Botswana Research and Development Unit: HPRD 6/14/1, and the Princess Marina Hospital Institutional Research Board (IRB) RE: PMH2/11AII (458). The assistance to gain access to the study participants was conferred with the NICU and postnatal heads of units and on-duty staff.

The decency of all participants regardless of their ethnicity, social or economic status was respected. Respect for persons requires that people's decisions are respected, including that individuals actually can make those decisions to be partakers of the study and not just used as research objects (Nagai, Nakazawa and Akabayashi, 2022). Participants signed informed consent that consisted of adequate information concerning the study and its potential risks and benefits to participants', understanding of the information, and the ability to make their own

decisions (autonomy) to be part of the study voluntarily/ without coercion. The right to withdraw from the study anytime they felt like it, without any repercussions was also highlighted to participants.

For confidentiality purposes, participants were not identified by their names, rather codes were used and data was also kept private. Beneficence is acting in such a way to benefit others while promoting their welfare and safety (Barrow et al., 2022). The study had no potential to cause physical harm to the participants, but possibility of emotional breakdown to the participants as they were sharing their experiences. However, a prior arrangement with the hospital psychology department was made to assist with psychological support services for such participants. Feeding times or their visit to the NICU were not interrupted as appointments were made the day before the interviews or early mornings.

CHAPTER FOUR: DATA ANALYSIS AND PRESENTATION

4.1 Introduction

This chapter gives insight into the findings obtained from the study. The data unfolds the social, economic and psychological challenges experienced by caregivers nursing babies admitted to Princess Marina Hospital Neonatal Intensive Care Unit. The challenges imposed by the facility however, were also identified and explored as part of the findings.The coping strategies employed by participants are also analysed. The data presented were obtained from a total of 17 participants who took part in the in-depth interviews using an interview guide after the employment of the selection criteria. The sample size was determined by data saturation. The participants comprised ten mothers whose babies were admitted to the NICU for at least seven days or more, five fathers and two grandmothers who were related to the mother, sharing mutual relationship and taking care of the mother and the baby during admission. An in-depth interview guide was used to collect the stated data.

4.2 Participants' Demographic Information

The demographic questionnaire supported the research data hence, the demographic information obtained and considered significant for this study included age, gender, nationality, residence, marital status, level of education, employment status/occupation and religion. The demographic data of the 17 participants is summarised in Table 4.2.1.

Table 4.2.1 Socio-Demographic Characteristics of the Participants

No.	Socio-Demographic Variable		Frequency	Percentage
Total			17	100
1.	Age	25-34	7	41.2
		35-44	8	47.0
		45-54	0	0.0
		55-64	1	5.9
		65-74	1	5.9
2.	Gender	Female	12	70.6
		Male	5	29.4
3.	Nationality	Batswana	15	88.2
		Malawian	1	5.9
		Tanzanian	1	5.9
4.	Residence	Rural	0	0.0
		Urban	17	100
5.	Marital Status	Married	5	29.4
		Not Married	4	23.5
		Cohabiting	8	47.1
6.	Level of Education	Never been to school	1	5.9
		Primary School	3	17.6
		Junior Secondary School	2	11.8
		Senior Secondary School	6	35.3
		Tertiary School	5	29.4
7.	Occupation	Teacher	1	5.9
		Government Official	1	5.9
		Night Watchman	1	5.9
		Private Security Officer	1	5.9
		Sales Assistant	1	5.9

		Street Hawker	1	5.9
		Street Barber Shop Owner	1	5.9
		Unemployed	8	47.0
		Retiree	1	5.9
		Pensioner	1	5.9
8.	Religion	Christianity	14	82.4
		Muslim	2	11.7
		None	1	5.9

Residence: All the participants were living in urban areas i.e. either in big villages surrounding Gaborone, within Gaborone or big villages classified under urban centres. The places of residence included Ghanzi, Selibe- Phikwe, Tlokweng, Molepolole, Mmopane, Mogoditshane, Tsholofelo East, Broadhurst, Block 9 and Tsolamosese.

The average length of stay for babies: the average length of stay for the ten babies whose caregivers were recruited in the study was 25 days. The participant who stayed the longest number of days was one mother whose baby had been admitted for the past 77 days during the conduct of the study, and the least had been hospitalised for seven days. Prematurity, neonatal sepsis and jaundice were the diagnoses of the ten babies.

4.3 Presentation of Themes, Subthemes and Categories

The findings have been presented according to overarching themes, subthemes and categories that emerged from the analysis.The themes depict explicit patterns of the experiences and feelings of participants regarding the socio-economic and psychological challenges they experienced when their babies were admitted to the NICU. 8 themes, 36 subthemes and 8 categories were extracted from the data. The following are worth noting:

Meaning units represent the antecedent context. Every meaning unit adopted is coded e.g. C8, where the letter C refers to the participant or caregiver who shared the meaning unit, while the numeral is the identification number or code of the participant/caregiver. By coding, an audit trail is enabled that is significant for auditing the data, and significant for confidentiality

purposes (Nowell et al., 2017). Care was taken in extracting and transferring the data units from transcripts to the specific categories to which they belong. However, not all meaning units were used in the data analysis, only those with specific categories under which they fall were used. Meaning units from other participants with the same significance, were excluded as they carry the same meaning as those included. The themes, sub-themes , categories and codes are presented in Table 4.3.1.

Table 4.3.1: Presentation of Themes, Sub-Themes, Categories and Codes

Themes	**Sub-themes and Categories**	**Codes**
1.0 The challenges of caregiving in the face of adversity	1.1 Caregiving responsibilities 1.2 Educational Challenges 1.3 Health Concerns 1.4 Impact on Family Dynamics	1. Sick Baby 2. Compromised State 3. Friend 4. Missed School 5. Responsibility 6. Losing Patience
2.0 The struggles of caregivers amidst isolation and limited support	2.1 Social Isolation 2.2 Limited Support Systems 2.2.1 Reliance on a Single Partner for Emotional and physical support 2.2.2 The Inconsistency of Support from Siblings and Relatives. 2.3 Familial Dynamics and Conflicts 2.3.1The Burden of Familial Expectations and Responsibility	1. At home, they do not care 2. Struggling Alone 3. Chased away from home 4. Family Conflicts 5. Siblings are never supportive 6. She was chased away from home 7. Extended family conflicts 8. I don’t know anyone in the city

	2.4 Longing for Home 2.5 Logistical Burdens	
3.0 Religious displacement in healthcare settings	3.1 Consent and Autonomy 3.2 Impact on Religious Practices 3.3 Cultural and Dietary Concerns 3.4 Acceptance and Resignation	1. Consent 2. Emotionally Traumatised 3. Shaved my Baby's Head 4. Certain Prayers 5. Accepted the Situation
4.0 Cultural expectations and responsibilities of fathers in healthcare contexts	4.1 Cultural Norms and Conduct 4.2 Personal Responsibility and Accountability 4.3 Beliefs and Traditions 4.4 Fear and Respect for Tradition	1. Traditional Beliefs 2.Confinement 3. Baby Protection 4. Responsibility 5. I truly believe in Setswana 6.We forget where we are coming from
5.0 Financial Struggles and Access to Basic Needs	5.1 Unpreparedness for Medical Emergencies 5.2 Transportation Challenges 5.3 Impact of Financial Hardships on Daily Life	1. Complicated 2. Early Delivery 3.Transport Costs 4. Business has Collapsed 5. Lack of Basic Necessities 6. Worried 7. Struggling to find money
6.0 Healthcare Staffing and Service Quality in Neonatal care	6.1 Staffing Shortages and Patient Care 6.1.1 Nurses Shortage 6.2 Staff Attitude	1.Running Up and Down 2. Insensitive Jokes 3. I got hurt 4. They forget about us

	6.2.1 Inappropriate Humour 6.2.2 Dismissive Responses 6.3 Poor Service Delivery 6.3.1 Hygiene and Safety Issues 6.3.2 Neglect of Caregivers' Needs 6.3.3 Negligence and Lack of Accountability	5. Healthcare providers 6. Negligent 7. Delayed Counselling
7.0 The Psychological Struggles of Caregivers Amidst Separation, Stress and Systemic Challenges	7.1 Joy and Relief of Birth 7.2 Loss and Grief 7.3 Impact of Separation 7.4 Stressful Interactions with healthcare providers 7.5 Fear and Anxiety about Infant Health 7.6 Gossip and Lack of Professionalism 7.7 Coping with Differences in Care 7.8 Communication Barriers 7.9 Delayed Counselling Services	1. Hapiness 2. Death of Babies 3. Emotionally Traumatised 4. My heart skipped a beat 5. Confussed 6. Gossip 7. Lost Hope 8. Fear 9. Anxiety 10. Painful 11. Shouting at Us 12. Poor Communication
8.0. Coping Strategies	8.1 Peer Support 8.2 Prior NICU Experience/Orientation 8.3 Resilience 8.4 The Belief in God	1. Patience 2. Experience 3. Orientation 4. He had patience and time 5. Let me be strong 6. Started praying

4.4 Analysis of Themes, Subthemes, Categories and Meaning words

The participants had diverse challenges following their babies' or grandchildren's admission to the NICU. These challenges were social, economic/financial and psychological. In addition, facility challenges and coping mechanisms were also captured. The themes, sub-themes, categories and meaning unit are analysed as follows:

4.4.1 Theme 1: The Challenges of Caregiving in the Face of Adversity

It is evident from the data collected that caregiving on its own brings tremendous and various challenges to NICU caregivers. Participants faced issues like fatigue, financial strain, and difficulties in balancing other obligations. The theme underscores how caregiving becomes even more strenuous if coupled with external or internal factors. The theme is discussed under the following subthemes:

4.4.1.1 Subtheme: Caregiver Responsibilities

The primary caregiver often had to juggle multiple responsibilities, including attending to the needs of children with disabilities and managing the household. This can lead to feelings of exhaustion and stress, as seen in the accounts of participants who were struggling to balance work and childcare. One of the participants revealed that:

"*… my firstborn is a child living with a disability, I have been taking care of her all along, let me just say 24/7…, so it means when I am here, she is left with… I have asked his father to remain with her. Even the father, is not like he is working, he is not, but depending on piece jobs. Now the piece jobs have stopped and he is focusing on caring for the child."* (C2)

Due to the increased caregiving responsibilities at home, the child's father had to assume full responsibility for caring for the other child at home who was also not well, while the mother was admitted with the newborn. The father did not have stable employment and typically relied on temporary piece jobs for income. This resulted in significant financial strain for the family alongside the emotional and physical challenges associated with caregiving and medical needs.

"…But I do have a difficult time taking care of our child here in the absence of the mother. You know, sometimes she becomes too stubborn she would be crying in the middle of the night saying she wants her mother, I find myself losing patience and disciplining her which does not seem to help." (C17)

The father was experiencing emotional fatigue as a caregiver, especially managing care without support. Even the child crying and insistence on wanting her mother likely reflected feelings of insecurity, anxiety and attachment disruption. For the father to interpret the child's emotional distress as sturbonness, might lead to inappropriate caregiving responses i.e discipline instead of comfort. Importantly, the father's awareness that his approach (discipline) was ineffective showed vulnerability and a need for emotional, practical and perhaps psychological support for both him and the child during the period of separation with the mother.

4.4.1.2 Subtheme: Educational Challenges

The subtheme indicate issues with children missing school due to lack of supervision in the mornings. The challenge of ensuring children got to school on time was exacerbated by the participants' work schedules and the need for him to take on multiple roles. The caregiver, 38 years old mother of 8 revealed that:

"…one of them has missed school as we speak, and the other one also told a lie that she was going to school during the afternoon shift, only to find that she was not telling the truth and had missed school also. They are with their father, the challenge is that he is a night watchman, by the time he arrives home in the morning, they are supposed to have already been at school, so it is a challenge."

The absence of the mother combined with father's night shifts exacerbated vulnerability to school abscenteeism and possible long term educational setbacks. The inability of the father to monitor the children's daily routine was not due to neglect but rather a structural challenge linked to his employment obligations. Without intervention or support, the patterns of missing school could lead to broader academic and behavioral issues for the children as well as increased stress for the father and the absent mother.

4.4.1.3 Subtheme: Health Concerns

The subtheme acknowledges that wellbeing of the children is a priority, but health issues can arise when caregivers are spread thin. For example, one child fell ill due to inadequate care while the caregiver was preoccupied or unavailable.

"*I had a helper who was assisting me at home. I have been living with my 2 years old son, other children are in Malawi...so when I came here, my helper left saying she could not manage to stay alone in the house. I took my baby to my friend who assisted me in caring for him. He fell sick because of this cold weather, he was not well taken care of. My husband is a truck driver, when he arrived he went to check on him and found him in a compromised state... We ended up taking him to another lady and agreed that we would pay her for the service. Even now as I am talking to you my baby is sick*." (bowed down the head and speaking with a clear sign of concern from her voice) (C8)

The caregiver's hospitalisation led to a sudden collapse of her informal support system when the helper left. This highlights the fragility and unreliability of informal caregiving arrangements in times of crises. The situation likely increased the caregiver's emotional burden, knowing her child was sick while she herself was hospitalised with another sick baby and unable to intervene directly. This points to the critical need for more reliable, structured support mechanisms for vulnerable caregivers during period of NICU hospitalisation.

4.4.1.4 Subtheme: Impact on Family Dynamics

The absence of one parent can significantly affect the family's dynamics. For instance, one parent having to leave for work or medical reasons can lead to complications in ensuring that children are cared for properly. This often results in reliance on extended family or friends, which may not always be feasible. The example is that of a participant father who narrated that;

"*… It is very difficult for me because the mother of my kids does not have parents, there are family conflicts and fights with those who are supposed to be related to her. …She was chased away from home with her brothers, where they were living as extended family. They do not have accommodation, and these are some of the things contributing to my pressure. There is no unity,*

and as I am talking to you right now, no one is interested just to go and visit her at the hospital. My siblings also declared that they cannot manage to look after my children…" (C15)

The extended family conflict from the above statement, has led to a breakdown in social and emotional ties that would traditionally provide assistance during times of crises. The caregiver is carrying a heavy emotional load, not only managing the needs of his hospitalised partner and children but also facing the psychological impact of family rejection and abandonment.

4.4.2 Theme 2: The Struggles of Caregivers Amidst Isolation and Limited Support

The theme highlights the emotional, physical as well as mental burden caregivers endured when their babies are admitted to the Neonatal Intensive Care Unit.

4.4.2.1 Subtheme: Social Isolation

Social isolation is an important but overlooked problem prevalent in human nature. The NICU participant caregivers were not spared from this dilemma as they narrated how the challenge was emotionally impacting on them. Some reported feelings of abandonment and neglect by family and friends as noted in the following statement:

"…at *home honestly, they do not care, because there is no one who comes and visits me, the only person who checks on us is the father of my kids*…" (C1)

The caregiver's words highlight a profound disengagement and possibly strained or broken relationships within her broader family network. Support seemed to be limited to only the children's father, which puts both caregivers under significant and practical pressure.
"… My siblings are around but they are never supportive, I don't know maybe it is because we have never communicated regularly." (C5)

The absence of sibling support during a critical period likely heightened the caregiver's emotional burden, stress levels and a sense of abandonment.

4.4.2.2 Subtheme: Limited Support Systems

The pressure that emanated from the NICU hospitalisation as evidenced by the predicaments endured by participants was a clear indication that there is a need for emotional, physical as well as tangible support, especially from family and friends. However, the limited support that substantiated from the dialogues proved otherwise. The following were noted:

4.4.2.2.1 Category: Reliance on a Single Partner for Emotional and Practical Support

The category speaks to the risks and draw backs that occurred with a limited support such that participant caregivers felt overwhelmed or burdened by the responsibility of meeting all emotional and practical needs.

"We do not have any support. Currently, the only person who is rendering support to me is the father of my children. My mother is too far at Letlhakane (Orapa), she is currently the one who is assisting with taking care of the rest of the kids. Even the burial of our baby we were only two, we had no support." (C7)

Griefing the loss of a child is already profoundly painful. Facing it without the community, extended family or friends made it even harder as there was no shared emotional outlet. Feeling alone in such a major life event was likely to deepen caregivers' emotional suffering and create a sense of being abandoned.

4.4.2.2.2 Category: The Inconsistency of Support from Siblings and Relatives

The difficulties the participants endured as a result of absent or minimal support from other relatives or rather, broken family relations were a concern.

"... Honestly there is no support that we are getting from our relatives, with all my 8 children I am used to struggling alone. I will be the one to take care of my fiancé during the period of confinement." (C12)

The 37 years old father of 8 revealed how constantly shouldering responsibility of confinements and raising children alone can lead to physical and emotional exhaustion. Long term stress was also likely to affect the father's health, patience and even the ability to cope.

4.4.2.3 Subtheme: Familial Dynamics and Conflict

In families with different dynamics, conflicts and misunderstandings proved to be a source of distress for NICU participants especially mothers who were left stranded with minimal or no support. The following are experiences and the difficulties that emanated from family issues faced by participants during the period of admission.

4.4.2.3.1 Category: The Burden of Familial Expectations and Responsibilities

The category captures a complex emotional and social dynamic, especially where one caregiver was expected to carry more than their share without support.

"*…She was chased away from home with her brothers, where they were living as extended family. They do not have accommodation, and these are some of the things contributing to my pressure*."(C15)

Being expelled from home by extended family felt like an act of rejection that wounds emotionally and disrupts sense of security or belonging . It was also an indication of how one caregiver's (the mother's) crisis became another's (father's) emotional and practical burden.

One of the participant fathers also revealed the challenges they experienced with financial lack, which caused emotional distress:
"I ended up deciding to protect her feelings and made sure I worked hard at the barber shop to be able to buy milk and made sure that she did not have stress. Even today it doesn't mean that I am managing, I am just trying what I can to buy because that woman should be stress free, without being provoked, and being told now and then to buy milk, she is still going through a lot." (C13)

The statement carries emotional complexity and reveals sacrificial caregiving, emotional suppression and the weight of responsibility that the father endured. The father's honest

admission revealed that he was not coping well but continued to push forward, masking his own struggle to maintain stability for the mother.

4.4.2.4 Subtheme: Longing for Home

The subtheme captures both physical and emotional yearning that extends beyond the desire for shelter. It can also reflect belonging, safety, stability as well as identity, as noted from the statement of the caregiver below:

"...and my relatives are also too far. No one can come here and visit me, I don't know anyone in the city, I just want to go back home. They told me that I was going back home, but even now, it has been three days and I am still waiting for the ambulance, and I am struggling as it is." (C10)

The mother mentioned her desire to return to familiar surroundings for better support as she was encountering feelings of displacement and struggle in an unfamiliar NICU environment.

4.4.2.5 Subtheme: Logistical Burdens

The subtheme speaks to the practical and everyday challenges that caregivers faced while trying to provide consistent and effective support during hospitalisation of their babies.

"...They are around but they have never visited her at the hospital. She would get into labour, and I would be running around alone to find a car to transport her to the hospital." (C12)

Challenges faced in accessing transportation and care during emergencies were shared by caregiver who mentioned being a sole provider to his fiancé in all the confinements they had. The additional responsibility of managing multiple children in the absence of the mother was also a burden.

4.4.3 Theme 3: Religious Displacement in Healthcare Settings

The theme refers to situations where individuals felt that their religious beliefs, practices or identity were ignored, marginalised or disrupted within the healthcare enviroment. This led to emotional distress, spiritual isolation especially during critical moments like the baby's sickness. Several sub-themes emerged from the above overarching theme.

4.4.3.1 Subtheme: Consent and Autonomy

The subtheme explored how caregiver's rights to make informed or voluntary decisions about the health of their babies were undermined in caregiving in NICU context.

"*I was hurt and left emotionally bruised when I found that they had shaved my baby's head without my consent. It is impacting negatively on my religious beliefs…There is nothing wrong with informing me as the mother if there is anything they would like to do to my baby, it could have made a huge difference."* (C4)

The mother revealed how some of the management practices that seem small and insignificant to others, can be emotionally destructive and impactful on someone's religious beliefs. Emotional distress caused by lack of communication regarding decisions made about the baby was one of the difficulties the mother endured, thus signifying the significance of parental consent in healthcare decisions.

4.4.3.2 Subtheme: Impact on Religious Practices

The subtheme explored how caregiving responsibilities, hospitalisation or displacement interfered with the caregiver's ability to engage in their religious or spiritual practices. One of the caregivers revealed that:

"*…I am a Muslim, and the fact that we are not allowed to enter the ward where the baby is admitted poses a great challenge, you know certain prayers should be carried out when a baby is born…"(C17)*

The caregiver shared how the common challenges faced due to restrictions on parental access to the baby in the NICU, and the inability to perform religious rituals and prayers associated with childbirth were not only negatively impacting his involvement in his newborn health, but also an impediment to some of his religious practices.

4.4.3.3 Subtheme: Cultural and Dietary Concerns

The how cultural and dietary needs are often overlooked or unmet within healthcare environment, leading to discomfort or nutritional compromise and exclusion for caregivers was revealed.

"Even the kind of meals my wife is eating currently, are not prepared accordingly…I mean the religious way, there are certain foods she is supposed to eat, now the challenge is that I am not in a position to prepare meals and take them to the hospital because of other commitments that I have." (C17)

The caregiver divulged that it was not only the issue of restriction but for the mother to be at the hospital for that extended period has proved futile in ensuring that dietary needs are met according to religious beliefs as he was faced with the struggle to provide appropriate meals for a spouse in a healthcare setting.

4.4.3.4 Subtheme: Acceptance and Resignation

The subtheme captures the emotional state in which caregivers came to terms with ongoing struggles or lack of spiritual support, not necessarily denoting their improved situations but because they no longer had the option or hope to resist it. It reflected a quite, often painful shift to emotional surrender or silent endurance. The following statements were noted from caregivers who seemed to have surrendered to this predicament:

"*… so there is nothing much I can do, I have just accepted the situation as it is."* (C17)

"*… However, we see things differently, I just concluded that maybe whoever shaved my baby's head felt lazy to call and inform me, or maybe found it unnecessary to do that*." (C4)

Caregivers responded differently to distinctive situations. They reported coming to terms with the situation despite emotional pain and challenges. The only option they had at their disposal was the acknowledgment of the limitations imposed by the healthcare system on their personal beliefs and practices.

4.4.4 Theme 4: Cultural Expectations and Responsibilities of Fathers in Healthcare Contexts

The following sub-themes was extracted from the above theme.

4.4.4.1 Subtheme: Cultural Norms and Conduct

The subtheme explored how deeply rooted cultural expectations social codes shaped caregivers behaviour, decisions and roles within caregiving during NICU hospitalisation. The following are staements from some of the caregivers in view of the cultural norms and conduct:

"We still live according to the traditions where we were bound as men not to do certain things concerning botsetsi(confinement). Some of us believe in God, we do not believe in the idea that a man cannot enter a house where their partner is cared for during confinement, because they can endanger the baby... I took care of my two older kids and I never had issues whatsoever, or any of my children becoming sick because I came in contact with them during confinement…" (C15)

The caregiver reflected how cultural beliefs dictate what is considered appropriate, acceptable or a respectable conduct, specifically according to gender roles during confinement, despite the emotional burden incured by the fathers.

"I take to mean that, if you know that you are promiscuous, you are not supposed to enter the house that the baby is in, or even asking at the hospital to see the baby when you know that you are not clean. If you go to the extent of asking to see the baby at the hospital, I take to mean you know that you are clean and not sleeping around. We know culturally that it is wrong for the father of the baby to sleep around with other women when he has a small baby. It is an issue of abstaining, whether you take nine months while the baby and the mother are in confinement, it is still okay."(C12, C13, C15)

The cultural belief that a father's lifestyle choices can affect the health and wellbeing of the newborn was a common knowledge amongst the three fathers, who were well acquainted with expectations regarding male behaviour during the mother's confinement, including abstaining from promiscuity.

4.4.4.2 Subtheme: Personal Responsibility and Accountability

The subtheme highlights how cultural beliefs and social expectations shaped the caregivers sense of duty, obligation and answerability in caregiving . At times caregivers felt pressured to keep traditions alive to avoid bringing misfortune.

"I mingle with a lot of people, pass some tracks as well, so when I go there, my body... you will find that somehow it is not fit, so when I get there, the baby is a person that even when you did not touch him/her, isn't it that I am the father, my blood is his, so when I am close to her, even she can sense that there is something close to me." (C13)

The caregiver understood the consequences of personal actions on familial dynamics and child health and believed there was a significant meaning to all this cultural controversy.

"I know my responsibility as a man, if I go around being promiscuous and then go to the baby, it is my responsibility and willingness for it to be that way. A serious man who wants to see his child healthy will not indulge in that reckless behaviour." (C15)

Acknowledging and understanding the role of the father in ensuring a safe environment for the baby as per cultural beliefs was a common knowledge amongst the fathers.

4.4.4.3 Subtheme: Beliefs and Traditions

The subtheme captured the powerful role that culture plays in shaping how caregivers understood life, sickness or diseases and responsibility.

"I personally, truly believe in Setswana. I believe that Setswana is a Setswana, the same one we found being practiced because if we ignore it, tomorrow we will be saying a lot of things, or we get sick or something or even things going wrongly for us because we forget where we are coming from. We forget Setswana." (C13)

The significance of cultural beliefs and traditions (e.g. Setswana) according to the participants, in guiding behaviour and parental responsibilities, as well as the importance of maintaining cultural practices to ensure the wellbeing of the family and newborn, was something that participant fathers felt could not be undermined.

"When you are a man and know and understand that your partner is in confinement, there is a way that you are supposed to conduct yourself to protect the mother and the newborn child. You are not supposed to mingle with many people and sleep with other women. These issues have the potential to affect the newborn baby. But if you understand yourself and know you have a small baby who needs to be protected from all harm, you know how you are supposed to behave." (C12)

The caregivers outlined self control as a virtue of manhood particularly when one has a baby depending on them. The statement reflect a broader societal expectation that a man's sexual behaviour should align with his role as a caregiver morally disciplined, once he enters fatherhood.

4.4.4.4 Subtheme: Fear and Respect for Tradition

The subtheme illustrates how cultural traditions operate both as constraints and through deep respect. In the context of fatherhood, tradition became a powerful force that defined caregivers' responsibility and acceptable behaviour including the rejection of promiscuity in favour of the newborn's protection.

"*…To me, I fear and respect botsetsi too much I don't have time to run around with other women and go to and forth from botsetsi (confinement). I respect that culture and I cannot nullify it, because I know that I am not doing anything that will affect the baby…"*(C15)

The above statement reveals tension between personal desires and cultural expectations leading to emotional distress was picked as participants were sharing their respect for cultural norms influencing a father's willingness to engage responsibly for the family.

One of the fathers shared his experiences and his fear in relation to traditional beliefs in the following statement:

"*… because after seeing him, he immediately passed on the moment I stepped outside the ward…Ever since then, the remaining baby…, the mother has asked me to come and see her, but I felt that it is not advisable...*"(C13)

The statement reveals a complex emotional and cultural situation layered with trauma and protective instincts. The caregiver's actions while possibly irrational on the surface, was shaped by a cultural framework that blended fear, traditional beliefs and an overwhelming desire to prevent further loss, hence believed that his presence had an impact or somehow contributed to the demise of one of his twins.

4.4.5 Theme 5: Financial Struggles and Access to Basic Needs

The financial burden incured by caregivers in Botswana, has not been thoroughly explored or understood, resulting in limited information about the challenges they incur. It is worth noting that Princess Marina Hospital as a government-aided health facility, offers free medical services to citizens, therefore caregivers are not incurring costs of consultation, treatment or diagnostic investigations. However, they are not spared from the cost of non-medical out of pocket costs like mothers' and babies' basic toiletries, and transport costs to the facility for visitation purposes. It is also not uncommon for mothers to purchase out-of-stock medications, most commonly supplements like multivitamins, vitamin D or iron supplements for their neonates. The theme was explored under the following subthemes:

4.4.5.1 Subtheme: Unpreparedness for Medical Emergencies

The subtheme reflects a situation where caregivers lacked the resources to respond adequately to sudden health crises.

"*…at a time when I do not have money… It is complicated by the fact that the baby is delivered earlier than we expected which we did not anticipate."* (C14)

Participants who faced unexpected preterm deliveries and the associated need for immediate resources expressed their challenges in the above narration.

"*…she told me that her breasts have since ceased milk production and nurses have told her to buy milk for herself. What worried me was that I explained to the matron my situation and she encouraged them to assist us with milk, but when the mother went for feeding, they would repeatedly remind her to buy milk for herself. This was the pressure we faced in a very short time and when people understand what you are going through…, and after promising that when*

I get the money I would buy, and imagine when your emotions are all over the place because of what you are going through." (C13)

The above father's experience, reflected emotional distress arising from unmet expectations. The pressure he described emphasises the psychological toll of facing perceived neglect during a critical time. Furthermore, his experience suggested a lack of coordinated care and an environment where socio-economic vulnerabilities are insufficiently acknowledged- the NICU.

4.4.5.2 Subtheme: Transportation Challenges

High transport costs affecting the ability to visit the mother in the hospital were also mentioned as a challenge participants encountered. One of them mentioned that:

"… *even this transport costs, I am just struggling to find money, how I do that is another issue, but the thing is that I am forced to go and visit her at the hospital. The day she is discharged will also be my responsibility to see how she arrives home*."(C13)

Financial strain from needing to travel frequently for healthcare needs, was noted to impede regular visits of relatives to the hospital, hence leading to emotional strain and to some it meant shortage or lack of necessities like basic toiletries.

"I have been struggling with hunger, the food ration here is too small and like I said where I am coming from at Tsolamosese is a bit far from here, so they can't keep visiting me several times because of transport costs." (C5)

The caregiver's statement reflects how geography and financial constraints limited access to familial or social support. This underscores the need for NICU to recognise and respond to the socio-economic realities of caregivers by providing relevant support services.

4.4.5.3 Subtheme: Impact of Financial Hardship on Daily Life

Loss of income due to health issues affecting self-employment was also mentioned as one of the challenges:

"For me I am self-employed and I am renting. The money that I use for rental is the one I get from my business. Right now, everything has come to a halt, the business has collapsed, and even the money for rental is a struggle to raise because I am no longer able to carry out my business because I am here." (C6)

The caregiver's hospitalisation with the baby had triggered a financial collapse exposing how health crises can devastate livelihoods for vulnerable, self-employed individuals who lack financial buffers.

Struggles to access sanitary products and baby supplies were the lamentations of some participants who found themselves stranded, which forced them to resort to desperate and uncomfortable measures.

"I have had a very difficult time while here, my sanitary pads got finished, and my babies' pampers also got finished I bought just a few disposable ones for hospital use knowing that I was not going to spend a long time in the hospital, I didn't know what to do. I found myself secretly taking the sunlight liquid that we are using for cleaning the babies' feeding cups and bottles and using it for bathing." (C5)

The caregiver's experience, underscores profound lack of basic necessities. Lack of access to these illustrates the harsh inequalities that existed within the caregiving or healthcare environment. The statement also indicates acute confusion, helplessness and emotional distress that the caregiver endured.

4.4.6 Theme 6: Healthcare Staffing and Service Quality in Neonatal Care

Shortage of staff has always been a challenge that is often associated with compromised care. Some of the mothers proclaimed that though the healthcare professionals were harsh on them, somehow, they believed it was because they were overwhelmed with work. The theme is discussed under the following sub-themes and categories:

4.4.6.1 Subtheme : Staffing Shortages and Patient Care

A limited number of staff members implies that minimal time is spent on individual patients; which has the potential to compromise personalised care and recognition. The subtheme was explored under the following categories:

4.4.6.1.1 Category: Nurses Shortages

There was a perceived lack of nursing staff, leading to inadequate monitoring and care for infants.

"My major concern remains with the staff, ideally those babies need close monitoring and care, they need nurses who are well staffed. To avoid situations that when I get there, I find that a baby has exposed himself, he is cold, in other words, there was no nurse who could see that. At least when they are well staffed, when they take rounds they will notice that the baby is exposed." (C4)

Some caregivers observed that nurses are often overwhelmed with too many patients, impacting their ability to provide proper care.

'*…So the nurse who came the following shift, that day when I arrived, let me say she was attending to so many babies, because when I told her that I needed assistance she said "okay…mothers I hear you, let me finish with others and come to you," because she was running up and down, even I could see that this person…, I felt they could be another nurse to help.'* (C2)

The caregiver's statement reflect both compassion for the nurse and concern about systemic inadequacy. Witnessing overwork shows a broader problem of healthcare understaffing which affected not only providers of care but also the emotional and practical experiences of NICU caregivers.

4.4.6.2 Subtheme: Staff Attitudes

Participants referred to the behaviour and the temperament they experienced from their interaction with NICU staff. Negative attitude led to conflicts and bad experiences, increased

customer complaints. Inappropriate and dismissive responses were also some of the concerns mentioned by caregivers.

4.4.6.2.1 Category: Inappropriate Humour

Instances of staff making insensitive jokes that may not be received well by parents, affecting trust and communication was reported by some caregivers.

"*Even the staff need to be informed that there is a time for jokes and sometimes jokes are not necessary at all. If I can give an example, there is a mother who once said, the heater was too small to provide heat to the whole room even to reach to her baby. And the healthcare provider responded by saying buy your own heater then, the mother called home to request them to bring the heater for her, only to find that on arrival, the nurse said she was only joking and didn't think the mother would take it seriously. So these are some of the things that should be taken into consideration, unless you know and understand that mother very well and knowing what kind of person she is… She is friendly and will not escalate matters if I make a joke. Others honestly don't feel well with these kind of jokes."* (C4)

The above statement emphasises the need to set clear boundaries between casual and professional behaviour. While humour can foster a positive atmosphere, there are times when it may be inappropriate especially in a serious and sensitive context like NICU admission.

4.4.6.2.2 Category: Dismissive Responses

Nurses responding defensively to parental concerns, leading to feelings of neglect and emotional distress for the parents were some of the encounters endured by some participants.

"*It is unfortunate the answers they give at times when you complain showing them the state of the baby, they will tell you that they are not looking after your baby alone. But if you analyse the situation and remember that… but this person I found him/her on Facebook or sleeping on the table… So when I find her sleeping on the table but giving me those kinds of answers, I get hurt emotionally."* (C4)

The response generally suggested a lack of empathy, dismissive replies might imply that staff are deflecting responsibility rather than addressing the issue constructively.

4.4.6.3 Subtheme: Poor Service Delivery

The provided services did not correspond with the expectations of participants hence escalated the challenges they experienced especially emotionally.

4.4.6.3.1 Category: Hygiene and Safety Issues

The category speaks to the reports of hazardous materials, such as used needles, being left in the vicinity of infants, raising serious safety concerns:

"So when it comes to doctors, they collect blood specimens from babies, they do operations on our babies, and several things. From there, you will find lancets on baby's blankets, lids of needles, and even used needles right there within the baby's blankets. If you are a mother and find those things in your baby, like mine; I am going to continuously give an example about my own, I used to collect those lids underneath him, only to find that one day the baby was restless moving up and down in the bed. They would be busy laughing thinking that my baby was more energetic, and active. Others (laughing) would even make a joke out of it saying he was practicing to dance the way we dance at church." (C4)

The caregiver's statement reveals a common practice of poor waste disposal practices. This highlights a critical gap in knowledge to proper biomedical waste disposal or even negligence,

4.4.6.3.2 Category: Neglect of Caregivers' Needs

The subtheme refers to situations where the emotional, physical or informational needs of caregivers were overlooked or inadequately addressed by healthcare professionals. One of the mothers shared her concerns and observation that it seemed as if they were forgotten in terms of health issues as mother lodgers once they are discharged from postnatal care after delivery.

"Our health as mothers is also a concern this side (frowning). Last week I had a terrible headache when I went to ask for assistance from the midwives that side, they told me to go back

and would follow me to the bed, but she did not come. It is like they do not have time for us. It is like our health issues are not taken into consideration as mothers who have babies in the NICU, the healthcare providers forget about us." (C7)

Participant mothers expressed that their own health concerns were overlooked while they cared for their babies in the NICU.

4.4.6.3.3 Category: Negligence and Lack of Accountability

Perceptions of nurse negligence and a lack of commitment to patient care, leading to emotional distress among parents were some of the experiences shared by some caregivers, as noted in the following statement:

"*Honestly what I have realised is that in that unit, nurses are there, but their responsibility in some of the things is questionable (throwing hands). Somehow, they become negligent. Additionally, there is something else that occurred… As I am telling you if you are a human being, sometimes when you focus on your job without considering the fact that the same people you are serving should be pleased with your service, you will find that you are just there for money but the love is not there (shaking his head). Are people's lives in danger or not is none of their business."* (C13)

The caregiver's statement underscores the emotional disconnect that occurred when healthcare professionals became too focused on the technical or routine aspects of their job, not neccesarily failing in medical care but failure to listen and care genuinely for caregivers. It further recognises that ignoring the emotional needs of caregivers led to delivery of care that did not truly serve the caregivers wellbeing.

4.4.7 Theme 7: The Psychological Struggles of Caregivers Amidst Separation, Stress and Systemic Challenges

4.4.7.1 Subtheme: Joy and Relief of Birth

Caregivers experienced initial joy and relief at the birth of their baby, only to be quickly confronted by the emotional toll of the NICU experience.

"*…Actually,(smiling) this is my only child, when I saw him, I was filled with happiness because he is my first baby to survive, and four have passed. I used to see them in the hands of healthcare workers telling me here is the baby, he is a boy, this is how much he weighs, if we had machines he could have survived, you see. So this is the only one that when I saw him, I declared that happiness has filled my heart (touching her chest), I have found my comforter and healing in my soul."*

This was an expressions of happiness and relief upon giving birth, especially for those participants who had longed for a child or had unpalatable experiences from the past.
"*…once you deliver you have that great relief and feel light as a sign that the load has been offloaded. So that is how I felt, I was very happy."* (C5)

Some felt that being blessed after overcoming health challenges during pregnancy was a breakthrough in their lives.

4.4.7.2 Subtheme: Loss and Grief

The subtheme relays the psychological impact of caregivers seeing their newborn in a critical state leading to death, and how the past experiences of loss impacted on the current hope amidst challenges.

"What has hurt me... I delivered twins, and unfortunately, the other one (the boy) died and I am left with a girl. It pained me a lot…even him(father) confessed that he is emotionally traumatised, even now I can see that he is having a lot of stress." (C7)

Experiences of loss and grief and the emotional impact of losing a twin was relayed.

"*She called me saying they also needed me… I could feel my heart skipping a beat. I just suspected that something bad had happened. When I got there, I met that woman (mother) along the way crying…I was too stressed… Within a minute I became confused, they asked me my phone number only to give them my Omang (Identity) number, when they asked me my Omang number I gave them the cell phone number* (shaking his head, and narrating his ordeal passionately). *Hey! My mind was all over the place I was not thinking straight at all!" (C13, a partner to C7)*

Another unsettled caregiver also shared his experiences of the challenges he found himself in, exacerbated by not knowing the prognosis of his baby. This is what he had to say:

"*I was very worried during the events that occurred leading to the delivery. You know this is my first baby to survive. We have lost four pregnancies. I did not believe that this baby would survive considering what we have been going through. I just thought history would repeat itself (shaking the head) but now here we are and remain hopeful everyday." (C14)*

Despite the fears incured, the caregiver expressed feelings of hope amidst uncertainty. A clear indication of how past losses impacted current hopes for the survival of the newborn.

4.4.7.3 Subtheme: Impact of Separation

The heartache and emotional strain caused by being separated from their infants, which affected the bonding process was a challenge explored under the above theme.

"You just go there to the NICU with a heavy heart not knowing what to expect, we are always concerned about what we will find when we go for feeding. They do not take care of our babies." (C6)

Feelings of distress and worry related to being far from home or separated from the baby during recovery were also a common concern amongst caregivers as noted in the following narration:

"I am not managing at all, it is very difficult for me, I depend on the mother to inform me how she is doing and these are some of the things that make me very unhappy."This issue of fathers not being allowed to see the baby during confinement is very painful." (C16, C12)

The participants' perceived 'hospital restriction policies' that restricted parental access to the newborn as one of the factors that caused their emotional strife.

"I went there because I could not cope with the suspension or sitting down not knowing what was happening. Remember I said this is my first child after many losses, the anxiety could not allow me and I had to seek clarification." (C14)

Another father who had painful experiences from the past narrated how he navigated his way into the secluded NICU for information and updates concerning his sick baby.

4.4.7.4 Subtheme: Stressful Interactions with Healthcare Providers

The subtheme relays the anxiety that came from feeling either unsupported or overwhelmed by healthcare professionals, compounded by poor communication.

"*… sometimes when we ask for help, they are usually harsh on us, not helping us accordingly, we are always stressed, they would be shouting at us, and sometimes we wonder why they are angry. Sometimes when we ask for something, someone will say I am tired, we are tiring and why couldn't we do things for ourselves?"* (C1)

Participants regarded nurses and doctors as harsh and neglectful leading to feelings of frustration and helplessness. Experiences of being shouted at or dismissed when asking for help or information were conveyed during the interviews denoting issues of poor communication.

4.4.7.5 Fear and Anxiety about Infant Health

Constant fear stemming from witnessing the death of babies, particularly preterm infants, contributed to a pervasive sense of insecurity regarding their own babies' health.

"Heeey! What has affected me in that place is the death of babies, especially prematures, it has affected me very much because babies are dying everyday, so we don't feel safe about our babies. When we get there, we are always afraid, babies are dying in large numbers." (C1, C3)

This fear of the outcome concerning their babies' health was a common concern that brought fear and anxiety.

"I cried like I lost hope because I delivered while they were transporting me in a wheelchair. I kept asking myself if he was like that, how was he going to survive." (C8)

The caregiver expressed a traumatic birth experience filled with fear, helplessness and profound worry for her newborn's survival, triggered by the dangerous and unplanned delivery situation.

4.4.7.6 Gossip and Lack of Professionalism

The subtheme unfolds the psychological toll caused by witnessing unprofessional behaviour among staff or even hearing rumours that heightened stress and confusion of the caregiver.

"*…so they were becoming angry towards me, I could see the way nurses were helping me, they were angry when I asked some questions…it is like they perceived me as someone who is bothersome, I follow up too much, and maybe I am not a good person. …some will be gossiping about you, there is a lot that is happening here, a lot! A lot! Even the cleaners and security officers are involved in the gossip. I have also accepted the fact that we are different and people cannot be the same, others will be harsh, and it is fine."* (C8)

The participant narrated how anxiety could not allow her to sit back but rather resorted to asking questions concerning her baby's health. However, according to her observations her inquisitive behaviour seemed to be an irritant to some of the healthcare professionals impacting the trust and rapport between caregivers and providers of healthcare. Observations of gossip involving healthcare professionals, encompassing non-medical cadres, added to the distress experienced by the caregiver.

4.4.7.7 Coping with Differences in Care

Caregivers struggled with inconsistent care or differing opinions from medical staff, leading to further confusion and stress.

"There are times when you call nurses for assistance, they will come quickly, there are those who are very quick to respond. When you tell them there is a situation, they rush to assist, it is not all of them who drag their feet. Like yesterday my baby just passed out while holding her after feeding, immediately I called, they came running, and they assisted her to continue breathing again." *(C7)*

There was variability in the quality of care provided by different staff members, leading to inconsistent experiences for parents. Despite the different attitudes encountered by participants, others however, proclaimed how grateful they were for the courtesy they received from few staff

members who seemed caring and very observant enough to pick up that they were not in a good space during those tight occasions, and needed reassurance and a shoulder to lean on.

4.4.7.8 Communication Barriers

One participant highlighted how at times what was supposed to be a civilised and professional communication between mothers and healthcare professionals, escalated into conflicts and emphasised the need for more respectful and empathetic communication between the two parties.

"Usually there are times I have witnessed nurses and doctors responding to mothers and even the way mothers also spoke to doctors and nurses… I mean there should be formal communication, not like I usually see, as if it would end up in a fight between a mother and a healthcare provide, at times it became so hectic that you could see the anger in the mother, not knowing whether to fight the nurse or doctor, the way they spoke, I could see that no, that person was really angry." (C4)

The statement reflects a failure in emotional regulation and formal communication protocols within the NICU. This not only undermined trust but also likely increased the psychological burden especially on caregivers who already felt anxious and helpless.

"*…I get different information from different people randomly who are not even healthcare providers, and this thing is stressing me because I don't even know what is correct…I was never called to be informed. I only heard the mother saying blood and food were going to the baby only, she no longer received them, which is why she ended up delivering through the operation. All these I hear from the baby's mother."(C15)*

The caregiver expressed confusion, frustration and emotional overload due to receiving conflicting updates about his baby's condition from various people whom were not even healthcare professionals. This also reflected a breakdown in communication protocol within the NICU which created an environment of uncertainity and distrust intensifying the caregiver's anxiety and fear especially as he felt the pressure of making decisions without fully understanding the situation.

4.4.7.9 Delayed Counselling Services

Concerns of frustration over prolonged waits for affirmed counselling services were expressed by caregivers.

"…*they have long said they would call me for counselling even now they have not yet returned to me, whether they decided not to or they are still coming I don't know."*(C1)

Still on issue of delayed counselling, another caregiver shared his concerns in the following statement :

"…*When was that? She gave birth on the 12th which was 12, 13, 14,15,16,17, I think it was the 18th, I think he took only 6 days and passed on. They took a very long time to do that since she gave birth on the 12th of June, they just called her for counselling on Friday (26/07/24). It is after a very long time and I believe by doing that they are just tampering with old wounds that have already begun the healing process. She has already started to heal the way she could manage." (C13)*

Counselling was often not provided promptly, leading to unmet emotional needs. Participants expressed concern that late interventions may disrupt their coping mechanisms.

4.4.8 Theme 8: Coping Strategies

Caregivers' coping strategies while their babies were admitted to the NICU included peer support, having a prior experience of the NICU, resilience and mostly their faith in God as their main source of strength and support.

4.4.8.1 Subtheme: Peer Support

The subtheme explores how caregivers received informational, emotional and practical support from others who were having similar experiences or typically mothers who previously had a baby in the NICU.

"I have realised that others are good hearted, you cannot be stranded. I have patience nowadays, I used to be a short tempered person now it has really assisted me because in life you have to be patient. I was taught by one mother because she was initially admitted with the baby

at Sir Ketumile, so she had experience with some of the things like how to handle a premature, and also how to feed using the tube, the one inserted in the mouth… I am thankful for that woman there was nothing that I knew. …" (C1)

The caregiver shared how she has experienced a change of behaviour as a result of meeting other mothers in the same situation as hers in the NICU, and teaching each other how to take care of their babies has also brought a sense of hope.

Caregivers who had been in the NICU before, shared their experiences and testimonies which brought hope and encouragement to other mothers.

"*…there are two women who were older than me. The other one told me that she is 46 years old, she told me her challenges and I realised that aah! Her situation is just like mine, she has lost several babies. The other one told me that she wanted to have a baby as her last born but she experienced a situation where her baby came as a pre. So those women when I found them, told me that they had long been here, the other one said she came in March and the other one in April. So those ladies are the ones who encouraged me, they told me that if I felt like crying, I should do exactly that…*" *(C4)*

The caregiver's statement reflects emphathy, connection with other mothers as well as shared grief. A highlight of how shared experiences especially painful ones like loss of a baby can create a deep understanding between NICU mothers, hence assist in coping.

4.4.8.2 Subtheme: Prior NICU Experience /Orientation

The subtheme explores how caregivers previous exposure to the NICU enviroment whether through previous hospitalisation or a formal orientation session impacted their psychological preparedness, emotional response and the ability to cope.

"In 2019 my firstborn was admitted to that side, so when I was told that my baby was admitted to NNU, I already knew how the place is and what is involved there. For me, I had an advantage because of the little knowledge I had, I could remember that ooh! This is what should be done and this is what was discouraged that time."(C2)

The caregiver acknowledged that even though healthcare is dynamic, she relied on her past experiences and applied the knowledge she gained in the past to help her take care of her sick baby.

While others appreciated the updates from healthcare professsionals as noted in the following statement:

"I have seen one Indian doctor, he usually moves from one mother to the other trying to explain what they are doing and how the baby is responding. He is the only person who after talking to me, I accepted the situation that I found my baby in, he explained clearly that I might end up staying in the hospital for 7 or 14 days because, at the end of the day, the baby has to be discharged in a good state. The way that old man talked to me, I saw that he had patience and time to talk to me." (C5)

The significance of orientation and regular updates was relayed by the caregiver who eventually found it easy to accept her situation following the updates from the healthcare professional.

4.4.8.3 Subtheme: Resilience

Accepting the situation and focusing on the bigger vision which they considered as seeing their babies discharged from the NICU, gave other caregivers the courage to endure all challenges that came along with stressful NICU caregiving.

"*The first time I was admitted I could say there were good things and bad things. It was really hard, but I counselled myself and told myself that I had to be strong for my baby, because once I became stressed, I knew milk production was likely to cease, and they would start giving him formula, mixing him, so I told myself that no! Let me be strong." (C8)*

Time factor was also very crucial in helping some caregivers cope as they realised that everyday that passed, brought new hope and strength.

"I ended up accepting the situation and asking myself that ah! Will I keep on crying everyday? I developed faith because the first time I arrived there, I was scared of the baby wondering if she would survive. But now I am seeing a great difference, she is becoming better with time."(C3)

4.4.8.4 Subtheme: The Belief in God

As a subtheme, the belief in God illustrated how spirituality acts as a psychological anchor, providing hope, strength and a way of navigating adversities especially where caregivers had an emotionally demanding roles of caring for their high-risk babies in the NICU.

"*… what has given me the courage is that I am a believer*,*… so when I used to see other babies dying, that thing gave me the strength and reminded me that, u know what, I came here for a purpose, maybe it was God's will for me to come here so that I witness what is happening in real life in the hospital. I started praying and praying to God that is when I found myself building up the strength, such that when I am here and my son is there receiving medical treatment, I as the mother am here interceding for him to receive help."* (C4)

The mother expressed a turning point where faith became a source of emotional resilience, and how spirituality can be a key coping mechanism in times of hardship like a period of NICU admission.

4.5 Conclusion

The themes described, represent the challenges encountered by caregivers when their babies were admitted to Princess Marina Hospital NICU, either social, economic or psychological. The caregivers conveyed mixed feelings from joy and happiness to confusion, anxiety, uncertainty and fear of the unknown especially those with preterm neonates considering their small stature and general complications that came along with premature delivery. Being separated from their babies made them unsettled as they kept thinking about the state they would find their babies in, when they went for feeding every two or three hours. The NICU environment on its own was one of the major stressors they had, witnessing dying and critically ill babies regularly kept them wondering if their own would survive.

Lack of social support was one of the predicaments most participants had to endure. Depending on family and friends to provide support to NICU caregivers was not feasible. Most relatives were far, struggling financially to meet the requirements for the mother and the baby during hospitalisation. Others because of family conflicts and dysfunction, had no or minimal support as the only source of support were the fathers who were also struggling with a lot of responsibilities

in the mother's absence, and also had to work hard to provide for the mother and other siblings, hence were overwhelmed.

Caregiving amidst financial challenges has proven to be stressful to caregivers who often found themselves in a critical shortage of basic toiletries like sanitary pads and baby needs. The requirement to buy out of stock medications and formula milk by those who ceased milk production, added to their calamity as they reported a difficult time to meet the demands due to their financial challenges.

Even though the study aimed to explore the socio-economic and psychological challenges faced by caregivers during NICU hospitalisation, the study findings revealed facility issues, consisting of attitudes of healthcare providers, negligence, poor service delivery, lack of resources, communication, lack of support from healthcare providers and strict NICU visitation as significant factors that contributed to the caregivers' difficult adaptation and caregiving. Coping strategies applied by caregivers included relying on other mothers for support, their past exposure made it easier for those who had experienced NICU before, resilience while others, their faith and hope in God kept them going despite all the challenges they encountered.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 Introduction

This qualitative phenomenological study aimed to explore the socio-economic and psychological challenges experienced by caregivers when their babies are admitted to Princess Marina Hospital Neonatal Intensive Care Unit. This chapter includes a discussion of major findings as related to the literature on challenges experienced by NICU caregivers, a conclusion, and what implications and recommendations may be valuable for use by policymakers and healthcare providers in improving overall neonatal care across Botswana health facilities.

5.2 Discussion of Findings

The study presents and discusses the findings based on the social, economic and psychological challenges experienced by caregivers of babies admitted to the NICU. Additionally, challenges related to facility issues encountered by caregivers are explored. The coping strategies employed by caregivers to manage difficulties which arose as a result of NICU admission are also discussed.

5.2.1 Social Challenges

Social issues, also called social problems or challenges, as defined by Chanda (2023), are a state of affairs that negatively affects the personal or social lives of individuals or the wellbeing of communities or larger groups within a society, and about which there is usually public disagreement as to its nature, causes, or solution.

5.2.1.1 The Challenges of Caregiving in the Face of Adversity

The birth of a newborn in general is a significant event coupled with jubilation and celebration, however, when complexities occur requiring medical care, this happiness can be outshined by anxiety, confusion, uncertainty and fear (Berlsford and Doheny, 2022). This present study revealed that the challenges and demands implicit in neonatal care, are not only confined to hospital settings and medical management, they negatively impact caregivers who are usually faced with multiple predicaments leading to roller coaster of emotions.

Shifting responsibilities to fathers made it impractical as it affected their role of fending and providing for the family, as some had to either halt going to work and look after other sick children. All these made it hard if not impossible, particularly for fathers to balance work and household. The findings from the current study are aligned with the results of the study conducted by Gibson et al., (2021) which acknowledge the impact of neonatal admission on the parenting of other child (ren), specifically, siblings of an admitted infant also found the time their mother spent away from them difficult; and mothers also found it hard to manage their other children's needs, alongside the needs of the admitted infant, hence turning to their partners for support.

The findings of the study further revealed that, with fathers confined to take on multiple roles, negatively impacted the education, health and general wellbeing of other siblings. With the absence of the mother, cases of missing school by some children were evident. Leaving children alone at night due to the work schedule of the other partner, presented an opportunity for them to miss school due to poor supervision and further compromised their safety. This further aggravated the stress levels of caregivers. The same results were obtained by (Lee and Choi, 2023) who discovered that fathers felt confused and burdened as they were given multiple new roles as caregivers, supporters, and decision makers related to their spouses and infants when admitted to the NICU.

The responsibility of looking after children culturally, has never been the obligation of a Tswana man, hence it did not come as a surprise when participant fathers encountered challenges in maintaining the family routine and stability. The study findings, also noted reliance on extended family members and friends as an alternative, though it was deemed unfeasible. Consequently, these fathers encountered feeling of desperation and emotional stress. Lee and Choi, (2023) in their study on the experiences of fathers whose babies were hospitalised in NICU, revealed the same finding where fathers felt a role burden as they were given multiple new roles when their infants were hospitalised. In Botswana, the long term consequences of NICU admission on families remains unknown, hence this study leaves a gap in that aspect that can be addressed by further studies.

Social isolation remains a sensitive challenge that affects not only NICU caregivers but it is an overlooked insult identified in different communities (WHO, 2024). The study established that some participants were not spared from isolation. The isolation of participants was ascribed to dysfunctional family units, long term unresolved conflicts between siblings and geographically distant relatives amongst others, adding to their challenges. On a similar note, the results of the study conducted by Stefana et al., (2021) revealed that fathers supporting their partners during their stay in the NICU, experience emotional distress and the need to be supported is often hidden, demanding a great deal of emotional and physical energy. Hence the need for healthcare professionals to be vigilant and priorities supporting NICU fathers.

Most studies underpin supporting mothers, fathers or families with babies in the NICU and even attest to the positive influence imparted by the family when the mother has a neonate needing NICU care (WHO, 2024); (Negarandeu et al., 2021). However, not much is documented in a situation where there are family divisions, conflicts or broken family bonds. There is a need to conduct further studies that unearth facts surrounding this predicament for Botswana NICU caregivers, and the impacts of family dysfunctions during neonatal care.

5.2.1.2 Religious Displacement in Healthcare Settings

A particular system of faith and worship, specifically religion which encompasses the belief in a Supreme Being or God has proven to be a source of comfort and hope for generations, no matter how catastrophic life events could be. Çaksen, (2023) insinuates that religion may provide a framework for understanding emotional and physical suffering and can facilitate perseverance or acceptance in the face of stressors. Concurrently, Genstler et al., (2022) connote it as one important way that humans can develop meaning in their suffering and find avenues for hope.

The current study findings, corroborating with the above, proclaim that faith became an important access point for relationships, a source of hope and discomfort among caregivers with babies in the NICU during their adversities. The most likely explanation for commitment to religious beliefs might be because for generations, families have subscribed to raising their children religiously, hence the parents' religiosity has a tendency to become the highest predictor of the current faith and belief in God for most family members (Gemar, 2023). Conversely,

individuals who have a background of religious faith are likely to become religious as adults. El-Khani, Calam and Maalouf, (2023) attest that religious beliefs and practices are fundamental to shaping family functioning, and they are often associated with a strong influence on parenting, and act as a potential resource for parents.

Despite the empirical evidence connoting spirituality as an important coping mechanism in calamities, the findings of the current study corroborating with Ozcan, Hoelterhoff and Wylie, (2021) study, revealed that perceived facility rules and protocols by caregivers and unprecedented choices made by providers of healthcare are some of the stressors likely to challenge the spiritual beliefs of caregivers. The unavailability of a blueprint in the PMH NICU that facilitates and incorporates spiritual care as part of holistic neonatal care, has the potential to obscure the spiritual needs of caregivers as their assessments are likely to be omitted. The oversight might be caused by possible staff ignorance, time constraints for assessing spiritual needs, insensitivity to the religious beliefs of caregivers, lack of information on how impactful religiosity/spirituality can be in healthcare or even failure to regard it as a priority (Valley and Leppard, 2019). Genstler et al., (2022) submit that many sentinel articles on spiritual care were published several decades ago leaving many wondering if the results from those studies are still applicable, given the values and cultural shifts in society. This leaves a question of how knowledgeable NICU staff are, concerning the same phenomenon. The literature identified that in general, the physical aspects of disease management are acknowledged and considered in nursing care, but that for much of the time, spiritual care of the patient and their extended family is often not formally recognised as a nursing priority, despite growing evidence to suggest that spiritual support improves health outcomes (Valley and Leppard, 2019).

No matter how insignificant the procedure or management practice may seem, this study revealed that informing and allowing caregivers in decision making is crucial as omitting to do so, challenges them emotionally. Thus highlighting the importance of engaging caregivers in management or decision making involving their neonates. Corroborating with the results of Borregas et al., (2021) study attesting that employing the principle of autonomy in the NICU can act as a source of empowerment, conflict alleviation and a way of fully engaging caregivers in neonatal care.

The literature does not have much on the perspectives of caregivers as well as their experiences with spiritual support during NICU hospitalisation. Therefore, this further signifies the importance of being religiously and culturally sensitive during the management of sick and vulnerable newborns. More emphasis is on observing the ethical principles during this era of sophisticated and modernised NICU care. Conducting further studies can also shed more light on how influential spirituality can be in the care and management of high-risk neonates.

Rules of restrictions to access the NICU were found to hinder common religious practices or ceremonies. Highlighted were some prayers that are supposed to be carried out when the baby is born, as a religious expectation. This was attributed to the secluded NICU regulations, no guiding principles that facilitate spiritual support in the unit, possible lack of knowledge and probably, overwhelming differences in religious cultures that might lead to conflicts of interest. In a previous study that validates the above findings, Genstler et al., (2022) allude that often there is hesitation in providing spiritual care due to the varied background of spiritual and religious perspectives. The result of this deficit is noted by authors to result in the provision of spiritual care that is often poor quality and limited in its scope (Genstler et al., 2022). This is contrary to the study conducted by Buys and Gerber, (2021) in a South Asian community where some participants experienced excellent care, staff proactively facilitated the presence of a Hindu priest to perform end-of-life prayers for their babies, even without the family having to request for the service.

Surrendering and accepting situations beyond their control became the only alternative for participants where NICU restrictions were concerned, despite emotional pain and spiritual challenges. The study findings accentuate the influence of religious beliefs, the significance of being religious sensitive of HCPs and a working support system to enhance caregivers' experiences.

5.2.1.3 Cultural Expectations and Responsibilities of Fathers in Healthcare Context

The findings of the study revealed that cultural and traditional beliefs are some of the stumbling blocks to fathers' involvement not only during NICU hospitalisation, but also on issues of

neonatal care or during the period of confinement in general. This is concurrent with the studies conducted in Botswana by Ncube, Barlow and Meyer (2016); Rempel et al., (2019) which pronounce that the cultural beliefs and practices, negative perceptions held by the communities regarding the role of fathers in the care of infants, and the extent to which clinicians allow involvement of families in NICU, represent a barrier to father's engagement since the father's role in pregnancy, childbirth, and parenting has been solely a mother's provider. Lee and Choi, (2023) also proclaim that in Niger, the mother and her newborn baby are kept in isolation for a certain period and the only people allowed are grandmothers and the elderly, as a way of protecting the newborn from diseases and evil spirits. Rempel et al., (2019) declare that cultural traditions are changing, and fathers provide both physical care and emotional support to the mother and baby. The same finding was revealed in the current study where all five fathers who participated were fully engaged and supportive of mothers, adding more evidence to the dynamics of culture.

In another study conducted by Nyaloko et al., (2024) the confinement restrictions seem not only directed to fathers but even to other people excluding grandmothers, as their role is believed to be essential and safe as they are considered free of negative energies due to their age, experience and abstinence from sexual activities. Findings from another study by Mirlashari et al., (2022) revealed that inappropriate behaviour of NICU personnel toward fathers, lack of social and emotional support towards them, and prevention of their presence and participation in FCC by female personnel have been due to the influence of the dominant religious and cultural background of Iranians.

In comparison of culture, tradition and religion, even though the three fathers in the study professed their faith and belief in God, they could not detach themselves from the cultural beliefs surrounding confinement and newborn care. This demonstrated the fear and respect they had for cultural norms and practices, leaving them unable to disregard or nullify the traditional beliefs and practices (Trivedi and Bose, 2018). The contemporary study therefore, highlights that while culture is evolving due to modern lifestyle and urbanisation, it continues to impact significantly maternal involvement in newborn care.

Buys and Gerber, (2021) attest that healthcare professionals are often unaware of their patients' cultural beliefs and practices and how these might be dismissed in the routine course of medical

intervention. There is therefore, a need to pay attention to the utterances of culturally diverse caregivers, to get acquainted with their various and isolated experiences. The significance of cultural education, awareness and sensitivity of medical staff and a support system to enhance caregivers' experiences is invaluable.

5.2.2 Economic Challenges

5.2.2.1 Financial Struggles and Access to Basic Needs

The findings of the current study revealed that the costs of medical and non-medical requirements during NICU pose a challenge to caregivers due to the demands that come with NICU admission. These findings are concurrent with the results of the study conducted by Wanduru et al., (2023) in which mothers described caring for the baby in the neonatal care unit as financially and physically draining. Their common expenses included paying for medicines and laboratory tests that were out of stock in the hospital, buying food and tea, and sometimes extra baby clothes.

The study findings indicate that medical emergencies like preterm delivery impose distinct financial hardships on caregivers. This was attributed to the elongated length of NICU stay, the caregivers' unsustainable income and reliance on a single source for financial support. The findings corroborate with the results of the study conducted by Mengesha et al., (2022), in which its findings revealed that health service delivery in the NICU was free from charges for maternal and newborn services. However, since the parents stayed in the hospital for a prolonged time and increased their expenditures, they incurred a shortage of finances (Al-shehri, (2024); Phibbs et al., (2019); Lambiase et al., (2024); Byiringiro et al., (2021)). The findings of the current study therefore, highlight a perceived link between preterm delivery and the financial challenges experienced by NICU caregivers.

Additionally the study findings revealed that lack of basic toiletries undermined the dignity and self-confidence of incapacitated mothers. The measures implemented to address the economic disparities among NICU mothers were unclear. Contrary to the findings of the current study, Enugu, Annan and Amponsah, (2024) in their findings, revealed that some participants acknowledged instances where nurses supplied them with toiletries for their babies.

The ongoing study further highlights that failure to assess and attend to the needs of caregivers, and implement policies or programs that support them, are likely to perpetuate cycles of desperation among mothers leading to significant stress. The effects of lack of necessities are well known and distinguishable (Wanduru et al., 2023), hence calls for responsiveness and collaboration between Social Work Department and NICU, to support disadvantaged caregivers.

The study also revealed that the geographical distance from home to the facility where the NICU is situated, impacted significantly the extent of support families were able to offer to mothers. This was ascribed to the fact that the PMH NICU is located in the city, and most participants came from surrounding villages which made transport costly. Provision of physical support and taking additional food items and all that was needed regularly was not feasible. The findings of this study align with a study conducted in Ethiopia in which findings revealed that Ethiopian NICU parents, faced financial challenges due to transportation fees as many were from rural areas, while the NICUs were located in cities and big villages. Therefore, they incurred additional costs when the need arose to bring food and water outside of the hospital, out-of-stock drugs and to pay for laboratory investigations at private pharmacies and clinics (Yassin, Legesse and Hailu, 2023).

In a nutshell, this study reveals that NICU admission comes with consequences of loss of income with those caregivers who are self-employed becoming more affected. The impact on caregivers was emotional distress and getting involved in debt to try and meet the increased NICU caregiving demands. Equivalently, Lambiase et al., (2023) argue that baby hospitalisation needs to be considered as a stressful multifaceted event impacting parents both psychologically and financially, as those two aspects may affect each other. Furthermore, previous studies emphasise that all the consequences due to NICU hospitalisation deserve to be accounted for in order to implement Family Centered Care that takes into account specific sources and needs of families (Lambiase et al., 2023). Other studies also highlight that a greater understanding of how baby medical concerns affect newborn growth, parental mental health, parent infant interactions, couple and family functioning is essential to recognise families and children who require additional care or help during and after NICU hospitalisation (Al-shehri, 2024).

In summary, the study highlight the urgent need to assess, understand, and implement policies to support families facing overwhelming costs, as a means to reduce disparities. At the time of conducting the study, there was no evidence that caregivers were benefiting from social work services. Records documenting the referral of disadvantaged NICU caregivers and the support they received, were not available both in the unit and at the Social Welfare Department. The need to carry out additional studies to explore healthcare professionals' perceptions of the provision of social services to caregivers as well as the short and long term financial implications on NICU caregiving remains inevitable.

5.2.3 Psychological Challenges

Previous studies have revealed that when a newborn is admitted to the NICU, parents are faced with the challenges of a critical care environment and its associated demands. This experience often leads to emotional distress and may result in long term negative emotional effects if adequate support measures are not provided during the hospitalisation period (Persson et al., 2023). Çaksen, (2023) corroborates that the hospitalization of newborn infants causes their parents to suffer stress, depression, feelings of powerlessness, emotions of shock, worry, fear, anguish, anxiety, and loneliness interspersed with those of faith, joy, and hope.

5.2.3.1 The psychological Struggles of Caregiving Amidst Separation, Stress and Systemic Challenges

The delivery of a newborn is a joyful event for families. When a baby is born before the expected date of delivery (premature), it can be a traumatic experience (Rihan et al., 2021). The present study revealed that participant mothers experienced mixed feelings of joy and happiness primarily stemming from the relief following delivery. For some, despite their babies being small, they felt elated as they had longed for a child for a significant period. As much as there is a need to explore the indispensable outlooks of neonatal care infants in Botswana, it is also significant to deliberate on the emotional support that caregivers need during this critical time of hospitalisation. Having insight into the medical aspects can help caregivers sail across the path to healthier forthcomings for both their babies and themselves.

Parental bereavement after the death of an infant in the NICU is reported by Lakhani et al., (2023) as a complex and nuanced experience, necessitating support from healthcare practitioners, which can have a significant impact on bereavement experiences in the short and long term run. This study has revealed the difficulties faced by grieving participants. Intertwined with the loss of a baby is a roller coaster of emotions including helplessness, confusion, sorrow, hopelessness and guilt. The extensive sorrow was accredited to the fact that death even of a neonate is not something to easily get used to. Some caregivers experienced emptiness nullifying the plans they had about the child.

The above findings are concurrent with the study conducted by Pires et al., (2023) in which the loss of a neonate brought great sadness and distress not only to the mother but the family and HCPs at large. Despite the challenges brought about by loss and grief, the present study established inconsistency or a gap in the support given to bereaving caregivers. The untimely psychological and social support aggravated the caregivers predicaments. This is contradictory to the findings of the study conducted in Canada on exploring and supporting parents' stories of a loss in the NICU. Parents' stories spoke to the value of candid and timely conversations that necessitated a caring relationship of trust in HCPs, and acknowledged that the support provided to help them come to terms with the loss of their babies, was the most invaluable and meaningful assistance they received (Lakhani et al., 2023). The differences in service provision between the study site and the Canadian NICU might be attributed to understanding and long term implementation of FCC approach in the Canadian facility. In contrast, this approach has not yet been established at the PMH NICU. The scarcity of resources in this facility, might also have repercussions in neonatal care, as well as neglect of the needs of caregivers. Lakhani et al., (2023) further proclaim that supporting parental bereavement is an essential aspect of holistic care, yet understanding how to assist parents to reach their goals and support their bereavement is incomplete. Dombrecht et al., (2020) shared the same notion by outlining that there are, however, various difficulties that HCPs face when engaging in conversations surrounding goals of care such as diagnostic uncertainty, prognostic ambiguity, and differing sociocultural beliefs of parents and practitioners. Shaw et al., (2020) propose employing a shared decision making model as the gold standard for approaching medical intervention, end-of-life, and other

consequential discussions. This underscores the need to conduct further studies to identify practical interventions that support grieving NICU caregivers.

The findings of this study also revealed that separating mothers from their babies is a highly stressful experience. This was attributed to the structural limitations of the NICU, which made it impossible for mothers to have lodging spaces within the unit. The situation was further exacerbated by the presumed rules and regulations which restricted mothers' access to the unit to specific hours, primarily feeding times. This arrangement left mothers in a constant state of worry and anxiety. The experience might also be accredited to a loss of trust and confidence in the capabilities of healthcare professionals, possibly compounded by the conditions in which participants' found their babies in during their visit to the NICU. Haward, Lantos and Janvier, (2020) also affirm that separation after birth is upsetting. The findings of the study align with the previous literature by Shrestha et al., (2020); Mimani et al., (2023) where mothers were not pleased with the set NICU rules for visiting their babies at set hours. The regulation prevented mothers from having access to their babies whenever they wished, subsequently leading to a sense of separation and loss of control which impacted their wellbeing.

Krick et al., (2021) proclaim that despite increasing evidence that minimising separation from mother and infant soon after birth is beneficial for both, there remains some reluctance to implement this practice with neonates and preterm infants in low and middle income countries. Masumo, (2021) highlights that the restriction of access to NICU does not conform to the FCC principles which advocate for non-restrictive access to the unit.

5.2.3.2 The Need for Comprehensive Support Services

The study findings revealed that the emotional needs of participants seemed to be disregarded, with no or delays in provision of psychological services. Similarly, a study conducted by Kynoe et al., (2020) in Norway, outlined that doctors did not have the ability to integrate medical care with the needs of the family. Namusoke et al., (2021) also proclaim that it seems physicians have a patient centered approach to care and in the cultural context of Iran, they do not have a holistic approach to the treatment and care of patients. This suggests that doctors only treated the infants and did not pay attention to caregivers. Contrary to the findings of the studies in which

psychological support was a mandatory service and even a neonatal psychologist was engaged in the provision of mental health services to families, in addition to support and staff training (Saxton et al., 2020); Marçola et al., (2020); Kynø and Hanssen, (2022). In Indonesia, Hariati et al., (2022) discovered that nurses were successful in supporting and empowering mothers of preterm infants, but having a multidisciplinary team helped promote proper nursing care.

The availability of specialised personnel e.g. neonatal psychologists dedicated to providing counselling to parents, the collaboration of multidisciplinary teams, and training programs might have enabled other NICUs to offer effective emotional support. In contrast, the shortage of specialised personnel in the low resourced PMH NICU, may contribute to the provision of certain services being less feasible. However, the availability of a psychology department in the facility can be effectively utilised to provide regular psychological services to NICU caregivers. Additionally, there is a need to develop specific training and in-service programs that will equip healthcare professionals with the necessary skills to recognise and address the needs of caregivers.

5.2.4 Facility Issues

Even though the study's main focus was to explore the socio-economic and psychological challenges experienced by caregivers with babies in the NICU, predominant factors that significantly impacted caregivers' experiences were revealed in the study's findings. Therefore, considering their supremacy, they were incorporated into the study findings.

5.2.4.1 Healthcare Staffing and Service Quality in Neonatal Care

Dye et al., (2023) assert that the need for complex respiratory, cardiovascular, nutritional interventions, interaction with clinicians, patient's families and the system or organisation where care is performed, influences the nursing workload required by each newborn within the NICU. However, they further highlight that mandated staffing ratios do not support the specific needs of individual patients. In the case of Princess Marina Hospital NICU, during the conduct of the study, the unit was staffed with 24 nurses not specialised in neonatal care. Within this number, atleast two nurses were granted annual leave monthly. Instances of unforeseen circumstances like an emergency, sick or maternity leaves were not catered for, i.e. no supplemental nurses,

hence the remaining nurses were subjected to overstrain in a NICU of 39 beds capacity with 6 beds for intensive care. The unit's monthly and yearly reports indicated that it typically operates beyond its capacity 50 percent of the time, with approximately 1200 admissions per year.

The unit operates on three shifts; morning, afternoon and night. The night shift was 12 hours duration, while morning and evening were 8 hours each. The staffing pattern varied between five, four, or three nurses per shift, and on very rare occasions six nurses in one of the shifts, specifically in the mornings. Although there are no conclusive global standards for staffing ratios for newborn care, some countries have set staffing ratio standards that could be used to calculate numbers, even though most are high income countries (WHO, 2020). In comparison with another study setting in Germany which discusses the impact of different staffing levels, and reflects on challenges and implications for practice, the regular capacity of this pure NICU was 11 beds, with a fixed staffing policy. Five nurses were staffed for early and late shifts each, while the night shift was staffed with four nurses, with an overall nursing staff of 52, all qualified in line with Neonatal Nurse Practitioners (Sülz et al., 2024). This implies that the above high resourced NICU had a 1:2 nurse-patient ratio, allowing for comprehensive delivery of neonatal care services.

In another Kenyan study, where the authors were evaluating the effects of supplementing ward nurses on the quality of newborn care across four public hospitals (A, B, C, D), their neonatal units' bed capacities were 53, 50 38 and 47 respectively. The nurse staffing numbers of 17, 11, 10 and 8 in order of the hospitals, two consultant paediatricians and medical interns across, and one and two medical officers in hospitals C and D respectively. The average annual neonatal admissions were 2357, 2514, 1299 and 1800 neonates (Imam et al., 2022). The disparities between this study site and the PMH NICUs are transparent, with the struggle being eminent in low and middle resource constraints countries like Botswana. Hence the study findings where other participants blamed the shortage of nurses for compromised and unsatisfactory care are not baseless.

It is therefore imperative to consider the nurse patient ratio as one way of alleviating stressful events for caregivers. The findings substantiate the study conducted by Negarandeh et al., (2021); Welborn et al., (2024); Mahmood et al., (2023) in which NICU shortage of staffing and

workload, power imbalances and structural constraints were identified as the main barriers to maternal support. Haddad, Annamaraju and Toney-Butler, (2023) affirm that nursing shortages lead to errors, dissatisfaction, higher morbidity, and mortality rates in hospitals with high patient to nurse ratios.

Kopischke et al., (2021) emphasises the importance of using acuity assessment to determine appropriate staffing levels that align with unit and organisational goals, quality standards, regulatory requirements, and a safe work environment. They also emphasise that factors such as staff skills mix, experience and competencies must be considered along with responsibilities like family care and teaching to ensure a safe and effective staffing plan. Therefore the ongoing study urges all facilities providing neonatal care to consider not only nurse to patient ratios in staffing plans but also acuity assessment to ensure better healthcare outcomes.

5.2.4.2 Lack of Communication and Support during NICU Admission

Exceptional communication is delineated to carry a positive impact acting as a source of reassurance and any disparity in this area escalates caregivers' stress (Bry and Wigert, 2023). This study findings revealed that the quality of communication which includes respect and a caring attitude, can help reassure and calm caregivers while the opposite usually has detrimental effects. Concerns of uncivilised or unprofessional communication between HCPs and mothers observed by some participants, which often escalated to conflicts and exchange of words, was a cue to the seriousness of this matter. This was attributed to the possible negligence of caregivers' needs, the attitude and conduct of individual HCPs and even caregivers' frustrations when they feel their expectations were not met. The findings are concurrent to the results of Klawetter et al., (2019) study, where primary barriers to communication were noted to be tripartite. These included lack of staff time, medical and equipment barriers, and parental fear of risks to very ill babies. In support of the aforementioned findings, several studies proclaim that some communication challenges and barriers are related to parents, their sensitivities, and conditions. Failure to accept the condition of the neonate and not being able to change it, not responding to treatment, blaming the nurses for the bad condition and the long term hospitalisation of the neonate are some of the challenges noted Carvalho, Vale and Magalhães, (2020). Jafari,

Kermarishahi and Vanaki, (2023) proclaim that negative communication experiences were said to cause emotional and physical distance between parents and HCPs.

The findings of this study revealed that nurses were often blamed by participants for their failure to update and give them information on the prognosis of their sick neonates. Contrary to previous studies which revealed that it was considered by both medical and nursing staff a medical responsibility to discuss clinical details (Negarandeh et al., (2021); Hamooleh and Heidari, (2024)). In consequence, the perception that nurses were not keen to support caregivers practically and information wise, has the potential to damage nurses' reputation, trust and professional relationships between nurses and caregivers, with the latter being mostly affected. This insight may stem from the fact that nurses spend a significant amount of time with mothers and are often responsible for numerous tasks. As a result they may become vulnerable to failing in this area if they forget or are unable to make time for providing regular updates. Their conduct and attitudes towards caregivers can also undermine or negate the positive impact of their efforts. To avoid the disparities, this study therefore, highlights the significance of communicating and giving feedback to caregivers by all those involved in neonatal care. Previous studies show that parents of newborns admitted to the NICU need information concerning the health and condition of their newborns, be involved in ethical and medical decisions and become true and active partners in caring for their sick infants and neonates (Riskin et al., 2022).

In their study involving conditions for communication between healthcare professionals and parents in a neonatal ward; Patriksson, Nilsson and Wigert, (2019) discovered that parents reported feeling upset and uninformed when communication was unfriendly or inhibited mothering. Additionally, language issues, information complexity and overload, untimely information, and medical jargon were mentioned as problematic. Byiringiro et al., (2021) attest that the provision of information about the findings of assessments contributed to the parent's understanding of the newborns' condition and was one key factor to the positive feelings and comfort to the mothers in the otherwise hopeless situations.

It was not clear why the issue of information dissemination seemed to be overlooked in the PMH NICU, but only speculations like staff being overwhelmed or lack of knowledge on how

impactful it was for caregivers to receive updates could be made. Additionally, even unprofound and negative perceptions of participants about healthcare professionals might have nullified their efforts. This study highlights the need for NICU management to deduce a functional arrangement for information, education and communication to caregivers for better health outcomes. The same sentiments were shared by Horwood et al., (2019); Labrie et al., (2021); Hamooleh and Heidari, (2024) who accentuate that effective communication between parents and members of the care team is an essential component for improving the quality of care. In-service training to impart knowledge on communication skills for all dealing with caregivers, could make conversations more competent and improve caregivers' wellbeing. Abukari and Schmollgruber, (2024) recommend the development of communication models and guidelines for respectful NICU care as they may aid in integrating families into NICUs as well as promoting quality healthcare outcomes. This study leaves room for further research that involves both caregivers and HCPs, to evaluate the barriers to communication and their effects on caregivers and NICU caregiving. Remedial strategies to improve the dissemination of information and education are invaluable for better and improved health outcomes.

5.2.5 Coping Strategies

Coping as defined by Wu et al., (2020); Feyisa, Merdassa and Biru (2022) refers to the thoughts and behaviours people use to manage the internal and external demands of situations that are appraised as stressful. The unfamiliarity of the unit, management practices and general staff conduct and attitudes are some of the challenges that brought emotional distress to participants. The study's findings highlighted emotional experiences such as fear, anxiety, confusion, helplessness and uncertainty. Similarly, the above findings were also reported by Dressler, (2024); Banjade et al., (2024); Grunberg, Vranceanu and Lerou, (2022) who assert that the NICU experience impacts parents differently and different aspects of the experience trigger the psychological manifestations. They further emphasised that the time spent in the NICU can cause psychological distress including stress, anxiety, and depression.

The findings of this study revealed that no single strategy was sufficient for participants as they had to find ways to navigate the stressors that came along with NICU admission, and adopt various strategies to cope and adapt. Positive outcomes were appreciated when measures like

mothers depending on each other, having prior information or exposure to the NICU along with updates from healthcare professionals, resilience and most importantly having faith in God were employed. The results of the study conducted by Malliarou et al., (2021) revealed that expressing negative feelings, seeking support and active positive coping were some strategies parents used to deal with the stress they felt due to their parental role. This result aligns with the findings of this study, where different coping mechanisms were noted to have effectively reduced stress and depressive symptoms of participant mothers.

5.2.5.1 Peer Support

The study revealed that interaction between mothers, sharing their testimonies and experiences had a significant impact and acted as a vital form of encouragement and motivation to others. Similarly, in their study, Banjade et al., (2024); Byiringiro et al., (2021) found that the most used coping strategy domain and a consistent source of support, was social coping that incorporated social interaction between parents staying together in the hospital rooms, and sharing their problems with each others.

Furthermore the husband's support was noted to be another form of a coping mechanism for mothers as all fathers were fully engaged and committed to ensuring the wellbeing of the mothers and neonates. Corroborating with Rihan et al., (2021) study findings in which fathers went an extra mile to ease the suffering of their spouses by offering all possible help and engagement .

5.2.5.2 Prior NICU Experience /Orientation

The study findings revealed that caregivers became equally affected by not being oriented to the NICU proceedings on what to expect when their babies were admitted. The findings are similar to the study conducted by Eduku, Annan and Amponsah, (2024), who attest that most participants in the study suffered from anxiety since they were not given enough information about the general and sensitive NICU environment.

The researcher therefore, underscores the importance of orientation and giving regular updates to caregivers as a way of alleviating their stress and assisting them cope better with the demands and sensitivity of the NICU.

5.2.5.3 Resilience

Resilience is defined by Wu et al., (2020); Feyisa, Mdassa and Biru, (2022); Perssons et al., (2022) as the capacity to adapt to challenging situations in the face of adversity. The authors, further define it as a positive adaptation to a challenge or threat and a key mechanism for managing stress or trauma.

The findings of this study, revealed that accepting the situation and continuing with caregiving was the response from some participants to the challenges they experienced during hospitalisation of their infants. This could be attributed to participants recognising that certain circumstances during their caregiving journey were beyond their control. The passing of each day, along with signs that their babies were responding well to treatment and and care, may have fostered the development of their resilience. In a study conducted by Buys and Gerber, (2021) some families expressed their acceptance of their circumstances because denial would not alleviate their fears. Time was a factor in accepting and accommodating their situation, therefore, over time, parents were more conceding with the ailment of their infants.

However, considering the findings of the current study, the researcher reiterates that healthcare professionals need to tread carefully when dealing with the kind of caregivers who do not portray any signs of distress, despite their adversities. Klein and McDonald, (2024) also emphasise that maternal distress is one potential response to the significant stressors experienced with a NICU hospitalisation. They further highlighted that it is possible that a mother of a NICU infant does not present with any distress symptoms. In further corroboration with the findings of the current study, previous studies revealed that parents of infants who require NICU admission, encounter stressors that place them at a higher risk of developing a mental health issue during and after discharge and they are often undiagnosed (Galea, Park and Hegadoren, 2021).

Therefore, this study highlights that the absence of visible signs of struggling during hospitalisation, does not necessarily indicate that a caregiver does not require psychosocial support. Therefore, no caregiver in the NICU should be overlooked or denied support based on the assumption that they are coping well as this can lead to long term psychological challenges like depression. Surprisingly, Orapeleng et al., (2024) in their study discovered that there was no

correlation between the severity of the neonate's sickness and maternal stress level, however, their other empirical findings denoted that all mothers with babies in NICU are stressed, regardless of the condition of their neonates, therefore all these mothers must receive special attention and support to alleviate the stress they experience.

In another previous study, Lian et al., (2021) assert that fathers also have unique concerns pertinent to having an infant in the NICU, juggling multiple roles and transitioning to emotions of resilience. In Setswana culture, a common expectation is that men, regardless of the calamities they face, are not supposed to show their distress or cry. 'Monna ga a lele' is a common Setswana proverb meaning men are supposed to clothe themselves with bravery regardless of the circumstances, otherwise, it will be a portrayal of a shameful weakness. In a different context the same ideology is endorsed by Garfield et al., (2018) study, when proclaiming that many fathers fail to show signs of stress until long after their infant is discharged from the hospital. Interestingly, in the present study, fathers managed to openly declare their grievances and the confrontations they encountered without a shame. This was attributed to the fact that culture is dynamic and their modern way of life and education might have contributed to this development. Unfortunately, different settings, resistance to change, negligence and reluctance remain hindrances to fully involve fathers in neonatal care and management. A verification of this perception is documented in studies conducted by Merritt et al., (2021); Merritt and Spencer, (2021) ; (Hearn et al., 2020) in which fathers reported that often, healthcare professionals tended to approach the mother when discussing prognosis and determining medical decisions, which made the fathers feel like observers and not active participants in their infants' care. These findings corroborate the findings of this study, where fathers had the same feelings of being denied their responsibility to care for their sick neonates. On a different note, Beck and Vo, (2020) study findings proclaim that fathers concealed the idea that their partners and child were more important than finding a solution to their own emotional agony.

Therefore, given the empirical evidence, healthcare professionals are urged to appreciate the unpredictability and various roles of fathers, render emotional support and furnish them with tailored information during NICU care and transition.

5.2.5.4 The Belief in God

This study revealed that participants used their faith in God to cope with the stress of having a baby admitted to the NICU. The acts of prayers and utterances that talked about the power of God were found to be daily routines for most participants. Therefore, adopted as one of the ways of overcoming challenges and fears they faced during the period of their babies' hospitalisation. A study conducted in India reported that prayer was the daily religious and spiritual routine geared towards the admitted infant for healing (Nimbalkar et al., 2019); this implies that parents use religious beliefs or faith in God, as one of the coping mechanisms during the period of NICU hospitalisation, consistent with the findings of the present study. Buys and Gerber, (2021) accentuate that religion may provide a framework for understanding emotional and physical suffering and can facilitate perseverance or acceptance in the face of stressors.

Caregivers' religious and spiritual needs should therefore, be unified into neonatal care to formulate a spiritually sensitive and informed support structure for caregivers. However, the literature accentuates the importance of considering that not everyone has a spiritual or religious outlook on life, for some, even the suggestion of spiritual distress or need may be considered offensive (Anderson and Aguas, 2024). Additionally, several societies are becoming increasingly secular, with fewer people subscribing to formal religions, with also varying perspectives within religions and an increase in personal and selective approaches to spirituality i.e an individual may be spiritual but not religious (Anderson and Aguas, 2024). All this empirical evidence is a cue to be vigilant in assessing the spiritual needs of caregivers. Furthermore, this study calls for a need for further studies to be conducted, inferring the spiritual needs and practices of NICU caregivers as well as feasible means of incorporating them into neonatal care.

5.3 Conclusion

The findings obtained in the current study grant the conclusion that the social, economic and psychological challenges experienced by caregivers with babies admitted to the NICU, are complex and differ per family. The findings of the study further acknowledge that finding a solution to those challenges will be a significant engagement even though it will bring forth various provocations for the NICU and healthcare in general. There is a gap in meeting the needs of caregivers which is exacerbated by staff and resource constraints, NICU rules and regulations,

conduct and attitudes of individual staff members and differences existing among families of caregivers. Improving the conditions of service for staff, like considering the healthcare professionals to patient ratio, and upgrading their competency in assessing and addressing the psychosocial needs of caregivers, will lead to improved health outcomes for both caregivers and neonates. Embarking on training and investing in refresher courses will also add to the establishment of mutual and trusting relationships between healthcare professionals, and caregivers as well as improved health outcomes.

Psychosocial and financial challenges incurred by incapacitated caregivers can be addressed by fully engaging the social work and psychology departments in the facility, therefore reducing the workload imposed on nurses and doctors. The two departments are also capable of providing a comprehensive assessment and support given their scope of practice and training. However, this does not deter healthcare professionals from exercising their responsibility and furnishing caregivers with regular updates, concerning the prognosis and general management of their neonates. The findings from the present study have disclosed that mothers get delight from being notified of simple and seemingly insignificant routine assessments like vital signs, therefore every effort regardless of how insignificant, is likely to bring a difference in the experiences of caregivers.

Proper orientation to the NICU can also reduce the emotional challenges mothers go through during their babies' admission to an unfamiliar environment. Embarking on empathetic communication, training staff on effective communication strategies, as well as capacitating caregivers on proper channels of communication to avoid unnecessary and avoidable conflicts are mandatory.

Despite the crowding and or how hectic it might get at times in the NICU, strategies to ensure privacy when caring for and dealing with sensitive discussions for sick neonates cannot be overemphasised.

5.4 Strengths of the Study

The Princess Marina Hospital, as the national referral hospital in the southern region, facilitated the recruitment of participants from diverse cultural, ethnic, educational and economic backgrounds, allowing for a wide range of experiences to be captured.

Furthermore, the simultaneous data collection and analysis helped determine saturation and also allowed the researcher to get in-depth data from the caregivers, especially when specific data gaps were evident in the preliminary analysis.

Conducting some of the interviews at participants' homes enhanced the rigor of the data, as it allowed the researcher to contextualise their experiences within their living conditions, thereby providing a more accurate and authentic depiction of their realities.

The study explored three significant and common aspects that contribute to daily struggles in the lives of families and individuals. As a result, its broad scope has established a foundation for understanding and summarising the common challenges incurred by NICU caregivers/families in Botswana. Furthermore, the study identified several gaps providing valuable guidance for future research endeavours.

5.5 Limitations of the Study

The study was only conducted at Princess Marina Hospital NICU, which may make the results of the study not generalisable to other neonatal settings across the country. The fact that the researcher could not manage to access all significant caregivers, e.g. those who were more than 650 km away from the NICU, and therefore never had a chance to visit the mother during the period of hospitalisation, also has the potential to affect the generalisability of the study.

There are few studies conducted in Botswana exploring the social, economic and psychological challenges experienced by caregivers with babies admitted to NICU. However, other studies were conducted on the phenomenon in other countries, mostly with different settings hence insufficient literature.

The study was also a self-disclosure with a newly developed questionnaire. Even though it was pilot tested on some peers, there were instances where participants needed more clarifications to answer some questions, hence the element of confusion is not ruled out.

All attempts were made to interview mothers in a private room within the postnatal unit, which was not always feasible as it was also used by doctors for consultations. Mothers lodging in the same rooms were quite understanding and provided each other with privacy for interviews, which was further facilitated by their differing feeding schedules. Nonetheless, the comfort of other mothers, was compromised even though they willingly gave each other space.

Additionally, interruptions by other hospital staff who came occasionally and briefly for the provision of some services that could not be avoided, remains questionable whether mothers were able to convey their opinions and experiences coherently.

5.6 Key Finding of the Study

Contending for the long term viability of comprehensive neonatal care is nullified by factors emanating from healthcare defaults, the 21st-century family structures, conflicts and strained family relationships, cultural influences and unemployment rates escalated by high inflation amongst others. Therefore, improving neonatal care locally, would not be a one day achievement, but a journey that requires planning, patience, commitment, dedication and hope for the best.

5.7 What is New in the Study

Achieving the best health outcomes and satisfactory care in the neonatal units is possible without the employment of expensive, more advanced skills and modern care. Simple measures like evidence-based practices including improved nurse-patient ratio, staff welfare, partnering with caregivers in the strive to achieve holistic care, staff training, positive staff attitude, empathy and commitment amongst others can make a difference. Collaboration with social services, psychology departments and non-governmental organisations is a significant intervention to achieve cheap and better health outcomes for neonates and their families. Additionally, subsequent research may help in shaping the future of neonatal care in Botswana.

5.8 Implications of the Findings

The fundamental implications of the study findings are deliberated in three sections encompassing neonatal nursing care, nursing education as well as research.

5.8.1 Implications to Neonatal Nursing Care

The NICU caregivers need the support of healthcare providers to affluently care for their babies in a technical and intimidating NICU environment. The perception of caregivers of nurses treating them as if they were another burden is a detrimental challenge and a stumbling block for holistic neonatal care. Hence effective and feasible neonatal care may be achievable by healthcare professionals, bringing on board caregivers as part of the healthcare team. Ameliorated communication, increased caregiver satisfaction with healthcare delivery, decreased prolonged hospitalisation and patient safety are likely outcomes of incorporating caregivers in NICU care. It is vital for nurses as the primary caregivers, to be vigilant and identify mothers and other caregivers who need either financial, emotional, informational, or psychological support. Being able to assess and appreciate the needs of caregivers, will lead to improved healthcare outcomes.

Building rapport with caregivers is essential to maintaining professionalism and supports healthcare professionals in providing effective care to neonates. The findings of the current study revealed that establishing trust, can foster open communication, enabling caregivers to share their challenges more freely, which helps healthcare professionals develop appropriate strategies to assist them. Incorporating professional values, morals and ethical principles can promote compassionate care and guide decision making and ethical problem solving. Therefore, healthcare professionals cannot do without these practices, which are highly emphasised in facilities offering neonatal care.

5.8.2 Implications to Nursing Education

The findings of the present study have revealed inadequate knowledge among caregivers concerning the NICU proceedings, what was expected of them and unaware of their babies' conditions. This is a challenge that can be averted by education support by nurses empowering

caregivers. The availability of nurses in the vicinity of caregivers around the clock and as the backbone of the healthcare sector, requires information equipped and confident nurses who can provide guidance and make informed decisions. Participants in the present study repeatedly blamed nurses for failure to provide them with information in the stressful journey of caregiving. Their trust in nurses was immeasurable but unfortunately faced a lot of disappointment, when the assistance they expected was not rendered. The need to support nurses acquire evidence-based information that matches dynamic neonatal care is emphasised. Refresher courses and in-service lectures can be handy in achieving this deficit. The unavailability of the FCC model of care in one of the highest and specialised referral centres in the country, yields a high possibility of it not being practiced even in smaller neonatal centres. This signifies a gap of possible lack of knowledge and awareness of the significance of involving families or caregivers in the care of neonates. The availability of the FCC model ameliorates the nurses' understanding of their impact on their scope of practice, in providing support to caregivers with babies admitted to the NICU. Therefore, this entails that during the revision of the curriculum, the training institutions should incorporate robust information on the Family Centered Care model.

5.8.3 Implications to Research

The current study's findings revealed the limited availability of local studies on issues surrounding challenges experienced by general NICU families. The majority of the comparisons with previous studies were from other and mostly developed countries with completely different settings and backgrounds, hence limiting the extraction of concrete and local information about the phenomenon under study. On that account, the findings of this study have bestowed fundamental information on challenges experienced by caregivers with babies admitted to the NICU. Upcoming studies can explore further the barriers and perceptions of healthcare professionals in providing neonatal care in public facilities.

5.9 Recommendations

Predicated on the results of the analysis of this present study, the following recommendations are relevant to healthcare professionals fully engaged in neonatal care:

5.9.1 Recommendations to the Management and the Facilities Entrusted with Neonatal Care

HCPs should exercise cultural sensitivity and extrapolate how culture influences experiences of NICU caregivers.

The NICU management should intergrate spirituality into holistic neonatal care by organising regular, short in-service trainings and workshops to enhance staff understanding and assessment of caregivers' spiritual needs, developing simple, practical tools for screening and addressing caregivers' spiritual concerns during admission and referring them to accessible spiritual spaces like chapel or prayer rooms in the hospital .

Establishment of a multidisciplinary assessment and referral system within the NICU is vital, comprising of social workers and HCPs. In which its mandate should focus on formulating, reviewing and updating Standard Operational Procedures (SOPs) for caregiver assessment, coordinate timely identification and referral of disadvantaged caregivers, tailor individual assessment support plans based on each cargiver's unique needs as well as monitoring outcomes to ensure that financial barriers and disparities are promptly addressed.

Caregivers must receive appropriate and timely counselling, health education, and regular updates about the illness of their newborns.

'Adopt the NICU strategy', should be considered as another option, where the PMH social work department and the hospital Public Relations Office (PRO), liaise to engage Non-Governmental Organisations (NGOs) and chain stores to assist with donations that encompass mothers and baby necessities.

The NICU and postnatal ward (PNW) departments should identify how best to ensure the continuation of care for discharged mothers lodgers with babies in the NICU. Consideration should be tailored to how and who attends to the health and needs of these women during the hospitalisation period.

Understanding of the specific barriers and challenges to implementing FCC in Princess Marina Hospital's NICU, is fundamental to the success of its implementation even in other neonatal care facilities in the country. The management should work towards measures to eliminate disparities between staff and caregivers. However, research that will eventually give insights into the barriers to implementing this crucial development in a similar setting is significant.

A controlled arrangement for key caregivers to access the NICU is mandatory. A visitation policy that is versatile, progressive and prudent should be formulated. Its conditions discussed and implemented by all staff members. Additionally making arrangements to update caregivers cannot be overlooked. This can be achieved during afternoons when the bulk of the work has been reduced and one of the doctors can be allocated to give comprehensive clinical updates to mothers and other caregivers in an open discussion forum or whichever way is feasible to the NICU staff.

5.9.2 Recommendations to the Ministry of Health

It is imperative for stakeholders involved in neonatal care policy formulation to revisit the historical practices implemented during the establishment of PHM NICU. They should aim to create a more supportive and welcoming environment, addressing the uncertainities and challenges faced by caregivers.The current study therefore, suggests measures that can be implemented based on challenges revealed and evidence from the literature for alleviating predicaments experienced by caregivers.

Ministry of Health to invest in neonatal care, so that the facility (PMH) can recruit neonatal nurses, medical officers trained in neonatology and other allied HCP's. Strategies that include formulation and revision of existing policies as well as adoption of globally attested ones with empirical evidence, to guide neonatal care, must be employed to address the current challenges on the ground.

5.9.3 Recommendations for Nursing Research

This study also calls for more advanced studies to extrapolate the impact of diversity in family structures and relationships, shifting gender roles, cultural as well as economic challenges. The

need for the above factors to be explored further to reveal how they challenge the delivery of neonatal healthcare and their impact on caregivers and caregiving during the period of admission, will significantly shape the future of neonatal care in Botswana.

The long term psychological impact; a study to track how NICU experiences affect parental mental health years later, and whether early interventions make a difference is mandatory. Furthermore, a study evaluating which types of social support best mitigate psychosocial and financial strain for NICU caregivers is vital.

5.10 Utilisation and Dissemination of Findings

Findings were presented at the Graduate Proposal Presentation Forum (GPPF). Bound copies of the dissertation to be submitted to the UNZA School of Nursing Sciences, Medical and Main Library. Other bound copies will be submitted to the Ministry of Health (Botswana) and Princess Marina Hospital.

The findings will be presented at conferences whenever the opportunity arises. Finally, findings will also be published in the International Journal of Health, Medicine and Nursing Practice. The documented findings of this study may have the potential to change the perceptions, attitudes and conduct of providers of healthcare, therefore become more receptive and motivated to go an extra mile in rendering better services to mothers and caregivers in NICU, as they will be having an insight to their challenges.

Furthermore, the findings of this study will be used by policymakers and stakeholders in revising the protocols and standards that govern neonatal care, hence leading to a more friendly and tolerable NICU environment where the needs, concerns, strengths and weaknesses of caregivers are embraced and met in a neutral and a conducive environment.

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LIST OF APPENDICES

Appendix I: Budget

NO.	ITEM DESCRIPTION	COST ESTIMATE (KWACHA)
1.	National Health Research Authority	**2040.00**
2.	University of Zambia Biomedical Research and Ethics Committee (UNZABREC)	**1500.00**
3.	Ministry of Health Research and Ethics Committee - Botswana (clearance)	**N/A**
4.	Stationery and Printing	**5500.00**
5.	Transcribing + Translation	**6000.00**
6.	Recorder	**1200.00**
7.	Transport	**4600.00**
8.	Contingency Fund	**2800.00**
9.	Publication	**2500.00**
10.	Total	**K 26140.00**

Justification

The proposed budget was intended for the effortless comportment of the study. The estimated cost of K 26 140.00 was obtained and covered the National Health Research Authority and the University of Zambia Biomedical Research and Ethics Committee approval fees at K 2040.00 and K1500 respectively. K 5500.00 was for the stationry and secretarial services that incorporated pens, A4 plain papers (rim), folders, printing and binding of the final research proposal. Transcription and Translation costs at K 6000.00, a voice recorder at K 1200.00 for easy referral of captured conversations, and K 4600 was used for transport costs from Zambia to Botswana and within Botswana to the research facility. Incidental or contingency expenses consisted of K 2800of the proposed budget. The sum of K 2500 was reserved for the publication costs of the study in a peer-reviewed journal.

Appendix II: Information Sheet and Informed Consent

Title of the study: Socio-economic and psychological challenges experienced by caregivers of babies admitted at Princess Marina Hospital Neonatal Intensive Care Unit Gaborone, Botswana

Principal Investigator

Boineelo Ketshabathupa (MSc Neonatal Nursing Student)): University of Zambia School of Nursing Sciences, P. O Box V1761, Ramotswa, Botswana, Cell: (+267 71479747/ +260 765452975/ +260 973880084), email: boineeloketshabathupa@gmail.com

Background and rationale of the study

You are invited to participate in a research study that aims to explore the challenges experienced by caregivers of babies admitted to Princess Marina Hospital Neonatal Intensive Care Unit in Gaborone, Botswana. The study is being executed following the undocumented and therefore unknown challenges that are experienced by families of NICU infants in Botswana.

Purpose of the study

Findings from other studies conducted globally, reveal the difficulties encountered by mothers and families during the period of NICU admission, however, in Botswana little information is available regarding this phenomenon of this study. It is in this regard that you are willingly invited to partake in this study that is intended to identify your sources of social, economic and psychological challenges, recognise your coping strategies, how best to render support and provide recommendations that will enable you to develop resilience and strengthen measures to involve you in the care of babies when admitted to NICU. Having achieved that, the outcome of this study will hopefully generate improved health outcomes in neonatal care across the country. Your participation and responses will be a significant input that will help in refining policies and protocols governing neonatal care.

Procedure: if you volunteer to be part of the study, you will be asked to partake in an in-depth interview which will be conducted in a private and confidential setting and will last for approximately thirty-five (35) minutes, depending on our conversation.

Study Participants

Significant contributors to this study are mothers who are admitted with the baby to Princess Marina Neonatal Intensive Care Unit. The study also includes people who support the mother during the period of admission, i.e. either the father or grandmother, aunt or whoever is taking care of the mother and the baby by ensuring that their daily needs are met.

Benefits

This study comes with no direct material benefits to you as the participant. However, the data collected will guarantee an improved healthcare service delivery in the Neonatal Units that will ensure better health outcomes for babies and families at large. It will also help policymakers revise the NICU protocols to make it a better and more tolerable environment for caregivers.

Costs

Any costs that might arise from the study are not attached to the participant. The study is supported by the government which is a sponsor to the researcher, and therefore does not come with any financial profits or benefits to the participants nor the researcher.

Compensation for participation in the study/Risk and discomforts

The researcher assures you that there are no major risks or discomforts attached to the study, except for maybe a common emotional breakdown on your part as you relate your experiences, of which psychological services can be arranged for you.

Reimbursement

No reimbursements are expected from the study. Study participants especially caregivers will be recruited when they visit the mother during their voluntary visiting times. The researcher must be available at the study site during visiting times to meet caregivers.

Questions

If you have any queries or further clarifications concerning the study, the contact information for relevant people to contact are availed at the end of this information sheet**.**

Statement of voluntariness

Please be advised that you are free to choose to participate without any pressure or coercion. You are equally able to withdraw at any point or leave the study without feeling an obligation to continue. You do not need to provide a reason for leaving the study either.

Confidentiality

The results of this study will be kept strictly confidential and used only for research purposes. My identity will not be concealed as far as the law allows. My name will not appear anywhere on the coded forms with the information. Paper and computer records will be kept under lock and key and with password protection respectively,

The interviewer has discussed this information with me and offered to answer my questions. For any further questions, I may contact the Chairperson, UNZABREC on the following details:

The Chairperson, Biomedical Research Ethics Committee, University of Zambia, and P.O. Box 50110, Lusaka, Zambia. Tel: (+260-1-256067), email: unzabrec@unza.com

STATEMENT OF CONSENT

…….has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not alter my own or my baby's usual medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name…… Signature of participant……Age……..

Date ….……

Thumb Print…… Date (DD/MM/YY)……

Researcher …… Signature……Date (DD/MM/YY)…….

Name of Witness…… Signature of Witness……..

Date (DD/MM/YY)…….

Other contacts for further clarifications/queries, please contact:

1. The Chairperson, Ministry of Health Botswana Research and Development Division, Private Bag 0038, Gaborone, Botswana. Tel: (+267 363 2751), email: hhealthresearch@govbots.onmicrosft.com

2. Professor Catherine Ngoma (Supervisor): University of Zambia School of Nursing Sciences, P. O. Box 50110, Lusaka Zambia. Tel (+260 966652879), email: catherine.ngoma@unza.zm

3. Dr Brenda Sianchapa (Core-Supervisor): University of Zambia School of Nursing Sciences, P.O. Box 50110, Lusaka Zambia. Tel (+260 95 5812823), email: brenda.sianchapa@unza.zm

Appendix III: Interview Guide

Section A: Socio-Demographic Information

Date_____ Code Number_____

Topic: Socio-economic and psychological challenges experienced by caregivers of babies admitted at Princess Marina Hospital Neonatal Intensive Care Unit- Gaborone, Botswana.

Instructions: indicate your answer by ticking or writing an appropriate answer in the box or space provided.

a) Age ……

b) Gender…….

c) Ethnicity ……..

d) Where do you stay? …….

e) Marital Status

- Single ☐ Married ☐ Widow☐ Divorced ☐
- Others (specify)…….

f) Level of Education: Never attended school ☐ Primary ☐

Secondary ☐ Tertiary ☐

g) Religious Affiliation: Nil ☐ Christian ☐ Muslim ☐ Hindu ☐

Other (Specify)……

g) Employment Status: Employed ☐ Unemployed ☐ Self-employed ☐
Pensioner ☐

h) Date of baby's admission …….. Number of days admitted……..

Section B: In-depth Interview

Table 1: Neonatal Intensive Care Unit mother's experiences interview questions.

Interview Questions	**Probes**
1. Can you describe your baby's condition and recount the reasons why he/she is admitted to the NICU?	a. What is your perceptions or experiences of having your baby admitted in the Neonatal Intensive Care Unit? b. Can you narrate your feelings when you were shown your baby immediately after delivery? Have you encountered any change of feelings since then?
2. What are your experiences in the physical environment of the NICU since your baby's admission?	a. What can you say about the NICU environment in general? b. How has the NICU environment influenced your experiences? c. Did you have any knowledge or prior experience about the unit before your baby's admission?
3. Can you narrate anything in the Neonatal Intensive Care Unit that has stirred your emotions?	Is there anything you can recount in the NICU that has affected you emotionally, whether positively or negatively i.e. has given you hope and assurance or rather instilled fear and left you hopeless?
4. What is your experience concerning your interaction with other mothers having their babies admitted to the same unit with almost the same situation as yours?	Are there any ways in which interacting with other mothers influenced your experience?

5. How has your baby's admission affected your family dynamics?	a. Are there any important changes in your life and regime that occurred due to your baby's admission? b. Is there any support you received and continue to receive from your significant others? c. What impact have they brought in your life and your baby's following admission? d. To what extent are they able to render their support towards you and your baby during admission? Are you satisfied with the support they are rendering? If not where do you find the short-fall?
6. What other challenges are you faced with since your baby's admission to the NICU?	a. How has being admitted affected your finances/ employment/education? b. Are there any cultural beliefs and or religious factors that emerged following the events surrounding your baby's delivery? If so, what impact are they having in your life right now?
7. Were you offered any emotional or counselling support?	That involved: a. Details about your baby's condition? b. Psychological services? c. Social services (if necessary)?
8. Is there anything you feel can be done differently to help you and other mothers adapt well following admission to NICU?	a. What are your expectations from this study? b) As we come to the end of this interview, what are your last words? It can either be a question, an applause, a recommendation or

	any other experience you would like to talk about that you have omitted?
	Thank you very much for your cooperation and time.

Section C: In-depth Interview

Table 2: Other Caregiver's Experiences Interview Guide

Interview Questions	**Probes**
1. What were the circumstances surrounding the baby's birth?	• How did you feel when hearing that the baby has been admitted to the Neonatal Intensive Care Unit? • Do you know the reasons behind the baby's admission?
2. What are your experiences as a caregiver in the NICU?	• How do you cope with having a baby admitted to the NICU? • What kind of support are you receiving in the NICU as you deal with the baby's admission? • Have you received any counselling or updates concerning the baby?
3. How do individuals, family, and the community influence your engagement in the NICU?	• What kind of challenges are you experiencing as a result of this admission? • Socially/religiously, financially/culturally and otherwise that occurred following the baby's admission. • Is there any way the above mentioned aspects are influencing the health outcomes of the baby?

4. How often do you see the baby in the Neonatal Intensive Care Unit?	• Are you content that you are providing enough support to the mother? Yes ☐ No ☐ • If not what is the reason? What is the biggest hindrance to providing the kind of support you would like?
5. Is there anything that you wish could be done differently to assist you in coping with the situation?	• Before we conclude do you have any last words? Questions, concerns, appreciation or recommendations that you did no mention earlier? • Thank you for your time and cooperation.

Appendix IV: Setswana Translated Version (Information Sheet and Consent form)

Mokwalo wa Tetla ya go Tsaya Karolo mo Potsolotsong

Setlhogo: Dikgwetlho tsa matshelo a batho mo gae, itsholelo le maikutlo, tse di itemogelwang ke batlhokomedi ba bana fa ba robaditswe kwa lefelo la tlhokomelo ya bana le le faphegileng mo kokelong ya Princess Marina mo Gaborone, Botswana.

Mmatlisisi Mogolo

Boineelo Ketshabathupa (MSc Neonatal Nursing Student)): University of Zambia School of Nursing Sciences, P. O Box V1761, Ramotswa, Botswana, Mogala: (+267 71479747/ +260 765452975), emaili: boineeloketshabathupa@gmail.com

Motlhala wa patlisiso

O lalediwa go tsaya karolo mo patlisisong e maikaelelo a yone e leng go batlisisa ka dikgwetlho tse batlhokomedi ba bana ba ba robaditsweng kwa lefelong le le faphegileng la bana kwa kokelong ya Princess Marina mo Gaborone mo Botswana ba di itemogelang. Patlisisiso e e diragala jaana go setswe morago go tlhoka go gatisiwa le go tlhoka go itse ka dikgwetlho tse ba malwapa a bana ba ba robaditsweng mo lefelong la bana le le faphegileng ba di itemogelang mo Botswana.

Maikaelelo a patlisiso

Dipatlisiso tse dingwe tse di dirilweng lefatshe ka bophara di supa mathata a batlhokomedi ba kopang nao fa bana ba robaditswe mo lefelong le le faphegileng la tlhokomelo ya bana, le fa gontse jalo, mo Botswana ga go na kitso e e kalo e e teng e e supang seemo se sa patlisiso. Ke ka moo o lalediwang go tsaya karolo mo patlisisong e, e maikaelelo a yone e leng go kanoka dikgwetlho tsa botshelo, itsholelo le maikutlo le go lemoga ka fa le itebaganyang le diemo tse ka teng, le gore re ka fa jang kemo nokeng le dikgakololo tse di ka le thusang go emelana le dikgwetlho, tse le go baakanya ditsamaiso tse di ka thusang go re le nne le seabe mo tlhokomelong ya bana ba lona ba ba robaditsweng mo lefelong le le faphegileng la tlhokomelo ya bana. Fa re ka fitlhelela se, tse di itemogetsweng mo patlisiong e go solofelwa fa di tla a tokafatsa tsa botsogo mo mafelong a tlhokomelo ya bana lefatshe leno ka bophara.Go tsaya

karolo ga lona mo patlisisong e le dikarabo tsa lona go tla a nna le seabe se segolo mo go baakanyeng ditsamaiso tse di itebagantse le tsa tlhokomelo ya masea.

Tsamaiso: Fa o tsaya karolo mo patlisisong e , o tla a kopiwa go tsaya karolo mo potsolotsong e e tla a dirwang mo sephiring e tsaya metsotso e le masome a mararo le botlhano , e laolwa ke puisano

Batsaya karolo

Batsaya karolo ba botlhokwa mo patlisisong e ke batlhokomedi ba bana ba ba robaditsweng mo lefelong le le faphegileng la bana la kokelo Princess Marina. Bone ba akaretsa mmaagwe le rraagwe ngwana, nkuku, mmemogolo kgotsa mongwe fela yo o tlhokomelang mmangwana le ngwana a netefatsa gore ba fitlhelela tse ba di tlhokang.

Dituelo/Dimpho

Patlisiso e, ga e na dikatso kana dimpho dipe tse di fiwang mmotsolotswa. Le fa gontse jalo, dintlha tse di bonweng mo potsolotsong di tla a thusa go baakanya ditirelo tsa botsogo mo go tsa tlhokomelo ya bana le ba malwapa a bone ka kakaretso.Se, se tla a thusa badiri ba molao go sekaseka ditsamaiso tsa tlhokomelo ya bana e e faphegileng go di tokafatsa le go dira gore lefelo le le kgone go nna le le amogelesegang mo batlhokomeding ba bana.

Ditshenyegelo

Ditshenyegelo dipe tse di tla a nnang teng mo patlisisong ga di ame ka gope le mmotsolotswa .Patlisiso e e rotloetswa ke puso e e leng yone e fang mmatlisisi thotloetso ka jalo ga go na dikatso dipe tse batsaya karolo kgotsa mmatlisisi a di bonang.

Dikatso tsa go tsaya karolo mo patlisisong/go tsena mo diphatseng le go tlhoka go tseega sentle

Mmatlisisi o go netefaletsa gore ga go na diphatsa kana go tlhoka go tseega sentle mo go lomaganngwang le patlisiso e, fa e se fela go gogomoga maikutlo mo go tlwaelesegileng fa mmotsolotswa a buwa ka maitemogelo a gagwe mo a ka rulaganyediwang tshidilo maikutlo.

Dikatso

Ga go na dikatso dipe tse di solofetsweng mo patlisisong e. Batsaya karolo mo patlisisong segolo jang batlhokomedi ba bana ba tla a kopiwa go tsaya karolo fa ba etetse bomma bana ka nako e go lekolwang ka yone. Mmatlisisi o tla a bo a le teng no lefelong le ka nako e go lekolwang ka yone gore a kopane le batlhokomedi.

Dipotso

Fa o na le dipotso kana sepe se o batlang go tlhalosediwa ka sone mabapi le patlisiso e, o tla fiwa dintlha kana megala e o ka e dirisang go ikgolaganya le batho ba ba maleba. Dintlha tseo di fitlhelwa kwa bofelong jwa mokwalo o.

Polelo ya Boithaopo

Tswee-tswee o gakololwa gore o gololesegile go tsaya karolo mo patlisisong e o sa patikiwe ke ope.O na le tshwanelo ya go ikgogela morago mo potsolotsong e nako nngwe le nngwe e o e batlang. Mme ebile gape o sa patelesega gore o ntshe mabaka a gore ke eng fa o dule mo potsolotsong e.

Sephiri

Dintlha tse di bonweng mo patlisisong e di tla a tshegediwa e le sephiri se se tseneletseng, e bile di dirisiwa fela mo mabakeng a patlisisong. Maina a me ga a ne a bolelelwa go setswe morago melawana ya patlisiso. Ga go na gope fa maina a me a tla a bonalang teng mo difomong. Dipego tse di mo dibala makgolong di tla a tlamelwa ka go nna le nomore ya sephiri e go senang ope yo o ka e fitlhelelang.

Mmotsolotsi o buisane le nna ka dintlha tse, e bile o solofeditse go araba dipotso tsa me. Fa go na le dipotso dipe fela, ke ka ikgolaganya le Modulasetilo wa UNZABREC mo dinomorong tse di latelang: **Modulasetilo, Biomedical Research Ethics Committee, University of Zambia, P.O. Box 50110, Lusaka, Zambia. Tel: (+260-1-256067), emaili**: unzabrec@unza.com

Maitlamo

……O ntlhaloseditse ka se se yang go dirwa, diphatsa, le dipoelo tsa patlisiso le ditshwanelo tsa me mabapi le patlisiso e. Ke tlhaloganya gore

tshwetso ya me ya go tsaya karolo mo patlisisong e tla a seke e fetole ka gope dithuso tsa me tsa botsogo tsa gale le gale. Mo patlisisong e, maina a me ga a ne a ntshediwa kwa ntle. Ke tlhaloganya gore ke ka tlogela go tsaya karolo mo patlisisong e ka nako nngwe le nngwe e ke e batlang. Ke tlhaloganya gore ka go baya monwana mo fomong e, ga ke tsuulole melawana epe e e ntshireletsang mme ke supa fela gore ke boleletswe ka patlisiso e ke ithaopelang go e tsenelela. Ke tla neelwa moriti wa fomo e.

Leina …… Monwana……Dingwaga…… Letsatsi……...

….…… ……..

Monwana o Motona Letsatsi: (DD/MM/YY)

Mmatlisisi……. Monwana…… Letsatsi ……

Leina la Mosupi…… Monwana wa Mosupi ……

Letsatsi (DD/MM/YY)…….

Fao batla go botsa dipotso kana go tlhalosetswa, o ka ikgolaganya gape le ba ba latelang:

1. Professor Catherine Ngoma (Supervisor): University of Zambia School of Nursing Sciences, P. O. Box 50110, Lusaka Zambia. Tel (+260 966652879), emaili: catherine.ngoma@unza.zm

2. Mrs. Brenda Sianchapa (Core-Supervisor): University of Zambia School of Nursing Sciences, P.O. Box 50110, Lusaka Zambia. Tel (+260 95 5812823), emaili: brenda.sianchapa@unza.zm

3. The Chairperson, Ministry of Health Botswana Research and Development Division, Private Bag 0038, Gaborone, Botswana. Tel: (+267 363 2751), emaili: hhealthresearch@govbots.onmicrosft.com

Kaedi ya Potsolotso

Letsatsi: _____ Nomoro _____

Setlhogo: Dikgwetlho tsa matshelo a batho mo gae, itsholelo le maikutlo, tse di itemogelwang ke batlhokomedi ba bana fa ba robaditswe kwa lefelo la tlhokomelo ya bana le le faphegileng mo kokelong ya Princess Marina mo Gaborone, Botswana.

Ditaelo: Supa karabo ya gago ka go tshwaa kana go kwala karabo ee maleba mo lebokosong kana molao o filweng.

Karolo ya ntlha: Tshedimosetso ka Motsaya Karolo ka go Farologana ka Bong, Setso, Boemo, Dithutego le tse Dingwe.

a) Dingwaga ……

b) Bong ……

c) Letso ……..

d) O nna kae? ……

e) Seemo sa tseo

Ga ke a nyalwa ☐ Ke nyetswe ☐

Re tlhalane ☐ Motlholagadi ☐

Tse dingwe (supa)…….

f) Seemo sa thuto : Ga ke ise ke tsene sekole ☐

Sekole se se botlana ☐

Sekole se se golwane ☐

Sekole sa go itshetlela mo tirong ☐

g) Ditumelo: Ga kena epe ☐ Mokeresete ☐ Mo Muslim ☐ Mo Hindu ☐

Tse dingwe (Supa)……

h) Seemo sa pereko: Ke a bereka ☐ Ga ke bereke ☐ Ke a ipereka ☐

i) Letsatsi le ngwana a robaditsweng ka lone ……

Palo ya malatsi a a robaditsweng ……..

Karolo ya Bobedi

Moalo wa ntlha: Dipotso tsa potsolotso ya mmangwana ka maitemogelo a gagwe.

Dipotso tsa potsolotso	**Tse di thusang go araba**
1. A o ka tlhalosa seemo sa ngwana wa gago yo o robaditsweng mo lefelong la tlhokomelo ya bana e e faphegileng, le gone gore o robaleditswe eng.	a. Maitemogelo a gago ke eng ka go nna le ngwana a robaditsweng mo lefelong la bana le le faphegileng. b. O ne wa ikutlwa jang fa o bontshiwa ngwana wa gago morago ga pelegi? A o itemogetse phetogo maikutlo nngwe fa e sale nako eo?
2. Ke afe maitemogelo a o nnileng le one ka lefelo la tlhokomelo ya bana le le faphegileng fa e sale ngwana a robadiwa mo go lone?	a. Ka kakaretso, o ka reng fela ka lefelo le la tlhokomelo ya bana le le faphegileng? b. Seemo kgotsa selebego sa lefelo se amile kgotsa se tlhotlheletsa jang maitemogelo a gago? c. A o ne o na le kitso kgotsa maitemogelo mangwe ka lefelo le, pele ga ngwana wa gago a robadiwa mo go lone?
3. A o ka tlhalosa ka sepe fela se se gwethileng kana sa ama maikutlo a gago mo lefelong le le faphegileng la tlhokomelo ya bana?	A go na le sengwe se o ka tlhalosang ka sone se se go amileng mo maikutlong, sa go itumedisa kgotsa sa go utlwisa botlhoko? Ke gore, sa go neela tshepo le tsholofelo kgotsa sa go tsenya poifo sa ba sa go tlogela o na le boitlhobogo?
4. Maitemogelo a gago ke afe, fa o ntse o kopana le bomme ba bangwe ba le bone bana ba bone ba robaditsweng mo lefelong le?	A go na le kafa go kopaneng le bomme ba bangwe go nnileng le seabe mo go gwetlheng boitemogelo jwa gago?
5. Go robadiwa ga ngwana wa gago go amile jang lelwapa la gago?	a. A go na le diphetogo dingwe tsa botlhokwa mo botshelong jwa gago le lelwapa tse di tlisitsweng ke go robadiwa ga ngwana wa gago? b. A go na le kemo nokeng nngwe e o e amogetseng kgotsa o tsweletse ka go e amogela mo go ba o ba ratang kgotsa ba lelwapa?

	c. Ba tsisitse pharologanyo efe mo botshelong jwa gago le jwa ngwana fa a sena go robadiwa? d. Ba dira go le kae go go fa kemo-nokeng wena le ngwana wa gago jaaka a robaditswe? A o a kgotsofalela kemo nokeng ya bone? Fa go sa nna jalo, o bona tlhaelo e le fa kae?
6. Ke dife dikgwetlho tse o kopanang natso fa e sale ngwana wa gago a robadiwa mo lefelong le le faphegileng la tlhokomelo ya bana?	a. Go robadiwa ga ngwana go amile jang tsa madi/ tiro/sekole, mo letlhakoreng la gago? b. A go na le dikgang dipe tse di amanang le tumelo kgotsa ngwao tse di tlhagogileng ntateng ya go robadiwa ga ngwana? A gona le sengwe se o ka se sedimosang ka tsone, di ama botsogo jwa gago le ngwana mo sebakeng sa gompienong?
7. A o ne wa fiwa thuso ya tshidilo maikutlo?	Ee akareditseng: a. Dintlha ka seemo sa ngwana wa gago? b. Ditirelo tsa tshidilo maikutlo? c. Dithuso tse di amanang le tsa botshelo (fa go tlhokafala)?
8. A gona le sengwe se o bonang se ka dirwa botoka go go thusa go itshetlela le bomme ba bangwe fa ngwana a robaditswe?	a. O solofetse eng go tswa mo patlisisong e? b. Lefoko la gago la bofelo ke lefe? A go na le sengwe se o ka buwang ka sone, e ka nna potso, kakgelo, kgakololo kgotsa boitemogelo bope fela jo o sa bo umakang pele re tla ko motsubong?
	Ke lebogela nako le tirisanyo mmogo ya gago le mo nakong e e tlang.

Karolo ya Boraro: Potsolotso e e Tseneletseng

Moalo wa bobedi: Kaedi ya potsolotso ya batlhokomedi le maitemogelo a bone.

Dipotso tsa potsolotso	**Tse di thusang go araba**
1. Ke mabaka afe mabaka aa amanang le go belegwa ga ngwana, kgotsa o belegetswe mo seemong sefe?	• O ne wa ikutlwa jang fa o utlwa go twe ngwana o robaditswe mo lefelong la tlhokomelo ya bana le le faphegileng? • A o itse mabaka a gore ke eng a robaditswe?
2. Maitemogelo a gago ke eng o le motlhokomedi ka lefelo la tlhokomelo ya bana le le faphegileng?	• O kgona jang go itebaganya le seemo se mo go sone ngwana wa lona a robaditsweng mo lefelong le le faphegileng la tlhokomelo ya bana? • O amogela kemo nokeng e e ntseng jang mo lefelong le mabapi le go robadiwa ga ngwana? • A o amogetse tshidilo maikutlo kana kitsiso epe fela ka botsogo jwa ngwana?
3. Botsalano jwa gago le ba bangwe, balelwapa, le lefelo le o tshelelang mo go lone di ama jang go tsaya karolo ga gago mo tlhokomelong ya ngwana mo lefelong le le faphegileng la tlhokomelo ya bana.	• Ke dikgwetlho dife tse o kopanang natso mabapi le go robadiwa ga ngwana? • A gona le dingwe tsa botshelo, tumelo, madi kgotsa ngwao, le tse dingwe fela jalo tse di tlhagogileng ntateng ya go robadiwa ga ngwana? • A o ka tlhalosa ka botlalo gore di

	ama jang botsogo jwa ngwana gongwe le jwa gago?
4. O bona ngwana wa gago ga kae mo lefelong la tlhokomelo ya bana e e faphegileng?	• A o kgotsofalela kemo-nokeng e o e fang mmangwana? Ee ☐ Nnyaa ☐ • Fa go sa nna jalo lebaka ke eng? Ke sefe sekgoreletsi se setona se se dirang gore o seka wa neela mmangwana kemo- nokeng e o e eletsang?
5. A go na le sengwe se se pharologanyo se se ka dirwang go go thusa go amogela seemo se o iphitlhelang o le mo go sone?	• Pele ga re ka wetsa potsolotso a go na le sengwe se o eletsang go bua ka sone? Matshwenyego, dikakgolo, kana se o eletsang se ka dirwa/ tokafadiwa mabapi le dintlha tse re sa tswang go buisana ka tsone? • Ke lebogela nako le tirisanyo mmogo ya gago.

Appendix V: Back to Back Translation

Questionnaire

Date: _____ Number _____

Topic: Socio-economic and psychological challenges experienced by mothers and caregivers of babies admitted at Princess Marina Hospital Neonatal Intensive Care Unit-Gaborone, Botswana.

Instructions Indicate your answer by marking (put a tick) or writing the correct answer in the box provided.

Section A: Socio-Demographic Information.

a) Age ……

b) Sex ……

c) Nationality …….

.

d) Residence ……

e) Status of Marriage

Single ☐ Married ☐

Divorced ☐ Widowed ☐

Others (Specify)…….

a) Academic level :

Never gone to school ☐

Primary ☐

Secondary ☐

Tertiary ☐

g) Religious affiliation: None ☐ Hindu ☐

Christian ☐ Muslim ☐

Others……

h) Work status: Working ☐ Not Working ☐ Self employed ☐

Pensioner ☐

i) Date of baby's hospitalisation ……

Number of days hospitalised ……..

Section B

Table 1: Neonatal Intensive Care Unit Mother's Experiences Interview Questions

Interview Questions	**Probes**
1. Can you please describe your baby's condition and give the reasons why he/she is admitted in the NICU?	a. What are your experiences regarding your child's admission in the NICU? b. How did you feel when you saw your baby for the first time, and how have your feelings changed ever since you gave birth?
2. Can you describe your experiences in the physical environment of the NICU ever since your baby's admission?	a. What can you tell me about the NICU environment in general? b. How has the NICU atmosphere propelled your experience? c. Before your baby was admitted here, did you know anything or have knowledge about the unit before?
3. Describe anything in the Neonatal Intensive Care Unit that has strongly affected you.	Whilst in NICU what made you happy, sad, terrified made to feel at ease or made you hopeful at ease?
4. Ever since being admitted in NICU, what have you learned after mingling with other mothers who have the same situation as yours?	How has meeting with other mothers in the NICU benefitted you and your experiences?
5. In what way has the baby's admission affected your family?	a. Have you noticed any significant changes after your baby's admission to the NICU? b. Are you receiving help from your family and those close to you? c. What changes have they made in your life and your baby's since hospitalisation? d. How much support are they giving you and your baby since admission? Are you satisfied with the

	support you are being offered? If not where do you think their support is lacking?
6. Are there any other difficulties you are going through following your baby's hospitalisation to the NICU?	a. How has this admission affected your finances/employment/ education? b. Are there any cultural or religious issues that affected you and somehow influenced the outcome of the health of your baby after delivery? If any what kind of influence or impact are they currently bringing in your life?
7. Were you given any emotional counselling or support?	Details concerning : a. The condition of the baby? b. Emotional and psychological services? c. Social services (if at all there are any)?
8. What can be done differently to support you and other mothers to adjust well to the to the NICU environment?	a. What is it that you are expecting from this study? b. Before we end this conversation do you have anything to say? That is questions, your gratitude, recommendations, or anything else you have not talked about.
	Thank you for your time and cooperation

Section C: In-depth interview

Table 2: Caregiver Experiences Interview Guide

Interview Questions	**Probes**
1. Describe the circumstances concerning your baby's birth.	• How did you feel when hearing that your baby has been admitted in the Neonatal Intensive Care Unit? • Do you know the reasons why your child has been admitted?
2. As a caregiver, what have you experienced in the NICU?	• How did you manage to deal with the issue of having your baby admitted in the Neonatal Intensive Care? • Is there any support you are getting in the NICU as you deal with your baby's admission? • Were you offered any counselling or updates about your baby?
3. How has your relationship with others, family members and your interaction with the environment you live in influenced the way you take care of your child admitted in the unit?	• What difficulties are you going through due to this admission? • They might be social, religious, financial or cultural. • What are the results of these challenges? Have the culture or religious influences somehow affected you and your baby's health?
4. How frequently do you see your baby in the Neonatal Intensive Care Unit?	• Are you satisfied with the support you are giving the mother? Yes ☐

	No ☐ • If not what could be the reason? What is the main challenge preventing you from giving her the kind of support you want?
5. What is it that you wish could be done better to help you to handle the situation in the NICU?	• Before coming to the end of our discussion, is there anything you want to add? Any worries, appreciation or recommendations you want to make? • Thank you for your time and cooperation

Appendix VI: Translator's Affidavit and License

AFFIDAVIT

I, the undersigned, Tshepo Ramanteba do hereby take oath and swear that:

1. I am admitted and enrolled by the High Court as a **Sworn Translator for the Courts in Botswana as per order 65 of the High Court rules.**

2. I do hereby swear solemnly and sincerely affirm that I translated research documents: patient information sheet, informed consent and in depth interview guide from English language to Setswana language, on behalf of Ms. Boineelo Ketshabathupa, studying at University of Zambia School of Nursing Sciences.

DEPONENT: .....

THUS DONE AND SWORN BEFORE ME IN GABORONE THIS ...13th..... **DAY OF** ...JUNE..... **AT** ...1100hrs..... **A.M/~~P.M~~ THE DEPONENT HAVING ACKNOWLEDGED THAT SHE KNOWS AND UNDERSTANDS THE CONTENTS OF THIS AFFIDAVIT.**

LOETO MORAPEDI..... **(Name)**

Editor
COMMISSIONER OF OATHS

COMMISONER OF OATHS

..... **(Signature)**

.....ATTORNEY **(Rank)**

Form B

REPUBLIC OF BOTSWANA

IN THE HIGH COURT OF THE REPUBLIC OF BOTSWANA

CERTIFICATE OF ADMISSION AND ENROLMENT TO PRACTICE AS A SWORN TRANSLATOR (ENGLISH AND SETSWANA AND VICE VERSA)

No. **MAHGB-000040-17**

This is to certify that **TSHEPO RAMANTEBA**

Of

P O BOX 41513
GABORONE

Certified true copy of the original
Name: Lefa Magadi
Signature: ..... Date: 13-6-24
Chief Law Reporter
High Court of the Republic of Botswana

has been admitted and enrolled as **A SWORN TRANSLATOR** of the Courts of Botswana.

On the **15TH** day of **FEBRUARY 2017**

Gaborone, Botswana

Date: **8TH MAY 2017**

M L MOTLHABI
Registrar of the High Court

Appendix VII: Permission Letters to Conduct the Study

PMH Approval Letter

TELEPHONE: 3621400 PRINCESS MARINA HOSPITAL
FAX: 3973776 P. O. BOX 258
PLOT NO. 1836 GABORONE
HOSPITAL WAY BOTSWANA

REPUBLIC OF BOTSWANA

RE: PMH 2/11AII (458) 17th July 2024

Boineelo Ketshabathupa

P O Box V1761

Ramotswa

Botswana

Dear Boineelo Ketshabathupa

RESEARCH APPROVAL: SOCIO-ECONOMIC AND PSYCHOLOGICAL CHALLENGES EXPERIENCED BY CAREGIVERS OF BABIES ADMITTED AT PRINCESS MARINA HOSPITAL NEONATAL INTENSIVE CARE UNIT GABORONE, BOTSWANA

This letter is to inform you that Princess Marina Hospital Ethics and Research Committee has reviewed your and **approved** your above-mentioned protocol. The approval period is 17th July 2024– 17th July 2025.

This approval is subject to compliance with the following requirements:

1. All changes of amendments, deviations, violations of your protocol are to be submitted for review again and approval by Princess Marina Hospital Ethics and Research Committee before implementation.
2. Only approved documents like informed consents, questionnaires and materials submitted with the protocol will be used.
3. Researcher must not change any aspect of the research without permission from the Princess Marina Hospital Institutional Research Board.
4. Any unforeseen circumstances including termination of the study must be reported to Princess Marina Hospital Research Board immediately.
5. The Princess Marina Hospital Research Board must have access to the on-going study anytime for auditing purposes.
6. After completion of the study, the researcher must submit a hard copy and soft copy of protocol to Princess Marina Hospital Ethics and Research Board.

Wish you prodigious triumph in your study.

Yours faithfully

Akanyang Tshiamo

Secretary PMH REC

For Hospital Superintendent

HRDC Approval Letter

TELEPHONE: 363 2500
FAX: 317 0155
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD

REPUBLIC OF BOTSWANA

MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REFERENCE NO: HPRD: 6/14/1 **08th July 2024**

Health Research and Development Division

Notification of IRB Review: **New application**

Boineelo Ketshabathupa
P.O Box V1761
Ramotswa

Dear Boineelo Ketshabathupa

PROTOCOL TITLE: SOCIO-ECONOMIC AND PSYCHOLOGICAL CHALLENGES EXPERIENCED BY CAREGIVERS OF BABIES ADMITTED AT PRINCESS MARINA HOSPITAL NEONATAL INTENSIVE CARE UNIT GABORONE, BOTSWANA

Review Type: Expedited/Health Research and Development Division
Review Date: 28th June 2024
Approval Date: 08th July 2024
Effective Date: 08th July 2024
Expiration Date: 07th July 2025
Risk Determination: Minimal Risk

Thank you for submitting new application for the above referenced protocol. The permission is granted to conduct the study.
This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained where applicable.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. **Approval is for academic fulfillment only.** Copies should also be submitted to all other relevant authorities.

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 7A.7 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from HRDD office, e-mail address: hhealthresearch@gov.bw or hhealthresearch@govbots.onmicrosoft.com. As a courtesy, the HRDD will send you a reminder

email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form.

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No.7A .7 or Ministry of Health website: www.moh.gov.bw or can be requested via e- mail from HRDD Office, e-mail address: hhealthresearch@govbots.onmicrosoft.com

In addition submit a copy of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

If you have any questions please do not hesitate to contact Mr Abia Sebaka at, asebaka@gov.bw, Tel +267-3632754 and Mr Kgomotso Motlhanka at, kgmmotlhanka@gov.bw, Tel +267-3632751.

Thank you for your cooperation and your commitment to the protection of human participants in research.

Yours Sincerely

Mr Abia Sebaka
for/PERMANENT SECRETARY

MINISTRY OF HEALTH
RESEARCH DIVISION
0 8 JUL 2024
P/BAG 0038, GABORONE
HEALTH POLICY RESEARCH & DEVELOPMENT

UNZABREC Approval Letter

UNIVERSITYOFZAMBIA

BIOMEDICALRESEARCHETHICSCOMMITTEE

Telephone: +260 977925304 Ridgeway Campus Telegrams: UNZA, LUSAKA P.O. Box 50110 Telex: UNZALU ZA 44370 Lusaka, Zambia

Fax: + 260-1-250753 E-mail: unzarec@unza.zm

Federal Assurance No. FWA00000338IRB00001131 of IORG0000774NHRAR-REC No 2021-05-0002

10th May, 2024

Your REF. No. 5152-2024

Ms. Boineelo Ketshabathupa,
University of Zambia,
School of Nursing
Sciences, P.O Box 50110,
Lusaka.

Dear Madam,

RE: SOCIO-ECONOMIC AND PSYCHOLOGICAL CHALLENGES EXPERIENCED BY CAREGIVERS OF BABIES ADMITTED AT PRINCESS MARINA HOSPITAL NEONATAL INTENSIVE CARE UNIT GABORONE, BOTSWANA (REF. NO. 5152-2024)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 9th May, 2024. The proposal is **approved**. The approval is based on the following documents that were submitted for review:

a) Study proposal

b) Questionnaires

c) Participant Consent Form

APPROVAL NUMBER : REF. No. 5152-2024.

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

i. **APPROVAL DATE : 10th May 2024**

ii. **TYPE OF APPROVAL : Standard**

iii. **EXPIRATION DATE OF APPROVAL : 9th May 2025**

iv. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the UNZABREC Offices should be submitted one month before the expiration date for continuing review.

v. **SERIOUS ADVERSE EVENT REPORTING**: All SAEs and any other serious challenges/problems having to do with participant welfare, participant safety and study integrity must be reported to UNZABREC within 3 working days using standard forms obtainable from UNZABREC.

vi. **MODIFICATIONS**: Prior UNZABREC approval using standard forms obtainable from the UNZABREC Offices is required before implementing any changes in the Protocol (including changes in the consent documents).

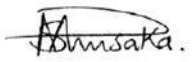
vii. **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the UNZABREC using standard forms obtainable from the UNZABREC Offices.

viii. **NHRA:** You are advised to obtain final study clearance and approval to conduct research in Zambia from the National Health Research Authority (NHRA) before commencing the research project.

ix. **QUESTIONS**: Please contact the UNZABREC on Telephone No. +260977925304 or by e-mail on unzarec@unza.zm.

x. **OTHER**: Please be reminded to send in copies of your research findings/results for our records. You are also required to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study. Use the online portal: unza.rhinno.net for further submissions.

Yours sincerely,



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

CHAIRPERSON

Tel: +260977925304

E-Mail: s.munsaka@unza.zm

NRHA Approval Letter

NATIONAL HEALTH RESEARCH AUTHORITY

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

Tell: +260211 250309/0777409076 | Email: znhrasec@nhra.org.zm | www.nhra.org.zm

Ref No: NHRA1192/17/05/2024 **Date: 7th June, 2024**

The Principal Investigator,
Ms. Boineelo Ketshabathupa,
University of Zambia,
School of Nursing Sciences,
P.O Box 50110,
Lusaka, Zambia,

Dear Ms Ketshabathupa,

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Socio-Economic and Psychological Challenges Experienced by Caregivers of Babies Admitted at Princess Marina Hospital Neonatal Intensive Care Unit Gaborone, Botswana."**

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

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;

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

Yours sincerely,

Prof Victor Chalwe

Acting Director/Chief Executive Officer

National Health Research Authority

All correspondences should be addressed to the Director/CEO National Health Research Authority

Appendix VIII: Timeline

2023 - 2024

ACTIVITY	SEP	OCT	NOV	DEC	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
Proposal Submission /Departmental	■															
Corrections and proposal completion n		■	■	■	■											
GPPF						■										
Ethics Submission							■	■								
Data Collection & analysis									■	■	■	■				
Report Writing & GPPF													■	■	■	
Final Submission																■