EXPERIENCES OF MOTHERS NURSING THEIR NEONATES ON END-OFLIFE CARE IN NEONATAL INTENSIVE CARE UNIT AT WOMEN AND NEW-BORN HOSPITAL UNIVERSITY TEACHING HOSPITALS, LUSAKA ZAMBIA.

BY

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A report submitted to the University of Zambia in partial fulfilment of the requirements for the award of the Degree of Masters of Science in Neonatal Nursing.

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DECLARATION

I, Lungowe Gladys Mwanamwalye, hereby do declare that the works contained in this report is my own, except where acknowledgements have been duly made through citations and references. I, further declare that this work has not previously been submitted for the award of any degree at the University of Zambia or any other University.

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DEDICATION

To the creator, the Almighty God, who gave me the physical and emotional strength to undertake and accomplish this report in the prescribed period of time.

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LIST OF ABBREVIATION

ERC	Ethics Review Committee
UTH	University Teaching Hospital
LBW	Low Birth Weight
NICU	Neonatal Intensive Care Unit
UNICEF	United Nations Children Fund
MOH	Ministry of Health
UNZA	University of Zambia
VLBW	Very Low Birth Weight
NNP	National Neonatal Protocol
ELC	End Life Care

ABSTRACT

Introduction: Neonatal intensive care unit is important to save the lives of a sick neonates; however, mothers are challenged by several stressful conditions during their stay including the ones nursing end of life care neonates. End of life care is a unique healthcare situation embedded with the scope of palliative care provision.

Methodology: The study had twelve participants and the participants were selected using purposeful sampling. The study was a phenomenological (descriptive) qualitative study. Data was collected using an interview guide and analysed using thematic analysis.

Findings: The study revealed that mothers suffered from inadequate emotional support and inadequate information as staff working in the Neonatal Intensive Care Unit were not readily available to give them emotional support, and lack of time for updates as the staffs seemed all busy.

Conclusion: This study explored the experiences of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-born Hospital, University Teaching Hospitals. Main findings indicated that parents experienced both psychological and emotional problems such as, anxiety, stress, worry, hopelessness, confusion and anger. In addition, the study revealed that mothers suffered from inadequate emotional support and differences in information delivery, lack of updates from staff and inadequate communication. Furthermore, mothers reported to have no emotional support from the spouse and little or no financial assistance.

CHAPTER ONE

1.0 Introduction

This chapter presents the background based on what other researchers have published at global, region and local levels. Furthermore, this chapter presented the statement of the problem, significance of the study, general and specific objectives of the study. The chapter also has the research questions, justification of the study as well as the motivation of the study. The chapter also presented the conceptual definitions of term as used in this study.

1.1 Background of the Study

When a mother conceives her expectations are very high such that they only expect a healthy bouncing baby. This expectation of giving birth to a healthy baby often accompanies a woman's pregnancy journey all the way till she gives birth (Aziato et al., 2016). When a baby is born with conditions such as extremely low birth weight (ELBW), hypoxic ischaemic encephalopathy grade three or congenital abnormalities, this expectation is obviously shattered and this result into the neonate being admitted to End-Life- Care (ELC) in Neonatal Intensive Care Unit (Wan etal.,2021). End of life care is a unique healthcare situation embedded with the scope of palliative care provision. Initially the parents are supposed to be encouraged spiritually, counselling and psycho-socio counselling (Salman et al.,2018). In Neonatal Intensive Care Unit Women and newborn hospital protocol, there is no information on how to take care of these mothers whose neonates are on end-of-life care to help them cope with the situation. (Neonatal Intensive Care Unit protocol 2019).

The highest mortality rates in childhood are reported in infancy, and neonatal intensive care units account for the majority of neonatal deaths (Salmani et al, 2018), of late there has been a reduction in neonatal mortality (WHO, 2020). Despite improved neonatal mortality rates, clinicians and families began to doubt medical interventions for neonates with life-threatening illnesses and those born severely prematurely in the early 1970s (World Health Organisation, 2015). Notwithstanding the advancement in increasing the survival rate of premature neonates, low-birth-weight infants, and those with deficiencies like severe asphyxia and congenital anomalies (Cherepnalkovski et al., 2021), Neonatal Intensive Care Unit teams are faced with fatal anomalies in newborns. Some of the anomalies are hardly cured by medical and surgical procedures due to factors such as the

extremely low birth weight (ELBW) (Goldenberg et al., 2018). In such situations, it becomes appropriate to consider several therapies and procedures that could lessen newborn pain on End-of-life care and improve parent quality of life (de Rooy et al., 2012). End of life care for neonates is a unique healthcare situation embedded with the scope of palliative care provision (Pierucci et al., 2001).

In general, admission to a neonatal care unit has a considerable stressful impact on parents and their families. As the primary caregivers and protector of their child, when a child gets diagnosed with a terminal illness, the family's life changes (Pease and McMillin, 2018). Parental request for continuing treatments and their subsequent struggles with the healthcare providers are among the challenging issues influenced by the cultural, religious, and spiritual background of families, as well as the differences in the attitudes toward palliative care (Salmani et al., 2018).

Planned and coordinated palliative care for neonates was earlier developed by Catlin and Carter in 2000 and they provided holistic care to neonates and their families, enabling parents and caregivers to make proper decisions for the life-threatening conditions affecting their newborns (Salmani et al., 2018). Ins terms of ethical, legal, and clinical issues, making a decision about providing palliative care to a newborn who is less likely to live is seen as a big challenge (de Rooy et al., 2012). It's understandable that palliative treatment in NICUs hasn't yet been deemed critical. Over the last two decades, the importance of palliative care and its consequences has been established in the adult population as a globally demanding concept (Romesberg et al., 2007), as a result, neonatal care has recently incorporated this healthcare idea (Kain et al., 2009). Moreover, palliative care is of paramount importance due to the high incidence of mortalities in Neonatal Intensive Care Units and responsibilities of the healthcare staff to relieve pain in the neonates and provide support to their parents (Ghoshal et al., 2017).

In Egypt, Shiabeid did a study entitled "Assessment of Depression and stress symptoms among mothers of premature and very sick neonates admitted to Neonatal Intensive Care Unit ". They found that 45% of studied mothers had mild anxiety during their neonates stay in Neonatal Intensive Care Unit. The sense of fear while persistent transitioned from fear to losing their babies, time spent in the Neonatal Intensive Care Unit. Furthermore, it was also reported that mothers were worried about their neonate's life expectancy, future health conditions and potential medical complications (Fernandez et al.,2018).

Mothers with neonates in the Neonatal Intensive Care Unit can feel a loss of control and cut off from their neonate (Nazari et al., 2020). These factors can create difficulties for mothers, such as delayed maternal attachment and a reduced ability to bond emotionally. Furthermore, the failure to fulfil this essential parental duty can cause anxiety and severe grief to the mothers with their newborn babies in Neonatal Intensive Care Unit. Gutiérrez et al.,.2020 further argued that the role of mothers is often replaced by technology and mothers must entrust the care of their vulnerable infants with uncertainties into the hands of Neonatal Intensive Care Unit staff. The mother's dream of seeing her child grow and develop into adulthood is lost, and mothers were forced to deal with the new reality of being a mother of a dying child, all the while hoping to survive a devastating period in her life (Rahman and de Souza, 2014).

Certainly, Neonatal Intensive Care Unit supportive interventions are relevant in reducing the stress of parents of neonates on end-of-life care. However, limited studies have considered the views of mothers concerning availability of supportive services in Neonatal Intensive Care Unit. Nonetheless, Coyne et al., 2018 asserted that participation of parents in the care is paramount to their psychological, physical and physiological well-being. Nurses must provide a welcoming environment for parents to take on the role of supervised caregiver in a secure setting. From the time of admission until discharge, parents should feel at ease in the Neonatal Intensive Care Unit and begin to engage in new-born care. Recognizing the human needs of parents in a high-tech environment like the Neonatal

Intensive Care Unit is essential. Therefore, forming a family-centred Neonatal Intensive Care Unit culture and an environment managed by effective leadership benefits everyone involved (Ferreira et al., 2021).

In Zambia no studies have been done on experiences of mothers nursing their neonates on end-of-life care hence this to explore the mother's experiences. The study intends to achieve the experiences of parents nursing their neonates on end-of-life care at Women and new-born Hospital, University Teaching Hospitals, Zambia.

1.3 Statement of Problem

Mothers experience many challenges in the Neonatal Intensive Care Unit due to their neonates' health status, inadequate information, and lack of support from healthcare providers (Weber et al., 2018). Mothers in Neonatal Intensive Care Unit (University

Teaching Hospitals), face similar problems. Neonatal care is critical to the new-born especially to those born with complications such as those born prematurity and the sick on the end-of-life care.

Table 1. Statistics of Neonates on End-of-Life Care

Year	Admissions	On End of life care	% of neonates on End of life
2021	1578	373	23%
2022	1589	406	26%
2023	1602	495	31%

Data source: NICU Records, 2021,2022,2023

This table above indicates the increase in magnitude of neonates admitted from 2021-2023. The table also indicates the increase in number of neonates on end-of-life care from 23% in 2021to 31% in 2023. This prompted this study to explore the mothers' experiences when nursing end of life neonates at Women and Newborn Hospital, University Teaching Hospitals. The conditions of neonates on end-of-life care include extremely low birth weight neonates, hypoxic Ischemic Encephalopathy grade three neonates, congenital abnormalities neonates and those who has brain death (Neonatal Intensive Care Unit records, 2021). The mothers of these neonates need counselling to cope with the situation. They also need to be spiritually counseled by the clergy. In Neonatal Intensive Care Unit Women and New-born Hospital they lack these services. If the process of end-of-life care is not handled well it can cause psychological problems like depression especially to the mother (Richard etal.,2019). In University Teaching Hospital Neonatal Intensive Care Unit protocol nothing has been documented on how to take care of mothers whose neonates are on end- of- life care before and during bereavement (National Neonatal records, 2021). When families receive high-quality end-of-life care, they feel supported and have a better grasp of the process. Families may feel helpless, furious, and as if their neonate has little value to others if quality end-of-life care is not provided (Cort Ezzo et al., 2014). Therefore,

little is known in Zambia about the experiences mothers go through while nursing their neonates on end-of-life care in Neonatal Intensive Care Unit. Hence, the need for this study to explore mothers' experiences of having neonates on end-of-life care in Neonatal Intensive Care Unit at the Women and New-born Hospital, University Teaching Hospitals, Zambia.

1.4 Research Objectives

1.4.1 General Objective

1. To explore the experiences of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at women and new-born hospital, University Teaching Hospitals Lusaka, Zambia.

1.4.2 Specific Objectives

1. To describe the experiences that mothers encountered as they nurse their neonates on end-of-life care in Neonatal Intensive Care Unit, Women and Newborn Hospital at University Teaching Hospitals.
2. To determine mothers' experiences when nursing their neonates on end-oflife care face Neonatal Intensive Care Unit, Women Newborn Hospital, at the University Teaching Hospitals.

1.4.3 Research Questions

1. What challenges do mothers face as they nurse their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and Newborn Hospital, University Teaching Hospitals?
2. What experience do mothers with their neonates on end-of-life care in Neonatal Intensive Care Unit have at the Women and Newborn Hospital, University Teaching Hospitals?

1.5 Justification of the study

Mothers experience many challenges in the Neonatal Intensive Care Unit due to their neonate's health status for example, inadequate information, lack of support from the healthcare providers (Weber et al.,2021). Neonatal Intensive Care Unit mothers experience

many stressful, psycho emotional conditions like shock, anxiety, fear, dissatisfaction, worries, anger and post-traumatic stress during admission and discharge. There's need for greater effort to promote and support the mothers who are nursing neonates in Neonatal Intensive Care Unit at Women and Newborn Hospital (University Teaching Hospitals). Moreover, the findings from this study are relevant for maternal and neonatal health care and it contributed tremendously to the existing evidence base which is urgently needed to inform the design and implementation of policies to promote optimal, holistic, and continual care support (stress- relieving measures like counselling and education) for mothers who have neonates on end -of- life care in Neonatal Intensive Care Unit.

1.6 Conceptual Definitions

End of life care: Care given to people who are near the end of life and have stopped treatment to cure or control their disease. It includes physical, emotional, social, and spiritual support for patients and their families (WHO, 2020).

Experience: Knowledge and skill that you gained through doing something for a period (Oxford dictionary, 1989).

Neonate: A child in first 28 days of life (UNICEF, 2021).

Neonatal intensive care unit: It is a special area in the hospital with advanced technology and trained healthcare professionals to give special care for the tiniest patients (WHO, 2021).

CHAPTER TWO

2.0 Literature Review

This chapter presents literature published from 2018 to date. Elsevier, PubMed, Google Scholar and ERIC were used to access the related literature. The literature review is presented according to themes that emerged from the research objectives which are; concerns of mothers as they nurse their neonates on end-of-life care in Neonatal Intensive Care Unit; experiences of mothers who have their neonates on end-of-life care; and whether the mothers with their neonates at end-of-life care in Neonatal Intensive Care Unit are satisfied with the service offered to their neonates.

2.1 Concerns of mothers at Neonatal Intensive Care Unit

In a qualitative study conducted from Iran by Negarandeh et al., 2021 which aimed to explore health care staff and mothers' experiences of meeting the mothers' support needs in the Neonatal Intensive Care Unit, concluded that mothers encountered a discrepancy between what they expected and what they received from health-care personnel. Although the health-care staff thought that mothers' support was important, it was not their primary focus, and they saw workload as a barrier to mothers' assistance in the Neonatal Intensive Care Unit. This study adopted a focused ethnographic approach that included 43 participants. The findings from this study were inadequate accompany of the mothers in care, assigning monitoring and care to the mothers, inadequate sharing of medical information. This study focussed on the support that the mothers needed in the Neonatal Intensive Care Unit and mothers with neonates on end -of -life were not included.

An Iranian study Valizadeh in 2018 used a descriptive method to find the effects of stress on mothers with premature infants in Neonatal Intensive Care Unit. They sampled 300 mothers with premature infants in Neonatal Intensive Care Unit and found from parents that Neonatal Intensive Care Unit was stress provoking environment. Parents experienced high stress level when their infants were in distress during medical procedures and treatments as they watched abnormal breathing pattern. They also felt stressed when the medical procedures were being done, sudden skin color changes, the helplessness of a tiny infant making facial grimaces indicating pain. Other stressful factors included the parent –

infant relationship such as separation, a sense of not being able to help the infant during painful procedures (Valizadeh et al., 2018).

Roed et al., 2021 also conducted another study which aimed to identify provider and user perspectives regarding the knowledge of and adherence to the Uganda Clinical Guidelines (UCG) recommendations in aspects of delivery and newborn care, both in cases of normal as well as complicated births. The study used qualitative methods with data collected from 57 participants and Malte Rud's Systematic Text Condensation (STC) was used for data analysis. The study findings showed that there was low knowledge about the UCG among the health workers. Various discrepancies between performed hands-on-procedures and the UCG were found related to neonatal care practices, including low use of portogram's, uncertainty around timing for cord clamping, routine or nasopharyngeal suction of newborns and inadequate implementation of skin-to-skin care. It is advised that the UCG be implemented with a continued focus on systemic methods. The study focused on health workers and did not include mothers to the neonates and those with neonates on end- of life care.

Mengesha et al., 2022 conducted a study which explored the lived experiences of parents in Neonatal Intensive Care Unit in Ethiopia. A phenomenological descriptive study design was used and qualitative data was collected from 18 parents. Findings showed that parents complained of psychological problems like anxiety, stress, worries, hopelessness, and a state of confusion. Furthermore, anger, crying, sadness, frustration, dissatisfaction, regret, disappointment, feeling bad, self-blaming, ` nervousness, disturbance, and lack of selfcontrol were found to be major emotional problems raised by the parents. Further the findings revealed that parents complained about health-care workers' indiscipline, lack of dedication, and unwillingness to cooperate. Similarly, many parents were concerned about lack of medicines, money, and time to visit their new-borns. The study concluded that parents with infants in the Neonatal Intensive Care Unit experienced a variety of psychological and emotional issues. The study focussed on lived experiences of parents in Neonatal Intensive Care Unit and did not include the end-of -life neonates and their mothers in the study.

A similar study was conducted by Kim et al., 2020 which assessed mothers' perspectives on their Neonatal Intensive Care Unit experiences and their unmet needs within the South

Korean cultural context. Qualitative data was collected from 232 mothers with Neonatal Intensive Care Unit experience from across South Korea. Thematic content analysis guided by the critical incident technique was used to examine their narrative responses. The findings indicated that mothers experienced unmet needs such as relationship-based support, lack of information and education-based support and system-level challenges. The study concluded that it is critical to emphasize the importance of building a family-friendly Neonatal Intensive Care Unit environment by providing unlimited access 24 hours a day, encouraging active parental involvement in newborn care, and actively supporting Neonatal Intensive Care Unit families through supportive words and actions. The study did not focus on mothers with end-life-care neonates.

A cross-sectional study that explored parents' experiences of the disruptions affecting newborns in need of special or intensive care was conducted by (Kosten Zer et al., 2022). Data collection was done from 1148 participants from 12 countries (Australia, Brazil, Canada, China, France, Italy, Mexico, New Zealand, Poland, Sweden, Turkey and Ukraine). The findings showed that in Australia, Canada, France, New Zealand and Sweden, both the mother and the father were allowed access to the new born, whereas in China, Poland, Turkey and Ukraine participants indicated that no one was allowed access to their newborns in Neonatal Intensive Care Unit. The study concluded that the application of IFCDC differs between countries. However, this cross -sectional study did not include the end-of -life care neonates and their mothers.

Esther et al., 2021 also conducted a study from Netherlands which explored parents' needs and perceived gaps concerning communication with healthcare professionals during their preterm infants' admission to the Neonatal Intensive Care Unit after birth. The study utilized an interview guide and retrospective interview with twenty parents of preterm infants admitted to a Dutch Neonatal Intensive Care Unit. Qualitative data was collected and deductive and inductive thematic analysis was performed. The findings showed that communication needs and gaps emerged across four main functions of Neonatal Intensive Care Unit communication which are; building/maintaining relationships, exchanging information, (sharing) decision-making, and enabling parent self-management. Communication gaps found included; lack of supportive physician communication, disregard of parents' views and agreements, missing communication about decisions, and the absence of written (discharge) information. It was further concluded that this study

improves the understanding and conceptualization of adequate Neonatal Intensive Care Unit communication by revealing persisting gaps in parent-provider interaction. The study focused on communication with health workers and did not address the experiences of mothers whose neonates are on end-of-life care.

2.2 Experiences of mothers who have their neonates on end-of-life care

Hafez et al., 2021 from Saudi Arabia conducted a systematic study where an electronic search was done in multiple databases, including the University of Wisconsin-Milwaukee Library, PsycINFO, PubMed, CINAHL, and Academic Search Complete. The included studies were published within the past five years, studies about End of Life/ End of Life Care, hospice care, paediatric care, quantitative, qualitative, and mixed methods studies. The study explored the recent studies that focused on experiences of mothers caring for a child receiving End of Life Care (EOLC) at home or a healthcare facility. Their findings indicated that there were decision making challenges, communication with healthcare professionals, parents' support system, and grief. Parents were included in most studies. There is lack of information on children's and their families' experiences at End of Life/End of Life Care in Saudi Arabia. The study focussed on mothers caring for end-of-life neonates both at home and healthcare facility which is different from this study as it looked at those admitted at the health facility alone.

A community-based cross-sectional study was undertaken by (Kebede et al.,2022) in Northwest Ethiopia which estimated the experience of mothers on neonatal danger signs and its associated factors. A total of 2335 mothers participated in the study and qualitative data was collected. The results showed that majority of mothers indicated that there were danger signs in their babies which made them not to be at ease, some mothers stated that they noticed these danger signs within 24-48 hours of delivery. Further the findings indicate that danger signs like baby feels hot, fast breathing, and difficulties in breathing. The study concluded that whereas mothers' understanding of neonatal danger signs is high, their practice or experience in applying that knowledge is quite poor. The study focused on danger signs of neonates and did not talk much of end-life- care in neonates.

Gondwe et al.,2021 conducted a related study that explored the experiences of mothers during the hospitalization of the infant at Malawi's Queen Elizabeth Central Hospital. It was descriptive qualitative study where twenty mothers of preterm or full-term infants

were interviewed. Directed content analysis approach was used to analyse data. The study indicated that perinatal experiences, the infant's condition and care, including breastfeeding, family support, and care from healthcare providers were the main concerns. Mothers of premature babies were also concerned about the costs of kangaroo mother care. It was concluded that in hospitals that provide limited nursing support to mothers and their infants, it is important to identify a support system for the mother and provide mothers with information on infant care. The study looked at the infant's condition, breastfeeding mothers but did not include those mothers whose neonates were on end-of-life care.

Similarly, a study was conducted by (Byiringiro et al., 2021) which explored the experience of parents in the Neonatal Intensive Care Unit of a rural district hospital in Rwanda. It was a qualitative study conducted with 21 parents whose new-borns were hospitalized in the Ruli District Hospital from Neonatal Intensive Care Unit September 2018 to January 2019. An interview guide was used to collect data then organized using Dedoose software for analysis. The findings showed that four themes emerged from the interviews and these were; parental adaptation to having a sick neonate in Neonatal Intensive Care Unit, adaptation to the Neonatal Intensive Care Unit environment, interaction with people (healthcare providers and fellow parents) in the Neonatal Intensive Care Unit, and financial stressors. Admission of a new-born to the Neonatal Intensive Care Unit is a cause of stress for parents and caregivers in rural Rwanda, according to the study, although there were numerous good factors that assisted mothers in adjusting to the Neonatal Intensive Care Unit. This study looked at the stressors in Neonatal Intensive Care Unit on parents and did not look at the end-of -life care and experiences of the mothers in Neonatal Intensive Care Unit.

Further, (Gakuna and Maina, 2019), conducted a similar study from Kenya which explored experiences of parents on Kangaroo mother care (KMC) in the neonatal clinic at the Kenyatta National Hospital. It was a qualitative study which involved 17 parents who had practiced Kangaroo Mother Care. Individual in-depth interviews were conducted, interviews were audiotaped and transcribed verbatim. The findings indicated that three major themes emerged from the analysis which are: Normalization of birth experience, need for commitment and enabling the practice. The participants reported that they were afraid and worried about their baby's survival before initiation into Kangaroo Mother Care. They also reported reduction of stress and anxiety and enhanced family relations which

gave them deep satisfaction as they got to know their infant. Participants associated reduction of infections, provision of warmth and faster growth to improved infant survival with Kangaroo Mother Care. The participants had mixed feelings regarding Kangaroo Mother Care practice due to limited information and the physical effects of the practice. Further, majority reported that they received enough support from their families and health team. The study concluded that Kangaroo Mother Care allows the parents to participate in the care, provides psychological healing, its tiring and time consuming and require a lot of commitment for its benefits to be realized. The study focussed on Kangaroo Mother Care and its importance but did not include those neonates on end -of-life care.

A qualitative study was conducted by (Katundu et al.,2018) which explored the experiences of male partners participating in Kangaroo Mother Care within the hospital and the home settings in Dedza district at Dedza District Hospital in Malawi. Qualitative data was collected and thematic analysis was used to analyse the data. The study revealed that most of the male partners had positive perceptions of their experience in participating in Kangaroo Mother Care at the hospital and at home such as perceiving it as a rewarding experience. However, the study showed that there were barriers, such as health care worker attitude, hospital environment and lack of time. Health care worker support and community sensitization are key elements in ensuring male participation. The findings gave nurse midwives an insight that it is possible and essential to promote male partner participation in Kangaroo Mother Care and to develop more strategies that can enhance their participation.

Nyondo et al., 2021 conducted a study which investigated the perspectives and experiences of a mother's quality of life while delivering facility-based kangaroo mother care. It was a secondary analysis of the qualitative data collected within the "Integrating a neonatal healthcare package for Malawi" project. A total of 51 participants were interviewed and content analysis was conducted on NVivo 12 (QSR International, Melbourne, Australia) based on the six World Health Organization Quality of Life domains (physical, psychological, level of independence, social relationships, environment, spirituality). Findings indicated that mothers experienced multidimensional challenges to their quality of life while delivering facility-based Kangaroo Mother Care. Though kangaroo mother care was considered a simple intervention, participants highlighted that continuous Kangaroo mother care was difficult to practice. Kangaroo mother care was an exhausting

experience for mothers due to being in one position for prolonged periods, compromised sleep, restricted movement, boredom, and isolation during their stay at the hospital as well as poor support for daily living needs such as food. The study concluded that a heavy burden is placed on mothers who become the key person responsible for care during kangaroo mother care, especially in resource-limited health settings. The study included neonates who were premature only and excluded those on end-of-life care and their mothers.

In Ghana a study was conducted by Amadu et al., 2021 which determined the experiences of mothers with hospitalized preterm babies in Tamale Central Hospital. It was a phenomenological hermeneutic qualitative design where 15 mothers with hospitalized preterm babies were interviewed. Interviews were audio recorded and verbatim transcribed and thematically analysed. It was found that the involvement of mothers in the care of their preterm babies in Neonatal Intensive Care Unit was helpful though they experienced fear in interacting with their babies initially due to adverse barriers such as fear of hurting the preterm baby and fear of equipment in the Neonatal Intensive Care Unit. The study concluded that the factors which led to mothers' anxiety such as fear in interacting with their babies, fear of equipment in the Neonatal Intensive Care Unit and non-explanation of the baby's condition would be reduced if mothers get the support from staff, other mothers from the Neonatal Intensive Care Unit and the participants' families assisted them to cope. The study reviewed that some parents were not involved in care due to fear but did not include the mothers who were nursing their neonates on end-of-life care.

Another study was conducted by (Bachegejoa et al.,2021) which explored the experiences of mothers of preterm babies regarding the support services they received at the Neonatal Intensive Care Unit of a mission hospital in Ghana. It was an explorative descriptive qualitative case study design where qualitative data was collected from 16 mothers of preterm new-borns and thematic content analysis was used to analyse the data. The findings indicated that mothers received some type of logistical support (sleeping room, mattresses, bath rooms, and toilets), psychosocial support services (counselling, peer support, kangaroo mother care), and health education from various health professionals, according to the findings. However, these support services were insufficient to meet their requirements. During their babies' hospitalization in the Neonatal Intensive Care Unit of a mission hospital in Ghana, mothers of preterm babies received less support. The mothers

also indicated a wish for health professionals in neonatal care facilities to provide physical and psychosocial support to parents of preterm new-borns in order to increase their capacity to care for their children. The study explored the experiences of mothers of preterm neonates regarding support but did not look at those neonates on end-of-life care and the parents' experiences.

Rihan et al., 2021 conducted a study that described parents' experience of having their infant in the Neonatal Intensive Care Unit. It was a qualitative descriptive design where qualitative data was collected from 16 parents of infants hospitalized for at least ten days regardless of gestational age, gender, or medical diagnosis were selected from a teaching hospital in Amman, Jordan. Four emerging themes emerged from the data analysis; living with the ambiguities of Neonatal Intensive Care Unit. admission, living with the burdens of their infants' hospitalization, coping with the stresses of a hospitalized infant, and reflecting on interactions with healthcare personnel and the environment. The findings of the study revealed parents' concerns and demands, as well as the usage of spirituality/religiosity as a coping method. It concluded that having a baby in the Neonatal Intensive Care Unit was a stressful experience that came with a slew of challenges. The majority of parents felt surprise, sadness, and tears, as well as concerns about their infant's health and a desire to learn the reason for their child's admission. The study described parents experience of having their neonate in Neonatal Intensive Care Unit but did not assess the experiences of mothers whose neonates are on end-of-life care.

Intharo et al., 2019 conducted a descriptive study from Thailand that explored the levels and correlations of needs, need responses and need response satisfaction in palliative care among mothers of premature infants with life-threatening illness. A total of 63 mothers with premature infants with life-threatening illnesses who were admitted to the Neonatal Intensive Care Unit were chosen using purposive sampling. Quantitative data was collected and descriptive statistics and Pearson's product moment correlation were used for data analysis. The results demonstrated that the mothers of premature children with lifethreatening illness had high total scores for needs, need responses, and need response satisfaction in palliative care. It was concluded that neonatal nurses should always assess the requirements of each mother and provide appropriate solutions. The study focused on the need response satisfaction in palliative care among mothers of preterm neonates and

did not look at the experiences of the mothers nursing their neonates in Neonatal Intensive Care Unit.

Similarly, (Wreesmann et al., 2021) conducted a systematic review which assessed the main functions of parent-provider communication in the Neonatal Intensive Care Unit and determine what adequate communication entails according to both parents and health professionals. A meta-analysis and systematic review of qualitative research was undertaken and researchers searched PubMed, Ebsco/PsycINFO, Wiley/Cochrane Library, Ebsco/CINAHL, Clarivate Analytics/Web of Science Core Collection, and Elsevier/Scopus for records on interpersonal contact between parents and newborn care professionals. Multiple, independent coders did title/abstract screening and full-text analysis. Deductive and inductive thematic analysis were used to examine the data from the included articles. A total of 43 records were included in the study. The Neonatal Intensive Care Unit Communication Framework was created through thematic analysis of data, and it includes four communication functions which are; building/maintaining relationships, exchanging information, (sharing) decision-making, enabling parent selfmanagement) and five factors that contribute to adequate communication across these functions (topic, aims, location, route, design) and, as a result, tailored parent-provider communication. The Neonatal Intensive Care Unit Communication Framework is found to be compatible with the goals of Family Integrated Care in terms of encouraging parental involvement in the care of infants. This framework is a first step toward understanding (appropriate) communication in Neonatal Intensive Care Unit settings.

Further, a post-Zam CAT qualitative study was conducted by (Sivalogan et al., 2018) which sought to understand the impact of newborn care health messages on care-seeking behavior for neonates and the acceptability, knowledge, and attitudes towards chlorhexidine cord care among community members and health workers in Southern Province. Data collection was done through five focus group discussions and 26 in-depth interviews. The findings showed that community perceptions and local realities were identified as fundamental to care-seeking decisions and influenced individual participation in particular health-seeking behaviors. Further, mothers stated that Zam CAT field monitors were effective in providing lessons and education on newborn care practices and participating mothers were able to share these messages with others in their communities. Although the study found no effect of chlorhexidine cord washes on neonatal mortality,

community members had positive views towards chlorhexidine as they perceived that it reduced umbilical cord infections and was a beneficial alternative to traditional cord applications. The study concluded that the acceptability of health initiatives, such as chlorhexidine cord application, in community settings, is dependent on community education, understanding, and engagement. The study did not look at the experiences of mothers nursing their neonates on end-of -life care.

Buser et al., 2019 also conducted another study that explored and described the cultural practices, knowledge, and beliefs of essential new-born care and health-seeking in rural Zambia. Qualitative data was collected from 646 participants. The results indicated that three themes emerged independently and these are; traditional new-born protective rituals from community members, strong sense of family and community protecting the new-born from health workers, and preservation of dignity. It was concluded that a maternal duality faced by women caring for new-borns between cultural and health system responsibilities was uncovered. The findings further highlighted the need for targeted health education by professional and community health workers towards younger and primigravida women. The study focussed on health care providers and not the mothers to the neonates on endof-life care.

A cross-sectional study was conducted by (Masumo et al., 2019) which aimed at identifying factors that contribute to stress in mothers nursing babies in the Neonatal Intensive Care Unit at the Women and New born Hospital in Zambia. The study adopted quantitative design where a total of 280 mothers of admitted neonates and their neonates who had to remain in the Neonatal Intensive Care Unit for at least 24hours were interviewed. It was found that Changes in the parental role, look and behaviour of their neonate increased stress in the respondent's. The admittance of the neonate was assessed as stressful by all participants too. Further the findings revealed that maternal characteristics that were associated with stress included education level. Duration of stay in Kruskal-Wallis's test showed a statistical difference between the stress subscales with alteration of parental role being the most stressful subscale. It concluded that mothers have different stress levels with most of them experiencing moderate and extreme stress; appropriate counselling targeted towards specific stressors identified is required. This study did not include the mothers or parents of the neonates on end-of life care.

Another study was conducted by (Adal et al., 2022) from Ethiopia which assessed parental satisfaction with Neonatal Intensive Care Unit services and associated factors. It was a hospital-based cross-sectional study at Jimma University Medical Centre where parents of admitted new-born infants were selected by convenience sampling. Quantitative data was collected from a total of 114 parents who took part in the study. The findings revealed that many parents said their infants receive better care in the incubator/bed. On the other hand, the study revealed that a significant number of parents were dissatisfied with the services provided by Jimma Medical Centre's New-Born Critical Care Unit. Parental satisfaction is linked to compassionate and respectful treatment. It was concluded that a significant number of parents were dissatisfied with the services provided by Jimma Medical Centre's new-born critical care unit. The study looked at the parents with admitted new-borns but did not include the ones on end-of-life care.

Further, (Hagen et al.,2019) carried out a study that explored associations between parental satisfaction and socio-demographic variables and, associations between parents' satisfaction and Neonatal Intensive Care Unit care-services. A total of 568 parents from six different Neonatal Intensive Care Units geographically dispersed in Norway completed the (NSS-8). All responses were rated and analyzed using nonparametric analysis and logistic regression. Findings showed that support from families and friends is the most important socio demographic area which links to reported levels of parental satisfaction. The decision-making procedures regarding the infant, respect and empathy from staff, and the continuity of treatment and care are the most crucial factors for parents' satisfaction with Neonatal Intensive Care Unit care services. Parents were least satisfied with how Neonatal Intensive Care Units facilitate ongoing care for siblings, parents and infants during later stages of their hospital stay. Parents reported being in need of more guidance and training in meeting their child's needs. It was concluded that to increase and sustain parents' satisfaction with Neonatal Intensive Care Unit care considerations should be given to separate elements of the total provision made for affected families.

A cross-sectional multi-centre study was conducted by (Gulo et al, 2021) which explored the parents' satisfaction with the care received in the Neonatal Intensive Care Unit in three hospitals in Ethiopia. Participants were recruited from three different Neonatal Intensive Care Units in Ethiopia upon discharge. Four open-ended questions were used to obtain qualitative data, and the findings were analysed. The findings showed that almost all the

parents answered to the questionnaire n = 386. Questionnaire items on satisfaction on average scored more than four. Further, different levels of parent satisfaction were observed across the Neonatal Intensive Care Unit levels showing a statistically higher satisfaction in level II Neonatal Intensive Care Unit compared to the other levels.

Education, place of residence and length of stay were associated with parental satisfaction and experience. The EMPATHIC-N questionnaire was validated in two Ethiopian versions to assess parents' experiences and satisfaction throughout their child's stay in the Neonatal Intensive Care Unit. The study focussed on parents' satisfaction with the care received but did not look at the parents' experiences when nursing neonates on end- of -life care. Another study which intended to assess parental satisfaction and its associated factors towards neonatal intensive care unit services was conducted in Northwest Ethiopia by Ali et al., 2021). It was an institutional-based cross-sectional study among parents of hospitalized neonates at the University of Gondar Comprehensive Specialized Hospital. A total of 317 respondents were chosen using a rigorous random sampling procedure and quantitative data was collected using an interviewer-administered structured questionnaire. The data was analysed using SPSS version 20. The findings revealed that the overall prevalence of parental satisfaction of neonatal care was at 50.0%. Results further indicated that half of the parents were satisfied with their neonatal care at the University of Gondar Comprehensive Specialized Hospital. Age group of below 25 years, being a mother and staying in the hospital for greater than or equal to four days increased the odds of parental dissatisfaction of neonatal care. To improve parental satisfaction with their neonatal care. It was concluded that it is better to provide prompt neonatal care services and provide continual training for health providers.

2.3 Summary

The views provided in the above cited studies indicate that there are still some mixed feelings on the concerns of mothers as they nurse their neonates on end-of-life care in Neonatal Intensive Care Unit. The key issues that emerged under this theme was that mothers had have different concerns ranging from poor treatment to lack of information on Neonatal Intensive Care Unit. While under the second theme literature has indicated that mothers with hospitalised neonates experienced stress, anxiety, disrespectful and many other including disregard from health workers. Under the third theme of this chapter, the key issues that emerged were that mothers were not satisfied with the services their

infants received from Neonatal Intensive Care Unit centres. This was like that as mothers cited lack of their participation in decision making about their infants on End-of-Life Care. In all the three themes reviewed, the researcher did not come across a study that was conducted at the Women and Newborn Hospital, University Teaching Hospitals. Thus, this study sought to cover this gap in knowledge by conducting a study at Women and Newborn Hospital, University Teaching Hospitals.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter presents the methodology that was used in the study. It has been presented as follows: study site, study design, study population, inclusion criteria and exclusion criteria**, s**tudy sample and sampling procedure, data collection tool, procedure for data collection, data analysis and ethical considerations.

3.1 Study Site

The study was conducted at the Women and New Born Hospital Neonatal Intensive Care Unit University Teaching Hospitals, a third level referral center in Lusaka Zambia. The hospital has a well-established Neonatal Intensive Care Unit for neonates on end-of-life care at Women and new-born hospital. It is the largest neonatal referral center in Zambia, with bed capacity of about 120. The hospital has trained staff in Neonatology both nurses and doctors.

3.2 Study Design

This study adopted a phenomenological research design (descriptive approach) in which qualitative methods was used. Qualitative phenomenological research design was used in this study because there it needed to develop profound discernment and an understanding of the experiences of mothers. Qualitative research is critical in educational research because it answers how and why research questions and allows for a better knowledge of experiences, events, and context. Qualitative research allows you to explore questions about human experience that are difficult to quantify (Cleland et al., 2017).

3.3 Study Population

In this study the study population consisted of all the mothers who nursed their neonates on End-of-life care in Neonatal Intensive Care Unit at Women and new-born hospital University Teaching Hospitals during data collection time (August, 2022-May, 2023).

3.4 Sample size

The sample size was 12 mothers who nursed their neonates on End-of-life care. The sample size was determined by data saturation.

3.5 Sample Selection

Purposeful sampling technique were used to select mothers who nursed their neonates in Neonatal Intensive Care Unit at Women and Newborn Hospital, University Teaching Hospitals.

3.6 Data Collection tool

The research instruments that were used for data collection from parents was an interview guide. An interview guide is an effective method for data collection when the researcher wants to collect qualitative, open-ended data, or to explore participant thoughts, feelings and beliefs about a particular topic, and to delve deeply into personal and sometimes sensitive issues (DE Jonckheere et al, 2019).

3.7 Data Collection Procedure

Data was collected using an interview guide. The questions in this interview guide were based on reviewed literature and addressed the research questions. Informed consent was obtained from the mothers before the commencement of an interview. The interview began with introductory questions to establish rapport and encourage the mother to comfortable and this was followed by open-ended question together with probing questions to elicit more information. The interviews were conducted at Women and Newborn Hospital, in the quiet room and the participants were given code in form of P1, P2, P3. … to help the researcher identify them easily.

3.8 Inclusion criteria and Exclusion criteria

3.8.1 Inclusion criteria

Mothers aged 18 years and above who are nursing their neonates on End-of-life care at Women and Newborn Hospital.

Mothers who spent three days and above in Neonatal Intensive Care Unit.

Mothers who gave consent for the interviews.

3.8.2 Exclusion criteria

Those mothers who were sick at the time of data collection as they may not concentrate.

Mothers who did not consent.

3.9 Data Transcription

The recorded interviews were transcribed verbatim by the researcher including marks of hesitation, laughs, silence and other expressions. The transcribed interviews were then analyzed by reading and re-reading the scripts to seek meaning in the data. Each line of the narrative was read and the text were divided into sections.

3.10 Data Analysis

Data analysis was done iteratively beginning at data collection until the end of the study. All the interviews were recorded using a recording device to make sure that all the views of the participants are taken. The recorded interviews were then transcribed verbatim. The researcher then read and re-read the data extensively to familiarize self with it and sought meaning in the data. Coding was done according to emerging theme. Each interview was read and if having direct link with objectives, it was identified, highlighted and coded electronically to ensure that any alteration can be made without wasting any materials. Coding frame was developed depending on the codes identified which included: code label, code name, description and quote from the transcript to illustrate the description. Then, codes with a common meaning were grouped into categories and then to sub themes, which were combined to form themes. To ensure trust and confidence in the findings of this study, the researcher conducted the interviews with all the participants using the same data collection tool in a quiet environment. Then thematic analysis was utilised to group the collected data into themes according to the research objectives. Thematic analysis is a method of analysing qualitative data. It is usually applied to a set of texts, such as an interview or transcripts.

Trustworthiness

Trustworthiness was ensured using Lincoln and Guba criteria which comprises credibility, dependability, transferability and confirm ability. Credibility was achieved by audio recording all interviews, transcribing verbatim and ensuring that the experiences were described accurately and faithfully. Confirmability was achieved through explanation of the topic to the participants, and them accepting by signing the consent form.

Transferability – results from this study can be used in policy making in Neonatal Intensive Care Unit and management level at Women and newborn Hospital. The researcher also ensured that each respondent listen to their own recording to confirm that this is their voice to achieve dependability of results. A field diary to take notes of all participants' gestures and non- verbal communication that cannot be captured by the tape recorder were also taken note by the researcher using her field notebook. The researchers' own interaction with the participant was recorded in the field notebook. All the records had dates and time of recording. was further ensured by the researcher collecting data personally to avoid distortions in the data from research assistant.

Dissemination of the results

This research will be published in a journal, a copy will be sent to University of Zambia library, a copy will also be sent to Women and Newborn Hospital management for implementation of results.

Ethical Consideration

This study took into consideration the following ethical considerations: Permissions were sought from the University of Zambia Ethics and Research Committee (4058-2023). The researcher also sought permission from National Health Research Authority (NHRAR-R209/07/03/2023) and obtained permission from Women and Newborn Hospital management University Teaching Hospitals to conduct the study in the institution after ethical approval. Further, the researcher obtained consent from all the participants before starting interviews. The informed consent informed the participants on the following; that they were participating in a research voluntary, no name would be mentioned and nothing was paid to them, the purpose of the study, the procedure to be used in data collection, the right to opt out of the interviews when they feel like quitting and that all personal details are treated with confidentiality. The researcher also obtained consent to record the interviews with the participants, and they were told that their choice to participate or withdraw from the study was not going to affect the services they were receiving from the hospital.

CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF THE FINDINGS

4.1 Introduction

The chapter presents the findings of the thematic analysis of interview guide to explore the experiences of twelve mothers nursing their neonates on End-of-Life care in Neonatal Intensive Care Unit at Women and New-born Hospital, University Teaching Hospitals, Zambia. Coding was done according to emerging theme. Each interview was read and if having direct link with objectives, it was identified, highlighted and coded electronically to ensure that any alteration can be made without wasting any materials. Coding frame was developed depending on the codes identified which included: code label, code name, description and quote from the transcript to illustrate the description. Then, codes with a common meaning were grouped into categories and then to sub themes, which were combined to form themes. Data was collected from every participant using the interview guide which were guided by open-ended questions that allowed for probing questions to occur to gain more insight into the experiences of ten mothers nursing their neonates on End-of-Life Care in Neonatal Intensive Care Unit at women and new-born hospital. Each interview lasted about 10-15 minutes. The data was read and re-read extensively to familiarize self with it and sought meaning. Then it was coded and grouped into sub-themes for interpretation. Then sub-themes were merged to make themes. Data were analysed using a hermeneutic phenomenological approach to correctly report and describe the meaning behind the individual's experience. Demographics of each participant were obtained prior to the initial interview, and the demographics of each participant are discussed in the first part of the findings in this chapter. The second part of the findings are an overview of the themes and subthemes together with the in-depth descriptions of the themes and subthemes of the experiences of ten mothers nursing their neonates on end-oflife care in Neonatal Intensive Care Unit at Women and New-born Hospital.

4.1 Table 2: Demographics of the Participants

Demographic of participants		Frequency
Marital status	Single Married	6 6
Educational level	Primary Secondary University	3 6 3
Employment status	Business Unemployed	5 7
Mothers age	18-25 25-40	5 7
Number of children	1-5 5 and above	10 2

In this phenomenological study, there were participants. All twelve participants were mothers of premature and sick neonates admitted at University Teaching Hospital's Women and New-born Hospital Neonatal Intensive Care Unit. The participants' ages ranged from 18 years to 40years old. Of the twelve participants, only six were married, the other six were single. The participants' education levels consisted of three who went up to university level, six at Secondary School level, and three who went up to Primary level. Only two of the twelve participants were first time mothers. The participants' employment status consisted of five self-employed who does business and while the other seven were unemployed.

Table 3: Demographics of Participants' neonates.

Participant	Infant's Weight at time of age	Weight at interviews	Infant's gestational Birth	diagnosis	Length of stay in Hospital
P1	40 weeks	3.0kgs	2.8kgs	hypoxic ischemic encephalopathy grade 3, sepsis	3 weeks
P2	30 weeks	1.5kg	1.2kgs	Hydrocephalus/congenital abnormalities	4 days
P3	38 weeks	2.5kgs	2.0kgs	hypoxic ischemic encephalopathy grade 3, post vent care	5 days
P4	32 weeks	2.0kgs	1.45kgs	Spinal bifida, congenital abnormalities	2months 2days
P5	34weeks	2.0kgs	1.9kgs	Gastroschisis, post operation, anemia, sepsis Intussusception	1 month
P6	30 weeks	2.4kg	2.3kgs	Congenital abnormalities/imperforate anus	1-month 2days
P7	31 weeks	1.5kg	1.4kgs	Omphalocele, congenital abnormalities, sepsis	1 month3 weeks
P8	38weeks 5days	3.2kg	3.0kgs	Anencephaly plus congenital abnormalities, sepsis	2 weeks
P9	30 weeks	1.2kg	1.1kgs	Tetralogy of Fallot in down syndrome Neonate	5 days

P10	30weeks 2days	800g	750g	Extremely low birth weight premature neonate, sepsis, jaundice	4days
P11	40 weeks	4kg	3.5kg	Hypoxic ischemic encephalopathy	2month
P12	32weeks	2.1kg	1.8kg	Congenital abnormalities	3weeks

The demographics of the participants' sick neonates indicates that twelve neonates admitted at Women and New-born Hospital's Neonatal Intensive Care Unit were neonates who suffered one of the following; hydrocephalus with congenital abnormalities, spinal bifida with congenital abnormalities, Gastroschisis / post operation, Sepsis/Intussusception (post-operative), Congenital abnormalities with imperforate anus (post-operative). The premature infants' gestational ages ranged from 30 to 34weeks. Prematurity was not the only reason for being admitted at women and new-born hospital's Neonatal Intensive Care Unit, as some of the neonates had other co-morbidities which required surgical interventions. The other neonates who reached a complete term were admitted to Women and new-Born Hospital's Neonatal Intensive Care Unit because they suffered from one of these; hypoxic ischemic encephalopathy grade 3 post vent, anencephaly with congenital abnormalities, Tetralogy of Fallot with down syndrome. According to Neonatal Intensive Care Unit Women and Newborn Hospital protocol, these neonates were considered to be on end-of life care. The usual routine like temperature, pulse and fluids or feeds plus medication were being administered on these neonates to improve the quality of life. The hospital length of stay at the time of interviews ranged from 4 days up to and 62 days.

Table 4: Themes and sub-themes that emerge from the study

Theme	Sub-themes	Personal Experiences	Challenges encountered
Inadequate information	-Differences in information delivery -Lack of updates from staff -Inadequate communication	"*I was advised by one of the staffs to start feeding my baby by cup then I breastfeed, but another one told me I start with a breast them cup" (p2).* *"I was told to sit on the bench for almost an hour for someone to update me on the condition of my baby but everyone seemed so busy. So, because I have a caesarean section, I could not wait any longer I left" (p3).* "*I was not explained to why I was being transferred to the next referral hospital (UTH). After reaching here (UTH) that's when I was told that my baby was born with very low birth weight with other health complications" (p4).*	-No continuous updates on neonate's condition.
Emotional roller coaster	-Psychological factor Sad Anger Crying Self-blame	*"I am confused and shocked because I don't even have time to process anything that is going on in here".* "*I am immersed in deep bad feeling, anger, and sadness. I cannot lie, right now I feel very disturbed that I spend most of my time crying inside myself" (p1).*	- Feeling Sad at times due to the condition of the neonate.

Lack of resources	-No financial and emotional support from the spouse. -Little or no financial support from family	*"My husband has stopped calling and coming to check on us. He is not even sending me money to use. Maybe he has given up" (p10).* *"Being in the hospital is expensive I need help financially either by family but it's not there". I used to do business but now I can't due to the situation am in" (p6, p12).*	- No money for hospital use.

During the data analysis process, the interviews were read and reread before coding took place. Each interview transcript was coded in the same manner by reading and rereading the data following the initial coding. This process improved the researcher familiarity with data. Different coloured highlighters and coloured pencils were used for coding the data to indicate similar statements and ideas. A codebook was kept with an index of each colour for identification purposes.

The categories and codes were then placed together to identify which one of the two objectives they are answering. Overall, there are six subthemes that emerged from the interviews that became evident during the data analysis process and these are, difference in information delivery, lack of updates from staff, inadequate communication, and emotional roller coaster, no financial support and no emotional support. The three emerged from the first objective and the fourth one came from the second objective and two emerged from the third one. The findings highlighted the experience of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-born Hospital at the University Teaching Hospitals.

4.2 Challenges mothers encountered in Neonatal Intensive Care Unit

The first objective of this study aimed to find out the challenges that mothers face at women and new-born Neonatal Intensive Care Unit, University Teaching Hospitals. The theme that imaged from this objective was inadequate information.

4.2.1 Inadequate information

This was the first theme that emerged. It has three sub themes differences in information delivery, lack of updates from staff and inadequate communication. Below, the sub themes are discussed in details.

4.2.1.1 Differences in information delivery

Mothers lamented during interviews that there was inconsistent in information delivery. Some staffs explained to parents that they should be starting with breastfeeding then cup feed. And other staffs said the opposite. This was explained by one of the parents as follows:

> *"I remember on how I was advised to feed my baby when I asked for help, they told me to start by cup feeding then I breastfeed by a staff. The following day I was advised to start by breast feeding then cup feed by a different staff. I don't know what to believe now".* Lamented P2

4.2.2 Lack of updates from staff

Another issue that came up was their lack of updates on neonates' condition from staff. The mothers felt that they were not being updated on conditions of their neonates as it should be. They felt somehow left out on the care. Some staff seemed too busy to answer or attend to us.

> *"It is difficult sometimes to understand the behaviour of healthcare workers treating our babies here. I remember one day when I was just two days old in the hospital, I wanted to find out why the baby had so many tubes and the general wellbeing, but I was told to wait as everyone seemed very busy to attend to me. After waiting for some time, I decided to leave as I was still not feeling well. At least they should be updating us on what is happening unlike what is happening.*

We appreciate their works but as parents we need information/ updates. (P3, field data)

Many of the participants were being attended to by a different doctor and a nurse at every round shift. Many of the participants lamented that they attempted to ask a question so there can be consistency medical care in but were often dismissed. One participant even alluded to the possibility that her concerns were not being taken seriously led to the condition of her baby no improving but instead getting worse.

"I have a problem with some nurses here, you find they cannot feed the baby. They are too busy to attend to our babies when it's feeding time. (p5, Field data)

4.2.3 Inadequate communication

Mothers lamented that they were left in the dark about the situation that was going on with their neonates. The participants also stated on many occasions the need for more information from the medical staff; however, despite the questions being asked, the participants' questions were not being answered accordingly. Many of the participants were ignorant about the reasons for being transferred to the University Teaching Hospitals Neonatal Intensive Care Unit from their birth hospital even when they were requesting information about the need for transfer, which was evident in P4's account of being uninformed by the health workers despite asking.

"In my case, after giving birth I was just informed that they were transferring me to University Teaching Hospitals, Women and New born Hospital's Neonatal Intensive Care Unit. So, I asked what was the problem with my child, I didn't get any answer and because I was weak, I just kept quiet and obeyed. After reaching here that's when I was told that my baby was born with very low birth weight with other health complications." (P4, field data)

Furthermore, the participants expressed their inability to participant in mothering occupations directly following the birth of their neonate due to the required medical attention. The participants stated they missed opportunities to mother following the delivery, which was expressed by the participants as a lack of opportunities to bond with their neonates due to the medical needs of not only themselves but also of their newborns. Additionally, the participants were unsure which questions to ask in regard to mothering in the medical setting, which was often rooted by their experience of not being heard thus

far by health care workers providing healthcare to their neonates. This is how one mother recounted her concerns as quoted below.

> *So, I didn't see him enough after delivery maybe due to resuscitations until the Neonatal Intensive Care Unit nurses had gotten him. Later, they wheeled him around up using the incubator. I did not see him until, the following day, I want to say, because, like the same day I was on magnesium and so with that I couldn't move or do anything like that, I had the catheter in still and all of that.* (P9, field data)

4.3 Experiences of mothers who have their neonates on end-of-life care in Neonatal Intensive Care Unit

This is the second specific objective. The themes that emerged is the emotional roller coaster and it had sub theme psychological factors. Lack of resources which had sub themes no financial and emotional support from the spouse and Little or no financial support from family. Below are explained in details.

4.3.1 Emotional roller coaster

This was the second theme that emerged from the study. Below is the subtheme.

4.3.1.2 Psychological factors

The participants told stories, which were enveloped with a variety of emotions from happiness to sadness. The participants not only spoke with emotions during the interviews but displayed these emotions as well. Hence, the participants frequently spoke about being afraid and being concerned for their sick neonates with tears in their eyes. These feelings were evident with P1.

> *"I am confused and shocked because I don't even have time to process anything that is going on in here. The situation is frustrating me each day that passes, I am just very upset because it seems that there is less hope. I think I am always a little nervous and have that fear because you never know with especially very sick babies, you never know what they're going to do. I think every day I'm on my toes, but every time there's good day/news, it relaxes me more. And every time I get an update (good news), like I feel a lot better."* (P1, field data)

Furthermore, other participants also spoke about feeling guilty about having a premature baby. They blamed themselves for not being able to carry the baby full term. Many felt they could have done something different to prevent the premature birth or to prevent the baby's need for surgery. P6 lamented her experience as quoted below;

> *"Sometimes I blamed myself for my baby's condition, I feel like I could have done something. I feel like it is my fault. I cannot even explain how I am feeling right now seeing my baby in this condition, I feel I could have avoided this what is happening here as a mother. Maybe it's the waking up early and lifting heavy things at the market that caused me to go for early labor."* (P6, field data)

While many of the participants had large support systems and significant others to lean on in time of need, some participants either did not have a lot of support or began to feel isolated and alone. Feelings of isolation and feelings of being alone in the Neonatal Intensive Care Unit affected an overall sense of wellbeing for some of the participants. Below is what one of the participants said during an interview with the researcher;

> *"I just feel very isolated and lonely. Even the nurses I think they just concentrate mostly on the neonates, neglecting our role also as mothers in the well-being of our neonates. My heart pains a lot every day that passes. So, this situation makes me feel lonely and I was even telling my mother when she came to check on us here that it was like even those people around me are not helping, I just feel so alone."* (P3, field data)

The study further indicated emotional factors like angry, crying, sadness, frustration, dissatisfaction, happiness, regret, compliant, disappointment, bad feeling, self-blaming, nervousness, disturbance, and lack of self-control play a great influence on the parental experiences in the Neonatal Intensive Care Unit. The majority of the mothers whose neonate health condition had gotten worse expressed their extreme sadness, disappointment, bad feeling, and anger. For instance, P2 stated:

> "*I am immersed in deep bad feeling, anger, and sadness. I am also disappointed when I look back and think of how things unfolded, starting from when I was told the birth weight of my baby then I realized the problem was more than I thought it*

was. I cannot lie, right now I feel very disturbed that I spend most of my time crying inside myself." (P2, field data)

Meanwhile, another one added this:

"The moment I was told how my child needed to come to University Teaching Hospitals, at that point I became nervous and I experienced lack of self-control, especially, when the health care providers told me that the neonates' condition was bad and needed specialized treatment (surgical intervention). Here again I have meant to go through different experiences which are even adding on the pain I have already." (P10, field data)

Although there were emotions that elicited crying and sadness during the interviews, the participants also portrayed happiness and proud moments when discussing their experience of being in Neonatal Intensive Care Unit with their neonate. From being happy about the small improvements their neonates are making to being amazed by their exuberance, each participant had something to be proud about when discussing their experience.

"I am praying. As I speak now, my baby's health status has been improving from day to day and able to breastfeed. Yeah, even if my baby has not fully recovered, at least I feel far much better than I was when coming here. I commend the nurses and doctors for their commitment. I am really happy and hopeful". So, when I think of that at least I feel very happy that I will be soon going back home with my baby even with others abnormalities." (P7, field data)

The participants recounted how environmental factors, such as the physical and services supported and hindered their mothers' occupations in the Neonatal Intensive Care Unit at the institution. The environmental factors, such as the physical layout of the Neonatal Intensive Care Unit, the technology involved, support and relationships with the staff, attitudes of the Neonatal Intensive Care Unit nurses, and services as well as hospital policies, all had a significant role in supporting mothers' occupations or acting as a barrier to mothers' occupations. Overall, the themes in this dissertation study have emphasized the experience of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-born Hospital at the University Teaching Hospitals.

4.3.2 Lack of resources

Lack of resources was the third theme from the findings. Explained below, are two subthemes that emerged from the main theme.

4.3.2.1 No emotional support from the from the spouse

Some participants were disturbed by the whole situation. They shared with the researcher how they were struggling alone without any financial support from the spouse. Their spouses went mute on them and were not concerned anymore. Furthermore, their spouses even stopped calling to check on them. They thought that their spouse was just tired from the whole situation. They felt neglected and not wanted. These feelings were evident with P1.

"*Two weeks ago, my husband stopped coming to check on us and even calling. He used to call or send money and at least I felt we were in this together but from the time he stopped I feel I'm alone carrying this burden". I don't even know what to think now".* P10 lamented.

4.3.2.2 Little or No financial support from family

Some participants complained on how they were struggling financially with the situation. They told the researcher that everything needed money at the hospital. The family were not helping much, as she needed money for diapers and food every day. The researcher was also informed about some drugs that the hospital didn't have that the nursing mother or mothers should buy. It was lamented by p6 during the interview.

"Here at the hospital am buying a lot of stuff for use. I buy "munkoyo" drink to help with milk production, diapers for the baby, sometimes drugs if the hospital doesn't have, food, so I need money for daily use. When I call for help from my family, I don't get it as required. So, it's really hard, sometimes my family sends money but it's too little that it finishes in two days. I used to do business but now I can't due to the situation am in". P6 lamented

4.4 Summary

The purpose of Chapter 4 was to present the findings from the analysis of the data from the interviews. In this phenomenological study, the researcher utilized an interview guide with all the twelve participants to explore the experience of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-born Hospital at the University Teaching Hospitals. The data analysis led to three main themes for the dissertation study and six sub themes which were further a lined to the objectives. This chapter, detailed descriptions of each participants' feelings and experience of nursing their neonates on end-of-life care in Neonatal Intensive Care Unit have been presented as reported by the participants. Some mothers said they felt good/sad. They lamented they felt good when they find the neonate has been fed and felt bad when they found milk was not fed to the neonate. Other findings indicated that mothers experienced both psychological and emotional problems such as, anxiety, stress, worry, hopelessness, confusion, anger, crying, sadness, frustration, dissatisfaction, happiness, regret, compliant, disappointment, bad feeling, self-blaming, nervousness, disturbance, and lack of selfcontrol.

CHAPTER FIVE

DISCUSSION OF THE FINDINGS

5.1 Introduction

This chapter presents the discussion of the study findings presented in chapter four of this study. This qualitative descriptive study aimed to explore the experiences of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-born Hospital, University Teaching Hospitals. This was answered by two questions which included "What are the experiences that mothers encountered as they nurse their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and newborn Hospital, University Teaching Hospitals?" and "What experiences do mothers with their neonates on end-of-life care in Neonatal Intensive Care Unit have at the Women and New born Hospital, University Teaching Hospitals?" Mothers nursing their neonates on end-oflife care in Neonatal Intensive Care Unit at Women and New-born Hospital at the time of data collection answered the questions through an interview guide. A total of twelve mothers participated in this study and were individually interviewed. Data analysis using a phenomenological approach (Cohen et al., 2000) yielded six subthemes that were grouped accordingly into the three themes that answered the two research questions. In this chapter, discussion of the findings has been presented just like they flow in chapter four.

5.1 Demographics of the Participants

Demographic information of this study has indicated that twelve mothers participated in this study and all are mothers of the new-born babies who were admitted with different problems in Neonatal Intensive Care Unit at the University Teaching Hospital's Women and New-Born Hospital in Lusaka. Findings revealed further that the age range of the participants was 18–40 years. Six of the twelve mothers were unmarried, and six of them were married. Of which, three completed primary school, six had completed secondary school, and three had reached the university level (Nelson et al., 2021).

The results also show that, of the twelve neonates to the Neonatal Intensive Care Unit at the Women and New-born Hospital, seven were neonates with one of the following conditions: spinal bifida with congenital abnormalities, hydrocephalus with congenital abnormalities, hypoxic ischemic encephalopathy grade 3 post ventilator care / anaemia,

sepsis/intussusception, congenital abnormalities with imperforate anus, hypoxic ischaemic encephalopathy grade 3 post ventilator , hypoxic ischaemic encephalopathy grade 3 post ventilator care. These findings are similar to the findings in the study done by Nelson and Ali, 2021. The other three, however, who carried their pregnancies to full term and were diagnosed with one of the following conditions: anencephaly plus congenital anomalies, tetralogy of Fallot in newborn with Down syndrome. The findings have further revealed that the gestational ages of the neonates ranged from 30 to 40 weeks. Some of the neonates at the Women and New-born Hospital had co-morbidities that necessitated surgical treatments, therefore their admission to the Neonatal Intensive Care Unit was not solely due to their diagnosis. At the time of the interviews, hospital stays ranged from four days to sixty-two days which is similar to the study done by Buser and Esther, 2021.

5.2 Challenges Mothers face when nursing neonates on end-of-life care at Neonatal Intensive Care Unit

This study's first objective was to explain the challenges mothers had or faced at the woman and newborn Neonatal Intensive Care Unit at Women and newborn hospital. The findings indicated one theme **inadequate information** which has three sub themes that emerged from the data obtained from the participants about response. The subthemes were difference information delivery, lack of updates and inadequate communication.

5.2.1 Differences in information

The findings revealed that mothers were being told different information regarding breastfeeding. Some staff said they should be starting with breastfeeding then cup feed and others said the opposite. “I was advised by one of the staffs to start feeding my baby by cup then I breastfeed, but another one told me I start with a breast them cup” (p2).

This is similar with study done by (Negarandeh et al., 2021) which concluded that mothers encountered a discrepancy between what they expected and what they received from health-care personnel.

Similar to the findings study done by (Yang et al., 2022), revealed that nurses and other staffs had different information regarding feeding the neonates at the right time. When confronted by the concerned parents, their responses were nowhere near comforting and made the parents lose trust. Another study done by (Wang et al., 2021) showed that it was

difficult for parents to get help from the nurses sometimes because of lack of being heard when bringing up issues with the care that their neonates were receiving in the Neonatal Intensive Care Unit.

5.2.2 Lack of updates

Some participants indicated that sometimes there were not being updated on conditions of their neonates due to work overload of staffs. Many of the participants lamented that they attempted to speak to medical staff but they were always busy. “I was told to sit on the bench for almost an hour for someone to update me on the condition of my baby but everyone seemed so busy. So, because I have a caesarean section, I could not wait any longer I left” (p3).

This is similar with the findings in Gutiérrez et al., 2020 study that showed that mothers needed to be heard as they participated in the care of their neonates.

The participants frequently revealed that how, in spite of the mother’s expectations or expressed worries, nurses frequently carried out caregiving duties in a different way. It is similar to the study by (Mengesha et al., 2022) that also showed that participants were frequently dissatisfied by this breakdown in medical care procedures, which left them with the impression that their thoughts about caring for their infants were disregarded and that the care was of inferior quality.

In this study, participants expressed anxiety for their neonates' survival when nurses from other wards were occasionally rotated into the Neonatal Intensive Care Unit. These findings are contrary to the findings of (Kosten Zer et al., 2022) who found that Neonatal Intensive Care Unit staffs were permanently stationed in the Neonatal Intensive Care Unit to ensure they are up to date with information and procedures.

5.2.3 Inadequate communication

Inadequate communication was another sub theme that emerged in during data analysis. Findings in this study showed that mothers of the admitted neonates were left in the dark about the situation or condition of their neonates. The results also showed that they frequently require additional information from the medical staff; nevertheless, the participants' questions were not addressed in spite of their inquiries. Furthermore, lacking communication from nurses on their neonates’ progress in terms of health was evident

during the interviews. This is contrary to Nazari and Nyondo 2020 findings that showed that mothers were not allowed to feed their neonates alone but with supervision from the nurses which they termed as nursing interference as they felt that they were viewed incompetent by the nurses (Nazari and Nyondo-Mipando, 2021).

In this study, the participants acknowledged a lack of opportunity to bond with their neonates due to the medical needs of both themselves and their neonates, resulting in missed opportunities to mother after the neonate was delivered. This is contrary to the results from (Rihan et al., 2021) where the participants' lack of knowledge about what questions to ask about mothering in a medical context was another issue after seeing how nurses interfered every time, they wanted to play a role in taking care of their neonates. This was frequently due to their past experiences of not being taken seriously by the doctors who were treating their neonates (Rihan et al., 2021).

5.3 Experiences of mothers who have their neonates on end-of-life care Neonatal Intensive Care Unit

This is the second specific objective of this study. The themes that emerged from this objective are emotional roller coaster and Lack of resources. Emotional roller coaster had a sub theme psychological factor. Lack of resource has two sub themes, no emotional support and Little or no financial support.

5.3.1 Emotional Rollercoaster

This was the second theme that emerged from the study. It had a subtheme psychological factor.

5.3.1.1 Psychological factors

The findings indicated how mothers told stories, which were enveloped with a variety of emotions from happiness to sadness. During the interviews, the participants not only expressed their emotions through their words but also showed these feelings. "I am immersed in deep bad feeling, anger, and sadness. I cannot lie, right now I feel very disturbed that I spend most of my time crying inside myself" (p1).

As a result, findings indicated how the mothers often spoke with tears in their eyes about their fear for their neonates. It was also indicated in the findings that parents were confused and shocked because they don't even have time to process anything that was happening at

the hospital (Salmani and Thomson, 2020). The findings indicated further that the situation was frustrating on mothers each day that passes. It has been reported in the findings that parents were nervous and afraid because they never knew what to expect from newborns, especially those who were born prematurely early and this similar to the findings in the study done by Salmani, 2020; and Wang, 2021.

Some of the mothers with premature neonates blamed themselves for not being able to carry the pregnancy to full term. Many felt they could have done something different to prevent the premature birth or to prevent the baby's need for surgery. The study reported further that sometimes mothers blamed themselves for their baby's condition, they felt like they could have done something to prevent their child's current condition. It has further been reported that some mothers could not even explain how they were feeling during interviews seeing their baby in the condition they could not explain as well. This was reported in the study findings of Williams, 2020; Mengesha, 2022.

While many of the participants had large support systems and significant others to lean on in times of need. Meanwhile, others did not have a lot of support or began to feel isolated and lonely. Feelings of isolation and feelings of being alone in the Neonatal Intensive Care Unit affected an overall sense of wellbeing for some of the participants. The findings of this study further revealed that anxiety, stress, worry, and confusion were the common psychological problems that mothers experienced in the Neonatal Intensive Care Unit. Nelson 2021; Mengesha ,2022 also found the similar findings in their study. Comparably, the anxiety levels of mothers were high and created unforgettable memories. Most mothers were depressed and stressed due to the Neonatal Intensive Care Unit atmosphere. The more likely explanation of this similarity could be due to unfamiliar parents with Neonatal Intensive Care Unit medical equipment. Similarly, the results from Mengesha., 2022; Salmani., 2020; and Sivalogan, 2018 found the same results.

In this study, sadness, crying and lack of self-control were emotional problems that were felt by mothers in the Neonatal Intensive Care Unit. Findings further revealed that mothers felt broken heartedness, disappointment, and fear. Furthermore, the Neonatal Intensive Care Unit mothers expressed that the situation was out of their control.

It was further discovered in the findings that even though mothers wanted to visit their neonates frequently, the hospital had a limited visiting schedule. In line with these findings, reports showed that mothers were challenged by strict visiting hours. The service provided in Neonatal Intensive Care Unit for neonates was delayed which might increase neonatal morbidity and mortality. Regarding the facility resources, shortage of space and sanitary situations was often overwhelming. Similarly, other studies showed that there were no private family rooms and a lack of waiting areas (Byiringiro and Ali 2021), further indicated that lack of compassionate and respectful care and unsupportive Health Care Providers had negative consequences on mothers that mean the Health Care Providers were not disciplined, and they lack commitment and cooperation while they gave care in Neonatal Intensive Care Unit. Other studies also showed that Health Care Providers were unsupportive, careless, and negligent (Rihan et al., 2021).

5.3.2 -Lack of Resources- This was the third theme from the findings. Two subthemes emerged from this theme which are no financial support from the spouse and little no financial support from family.

5.3.2.1 No Emotional support from the spouse

Some participants indicated how they had no emotional support from their spouses. “My husband has stopped calling and coming to check on us. He is not even sending me money to use. Maybe he has given up” (p10).

They lamented that at first the support was there but later on the spouses stopped calling to check on them with the baby and even just coming to see them at the hospital for emotional support. They said they felt alone because of this act. This is similar with the findings in Gutiérrez et al., 2020 study that showed that some mothers had no support during hospitalization as they took care of their neonates. He further found out that when there is no emotional support there is stress to nursing mothers.

5.3.2.2 Little or no financial support from family

The findings of this study further revealed that some participants had little or no support financially from either spouse or family. It also revealed that sometimes they were sending money for use but due to high demand, it lasted for two-three days. “Being in the hospital is expensive I need help financially either by family but it’s not there I used do business

but now I can't due to the situation am in" (p6, p12)". This finding is similar to what Nelson 2021; Mengesha ,2022 study that showed that some parents complained of high cost of living. This is contrary to what Wang, 2021 found in his study, where he found out that more than half of the participants didn't have financial problems.

5.4 Conclusion

This study explored the experiences of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-born Hospital, University Teaching Hospitals. Main findings indicated that mothers experienced both psychological and emotional problems such as, anxiety, stress, worry, hopelessness, confusion, anger, crying, sadness, frustration, dissatisfaction, happiness, regret, compliant, disappointment, bad feeling, self-blaming, nervousness, disturbance, and lack of self-control. In addition, the study revealed that mothers suffered from inadequate emotional support and differences in information delivery, lack of updates from staff and inadequate communication. Furthermore, mothers reported to have no emotional support from the spouse and little or no financial assistance. The study also revealed that some nurses attending to their neonates lacked commitment, discipline, were not cooperating, and were also unsupportive to them. However, the study also reported some positives as some mothers registered their happiness on the progress recorded each day on the health of their newborns. The study also revealed that mothers actually had a burden as they cared for their neonates. Finally, the study has showed that the Neonatal Intensive Care Unit is not conducive to the formation of a mother-child bonding, but a healthy bond can nevertheless be accomplished with the help of dedicated nursing staff who are committed to altering standard Neonatal Intensive Care Unit nursing practice to consider mothers' emotions. The findings are important as they can help in policy making at the hospital management level to easy the hospital stay of mothers nursing their neonates on end-of -life care in Neonatal Intensive Care Unit. The results also can help in "change of Practice" on certain things for example on mothers' updates and breast-feeding procedure to allay the anxiety.

5.6 Limitations of the study

1. The fact that the results cannot be applied to the entire population is one of its limitations. However, generalization was not the aim of this study.
2. The population and sample size were chosen as supported by qualitative study principles, which was achieved with twelve mothers of infants admitted in the Neonatal Intensive Care Unit.
3. Constraints in resources was another limitation as this was a self-sponsored study.

5.7 Recommendations of the Study

The study gave the following recommendations;

1. Ministry of health to provide more staffing to Women and new born hospital Neonatal Intensive Care Unit so that there is time for updates to parents to alleviate negative emotions.
2. The Women and new born hospital management to provide training on compassionate and respectful care for healthcare providers to enhance motherhealthcare provider communication and supports.
3. The breastfeeding procedure to be included in the Neonatal Intensive Care Unit protocol by Women and Newborn Born Hospital management to help staffs have one voice when delivering care to the neonates and the mothers.
4. Women and New born Hospital Management to involve the clergy from University Teaching Hospitals chapel (Reverends and Fathers) for spiritual and emotional support to the mothers to neonates on End-of-life care.

Further studies

The focus of this current study was to explore the experience of mothers nursing their neonates on end-of-life care in Neonatal Intensive Care Unit at Women and New-Born Hospital, University Teaching Hospitals. The investigator suggest that future research should focus on the following areas;

1. Future qualitative research should explore the continued development of supportive care in the Neonatal Intensive Care Unit and the subsequent experiences of mothers utilizing family-centred care.
2. Another study can focus on how fathers of infants admitted in Neonatal Intensive Care Unit in an urban setting on referral from rural health centers cope with the condition of their infant and the new environment at the same time.
3. Experiences of staff in the Neonatal Intensive Care Unit when nursing neonates on End-of-life care.

REFERENCES

Ali, M. S., Enyew, G. M., & Workneh, B. S., (2021). Parental satisfaction and associated factors towards neonatal intensive care unit services at the University of Gondar Comprehensive Specialized Hospital, Northwest Ethiopia, International Journal of Africa Nursing Sciences, Volume 15, https://doi. 10.1016/j.ijans.2021.100364

Atout, M., Hemingway, P., & Seymour, J. (2017). *The experience of decision making in the care of children with palliative care needs: the experiences of Jordanian mothers*. Comprehensive Child and Adolescent Nursing, 40(4), 240-256. 10.1080/24694193.2017.1330371

Aziato, L., Odai, P. N. A. & Omenyo, C.N. (2016). Religious beliefs and practices in pregnancy and labour: an inductive qualitative study among post-partum women in Ghana. *BMC Pregnancy Childbirth* 16, 138: https://doi.org/10.1186/s12884-016-0920-1

Beltran, S. J., & Hamel, M. N. (2021). Caring for Dying Infants: A Systematic Review of Healthcare Providers' Perspectives of Neonatal Palliative Care. *The American journal*
of hospice & palliative care, *38*(8), 1013–1027. https://doi.org/10.1177/1049909120965949

Buser, J. M., (2019). Cultural Practices, Knowledge, and Beliefs of Newborn Care and Health-Seeking in Rural Zambia. A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy (Nursing) in the University of Michigan

Buser, J. M., Cheryl, B., Zulu, C., Hazemba, D., Mtenje, A., Jones, J., Lori, A., (2020).

Cultural beliefs and Health-Seeking Practices: Rural Zambians' Views on MaternalNewborn Care. Midwifery. 85. 102686. 10.1016/j.midw.2020.102686.

Byiringiro, S., Wong, R., Logan, J., Kaneza, D., Gitera, J., Umutesi, S., Gitera, J., Umutesi, S., Kirk. C. M., (2021). A qualitative study to explore the experience of parents of newborns admitted to neonatal care unit in rural Rwanda. PLoS ONE 16(8): e0252776. https://doi.org/10.1371/journal.pone.0252776

Cherepnalkovski, A. P., Pavlov, V., Furlan, I., & Bucat, M. (2021). The Extremely Low Birth Weight Infant. In P. Tsikouras, N. Nikolettos, W. Rath, & G. F. V. Tempelhoff (Eds.), Current Topics in Caesarean Section. IntechOpen. https://doi.org/10.5772/intechopen.96921

Cleland J. A. (2017). The qualitative orientation in medical education research. *Korean journal of medical education*, *29*(2), 61–71. https://doi.org/10.3946/kjme.2017.53

Cortezzo, D. E., & Meyer, M. (2020). Neonatal End-of-Life Symptom Management. *Frontiers in pediatrics, 8,* 574121. https://doi.org/10.3389/fped.2020.574121

Cortezzo, D., Sanders, M., Brownell, E., & Moss, K. (2014). End-of-Life Care in the Neonatal Intensive Care Unit: Experiences of Staff and Parents. American journal of perinatology. 32. 10.1055/s-0034-1395475.

De Rooy, L., Aladangady, N., & Aidoo, E., (2012). *Palliative care for the newborn in the United Kingdom.* Early Hum Dev. 2012; 88(2):73-7.

Esther S. Lorié, Willem-jan W. Wreesmann, Nicole R. van Veenendaal, Anne A.M.W. van Kempen, Nanon H.M. L., (2021). Parents' needs and perceived gaps in

communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study, Patient Education and Counselling, Volume 104, Issue 7, Pages 1518-1525, ISSN 0738-3991, https://doi.org/10.1016/j.pec.2020.12.007 .

Ferreira, A., Ferretti, E., Curtis, K., Joly, C., Sivanthan, M., Major, N., & Daboval, T. (2021). Parents' Views to Strengthen Partnerships in Newborn Intensive Care. *Frontiers in pediatrics*, *9*, 721835. https://doi.org/10.3389/fped.2021.721835

Gakuna, M. N., & Maina, D. (2019). *Experiences of Parents on Kangaroo Mother Care in the Neonatal Clinic at Kenyatta National Hospital*. University of Nairobi

Wang, L. L., Ma, J. J., Meng, H. H., & Zhou, J. (2021). Mothers' experiences of neonatal intensive care: A systematic review and implications for clinical practice. *World journal of clinical cases*, *9*(24), 7062–7072. https://doi.org/10.12998/wjcc.v9.i24.7062

Gutiérrez, S. S., García, P. E., Prellezo, A. S., Paulí, L. R., Del Castillo, B. L., Sánchez, R. B. (2020). *Emotional support for parents with premature children admitted to a neonatal intensive care unit:* a qualitative phenomenological study. Turk J pedlar. 62(3):436-49.

Hafez, S., Snethen, J.., Ellis, J., Taani, M., Ngui, E.., & Baothman, A. A. (2021). Mothers Caring for a Child at End of Life: A Systematic Review. *Journal Of Nursing Practice*, *5*(1), 36–54. https://doi.org/10.30994/jnp.v5i1.143

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., & Bruera, E. (2014). Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review. Journal of Pain and Symptom Management, 47(1), 77-89.

http://dx.doi.org/10.1016/j.jpainsymman.2013.02.021

Intharo, W., Punthmatharith, B., & Wiroonpanich, W. (2019). Needs, Need Responses, and Need Response Satisfaction in Palliative Care among Mothers of Premature Infants with Life-threatening Illness. *Songklanagarind Journal of Nursing*, *39*(4), 26–39. Retrieved from https://he02.tci-thaijo.org/index.php/nur-psu/article/view/233274

Katundu, Y., (2018). Experiences of male partners participating in Kangaroo mother care within the hospital and home settings in Dedza district. Degree of Master of Science in Midwifery. University of Malawi

Kebede, Z. T., Toni, A. T., Amare, A. T., Ayele, T. A., Yilma, T. M., Delele, T. G., Biks, G. A., & Gelaye, K. A. (2022). Mothers experience on neonatal danger signs and associated factors in northwest Ethiopia: a community based cross-sectional study. *The Pan African medical journal*, *41*, 83. https://doi.org/10.11604/pamj.2022.41.83.32176

Kitao, M., Setou, N., Yamamoto, A., & Takada, S. (2018). Associated Factors of Psychological Distress among Japanese NICU Nurses in Supporting Bereaved Families Who Have Lost Children. *The Kobe journal of medical sciences*, *64*(1), E11–E19.

Kostenzer, J., von Rosenstiel-Pulver, C., Hoffmann, J., Walsh, A., & Made, S. (2022). Parents' experiences regarding neonatal care during the COVID-19 pandemic: countryspecific findings of a multinational survey. BMJ Open 2022; 12: e056856. Doi: 10.1136/ bmjopen-2021-056

Ma, R., Zhang, Q., Ni, Z., & Lv, H., (2021). Transitional care experiences of caregivers of preterm infants hospitalized in a neonatal intensive care unit: A qualitative descriptive study. **https://doi.org/10.1002/nop2.899**

Masumo, M., Mwape, L., Katowa, P., Maimbolwa, M., & Chirwa, E. (2019). Perception of stressors by mothers with babies admitted to the Neonatal Intensive Care Unit in

Women and New Born Hospital, Lusaka, Zambia. International Journal of Nursing and Midwifery. 11. 25-31. 10.5897/IJNM2018.0350.

Mendizabal-Espinosa, RM; Price, J. E; (2021) Family centred neonatal palliative care in children's hospices: A qualitative study of parents' experiences. Journal of Neonatal Nursing. 27 (2) pp. 141-146. 10.1016/j.jnn.2020.08.005.

Mengesha, E. W., Amare, D., Asfaw, L. S., Tesfa, M., Mitiku B. D., & Fentie, A. G., (2022). Parental experiences in neonatal intensive care unit in Ethiopia: a phenomenological study, Annals of Medicine, 54:1, 121-131, DOI: 10.1080/07853890.2021.2004320

Nazari, R., Moradi, K. F., Rezaie, S., Akbari, N., Qolizadeh, A., & Sabzi, Z. (2020). *Experiences of the mothers of infants hospitalized in the neonatal intensive care unit (NICU)*. J Neonatal Perinatal Med. (Preprint):1-9.

Nyondo-Mipando, A. L., Kinshella, M. W., Hiwa, T., Salimu, S., Banda, M., Vidler, M., Molyneux, E., Dube, Q., Goldfarb, D. M., & Kawaza, K. (2021). Mothers' quality of life delivering kangaroo mother care at Malawian hospitals: a qualitative study. *Health and quality of life outcomes, 19*(1), 186. https://doi.org/10.1186/s12955-021-01823-8

Pease, K., & McMillin, S. E. (2018). Practice Concepts and Innovations for Pediatric End of-Life Care by the Interdisciplinary Care Team. *Journal of social work in end-of life & palliative care,* 14(2-3), 143-152. 10.1080/15524256.2018.1493628

Rahman, S., & De Souza, J. (2014). Disenfranchised grief following a non-fatal road traffic incident: *A case study exploring a mother's experience. International emergency nursing, 22(3),* 169-171. http://dx.doi.org/10.1016/j.ienj.2013.09.001

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.org/10.7759/cureus.16747

Salmani, N, Rassouli, M., Mandegari, Z., Bagheri, I., & Fallah, T. B. (2018). Palliative Care in Neonatal Intensive Care Units: Challenges and Solutions. Iranian Journal of Neonatology: 9(2). DOI: 10.22038/ijn.2018.25521.1337

Salmani, N., Marvast, M. Z., Kahdouei, S., & Weiss, M. E., (2020)."Adaptation of the Parent Readiness for Hospital Discharge Scale with Mothers of Preterm Infants Discharged from the Neonatal Intensive Care Unit". College of Nursing Faculty Research and Publications. 811. https://epublications.marquette.edu/nursing_fac/811

Sivalogan K, Semrau KEA, Ashigbie PG, Mwangi S, Herlihy JM, Yeboah-Antwi K, et al. (2018). Influence of newborn health messages on care-seeking practices and community health behaviours among participants in the Zambia Chlorhexidine Application Trial. PLoS ONE 13(6): e0198176. https://doi.org/10.1371/journal.pone.0198176

Thomson, G., Flacking, R., George, K., Feeley, N., Haslund, T. H., De Coen, K., Schmied, V., Provenzi, L., & Rowe, J., (2020). Parents' experiences of emotional closeness to their infants in the neonatal unit: A meta-ethnography. Early Human Development, 149. p. 105155. ISSN 0378-3782

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Tinetti, M. E., Naik, A. D., & Dodson, J. A. (2016). *Moving From Disease-Centred to Patient Goals-Directed Care for Patients with Multiple Chronic Conditions:* Patient Value-Based Care. JAMA cardiology, 1(1), 9–10. https://doi.org/10.1001/jamacardio.2015.0248

Wang, L. L., Ma, J. J., Meng, H. H., & Zhou, J. (2021). Mothers' experiences of neonatal intensive care: A systematic review and implications for clinical practice. *World journal of clinical cases*, *9*(24), 7062–7072. https://doi.org/10.12998/wjcc.v9.i24.7062

Wang, L. L., Ma, J. J., Meng, H. H., & Zhou, J. (2021). Mothers' experiences of neonatal intensive care: A systematic review and implications for clinical practice. *World journal of clinical cases*, *9*(24), 7062–7072. https://doi.org/10.12998/wjcc.v9.i24.7062

Webbe J., Brunton, G., Ali, S, et al. (2018). *Parent, patient and clinician perceptions of outcomes during sand following neonatal care:* a systematic review of qualitative research. BMJPO. 2018; 2(1):000343.

Together for short lives - https://www.togethershortlives.org.uk

The True Colours Trust – https://www.truecolourstrust.org.uk

Teach Me Paediatrics- https://www.teachmepaediatrics.com

E Hospice - https://ehospice.com

Williams L, I'Anson J, Malarkey M, et al. (2020). *Information sharing in neonatal intensive care: parental perceptions and preferences.* J Paediatric Child Health; 56(7):1121–1125.

Yang, Y., Brandon, D., Lu, H., & Cong X., (2019). Breastfeeding experiences and perspectives on support among Chinese mothers separated from their hospitalized

preterm infants: a qualitative study. *Int Breastfeed J* 14**,** 45. https://doi.org/10.1186/s13006-019-0242-9

Youngblut, J. M., Brooten, D., Glaze, J., Promise, T., & Yoo, C. (2017). Parent grief 1–13 months after death in neonatal and pediatric intensive care units. *Journal of Loss and Trauma, 22(1), 77-96*. http://dx.doi.org/10.1080/15325024.2016.1187049

Yufei, G., & Shuyan, X. (2020). *Nurse's experience of caring infants in neonatal intensive care unit.* Faculty of Health and Occupational Studies. University of Gavle

Zhuang, Y., Zhang, R., GAO, X., Zhu, L., & Latour, M. J., (2022). Validation of the Chinese Empowerment of Parents in the Intensive Care (EMPATHIC-30) Questionnaire Among Parents in Neonatal Intensive Care Units: A Prospective Cross-Sectional Study. https://doi.org/10.3389/fped.2022.851291

APPENDICES

Appendix i: Consent Form

Topic- Experiences of parents when nursing their neonates on End -of -life care in Neonatal Intensive Care Unit at Women and Newborn Hospital University Teaching Hospitals. The principal investigator is Lungowe Mwanamwalye currently post graduate student at the University of Zambia. The information collected will be treated with utmost confidentiality and at no time will you be required to identify yourself by name. No blood will be drawn from the patient or participant. The participant has the right to refuse or accept the interview as it is not mandatory. The participant has a right to also withdraw from the study if she wishes. They will be no payments to be made, the purpose of the study is for school, the procedure to be used in data collection is interview guide, the right to opt out of the interviews when they feel like quitting and that all personal details will be treated confidential.

I ……...agree to participate and that all personal details will be treated with confidential.

Sign……. finger print…….

PARTICIPANT INFORMATION SHEET.

This interview is part of a Master's of Neonatal Nursing project on Experience of mothers when nursing their neonates on End-of-life care in Neonatal Intensive Care Unit at Women and new-born hospital, University Teaching Hospitals.The principal investigator is Lungowe Mwanamwalye, currently a postgraduate student at the University of Zambia. The information collected will be treated with utmost confidentiality and at no time will you be required to identify yourself by name.

1) It is assured that the data you will provide shall be used only to gain an understanding on experiences of mothers when nursing their neonates on

Endof-life care in Neonatal Intensive Care Unit at Women and new-born hospital University Teaching Hospitals.

2) The interview will take place at the neonatal side ward in the quiet observation room.

3) Each interview will last about 40-45minutes and will be audio-recorded with the participant's consent.

4) Participant will be allowed enough time to express themselves.

5) The interviews will be identified by the letter 'P' (Mother), to ensure anonymity and data collected will be kept confidential.

6) The information gathered is not punitive in any nature and it will not interfere with your rights of receiving further services and management in the hospital.

Appendix iii: Interview Guide

Parent's Demographic information

1. Sex
2. Age a. 21 to 25years b. 26 to 30years c. 31 to 35years d. 36 to 40years over 40years
3. Level of education a. primary b. Secondary c. college d. University
4. Occupation ……
5. Marital status ……. Single/Married

Infant Biographic Information

Mode of delivery

Sex

Birth Weight

Gestational age at birth

Current weight

Mode of feeding

Duration on End-of-Life Care

Concerns of mothers as they nurse their neonates on End-of-Life Care in NICU at Women and Newborn Hospital.

1. How did you receive it when you were told that your baby has been put on End-of-Life Care?
2. What information were you given?
3. Explain to me your worries having that your baby is on end of life in

NICU?

4. How can you describe the care your baby is receiving?
5. How did you feel about other mothers with children on End-of-Life Care?
6. Explain to me how your interaction has been with other mothers?
7. What were your anticipations as a pregnant woman?

Experiences of mothers who have their neonates on End-of-Life Care at the Women and New born Hospital.

8. How do you feel as a mother being here because your baby is on End-oflife Care?
9. Explain to me how has been your experiences as a mother?
10. Explain to me how you feel about being a mother?
11. What is your worst experience as a mother whose child is on End-of-Life Care?
12. How often do you visit your child on End-of-Life Care in NICU?

Whether the mothers with their neonates at End-of-Life Care in NICU are satisfied with the service offered to their neonate.

13. What are your expectations as a mother with a child on End-of-Life Care in NICU?
14. Explain to me whether your expectations are being met or not……...
15. What information did you receive from health care provider about End-of-Life Care?
16. Explain to me how satisfied you are with the care your baby is receiving…...
17. What do you think should be done as a mother to improve the services?