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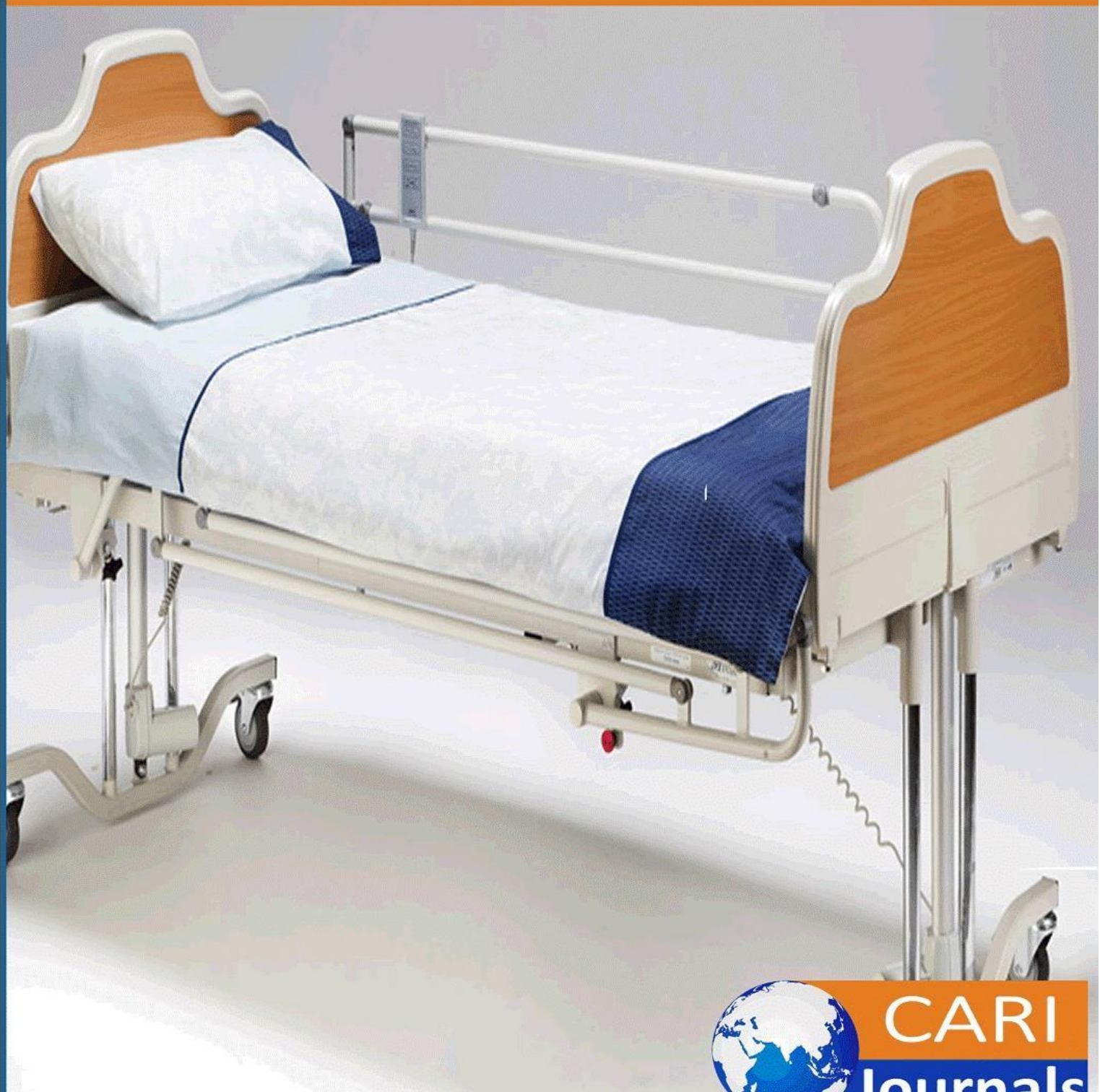

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Socio-Economic and Psychological Challenges Experienced by Caregivers of Babies Admitted at the Princess Marina Hospital Neonatal Intensive Care Unit Gaborone, Botswana

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Abstract

Purpose: The purpose of this study was to explore the social, economic and psychological challenges experienced by caregivers when their babies are admitted to Princess Marina Hospital (PMH) Neonatal Intensive Care Unit (NICU) in Gaborone, Botswana.

Methodology: The study adopted a descriptive phenomenological design using structured in-depth interviews to explore the social, economic and psychological challenges experienced by NICU caregivers. Interviews were transcribed verbatim and analysed using thematic analysis.

Findings: Findings revealed that the social, economic and psychological challenges experienced by caregivers when their babies are admitted to the NICU are complex and vary per family. Distance from the facility, family relationships and support, financial status amongst others, were found to significantly contribute to the challenges experienced by caregivers. Consequently, some facility issues exacerbated the challenges incurred by caregivers. Considering their supremacy, they were also incorporated into the study findings.

Unique Contribution to Theory, Practice and Policy: The challenges that comes with NICU admission are multifactorial, and multidisciplinary approaches like engaging social work and psychology departments to assist in supporting NICU caregivers is crucial. Measures including staffing, incorporating family centred care (FCC) and regular training of staff are also mandatory to achieve sustainable and satisfactory neonatal care.

Keywords: *Neonatal Intensive Care Unit, Caregivers, Challenges, Experiences*

1.0 BACKGROUND INFORMATION

The NICU offers advanced and specialised treatment for newborns with complex medical needs. 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) revealed that the theme of NICU, its physical environment and regulations encompasses everything from medical machines and devices, alarms, hectic interactions with medical staff and distressed families to the rules of the NICU and the manner in which they were enforced. In another study conducted to explore the needs and psychosocial support of parents of extremely premature infants, and how the NICU and its staff meets or fails to meet these needs, Bry and Wigert, (2019) outlined the major sources of stress and anxiety for parents as fear of their child's health, alteration in their parental role, infant's behaviour and the highly technical NICU environment. Harrison, Wasserman and Goodman, (2018) attest that in NICU, parents need emotional and practical support during infant hospitalisation, nevertheless, friends and families of parents may constitute the most significant providers of this support, even though it remains unclear when and how significant others can be present and involved.

Haward, Lantos and Janvier, (2020) study revealed that many parents who have had children in the NICU suffer from post-traumatic stress disorder (PTSD), anxiety, depression and prolonged grief, whereas others develop resilience adapting constructively to traumatic experiences. Green and Little (2019) attest that family members may find help and spiritual support by drawing on the source of their religion or spiritual practices. The authors however, highlight the possibility of the health crisis itself, undermining the basic assumptions upon which religious or spiritual support rests.

Lambiase et al., (2023) described the financial burden, as typically one's perceptions of subjective pressures and economic challenges. Even though a number of studies highlighted the financial burden experienced by families during NICU hospitalisation, its annotation remains unclear (Lakshmanan et al., 2022). To the researcher's knowledge, hardly any studies examined the financial burden experienced by families of NICU graduate infants during hospitalisation in Botswana, hence the financial predicaments of NICU families remain unknown. Furthermore, despite the increasing evidence of the NICU environment as a contributing factor to PTSD of caregivers, the rate at which this outcome occurs in Botswana is not well understood, and there was no evidence that the research population benefit from the psychological and social services available in the study facility.

A study conducted by Ncube, Barlow and Mayers (2016) in Botswana, revealed that reduced access to the NICU has been identified as a key barrier to fathers and significant others direct involvement in infant care. Additionally, the cultural beliefs and practices, negative perceptions held by the communities regarding the role of fathers in care of infants, and the extent to which clinicians allow involvement of families in NICU represent a barrier to family engagement; however, its impact has never been evaluated. Guidelines for the implementation of Family

Centred Care (FCC), were not available for the NICU during the conduct of the study, and there was limited information regarding how healthcare providers (HCPs) share information and engage with families, hence the PMH NICU remained one of the most secluded units in Botswana healthcare facilities.

2.0 METHODOLOGY

2.1 Study Design

A qualitative descriptive phenomenological design was used to explore the socio-economic and psychological challenges experienced by caregivers of babies admitted to PMH NICU.

2.2 Study Setting

The study setting was the Princess Marina Hospital NICU, one of the two national referral hospitals, consisting of the largest neonatal intensive care setting in the southern region of Botswana. It is a 39-bed unit with six intensive care beds, functioning above the required capacity half (50 percent) of the time, with total admissions of approximately 1200 per year. The hospital was chosen as a research site since it is a high-volume government run health facility, serving all patients regardless of their socio-economic status.

2.3 Sampling Technique

Purposive sampling with data saturation as the determining factor for sample size was employed. Included in the study were mothers 18 years old and above, those whose babies 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. Mothers of babies who were initially sick but improved in due course, caregivers (fathers and grandmothers) who were staying with the mother or rendering support during hospitalisation were also included. Excluded were sick mothers, those whose babies were re-admitted to the unit, and those who delivered at home or before arrival at the health facility. Mothers of babies with newborns on end-of-life care and those with severe congenital anomalies that were not compatible with life were also excluded. Mothers were consulted for the involvement of their caregivers and phone call appointments were made with five of the caregivers who were not accessible at the study site during data collection. Interviews were conducted at their homes in places that incorporated Tlokweng, Mogoditshane and Tsolamosese. A total of 17 caregivers; (10 mothers, 5 fathers and 2 grandmothers) participated in the study.

2.4 Data Collection

The study was conducted between July and early August 2024. 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. An in-depth questionnaire, structured according to the phenomenon of interest was used for collection of data. It consisted primarily of open ended questions that were structured by the researchers, 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. Pilot testing of the tool was conducted at the study facility and the participants interviewed were excluded from the study. Ayesha and Khan, (2020) attest that 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. Therefore, four participants (2 mothers, 1 father and 1 grandmother) were recruited for pilot testing of the study tool.

2.5 Data Analysis and Presentation

The conducted interviews were verbatim transcribed immediately after the interviews were conducted to single out errors and find meaning when the interviews were still ongoing. The steps of thematic analysis outlined by Braun and Clarke (2019), involving familirisation with the data, identifying initial themes, coding, categorising and forming insightful descriptive themes was employed. NVivo 14 software was also used to aid in managing the data.

2.6 Ethical Approval

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 PMH Institutional Research Board (IRB) RE: PMH2/11AII (458). The study was also conducted following rules specified in the Helsinki Declaration.

3.0 RESULTS

3.1 Participants Demographic information

The participants ages ranged between 29 and 73 years. 15 participants were Batswana, while a father and a mother were Tanzanian and Malawian nationals respectively. All participants were living either in the city or villages classified as urban areas i.e Ghanzi, Selibe-Phikwe, Tlokweng, Molepolole, Mmopane, Mogoditshane, Tsholofelo East, Broadhurst, Block 9 and Tsolamosese. Five participants were married, eight cohabiting and four reported not married. One participant had never attended school, three completed primary school, two had junior secondary school certificates, six were senior secondary school certificate holders and five had completed tertiary education. One grandmother was a pensioner, and the other a retiree, eight participants were unemployed, two self-employed and five had regular jobs. Christianity was the most common religion with 14 participants, two were affiliated to Islam and one was not affiliated to any religion. The average length of stay for the ten babies whose caregivers were recruited in the study was 25 days.

3.2 Themes

Following analysis of data, eight overaching themes which depict explicit patterns of the experiences and feelings of participants regarding the socio-economic and psychological

challenges they experienced when their babies were hospitalised were distinguished. Specifically; The challenges of caregiving in the face of adversity, The struggles of caregivers amidst isolation and limited support, Religious displacement in healthcare settings, Cultural expectations and responsibilities of fathers in healthcare contexts, Financial struggles and access to basic needs, Healthcare staffing and service quality in neonatal care, Emotional turmoil during childbirth and NICU experience as well as Coping strategies.

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

The theme underscores how caregiving became even more strenuous if coupled with external or internal factors. The theme is explored in the following subthemes:

3.2.1.1 Caregiver Responsibilities

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

"M*y firstborn is a child living with a disability, I have been taking care of her all along, 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)

3.2.1.2 Educational Challenges

The texts 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 them to take on multiple roles.

"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." (C5)

3.2.1.3 Health Concerns

The 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, 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." (C8)

3.2.1.4 Impact on Family Dynamics

The absence of one parent significantly affected the family's dynamics. For instance, one parent having to leave for work or medical reasons led to complications in ensuring that children are cared for properly. This resulted in reliance on extended family or friends, which was not always feasible.

"*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. 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)

3.2.2 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 were admitted to the NICU.

3.2.2.1 Social Isolation

Some participants reported feelings of abandonment and neglect by family and friends as narrated below:

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

"My siblings are around but they are never supportive, I don't know maybe it is because we have never communicated regularly." (C5)

It was quite evident from the interview that the impact of losing a parent on emotional support networks was weighing heavily on one of the participants.

"*I do not have parents who come and see me, my mother died in 2013. I am really lost, if not for the father of my kids I do not know where I would be."(C1)*

3.2.2.2 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. The burden of relying on a single partner for emotional and practical support were evident.

"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. Even the burial of our baby we were only two, we had no support." (C7)

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

3.2.2.3 Familial Dynamics and Conflict

In families with different dynamics, conflicts and misunderstandings proved to be a source of distress for NICU caregivers especially mothers who were left stranded with minimal or no 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)

3.2.3 Theme 3: Religious Displacement in Healthcare Settings

Religion which encompasses the belief in a Supreme Being or God has proven to be a source of comfort and hope for caregivers. It became a detrimental effect for caregivers when they were imposed with regulations and protocols that they had no control over as noted in the following subthemes:

3.2.3.1 Consent and Autonomy

One mother shared how some of the management practices which seemed small and insignificant to others, can be emotionally 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 participant had to endure.

"*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)*

3.2.3.2 Impact on Religious Practices

One of the father revealed 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.

"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)*

3.2.3.3 Acceptance and Resignation

The participants reported coming to terms with the restrictions despite emotional pain. The only option they had was the acknowledgment of the limitations imposed by the healthcare system on their personal beliefs and practices.

"*… 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)

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

Culture and traditional beliefs were perceived as one of the stumbling blocks to fathers' involvement not only during NICU hospitalisation but also on issues of neonatal care in general. Three fathers related the secluded NICU to cultural beliefs and practices. The following sub-themes emanated from this controversy.

3.2.4.1 Cultural Norms and Conduct

The distress incurred by participant fathers having the perception that they were being barred from seeing their newborns in the NICU was evident from the interviews conducted with three fathers speaking unwaveringly about cultural norms and traditions.

"This issue of fathers not being allowed to see the baby during admission is very painful as they usually say men are not allowed. It is only a hindrance to us men who want to take full responsibility for their children." (C12, C15)

Another participant, a 34 years old father shared his perceptions about how cultural practices were still dominating despite the cultural shifts and modern way of life.

"We still live according to the traditions where we were bound as men not to do certain things concerning 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 being taken care of 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)

3.2.4.2 Beliefs and Traditions

The significance of cultural beliefs (e.g. Setswana) according to some 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, could not be undermined as some participants outlined in the following notations:

"I personally and 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)

"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)

3.2.4.3 Fear and Respect for Tradition

The tension between personal desires and cultural expectations leading to emotional distress was picked as participants were sharing their respect for cultural norms impacting a father's willingness to engage responsibly with the family. Additionally, regardless of how much the fathers expressed their belief in God, they could not distance themselves from the influence of cultural beliefs and practices.

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

3.2.5 Theme 5: Financial Struggles and Access to Basic Needs

The financial needs of participants were varied. Several sub-themes concerning caregivers finacial insults were extracted from the data collected as noted below.

3.2.5.1 Healthcare Access and Medication Shortages

The unexpected shortage of essential medications and vitamins which were reportedly out of stock in the hospital were common, bringing along emotional distress.

"So we come here knowing that I am going to the hospital and I will be provided with medication , then when you get here, you are told there is no multivitamin but the baby needs it, there is no vitamin D, but the baby needs it, tell them to buy for you at home. You know, it is not everyone who can afford that."(C2)

"*What is affecting me emotionally are financial issues, because sometimes I need things like molasses because they say I have low blood, so I usually find myself stranded and not knowing what to do."* (C1)

3.2.5.2 Transportation Challenges

High transport costs affecting the ability to visit the mother in the hospital was also mentioned as one of the challenges.

"*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)

"...like I said where I am coming from at Tsolamosese is a bit far from here, so they cannot keep visiting me several times because of transport costs." (C5)

3.2.5.3 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 it because I am no longer able to carry out my business as I am here." (C6)

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)

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

There was a perceived lack of nursing staff, leading to inadequate monitoring and care for infants.The theme is discussed under the following subthemes:

3.2.6.1 Staffing Shortages and Patient Care

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

"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)

"*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 was running up and down, even I could see that this person…, I felt they could be another nurse to help."* (C2)

3.2.7 Theme 7: Emotional Turmoil during Childbirth and NICU Experience

Caregivers were confronted with the critical care setting and all its anticipated demands which left them in emotional turmoil as noted in the following subthemes:

3.2.7.1 Joy and Relief of Birth

There were 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.

"Actually,this is my only baby, 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 providers 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, I have found my comforter and healing in my soul." (C4, a 40 years old mother)

3.2.7.2 Loss and Grief

Experiences of loss related to previous pregnancies and the emotional impact of losing a baby were narrated:

"*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 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. Hey! My mind was all over the place I was not thinking straight at all!" (C13, a partner to C7)*

In a different interview (C14), the husband to (C4), expressed feelings of hope amidst uncertainty.

"*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, but now here we are and remain hopeful everyday."*

3.2.7.3 Impact of Separation

Feelings of distress and worry related to being separated from the baby were also common concerns amongst caregivers.

"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)

Another father who had painful experiences from the past also recounted how he navigated his way into the NICU.

"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)

3.2.7.4 Stressful Interactions with Healthcare Providers

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 as stated below:

" S*ometimes when we ask for help, they are usually harsh to 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, C6)

"*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 found her sleeping on the table but giving me those kind of answers, I got hurt emotionally."* (C4)

3.2.7.5 Fear and Anxiety about Infant Health

Constant fear stemming from witnessing the death of babies, particularly preterm infants, led to mother's pervasive sense of insecurity regarding their own babies' health:

"Hey! 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." (C1)

"That place honestly is not nice, when we get there, we are always afraid, and another thing, we see dying babies. Babies are dying in large numbers in that place." (C3)

3.2.7.6 Information Gap and Lack of Updates

Participants expressed frustration over not being informed about their babies conditions and treatment in the following words:

"*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)*

"*…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. 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)

Providing education on procedures and care protocols, was noted to be vital to prevent misunderstandings and mistakes that are likely to occur when mothers are not informed as stated below:

"We lack information and we need to be taught and informed what to do and what not to do so that we understand. It is easy to commit a mistake when you do not understand and that mistake can cost the baby's life." (C7, C14)

3.2.8 Theme 8 : Coping Strategies

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

3.2.8.1 Peer Support

(C4) shared how hearing about other mother's past experiences and how they overcame similar situations, gave her hope that she too would make it out of the NICU with her baby alive.

"*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, they 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.*"

3.2.8.2 Prior NICU Experience /Orientation

Some participants shared that for them to be admitted to the NICU again was an advantage and acted as one of the coping strategies to deal with the stress of having a baby admitted to the NICU.

"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)

3.2.8.3 Resilience

Accepting the situation and focusing on the bigger vision which they considered as seeing their babies discharged from the NICU, gave some participants the courage to endure all challenges that came along, others declared that time factor was also very crucial in helping them to cope as they realised that everyday that passed, brought new hope and strength.

"*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)

"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)

3.2.8.4 The Belief in God

A mother who shared having not been successful in four pregnancies , narrated how she never lost her trust in God despite all the past circumstances and being a believer, she learned to depend on prayers and that have been worthwhile to her and his baby.

"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, you 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 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 healing." (C4)

4.0 DISCUSSION OF FINDINGS

The overarching themes were further categorised into social, economic, psychological, facility issues and coping strategies, and discussed in details as follows:

4.1 Social Challenges

4.1.1 The Challenges of Caregiving in the Face of Adversity

The study revealed that the impact of neonatal care on caregivers, extend beyond hospital settings to affect family dynamics. Fathers when taking on additional caregiving responsibilities, often faced difficulties balancing work and family. This shift negatively impacted the education, health and wellbeing of siblings, with some missing school due to inadequate supervision. The findings align with studies conducted by Gibson et al., (2021); Lee and Choi, (2023), which also emphasise the broader consequences of neonatal admission on parenting and family stability.

Some caregivers experienced social isolation due to abandonment and neglect by family and friends, factors such as unresolved sibling conflicts, geographically distant relatives and the loss of immediate parents contributed to their predicaments. This contrasts with Shrestha et al., (2020); Miami et al., (2023) study findings, where family members provided support during pregnancy and child birth.

The study revealed that faith played a vital role for NICU caregivers, offering emotional support, hope and a sense of connection through shared prayers and scriptures. Despite this, healthcare professionals did not seem to offer spiritual support. Caregivers' strong religious commitment was likely influenced by generational traditions. Echoing El-Khani, Calam and Maalouf, (2023) study

findings which confirmed that religious beliefs shape family dynamics and parenting. However, hospital policies and medical decisions sometimes conflicted with caregivers' beliefs. The lack of formal guidelines for spiritual care in the NICU often resulted in caregivers' spiritual needs being overlooked, possibly due to time constraints, low awareness or the low prioritisation of spirituality in healthcare. Previous studies also revealed that nursing care typically emphasises physical health, with spiritual care rarely prioritised (Valley and Leppard, 2019).

The study highlights that it is vital to employ autonomy even in minor procedures as excluding caregivers from decision making is likely to cause them emotional distress. One mother for example, was deeply affected upon discovering that her baby's head had been shaved without consultation, as it conflicted with her religious beliefs. Similar findings were outlined by Borregas et al., (2024) in their study, attesting that informing caregivers beforehand could help mitigate such spiritual and emotional challenges.

4.1.2 Impact on Religious Practices

NICU access restrictions were found to hinder religious practices, such as prayers expected at birth due to the absence of guiding principles addressing conflicts of interest. As a result, caregivers often had no choice but to surrender and accept these limitations, despite experiencing emotional and spiritual distress. Contrary to a South Asian Buys and Gerber, (2021) study where staff proactively facilitated religious rituals like end-of-life prayers without family requests. Genstler et al., (2022) allude that many NICUs hesitate to provide spiritual care due to diverse religious backgrounds, leading to limited and poor quality support.

4.1.3 Cultural Expectations and Responsibilities of Fathers in Healthcare Contexts

The study findings revealed that cultural and traditional beliefs often hinder fathers' involvement during NICU hospitalisation and the postpartum period. Three of the five fathers were familiar with the cultural belief that a father's lifestyle choices can impact a newborn's health. They understood the expectations for male behaviour during the mother's confinement, including abstaining from promiscuity. However, they were frustrated by their exclusion from NICU access during a critical time, despite having previously supported their partners during confinements at home without issue. This aligns with the studies conducted in Botswana by Ncube, Barlow and Meyer (2016); Rempel et al., (2019) which highlights cultural norms, community perceptions and clinical restrictions as barriers to paternal engagement. However, Rempel et al., (2019) study findings revealed that cultural norms are evolving, with fathers increasingly providing physical and emotional support, as seen in the present study, where all five fathers were actively engaged and supportive to their partners.

4.2 Economic Challenges

4.2.1 Unprepared for Medical Emergencies

Caregivers unprepared for medical emergencies like preterm delivery faced significant financial burdens. This was mainly due to requirement to buy out-of-stock medications, prolonged NICU

stays, lack of financial readiness and reliance on a single source of support (father) or unemployment. The findings concur with the results of the study conducted by Mengesha et al., (2022); Phibbs et al., (2019) and Lambiase et al., (2024) which revealed that despite free maternal and newborn services, prolonged NICU hospitalisation still led to increased caregiver expenditures.

4.2.2 Basic Necessities

The study findings revealed that lack of basic toiletries affected the dignity and confidence of incapacitated mothers. Measures implemented to address economic disparities among NICU mothers remained unclear. Contrary to the findings of the study conducted by Enugu, Annan and Amponsah, (2024) in which some mothers were assisted with toiletries. This study further highlights that neglecting caregivers' needs and lacking supportive policies can perpetuate cycles of desperation.

4.2.3Transportation Costs

The study found that the distance between home and the NICU limited family support. High transportation costs made regular visits and supply of deliveries difficult. The findings align with Yassin, Legesse and Hailu, (2023) Ethiopian study, which also revealed financial challenges due to transportation costs for rural parents.

4.2.4 Loss of Income

The study further revealed that NICU admission often leads to income loss, especially for self-employed caregivers as some had to abandon their businesses due to a lack of trusted help, leading to financial strain and debt. This aligns with Lambiase et al., (2023) study findings that NICU admission is a stressful event with both psychological and financial impacts, as these factors influence each other.

4.3 Psychological Challenges

4.3.1 Joy and Relief of Birth

The delivery of a newborn is a joyful event for families, but when a baby is born prematurely, it can be a traumatic experience (Rihan et al., 2021). The study revealed that participant mothers experienced 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.

4.3.2. Loss and Grief

The study revealed profound grief experienced by caregivers following neonatal death, noting that such loss even if its of a neonate is difficult to accept. Some caregivers felt a deep emptiness as their hopes and plans for the child were shattered. The findings align with the Pires et al., (2023) study findings which showed that neonatal loss impacts not just the mothers but families and HCPs as well. However, the study revealed inconsistent support for grieving caregivers. For instance,

one mother had not received psychological support more than a month after losing one of her twins. This contrasts with Lakhani et al., (2023) Canadian study on exploring and supporting parents' stories of a loss in the NICU, where parents felt supported and included in the care process during their NICU experience.

4.3.3 Fear and Anxiety about Infant Health

This study highlight that repeatedly witnessing the death of other neonates in the NICU impacts the emotional wellbeing of mothers. This can be attributed to the NICU environment where admission of premature and critically ill neonates is inevitable. Similarly**,** a study conducted by Wanduru et al., (2023) in Uganda, revealed that the mothers' primary concern was ensuring their sick newborns stayed alive. Consequently, their fears concerning their babies' survival may have been intensified by the NICU environment, where newborn deaths were frequent.

4.4 Facility Issues

The study findings revealed that perceived unsatisfactory services in the NICU are multi-factorial, with nurses shortages and resulting burnout being significant challenges. This substantiate the study findings conducted by Negarandeh et al., (2021); Welborn et al., (2024); Mahmood et al., (2023); (Imam et al., 2022); in which staff shortage, workload, power imbalances and structural limitations hindered maternal support. At PMH NICU, the unit had 24 non-specialised nurses with frequent understaffing due to either annual, maternity or emergency leaves. Shifts were divided into three, with numbers varying from three to six per shift, rarely reaching optimal levels. Although no universal standards exist, some high-income countries have established staffing ratios that could guide improvements (WHO, (2020); Sülz et al., (2024).

4.4.1 Staff Attitude

Dismissive responses, issues of perceived laisser-faire, negligence, insensitivity and unprofessionalism were identified as challenges raised by the participants, particularly in interaction with HCPs. Some participants reported defensive responses from HCPs, which led to feelings of neglect. Similar findings were revealed by McLeish et al., (2021) study to explore the experiences of first time mothers on social support from HCPs, in which findings revealed that mothers' emotional wellbeing was undermined when HCPs dismissed their concerns.

4.4.2 Lack of Communication and Support during NICU Admission

The study revealed widespread concern among participants concerning poor communication from HCPs, leaving most of them feeling uninformed and frustrated. A clear communication gap existed as HCPs were perceived to deprioritise information sharing. While previous studies viewed discussing clinical details as a medical responsibility (Negarandeh et al., (2021); Hamooleh and Heidari, (2024)), this study found nurses were often blamed for failing to provide updates. Additionally, excluding caregivers specifically fathers and grandmothers caused emotional distress as they had to rely solely on mothers for information, often leading to confusion and

misinformation. This highlight that expecting only NICU mothers to keep other caregivers informed is not feasible and can cause emotional distress.

4.5 Coping Strategies

4.5.1 Peer Support

Most participant mothers were noted to appreciate connecting with other NICU mothers, finding encouragement and motivation through shared experiences. Similarly, studies by Banjade, et al., (2024); Byiringiro, et al., (2021); Rihan et al., (2021) and Buys and Gerber (2021) highlighted social coping and family support as key strategies for mothers managing NICU stress.

4.5.2 Prior NICU Experience /Orientation

The study revealed that caregivers with prior NICU experience, experienced less stress due to their familiarity with the enviroment. Orientation and regular updates from HCPs eased anxiety, while lack of information and missed orientations had negative psychological impacts. These findigns align with Eduku, Annan and Amponsah, (2024) study, which showed that inadequate information often led to caregiver anxiety.

4.5.3 Resilience

Some participants coped with challenges by accepting their situation, recognising that certain circumstances were beyond their control. Buys and Gerber, (2021) study findings also revealed that families accepted their circumstances over time, as denial did not ease their fears. Lian, et al., (2021) in their study, highlighted those fathers faced unique concerns, balancing multiple roles while building emotional resilience. In Setswana culture, ‘monna ga a lele’ is a common proverb meaning men are supposed to clothe themselves with bravery regardless of their circumstances, otherwise it will be a portrayal of shameful weakness. Interestingly, the study revealed that fathers openly expressed their grievances likely influenced by cultural shifts, modern life style and education. Contradictory to Garfield et al., (2018) study findings which noted that many fathers did not show stress until after their infant’s discharge. The study also revealed that resistance to change, negligence and reluctance are likely to hinder full involvement of fathers and other caregivers in neonatal care, aligning with findings of studies conducted by Merritt et al., (2021); Merritt and Spencer, (2021); Hearn et al., (2020); Beck and Vo, (2020).

4.5.4 The Belief in God

The study revealed that participants used their faith in God to cope with the challenges 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. Concurently, a study conducted in India affirms that prayer was the daily religious and spiritual routine geared towards the admitted infants for healing (Nimbalkar et al., 2019). However, previous studies highlight the importance of considering that not everyone has a spiritual or religious outlook on life, as for some, even the suggestion of spiritual distress or need may be considered offensive (Anderson and Aguas, 2024; Genstler et al., 2022)

5.0 CONCLUSION

The findings of the study grant the conclusion that the social, economic and psychological challenges experienced by NICU caregivers, are complex and differ per family. 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 relationships between HCPs and caregivers as well. Psychosocial and financial challenges incurred by caregivers can be addressed by multidisciplinary collaboration like engaging the social work and psychology departments in the facility.

6.0 RECOMMENDATIONS

Multidisciplinary team approach between NICU management and staff to execute timely referrals of underprivileged caregivers, to social work and psychology departments is mandatory. Inconsistent referral of grieving mothers as noted from the findings of the study is not sufficient, hence every NICU mother qualifies to undergo emotional support, at least during the period of hospitalisation. The NICU and postnatal ward (PNW) departments should identify how best to ensure the continuity of care for discharged mother lodgers. HCPs tasked with the care of sick and vulnerable neonates are being spread too thin and neonatal services are under extreme constraint, thefore the study recommends the ministry of health to invest in neonatal care for facilities to recruit neonatal nurses, medical officers trained in neonatology and other allied HCPs. Stakeholders engaged in neonatal care policy formulation, should review the historical practices that were adopted during the establishment of neonatal units in Botswana, and strive to make them a friendly and tolerable environments. Understanding the specific barriers and challenges to implementing FCC in PMH NICU is fundamental to the success of its roll-out even in other neonatal care facilities in the country. More advanced studies to extrapolate the influence of diversity in family structures and relationships, shifting gender roles, cultural as well as economic challenges to comprehend the intricate challenges of neonatal caregiving are mandatory.

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Conflict of Interest

The authors declare no conflict of interest.

Author contribution

Boineelo Ketshabathupa conceptualised the study, developed the proposal, collected, analysed data and participated in manuscript writing.

Catherine M. Ngoma and Brenda Sianchapa participated in the research proposal development, analysis of data and interpretation of findings and revision of the manuscript. All authors approved the manuscript publication.

8.0 REFERENCES

Anderson, J. & Aguas, J. (2024). South Asian Families' Experiences of Neonatal Care. *Bliss, UK*, 1002973: 1-18. https://s3.eu-west2.amazonaws.com/files.bliss.org.uk/images/SAF-report_final-draft_highres.pdf

Ayesha, A. & Khan, N. (2020). The Potential Uses of Pilot Study in Qualitative Research. *Journal of Research and Reviews in Social Sciences*, 3(1), pp 750-767. https://www.kinnaird.edu.pk/

Banjade, M.B., Pun, M.K., Khatri, S. & Phokarel, S. (2024). Stress and Coping Strategies among Parents of Infants Admitted in Neonatal Intensive Care Unit at Tertiary Level Hospital. *Medical Journal of Shree Birendra Hospital*, 22(2). https://doi.org/10.3126/mjsb

Beck, C.T. & Vo. T. (2020). Fathers stress related to their infants' NICU hospitalisation: A mixed research synthesis. *Achieves of Psychiatric Nursing*, 34(2), 75-84. https://doi.org/10.1016/j.apnu.2020.02.001

Borregas, P.S., Bellón-Vaquerizo, B., Velasco-Echeburúa, L., Niño-Díaz, L., Sánchez-Aparicio, S., López-, M., & Pallás-Alonso, C.R. (2024). Parental Autonomy in the Care of Premature Newborns and the Experience of a Neonatal Team: Observational Prospective Study. *JMIR Pediatrics and Parent*, 7: e55411. https://doi.10.2196/55411

Braun, V. & Clarke, V. (2019).Thematic Analysis: A Practical Guide. *SAGE Publications*, Chapter 4, 75-116. https://books.google.co.zm/books?id=mToqEAAAQBAJ&printsec=frontcover#v=onepage& q&f=false

Bry, A. & Wigert, H. (2019). Psychosocial Support for parents of extremely preterm infants in neonatal intensive care: a qualitative study. *BMC Psychology*, 7(76), 1-12. https://doi.org/10.1186/s40359-019-0354-4

Buys, K. & Gerber, B. (2021). Maternal experiences of caring for preterm infants in a vulnerable South African population. *Health SA*, 30(26):1549. https://doi.10.4102/hsag.v26i0.1549

Byiringo, S., Wong, R., Logan, J. & Kaneza, D. (2021). A qualitative study to explore the experiences of parents of newborns admitted to neonatal care unit in rural Rwanda. PLOS ONE, 16(8): E0252776. https://doi.10.1371/journal.pone.0252776

Eduku, S., Annan, E. & Amposansah, A.M. (2024). Maternal social support and resilience in caring for preterm newborns at the neonatal intensive care unit (NICU): A Qualitative Study. *Heliyon*, 10 (14): e34731. https://doi.org/10.1016%2Fj.heliyon.2024

El-Khani, A., Calam, R. & Maalouf, W. (2023). The role of faith in parenting; considerations when implementing family skills interventions with families affected by armed conflict or displacement. *Frontiers in Psychiatry*, 14:1118662. https://doi.10.3389/fpsyt.2023.1118662

Garfield, C. F., Simon, C. D., Rutsohn, J., & Lee, Y. S. (2018). Stress From the Neonatal Intensive Care Unit to Home: Paternal and Maternal Cortisol Rhythms in Parents of Premature Infants. *The Journal of perinatal & neonatal nursing*, *32*(3), 257–265. https://doi.org/10.1097/JPN.0000000000000296

Genstler, K., Terrones, A.B., Chow, B., Roxas, K., Tan, J., Barbara, C., Hernandez, D.D & Chad, V. (2022). Spiritual Care in the NICU from the Parents' Perspective: A Mixed Methods Study. Academic Journal of Pediatrics and Neonatology; 12(2): 555889. https://doi.org/10.19080/AJPN.2022.11.555889

Gezmu, A.M, Shifa. J.Z., Quinn, G.E., Nkomazana, O., Ngabula, J.C., Joel, D., Banda, F.M. & Nakstad, B. (2020). Incidence of Retinopathy of Prematurity in Botswana: A Prospective Observational Study. Dove Press, Vol 2020, 2417-2425. https://doi.org/10.2147/OPTH.s265664

Gibson, C., Ross, K., Williams, M. & Devries, N. (2021). The Experiences of Mothers in a Neonatal Unit and Their Use of the Babble App. SAGE Journals, 11(2). https://doi.org/10.1177/21582440211023170

Green, R.M, & Little, A. (2019). Religion and Ethics in Neonatal Intensive Care Unit. New York, online edn: Oxford University Press, 84. https://doi.org/10.1093/med/9780190636852.001.0001

Hamooleh, M.M. & Heidari, H. (2024). Parents and Health Care Teams Perceptions of Communication in Neonatal Intensive Care Unit, the Qualitative Report. *Researchgate*, 29 (2), 1266-1278. https://doi.org/10.46743/2160-3715/2024.6233

Harrison, W. N., Wasserman, J. R., & Goodman, D. C. (2018). Regional Variation in Neonatal Intensive Care Admissions and the Relationship to Bed Supply. *The Journal of pediatrics*, *192*, 73–79.e4. https://doi.org/10.1016/j.jpeds.2017.08.028

Haward, M.F., Lantos, J. and Janvier, A. (2020). Helping Parents Cope in the NICU. *American Academy of Paediatrics*, 145(6):e20193567. https://doi.10.1542/peds.2019-3567

Hearn, G., Clarkson, G. & Day, M. (2020). The Role of NICU in the Father Involvement Beliefs and Confidence: A Follow-up Qualitative Study. Research Gate, 20(1), 80-89. https://doi.10.1097/ANC.0000000000000665

Imam, A., Gathara, D., Aluvaala, J. & Maina, M. (2022). Evaluating the effects of supplementing ward nurses on quality of newborn care in Kenyan neonatal units: protocol for a prospective workforce intervention study. *BMC Health Services Research*, 22:1230. https://doi.org/10.1186/s12913-022-08597-9

Lakhani, J., Mack, C., Kunyk, D., Kung, J. & van Manen, M. (2023). Considerations for practice in supporting parental bereavement in the neonatal intensive care unit - a systematic review. *Journal of Palliative Care*, 39(2), 138-160. https://doi.10.1177/08258597231158328

Lakshmanan, A., Song, A. Y., Belfort, M. B., Yieh, L., Dukhovny, D., Friedlich, P. S., & Gong, C. L. (2022). The financial burden experienced by families of preterm infants after NICU discharge. *Journal of Perinatology*, *42*(2), 223-230. https://doi.org/10.1038/s41372-021-01213-4

Lambiase, C.V., Mansi, G., Salome, S., Laura, M.C., Vendemmia, M., Raimondi, F. & Capasso, L. (2024). The Financial Burden Experienced by Families during NICU Hospitalization and After Discharge: A single Centre, Survey - based study. *European Journal of Paediatrics*, 182(12), 903-913. http://doi.org/10.1007/s00431-023-05352-y

Lee, J., & Choi, S. (2023). The experience of fathers whose infants were hospitalized in Neonatal Intensive Care Unit in South Korea: A scoping review. *Journal of pediatric nursing*, *72*, 36–44. https://doi.org/10.1016/j.pedn.2023.03.015

Lian, B. X., Amin, Z., Sensaki, S., & Aishworiya, R. (2021). An active pursuit of reassurance-coping strategies of fathers with infants in the Neonatal Intensive Care Unit. *Journal of perinatology : official journal of the California Perinatal Association*, *41*(8), 2019–2027. https://doi.org/10.1038/s41372-020-00853-2

Mahmood, I., Shahbaz, T., Farooq, Z., Parveen, I., Sharif, R., Munir, S., & Shamoun, A. (2023). Impact of shortage of staff nurses on quality care of patients at specialised hospitals in Lahore. *Biological and Clinical Sciences Research Journal*, 1:409. https://doi.org/10.54112/bcsrj.v2023i1.409

McLeish, J., Harvey, M., Redshaw, M. & Alderdice F. (2021). A qualitative study of first time mothers' experiences of postnatal social support from health professionals in England. *Women Birth*, 34(5), e451-e460. https://doi.10.1016/j.wombi.2020.10.012

Mengesha, E.W, Amare, D., Asfaw, L.S, Tesfa, M.B., Debela, M. & Ambaw, G. F. (2022). Parental experiences in neonatal intensive care unit in Ethiopia: a phenomenological study. *Annals of Medicine*, 54 (1), 121-131. https://doi.org/10.1080/07853890.2021.2004320

Merritt, L. & Spencer, B. (2021). Needs of Socioeconomically Diverse Fathers of Premature Hospitalised Infants: A Multicentre Study. *Advances in Neonatal Care*, 21(1), 11– 22. https://doi.org/10.1097/ANC.0000000000000767

Merritt, L., Maxwell, J. & Urbanosky, C. (2021). The Needs of NICU Fathers in Their Own Words: A Qualitative Descriptive Study. Advances in Neonatal Care. *Advances in neonatal care*, 22(3), 94–101. https://doi.org/10.1097/ANC.0000000000000934

Mimani, M.W., Lera, T., Haile, D., Badacho, A.S., Bekele, B., Gezume, G. A., Nigussie, B. G. & Bashe, B. (2023). Lived Experience of Mothers Having Preterm Newborns in a Neonatal Intensive Care Unit at Wolaita Sodo University Comprehensive Specialised Hospital Southern Ethiopia: A phenomenological Study. *Research and Reports in Neonatology*, 2023(13): 1-14. https://doi.org/10.2147/RRN.S417173

Ncube, R.K., Barlow, H. & Mayers, P.M. (2016). A life uncertain – My baby's vulnerability: Mothers lived experience of connection with their preterm infants in Botswana neonatal intensive care unit. *Curationis*, 39(1). http://dx.doi.org/10.4102/curationis.v39i1.1575

Negarandeh, R., Hassankhani, H., Jabraelli, N., Abbaszadeh, M. & Best, A. (2021). Health care support for mothers in NICU: a focused ethnography study. *BMC pregnancy childbirth*, 21:520. https://doi.org/10.1186/s12884-021-03991-3

Nimbalkar, A.S., Mungala, B.M., Khanna, A.K., Patil, K.H, & Nimbalkar, S.M. (2019). Prayers and beliefs among relatives of children admitted in paediatrics wards. *Journal of Family Medicine and Primary Care*, 8(3), 1123–1128. https://doi.10.4103/jfmpc.jfmpc_333_18

Phibbs, C.S., Schmitt, S.K., Cooper, M., Lee, H.C., Profit, J. & Lorch, S.A. (2019). Birth hospitalization costs and days of care for mothers and neonates in California. *European Journal of Pediatrics*, 204: 118–125. https://doi.org/10.1016/j.jpeds.2018.08.041

Pires, L. de C., Costenaro, R.G.S., Gehlen, M.H., Pereira, L.A., Hausen, C.F. & Neves, E.T. (2023). Parental bereavement: experiences of the nursing staff in neonatal intensive care. *Cogitare Enferm*, 28:e89837. http://dx.doi.org/10.1590/ce.v28i0.89837.

Rempel, L., Motshedisi, S., Rempel, J., Swart, N. & Molefi, K. (2019) .The transitioning role of Botswana fathers in breastfeeding, *Botswana Journal of African Studies*, 33(1). https://journals.ub.bw/index.php/pula/article/view/1693.

Rihan, S.H., Mohamadeen, L.M., Zayadneh, S.A., Hilal, F.M., Rashid, H.A., Azzam, N.M., Khalaf, D.J., Badran, E.F. & Safadi, R.R. (2021). Parents' Experience of Having an Infant in the Neonatal Intensive Care Unit: A Qualitative Study. *Cureus*, 13(7):e16747. https://doi.10.7759/cureus.16747

Shrestha, T., Singh, A., Bhattarai, S.K.G. & Raut, K.S. (2020). Experience of mothers having preterm newborns in neonatal care units. *Journal of Karnali Academy of Health Sci*ences, 3(2), 47–56. https://doi.10.3126/jkahs.v3i2.30782

Sülz, S., Fügener, A., Becker-Peth, M. & Roth, B. (2024).The potential of patient based nurse staffing – a queuing theory application in the neonatal intensive care setting. *Health Care Management Science* 27(2), 239–253. https://doi.org/10.1007/s10729-024-09665-8

Valley, T. & Leppard, L. (2019). Spiritual Care Guideline: Spiritual Care on the Neonatal Unit, *Thames Valley & Wessex Neonatal Operational Delivery Network*, Version 3, 1-17. https://www.piernetwork.org/uploads/4/7/8/1/47810883/spiritual_care_guideline_version_3._ratified_june_2022.pdf.

Wanduru, P., Hanson, C., Waiswa, P. et al., (2023). Mothers' perceptions and experiences of caring for sick newborns in Newborn Care Units in public hospitals in Eastern Uganda: a qualitative study. *Reprod Health* 20, 106. https://doi.org/10.1186/s12978-023-01649-1

Welborn, A. C., Nichols, T., Gringle, M., & Lewallen, L. (2024). Neonatal intensive care nurses' accounts of care for mothers/families with substance-exposed pregnancies: A critical discourse analysis. *Journal of Advanced Nursing*, 80(2), 566-579. https://doi.org/10.1111/jan.15807

William, K., Stausmire, J.M., Bridges, C., Mathis, M.W. & Barkin, J.L (2018).The Neonatal Intensive Care Unit: Environmental Stressors and Supports. *Pubmed Central*, 15 (1): 60. https://doi.10.3390/ijerph15010060

World Health Organisation (2020). Human Resource Strategies to Improve Neonatal Care in Health Facilities in Low and Middle-Income Countries, Geneva: *World Health Organisation*, p 19.https://iris.who.int/bitstream/handle/10665/336677/9789240015227-eng.pdf?sequence=1

Yassin, A.M., Legesse, H. & Hailu, M. (2023).The lived experiences of parents' challenges in a neonatal intensive care unit at Diachora referral hospital, Ethiopia: a phenomenological study. *Researchgate.* https://doi.org.10.21203/rs-2555096/v1