COLLEGE OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

DEPARTIMENT OF NURSING

PERCEPTIONS AND CHALLENGES OF MOTHERS WITH PRETERM BABIES IN NEONATAL INTENSIVE CARE UNIT AT TIKUR ANBESA SPECIALIZED HOSPITAL ADDIS ABABA, ETHIOPIA, 2025: QUALITATIVE STUDY

PRINCIPAL INVESTIGATOR: TIHITINA MULUGETA (BSC)

A THESIS SUBMITTED TO ADDIS ABABA UNIVERSTY COLLEGE OF HEALTH SCIENCES SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING, FOR THE PARTIAL FULIFLMENT OF THE REQUIRMENTS FOR DGREE OF MASTERS OF SCIENCE IN NEONATAL NURSING.

JUNE, 2025

ADDIS ABABA, ETHIOPIA

ADDIS ABABA UNIVERSITY

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MAY, 2025

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STATEMENT OF DECLARATION

By my signature below, I declare and affirm that this thesis is my own work. I have followed all ethical principles of scholarship in the preparation, data collection analysis and completion of this thesis. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this thesis. This thesis is submitted in partial fulfillment of the requirement for a graduate degree from Addis Ababa University at College of Health Sciences, School of Nursing and Midwifery. The thesis is deposited in the Addis Ababa University Digital Library and is made available to the local, national, and international scientific communities. Solemnly declare that this thesis has not been submitted to any other institution anywhere for the award of any academic degree, diploma or certificate. Brief quotations from my thesis may be used without special permission provided that accurate and complete acknowledgment of the source is made. Requests for permission for extended quotations from, or reproduction of, this thesis in whole or impart may be granted by the Head of the Department or all advisors of these when in his or her judgment the proposed use of the material is in the interest of scholarship and publication. In all other instances, however, permission must be obtained from the author of the thesis.

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ACKNOWLEDGEMENT

First of all, I would like to thanks the Almighty God for helping me in all aspect of my life.

Next, I would like to express my heart-felt gratitude to my advisors, Dr Habtamu Abera (Ph.D., RN, Assistant Professor) and Mr Yosief Tsige (RN, HDHST, BScN, MScN, Assistant Professor) for their unconditional guidance and constructive comments in carrying out this study.

I would like to express my deepest gratitude to my family and my husband for all the support they have given me throughout this journey.

I would also like to thank Addis Ababa University for giving me the chance to conduct this research and Wolaita Sodo University for sponsoring my study.

Finally, I extend my sincere appreciation to the mothers in the Neonatal Intensive Care Unit of Tikur Anbesa Specialized Hospital who participated in this study.

LIST OF ABBREVATION AND ACRONYMS

AAU: Addis Ababa University

ETB: Ethiopian Birr

FMOH: Federal Ministry Of Health

NICU: Neonatal Intensive Care Unit

NMR: Neonatal Mortality Rate

PI: Principal Investigator

SSA: Sub-Saharan Africa

TASH: Tikur Anbessa Hospital

WHO: World Health Organization

TABLE OF CONTENTS

Contents

ACKNOWLEDGEMENT.....v

LIST OF ABBREVATION AND ACRONYMS.....vi

TABLE OF CONTENTS.....vii

LIST OF TABLES.....x

ABSTRACT.....xi

1. INTRODUCTION.....1

1.1 Background.....1

1.2 Statement of the problem.....3

2. LITERATURE REVIEW.....6

2.1 Mothers understanding of preterm babies.....6

2.2 Perceptions of Mothers on the cause of preterm birth and care of preterm newborns.....7

2.3 Perceived challenges of mothers with preterm babies.....8

2.4 Summary.....9

2.5 Significance of the study.....11

3. OBJECTIVES.....12

3.1 General objective.....12

3.2 Specific objectives.....12

4. METHODS.....13

4.1 Study area and period.....13

4.2 Study period.....13

4.2 Study design.....13

4.3 Study participants.....13

4.4 Inclusion and exclusion criteria.....13

4.4.1 Inclusion criteria.....13

4.4.2 Exclusion criteria.....14

4.5 Concept definition.....14

4.6 participant recruitment.....14

4.7 Interview guide and procedures.....14

4.8 Trustworthiness.....15

4.9 Data processing and analysis 16
4.10 Ethical consideration............ 17
5. RESULT 18
5. 1 Socio demographic characteristics of mothers 18
5.2 Themes............ 19
Theme 1 Mothers' perception of Preterm babies 19
Subtheme 1.1 Mothers' initial reaction and understanding of preterm babies (gestational age, physical appearance............ 19
Subtheme 1.2 Perceived cause of preterm birth............ 21
Subtheme 1.3 Caring practice for preterm baby 21
Theme 2 Mothers' emotional experience 23
Subtheme 2.1 Sadness and hopelessness 23
Subtheme 2.2 Being worried, stressed 23
Theme 3 Need for support 24
Subtheme 3.1 Support from health care provider 24
Subtheme 3.2 Support from family and the community 24
Theme 4 Challenges faced during NICU stay 25
Subtheme 4.1 Inadequate counseling 25
Subtheme 4.2 Lack of resource 25
Subtheme 4.3 NICU environment............ 26
6. DISSCUSSION 27
7. CONCLUSION AND RECOMMENDATIONS 31
7.1. Conclusion 31
7.2. Recommendations............ 31
Strength and Limitation of the Study............ 32
Strength of the study 32
Limitation of the study 33
8. REFERENCES............ 33
9. APPENDIX 38
Appendix A: English version of information Sheet for study participants............ 38
Appendix B: English version of informed consent............ 40
Appendix C: English version of a Semi-structured interview guides............ 41

Appendix D: Amharic version of the information sheet..43
Appendix E: Amharic version of informed consent 45
Appendix F: Amharic version of interview guides...46

LIST OF TABLES

Table 1 socio-demographic characterstics of the mothers in NICU of TASH, Addis Ababa, Ethiopia, 2025...18
Table 2 Identified themes that describe the mothers perceptions and challenges with preterm babies in NICU of TASH, Addis Ababa, Ethiopia, 2025…..19

ABSTRACT

Background: Mothers who experience preterm delivery express feelings of failure and inadequacy, as they perceive an inability to carry their pregnancy to full term and to defend their babies from damage and distress. Most of them suffered emotional stress because of their lack of preparation for the premature birth and the uncertainty surrounding the newborn's survival and longevity.

Objectives: To explore the perceptions and challenges of mothers having preterm newborns in a Neonatal Intensive Care Unit at Tikur Anbesa Specialized Hospital Addis Ababa, Ethiopia

Methods: A descriptive phenomenological study design was conducted among 10 mothers of preterm babies at Tikur Anbesa Specialized Hospital from Jan 20 to Feb 20, 2025. Purposive sampling technique was used to select study participants. Open-ended interview guide was used for collecting data. The interview was audio recorded, transcribed, and translated to English. The transcript was imported to Atlas.ti 25 qualitative data analysis software for coding. Finally, Colaizzi's 7-step approach to inductive thematic analysis of the results was used. Trustworthiness was ensured by implementing Lincoln and Guba criteria of credibility, transferability, dependability, and conformability.

Result: Mother recognized preterm babies by gestational age and physical characteristics. As babies born early, nine months before, and small in size, they have underdeveloped organs and reduced alertness. Mothers described the experience of preterm birth as a sudden, overwhelming, and emotionally traumatic event, often accompanied by negative emotions like feelings of fear, sadness, worries, and hopelessness. Many perceived that preterm babies might not survive. During their stay in the NICU, these mothers faced numerous challenges, including a lack of adequate counseling, scarce resources, and the unfamiliar and intimidating environment of the NICU. They emphasized the need for both emotional and practical support from healthcare providers, family members, and community.

Conclusion and recommendation: Mother's perception of preterm babies is, in itself, a source of emotional distress in the NICU, alongside unexpected early birth, early separation from their baby, and uncertainty about survival. Strengthening emotional support, improving hospital

facilities, counseling services and raising awareness are vital to reduce stress and promote better outcomes.

Keywords: Mothers' perceptions, Preterm, Neonates, challenges, Neonatal Intensive Care Unit.

1. INTRODUCTION

1.1 Background

A preterm newborn is one that is born alive before 37 full weeks of pregnancy (1). Preterm birth is occurring due to spontaneous preterm labor or through induction of labor for medical indications to terminate pregnancy. According to World Health Organization (WHO) report an estimated fifteen million babies are born prematurely worldwide in each year, indicating more than 1 in 10 babies (2, 3). Approximately one million newborns die every year due to complications associated with preterm birth (4). The burden of premature birth is high in low- and middle-income countries, especially those in southern Asia and sub-Saharan Africa (SSA). There is a significant difference in survival of premature babies between the countries, more than 90% of extremely preterm babies (less than 28 weeks) born in low-income countries die within the first few days of life, yet less than 10% of extremely preterm babies die in high-income settings (5).

Premature babies are prone to severe illness or death during the first 28 days of life. The survival and health outcomes of premature babies depend on the interventions provided to their mothers early, either before or during birth. These interventions include steroid injections before birth, antibiotics administered when the membranes rupture prior to labor, and magnesium sulfate to prevent future neurological impairment in the child. Additionally, there are specific interventions for preterm newborns, such as thermal care, feeding support, Kangaroo Mother Care, and respiratory support (6, 7) . Many survivors face a lifelong disability such as learning difficulty, visual impairment, hearing problems and non-communicable diseases in their later life (8).

Mothers with preterm births are at a higher risk of experiencing compromised postpartum mental health and negative feelings about their babies, as well as the unpredictability of the life event (9, 10). Their perceptions of preterm births are deeply influenced by emotional, cultural, and situational factors. Many mothers feel anxiety and fear for their baby's health, survival, and future development, often coupled with guilt or self-blame for the early birth (10, 11). They perceive their preterm babies as fragile and in need of constant care and monitoring

(12). Interactions with healthcare systems, especially NICUs, can be overwhelming but may also build trust if the care provided is supportive. Social influences, including family support and cultural attitudes, play a crucial role, while stigma can negatively impact self-perception (13).

According to World Health Organization 2022, new recommendation on the care of preterm infants simple interventions such as kangaroo mother care immediately after birth, early initiation of breastfeeding, use of continuous positive airway pressure (CPAP) and medicines such as caffeine for breathing problems can substantially reduce mortality in preterm babies (14). The guidance stresses the need to ensure the mother and family take the pivotal role in their baby's care. Mothers and newborns should remain together from birth and not be separated unless the baby is critically ill. The recommendations further call for improvements in family support including education and counseling, peer support and home visits by trained health-care providers (7, 14).

According to a few studies conducted in our country Ethiopia on premature babies caring practice, the community has misconceptions, myths, and negative attitudes regarding the care of premature infants (3). Mothers of premature babies face several challenges to caring for preterm newborns such as difficulties with skin-to-skin contact, feeding and bathing, premature babies falling sick often, economic and psychosocial impacts, limited social participation, lack of support from husbands and lack of knowledge on how to give proper care for them (15). Also mothers faced financial problems during their hospital stay due to lack of medicine and laboratory tests for the baby's care (16). Additionally mothers experienced difficulties related to inadequate counseling and guidance from health care providers and lack of supportive environment in Neonatal Intensive Care Unit (NICU), as well as issues with inadequate facility (17).

NICU is often an unfamiliar and frightening environment for parents (18). Mothers whose infants admitted to the NICU were suffered from psychological and emotional problems such as anxiety, stress, worry, hopelessness, confusion, anger, sadness, frustration, dissatisfaction, guilt, compliant, disappointment, bad feeling, self-blaming, nervousness, disturbance, and lack of self-control due to the infant's uncertain health conditions and stressful NICU environments (19, 20). Evidence suggests that parent-infant bonding and active involvement of

mothers/parents in caring for hospitalized preterm infant can improve both mothers and infant health outcomes (21). Parents/mothers-infant bonding and involvement in the care is affected by several factors including the infant size and physical appearance, the clinical condition, parental health, parental knowledge and skill, support from family, support from health care professionals, environmental condition and institutional visiting policies (22).

1.2 Statement of the problem

Globally every year, over 3.3 million babies die within their first month of life, and neonatal mortality has increased in all regions of the world, with a current estimation of 47% (23). Most of these deaths (>90%) occur in regions with limited economic resources. SSA accounts for one-third of all newborn mortality. Neonatal deaths in Ethiopia account 42% of under-five mortality (24). According to the WHO 2024 report, approximately one million newborns pass away in the first 24 hours of life, and 75% of neonatal deaths occur during the first week of life. Premature birth is the leading cause of neonatal death followed by birth complications (like birth asphyxia/trauma), congenital abnormalities, and neonatal infections (25). Also prematurity is the significant cause of under five children death (26). Including preterm newborns, an estimated 64 to 80 newborns per 1000 live births are admitted to the Neonatal Intensive Care Unit annually worldwide (27). In Ethiopia, prematurity accounts approximately 10.48% from all births (28).

Preterm babies are usually admitted to the neonatal intensive care unit for stabilization and treatment. After a preterm baby admission for a variety of reasons, such as infection, noise, or to reduce handling of preterm newborn, the mothers or parents are not allowed to visit the neonatal intensive care unit, avoid the mother from getting closer to her baby (1, 29). Then following hospitalization of preterm newborns, mothers can experiencing unexpected and stress full events, mainly due to interruption of contact between the mother and newborn, and such factors like early and prolonged separation, baby size, advanced medical equipment, continuous sound stimulation, tube feeding and infant health can result in stress and worry to the mother (30).

When a baby is born prematurely, the end of the pregnancy is usually sudden and unexpected (31). Mothers who experience preterm delivery express feelings of failure and inadequacy, as they perceive an inability to carry their pregnancy to full term and to defend their babies from

damage and distress. Moreover, when mothers have the opportunity to see their newborn, many find the infant's physical appearance and behavior to be a source of stress. Half of the mothers of preterm infants experiencing negative emotions during their initial encounter with their baby, including fear regarding the infant's small size, concerns about their medical condition, and feelings of detachment. Among these mothers, 31% expressed a sense that the baby did not feel like their own (12).

Premature birth can have a pernicious effect on mother's ability to cope, which can alter how she takes care of the newborn infant and leading to postpartum depression (17, 27). Also mothers' perceptions have a great impact on their emotions, coping ability, and caregiving practice (3, 22). Despite appropriate care and treatment is given for preterm and sick term neonates, infant admission to NICU has adverse effect on maternal mental health and wellbeing. The risk is increased in mothers of preterm infants due to unpredicted birth, the uncertain survival and lifespan of their child. which can have long-term negative impact on both mother and infants (32).

Various studies indicate that the hospitalization of infants to NICU is a difficulty experience, described by mothers as "full of stress'' (33). Maternal stress can have long-term negative effects on the mother and infant, and those infants are at increased risk for adverse developmental, cognitive, and mental health outcome (34). However, few interventions are available to address the problem (35). But the identified problems and interventions are in general for all mothers. So, there is a gap in finding the challenges and its solution specifically for those mothers who give birth before 37 completed weeks of pregnancy. Also, various studies explored the impact of prematurity on infant development, but only a few qualitative studies focused on the effect of preterm birth on maternal well-being. So understanding this complex parental/mothers experience to a greater degree is important to take an evidence-based action to improve maternal health, promote child development, and improve long-term health outcomes for both mothers and their preterm babies. Finally, preterm babies are needs follow-up and prolonged care at home after they discharged from the NICU. For these mothers have a great responsibility to care their child's. So maintaining maternal health and wellbeing is an important issue. To achieve this, further research is necessary for deep understanding of

mothers' perception to create awareness and to identify effective interventions and supports based on the identified challenges faced by mothers with preterm infants.

2. LITERATURE REVIEW

2.1 Mothers understanding of preterm babies

A study conducted in Bangladesh shows that mothers defined preterm babies based on the length of gestation as "birth that occur before time" they look upon normal length of gestation between nine to then months, any births occur before nine months considered to be early. Mothers can understand the preterm babies based on the appearance of the newborns they described as the babies born early are small in size, weak, underweight, have visible veins around the abdomen, wrinkled skin and have sunken forehead (36).

An explorative descriptive study conducted in Bawku, East Region of Ghana showed-mothers of preterm babies recognize premature newborns based on the gestational age, baby size and physical characteristics of newborns. If the baby born before nine month and is too small in size considered as preterm and also they mentioned some of physical characteristics of preterm baby such as breathlessness, absence of eye lash, have a weak muscle, inability to feed breast and baby looks white and transparent (37). According to a descriptive study conducted in Malawi on Qualitative assessment of attitudes and knowledge on preterm birth, participants defined premature birth as "born too soon" which means the baby born earlier to 9 months as they describe normal length of gestation nine month to ten months (38).

Similarly, a study conducted in Arbaminch southern Ethiopia revealed that most participants defined preterm babies as babies born before completing 36 weeks of pregnancy. Also they stated that if the mother gives birth earlier to the seventh month or at seventh month and the baby is not live, is called abortion and babies delivered at the 32 weeks may not survive. Mothers recognize premature babies based on their physical appearance and the range of motion, they describe as premature newborns have transparent skin that allows them to be easily seen their blood vessels and bones, and have limited range of motion due to underdevelopment of their muscles and nerves (3).

2.2 Perceptions of Mothers on the cause of preterm birth and care of preterm newborns

A study conducted in Western African countries on mother's knowledge on preterm birth found that mother's knowledge concerning the causes of preterm birth includes elevation of maternal blood pressure during pregnancy, fetal malposition, maternal stress during pregnancy and having problem in marriage (39). A similar study conducted in rural Mangoch, Malawi the perceived causes of preterm birth according to participants report can be grouped in to two parts such as maternal factors at pregnancy time and social factors, maternal factors include pregnant woman not eat good quality and adequate food, excess household duty/task, husband beating, frequent illness during pregnancy, having an abortion previously, family history of preterm birth, spiritual and social related factors where will of God, use of herbal medicine during pregnancy, hereditary, and the use of family planning methods (15). Another study conducted in similar region revealed that the causes of preterm birth perceived by participants are maternal illness (like anemia, malaria, infections), short pregnancy interval, periodontal diseases, hypertension, fistula, recurrent abortion, stress, overwork during pregnancy, domestic violence, sexually transmitted disease and being young mother (38).

According to the study conducted in southern Ethiopia, on community perception of preterm infants, participants stated that premature birth occur when the mother being young, carrying heavy loaded material, accident at pregnancy time, family conflict, being beaten by a husband and having a serious illness during pregnancy. The will of God, evil eye and curse were perceived as sociocultural and spiritual causes (3).

Several studies conducted in different country including Ethiopia, on community perceptions and experience on caring of premature babies found that warmth for preterm newborns was universal care. It is provided by wrapping with cotton cloth, making fire inside the house, closing window and doors, exposing to sunlight, delayed bathing after birth and keeping the baby inside the house all the time. Besides this expressing or squeezing breast milk to a cup and using a spoon to feed the preterm newborn is a widespread practice across all countries. Also frequent bathing, changing cloth, cleaning equipment, cleaning breast before feeding and using wipes was the most common practice to keep premature babies hygienic. In contrast the

studies found some malpractices were not appropriate for preterm newborn such as giving fresh cow milk, butter, cow milk mixed with boiled alcohol to kill germs, and sugar water, when mother perceived that she did not have enough breast milk. Also they put lighting lamps and charcoal stoves under the babies' bed and hot water jerry cans or plastic bottles put close to the baby in a sense of keeping a baby warm, that may harm the baby if not controlled (3, 15, 40-42).

In a retracted article in a middle-income country, experience of mothers in caring preterm infants at home shown as feeding, maintaining temperature and infection prevention as a necessary task that was equivalent to a full time job. They were monitoring environmental temperature constantly, using Kangaroo Mother Care, practicing hand washing and keeping a clean environment. Also they desire to breastfeed exclusively, but due to their circumstances, they had to use both formula and breast milk. Beside this good practice Mothers talked about how difficult it is to care for their infants while also attending to the needs of other family members (13).

2.3 Perceived challenges of mothers with preterm babies

A study conducted in Bhairahawa revealed that the majority of mothers who had preterm babies expressed negative emotions like anxiety and guilty about their babies due to unexpected early birth and detachments following NICU admission, and also they worried about their newborn babies when they seeing babies attached with medical equipment's (43).

A study conducted in NICU of selected hospitals, in United Arab Emirates found that admission of preterm babies to NICU is a stressful situation for parents. Especially the mothers have feelings of anger and sad due to the unexpected birth of baby who needs separation and admission. Also they become scared when they saw their baby in NICU, they were very small in size and surrounded with machine, tubes in mouth and nose and other medical device (44). Similar studies conducted in Tribhuvan University, Teaching Hospital in Nepal, and Rwanda, revealed that mothers of preterm babies are experienced anxiety, fear, feeling of guilt and hopelessness due to their perception of their newborns condition and uncertainty about their survival, and also due to lack of adequate information and guidance from health workers (17, 45).

Research done in Nigeria, explore some challenges faced by mothers of preterm infants during Hospital admission mainly limited contact with babies, inadequate support from the family, high cost of treatment, difficulty with initiation and maintaining feeding and expressing breast milk (46).

A study done at a tertiary hospital in Ghana stated that admission of preterm infant to the NICU put the mother on enormous psychological and emotional stress due to uncertainty related to the prognosis of the neonate. Also they faced significant social and financial challenges (47). Similar descriptive study conducted in urban setting in the Greater Accra region of Ghana, found that mothers have challenges with home care. They described their experiences to be challenging and felt overburdened with their daily tasks such as feeding, temperature control, infection prevention, and close observations. Mothers with limited access to counseling and support services are more vulnerable to ineffective coping especially when they lack of knowledge to differentiate the immediate and ongoing needs of their preterm babies. Reactions from society influenced the mothers' self-perception, making them feel ashamed and alone. Several mothers were harassed by friends for investing in their preterm babies who may not live long or could have developmental delays, and this lead to mothers withdrawing (13).

According to the study done in Nigist Elleni memorial specialized hospital, southern Ethiopia, mothers of who admit preterm babies in the NICU have faced emotional problems like anger, fear, crying, anxiety, sadness, frustration, dissatisfaction, disappointment, bad feelings, self-blaming, nervousness, disturbance, and lack of self-control. Additionally they suffered from lack of space to take rest, shortage of some Medicines and laboratory test and restriction to visit their newborn (27).

2.4 Summary

This review of literature indicate that, across different setting mothers define and recognize preterm babies based on the gestational age, physical appearance and physical maturity of the new born. In most regions commonly the concept of preterm birth is linked to birth occurring before the completion of a full-term pregnancy, baby is too small, born with few hairs, have few eye lashes, have transparent lips which are soft, have sunken forehead, fails to breathe

properly, fails to breastfeed and have limited motion. But some misunderstandings exist with local beliefs and cultural norms on normal range of pregnancy period and survivability of preterm babies. Regarding the causes of preterm birth, they associate with medical, socio-cultural, and spiritual factors. These include maternal illnesses, short intervals between pregnancies, young maternal age, stress, family conflicts, domestic violence, use of herbal medicines and spiritual beliefs such as the will of God, curses, and the evil eye.

Mothers of preterm babies face a various emotional and socio-economic challenges. The emotional and psychological problems include feelings of anxiety, fear, guilt and depression. Social pressures, such as stigma and judgment from the community, leads mothers' to isolation and stress, additionally inadequate family support, high medical costs, insufficient counseling from health workers, uncomfortable NICU environment and challenges with feeding are existed problems. Also Mothers apply a variety of practices both appropriate/good and malpractice for caring of preterm infants, depending on local resources and cultural norms.

2.5 Significance of the study

Having a preterm infant is a stress full event for families. In particular, the unexpected early delivery results negative feelings in mothers. Understanding the insight of mothers and their challenges with preterm babies is important to deal with the difficulties, plan appropriate care and support for them. In Ethiopia, especially in the study area the understanding of the mothers about preterm birth, and the challenges they face with preterm babies have not been thoroughly investigated.

Not only in Ethiopia there is a gap over the world in examining mothers' perception and challenges faced by mothers associated with preterm baby. So this study will be aimed to address this gap, by exploring the perceptions and challenges of mothers having preterm newborns in the study area. Also this study will be served as a base line source of information for future researcher.

3. OBJECTIVES

3.1 General objective

To explore the perceptions and challenges of mothers with preterm newborns in Neonatal Intensive Care Unit at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2025

3.2 Specific objectives

To explore the perceptions of mothers with preterm newborns in Neonatal Intensive Care Unit at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2025

To find out the challenges faced by mothers with preterm babies in Neonatal Intensive Care Unit at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2025

4. METHODS

4.1 Study area and period

This research was conducted at Tikur Anbessa Specialized Hospital. It is found in Addis Ababa, Ethiopia. Tikur Anbessa Specialized Hospital is a specialized hospital and a main teaching hospital for Addis Ababa University. It was established in 1961 by Emperor Haile Selassie as “Prince Mekonnen Memorial Hospital” and got its current name in 1976. The hospital was constructed using contributions from the entire Ethiopian people and has been providing services for all community. It is now reached by treating over 500 thousand outpatients and more than 21 thousand inpatients annually (48).

The neonatal intensive care unit (NICU) at Tikur Anbesa Specialized Hospital has two separated critical, subcritical and KMC rooms with 45 beds and 6 incubators for managing term and preterm infants. On average 696 preterm infants admitted annually. The NICU has one neonatologist, ten neonatal nurse practitioners and 45 nurses.

4.2 Study period

The study was conducted from Jan 20- Feb 20/2025

4.2 Study design

In the study, a descriptive phenomenological approach was used to gain an in-depth understanding of mothers’ perceptions and lived experience with preterm babies in NICU.

4.3 Study participants

Mothers of premature neonates admitted to NICU at Tikur Anbessa Specialized Hospital.

4.4 Inclusion and exclusion criteria

4.4.1 Inclusion criteria

Mothers who gave birth before 37 completed weeks of gestation and whose babies were admitted in the NICU of Tikur Anbessa Specialized Hospital for at least one week during study period were included in the study.

4.4.2 Exclusion criteria

Mothers who were unwilling to provide voluntary informed consent were excluded in adherence to ethical research guidelines, as participation must be entirely voluntary. Additionally, mothers who were extremely ill or had a known history of mental illness were excluded to avoid placing stress on them and to ensure the reliability of the data.

4.5 Concept definition

Preterm: - Neonates who are born at ≤ 36 weeks plus 6 days of gestational age.

4.6 participant recruitment

This study employed purposive sampling to select participants intentionally who had firsthand experience with the phenomenon being studied and who could provide rich and relevant information. Before recruiting study participants, i reviewed the newborns' profiles with the assistance of NICU staff particularly to determine their gestational age and admission date to select appropriate mothers for the in-depth interview. Finally mothers who experienced preterm birth and admitted to NICU of TASH for at least one week, willing to participate in the study and have ability to communicate in Amharic were recruited.

A total of 10 mothers were included in the study. The number of participants was determined based on the principle of data saturation, where no new ideas or concepts emerged from additional interviews. Saturation was assessed continuously throughout data collection and daily analysis. In this study, redundancy was observed, as the last two participants repeated ideas already expressed by earlier participants. This repetition occurred particularly in areas such as mothers' understanding of preterm birth, their emotional responses to preterm delivery and NICU admission, perceived challenges, and the need for social and familial support.

4.7 Interview guide and procedures

The interview guide was developed after review of relevant literature and related studies. It was initially prepared in English and then translated into Amharic to facilitate effective communication during interviews. The semi-structured guide included topics such as participants' socio-demographic characteristics, perceptions of preterm birth, perceived causes, infant care practices, challenges faced, emotional responses, and support they needed.

Data were collected through in-person, face-to-face in-depth interviews using the semi-structured interview guide with open-ended questions, allowed participants to express their perceptions and experiences of having a preterm newborn, from the birth of the preterm baby through admission to the NICU, including their plans and concerns for care after discharge.

All interviews were conducted by the principal investigator at Tikur Anbesa specialized Hospital. Audio recording were made with the participants' consent, and observational notes were taken to capture non-verbal responses such as facial expressions and emotional reactions. Each interview was transcribed verbatim at the end of the day after listening and re-listening of the recordings two to three times to ensure accuracy.

4.8 Trustworthiness

In ensuring trustworthiness four basic Lincoln and Guba criteria of qualitative study were maintained.

Credibility: - To ensure the credibility of the study; prolonged engagement of investigator with study participants was done, starting from thinking in researcher mined about participants recruitments, through audio recorded interview with iterative questioning, and through verbatim transcription after listening and re-listening records two to three times. Member checking was conducted after the interviews were transcribed and preliminary findings were identified. Summaries of key findings were shared with some available participants to review and confirm whether the interpretations accurately represented their perceptions and experiences.

Transferability: - thorough detailed description of the study area, research design, data collection, and analysis process the results were given in to ensure the transferability of the research findings to similar settings.

Dependability: - To ensure dependability, each stage of the research process was carefully documented, including interview transcripts, the coding process and key decisions made from data collection to analysis. The entire process from listening to the recordings to analysis was carried out with a peer researcher (a colleague with similar academic qualifications) to enhance the study dependability. Additionally, the complete audit trail will be made available for examination by an external auditor to assess the consistency of the study.

Conformability: - Field notes and audio records was kept as an audit trial to confirm that the data interpretation accurately reflects the participants' own words rather than the researchers' opinions or views by using the participants' own words from interview transcripts. Additionally, a reflexive journal was kept to document the researcher's reflections, assumptions, and decisions. This documentation allowed for external review and helped ensure that interpretations remained grounded in the participants' accounts.

4.9 Data processing and analysis

Data collection and analysis were carried out simultaneously. The audio-recorded interviews were transcribed and translated verbatim into English by the principal investigator (PI), including non-verbal responses such as facial expressions and emotional reactions. The interview transcripts were then coded using the qualitative data analysis software ATLAS.ti version 25. The interview transcripts were analyzed using inductive thematic analysis following Colaizzi's descriptive phenomenological approach(49). Step 1: Familiarization, this step involves immersing oneself in the data to gain a comprehensive understanding of participants' lived experiences. To achieve this, I (the researcher) repeatedly listened to the audio recordings and read the verbatim transcripts of all interviews multiple times. Step 2: Identifying Significant Statements, in this step, I reviewed the interview transcripts in ATLAS.ti and systematically identified statements that were directly related to the phenomenon being investigated. Using the software's coding function, I highlighted and coded important statements and sentences that reflected the participants' perceptions and lived experiences. Step 3: Formulating meanings, during this step, related codes were grouped in ATLAS.ti to develop conceptual categories that reflected shared meanings across participants' statements. Step 4: Clustering theme, in this step, based on the formulated meanings, clusters of related ideas were developed and organized into broader themes that represented the key aspect of participants' perspectives. Step 5: Developing an Exhaustive Description, step 6: Producing the fundamental structure of the phenomenon. Step 7: Seeking verification of the fundamental structure, in this final step, I (the researcher) attempted to contact several participants to validate the findings. Although a few participants responded, this process ensured that the interpretations accurately reflected their insight and experiences and allowed for any necessary clarifications or corrections to enhance the study's credibility.

4.10 Ethical consideration

Ethical clearance for the start of the study was obtained from the Research Ethical Committee of Addis Ababa University, College of Health Sciences, School of Nursing and Midwifery, Department of Nursing. Official letters of cooperation was obtained from the pediatrics department of TASH to NICU ward of TASH. Before conducting the study the purpose, general content and nature of the investigation was explained to each respondent. Protection of the rights of participants was ensured by giving due freedom to participate in the study or not and also to withdraw from the study at any time. The subjects were informed that any information they provide were kept confidential and their names was replaced by a code identification number during data collection, analysis and reporting. Additionally, the respondents were informed that their responses would not bring any harm to them. The participants signed the consent form indicating their voluntary participation in the study and permission for the audio recording of the interviews.

5. RESULT

5. 1 Socio demographic characteristics of mothers

In this study, ten mothers who experiencing preterm birth and whose preterm newborns were admitted to the NICU were included. Majority of mothers were 25-34 years old and, the residence of all of them were from urban area. Eight of mothers were orthodox religion followers and other two were Muslim. Nine mothers were married and seven of mothers were house wife by their occupation. Regarding educational status half of them attended secondary school, two mothers had no formal education and three mothers were degree holders.

Table 1 Socio-demographic characteristics of the mothers in NICU of TASH, Addis Ababa, Ethiopia, 2025

Participant ID	Age	Marital status	Educational status	Occupation	Residency	Religion	Parity	New born age at birth(GA)	Time spent in the NICU (days)
P1	32	Married	Secondary	Housewife	Urban	Orthodox	Multiparous	33	7
P2	33	Not married	Secondary	Housewife	Urban	Orthodox	Primiparous	28	15
P3	26	Married	Secondary	Housewife	Urban	Orthodox	Multiparous	33	9
P4	20	Married	No formal education	Housewife	Urban	Orthodox	Primiparous	32	8
P5	34	Married	No formal education	Housewife	Urban	Orthodox	Multiparous	35	14
P6	32	Married	Degree	Governmental employee	Urban	Orthodox	Multiparous	30	8
P7	34	Married	Degree	Self-employee	Urban	Orthodox	Multiparous	32	24
P8	27	Married	secondary	Housewife	Urban	Muslim	Multiparous	34	10
P9	30	Married	Degree	Governmental employee	Urban	Orthodox	Multiparous	31	13
P10	33	Married	Secondary	Housewife	Urban	Muslim	Multiparo	33	16

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5.2 Themes

In this study, 29 codes, 10 sub-themes and 4 main themes were identified regarding the perception and challenges of mothers with preterm babies in neonatal intensive care unit. The themes extracted were: Mothers’ emotional experience, Mothers' perception of Preterm birth, Need for support, and Challenges faced during NICU stay.

Table 2 Identified themes that describe the mothers’ perceptions and challenges with preterm babies in NICU of TASH, Addis Ababa, Ethiopia, 2025.

Main Themes	Sub-Themes
Mothers' perception of Preterm babies	Mothers initial reaction and understanding of preterm babies (gestational age, physical appearance)
	Perceived cause of preterm birth
	Caring practice for preterm baby
Mothers’ emotional experience	Sadness and hopelessness
	Being worried, stressed
Need for support	Support from health care provider
	Support from family and the community
Challenges faced during NICU stay	Inadequate counseling
	Lack of resource
	NICU environment

Theme 1 Mothers' perception of Preterm babies

Subtheme 1.1 Mothers’ initial reaction and understanding of preterm babies (gestational age, physical appearance)

Since preterm birth is an unexpected event for which mothers were often unprepared, most of the mothers in this study reported experiencing a range of negative feelings initially after preterm birth, including fear of losing their baby and difficulty coping with early separation. Many mothers believed that a baby born prematurely might not grow, and they expressed uncertainty about whether their newborns would survive.

One mother described the experience of having a preterm baby as deeply painful and overwhelming, likening it to a disaster:

"Having a premature baby is very painful because it feels like a disaster or "meati" has come upon you. Raising a premature baby is a huge burden. I feel like I could lose her suddenly over some small thing. I'm in two minds about whether or not she will survive. it is a huge disappointment. When my baby was born prematurely and was admitted to the neonatal intensive care unit, I felt like I wouldn't be able to find her alive, that I wouldn't be able to hold her and that my baby would die". (Participant 7)

Another mothers expressed initial shock at seeing their newborns and fearing for their baby's survival, and expressed regret and a sense of loss, believing that their child's suffering could have been avoided if the baby had been born on time.

"I was not feeling well; when I came to see her, I was overwhelmed, shocked and didn't think she would survive. But then I saw her she was breathing and I felt a bit calmer. When the nurses told me to bring milk, I thought, 'Can she survive, or will she die?" (Participant 6)

"I would have been happy if my son had been born on time, but he was born prematurely. If he had been born on time, I think he would not have suffered this pain and might have been healthy." (Participant 1)

Additionally, the majority of participants in this study recognized a preterm baby based on gestational age and physical appearance. Many described it as "a baby born early before the normal due date." They perceived a full-term pregnancy as lasting nine months, and considered babies born before completing nine months at seven or eight months as preterm. The following statements from participants illustrate their understanding of preterm birth based on gestational age

"A baby born after nine months is called full-term, while a baby born at seven or eight months is considered preterm". (Participant 8)

"A premature baby is a baby born early before the normal due date…." (Participant 9)

In addition to gestational timing, mothers also identified premature babies by their size, physical appearance, and certain characteristics. They described them as small, fragile, and underdeveloped, with low birth weight, reduced alertness, and difficulties with breathing and feeding. As expressed by the mothers:

"A child born prematurely is not the same as one born full-term. He is smaller, has a low birth weight, is weaker, less alert, and his overall state is more fragile". (Participant 5)

"Premature babies are very weak, sleep a lot, and often have difficulty feeding. Their bodies, arms, and legs are very small. I don't think they will grow up to stand and walk". (Participant 6)

Subtheme 1.2 Perceived cause of preterm birth

In this study, mothers' perceptions of the causes of preterm birth included factors such as the will of God, maternal health problems or illness, hereditary factors, overwork during pregnancy, and cultural beliefs. Most participants identified diseases that occur during pregnancy, such as hypertension, diabetes, and premature rupture of membranes, as the most common causes of preterm birth. A few participants also believed that carrying heavy materials, not getting enough rest, and having an imbalanced diet during pregnancy were causes of preterm birth.

"I think some reasons for premature birth include maternal illnesses during pregnancy, such as hypertension, diabetes, and premature rupture of membranes". (Participant 1)

"I think the things that cause a baby to be born prematurely are not taking care of yourself during pregnancy, not getting enough rest, working too much without rest, and not following a proper diet, meaning not eating on time and not eating a balanced diet." (Participant 7)

Other causes of preterm birth perceived by participants were linked to spiritual and socio-cultural beliefs, such as the will of God and the cultural belief of "michi," which is thought to cause preterm birth.

"For me, "Medihanialem" is the one who gave me my preterm baby from above. I say Amen and accept it. He is the one who created everything, and I believe that He is the reason why some children are born prematurely. He gives in time and without time". (Participant 2)

"….some mothers also have conditions like 'Michi,' which can lead to premature births". (Participant 4&5)

One participant, a 32-year-old mother, believed that a hereditary factor could cause preterm birth. She shared:

"*I think the reason children are born prematurely is probably genetic, because I heard my grandfather say that he was born prematurely. Now, I too have had a premature child". (Participant 6)*

Subtheme 1.3 Caring practice for preterm baby

Perceptions of mothers about their future plan of caring their preterm baby; primarily focused on thermal care, exclusive breastfeeding, hygiene, and infection prevention. Almost all participants recognized the importance of keeping their babies warm and reported using various methods such as exposing the baby to sunlight, wrapping the baby in layers of clothing, practicing skin-to-skin contact (kangaroo mother care), keeping doors and windows

closed, placing pots of hot water in rooms, and using charcoal fires to maintain a warm environment. Most mothers also planned to exclusively breastfeed their babies for the first six months, with some expressing intentions to continue breastfeeding alongside complementary foods beyond that period.

"Since her birth weight is small, after bathe her let her warm up in the sun, and wrap her in thick clothes to maintain her body temperature. I know that warmth and sleep are more important for her than eating to gain weight. I also give my baby only breast milk until she is six months old, and after six months, I will continue to breastfeed her and provide complementary food". (Participant 5)

"I think keeping a premature baby warm is very important because they come out of the womb early. I've heard that placing the baby on the chest helps keep them warm, so I put him on my chest and wrap him in layers of clothing. I exclusively breastfed my baby until 6 months, and then I will start giving him formula and other necessary foods". (P articipant10)

".... I can keep my baby warm in different ways: by applying Vaseline to his body and warming him in the sun. If sunlight is not available, I can keep him warm by placing a well-lit charcoal inside the house." (Participant 1)

In addition to thermal care and feeding, participants also emphasized hygiene and infection prevention as key components of their caregiving plans. They noted that frequent hand washing, maintaining their own personal hygiene, keeping their babies clean, limiting the number of visitors, and avoiding contact with people who might be sick. Some mothers mentioned that they avoid taking their babies outside. A few participants also mentioned relying on spiritual practices, such as praying for the baby's health.

"I plan to completely change my lifestyle to ensure my child stays healthy. Maintaining hygiene is my top priority this includes my child's hygiene, my personal hygiene, and the cleanliness of our entire family. I will also keep my child away from others and avoid sharing things with people. When I say cleanliness, I don't just mean bathing and clean clothes, but also not touching my child without washing my hands and ensure that others do the same". (Participant 7)

"To keep my son from getting sick, I will keep him clean, feed him properly, bathe him every two or three days, wash my hands before breastfeeding him, and finally, let him to God to protect him". (Participant 8)

Theme 2 Mothers’ emotional experience

Subtheme 2.1 Sadness and hopelessness

Many mothers described experiencing deep emotional distress following the premature birth and admission of their babies to the Neonatal Intensive Care Unit (NICU). These unexpected events led to feelings of sadness, hopelessness, fear, and emotional detachment. Several mothers expressed that they initially believed their babies would not survive due to their immaturity and fragile condition. The physical separation from their newborns immediately after birth worsened their emotional distress, as many longed to hold, breastfeed, and care for their infants but were unable to do so. Some mothers also mentioned turning to prayer, placing their hope in God for their babies' survival and well-being during these emotionally challenging time.

“I am so sad that my son has been admitted to the Neonatal Intensive Care Unit. I am crying all the time. Because he is so small, his veins are difficult to find, and he is struggling. The nurses are having a hard time finding his blood vessels. My son is suffering, so I am so sad and crying.” When you see your son close to you, you feel happy and forget your own pain. I was so sad to be separated from my son as soon as he was born. I couldn't believe he was alive until I saw him.” (Participant 1)

“I didn't think my baby would survive because he was born prematurely. When the midwives told me he was going to the Neonatal Intensive Care Unit, I felt bad. I had no hope because he was born too early. I was worried about whether he would survive or not and kept thinking about what would happen.....“ (Participant 4)

Subtheme 2.2 Being worried, stressed

Worry and stress were the mother’s major negative emotional experiences due to unfamiliar NICU environment, their babies’ conditions and the need to walk back and forth to the NICU repeatedly. Majority of mothers reported being worried and stressed when they saw their newborns attached with different medical equipment, breathing on oxygen machines, feeding by tube, and when their babies unable to breastfeeding, and also babies size/feature appeared fragile and too small. Mothers expressed their emotional experiences as:

“I'm really worried about having a premature baby. I'm worried because I see that she is very small, and I feel like she might die from something small. I don't think she’ll even grow up. My baby is not breastfeeding well, and I am worried about this.” (Participant 6)

"When I first entered the neonatal intensive care unit, I was shocked to see my son with his nose, hands, and feet attached to medical instruments. I didn't expect it to be like that it wasn't what I had initially thought." (Participant 10)

Theme 3 Need for support

Subtheme 3.1 Support from health care provider

The majority of mothers expressed a need for support from healthcare providers, as the experience of having a premature baby was new and overwhelming for them and they have deep concern for their babies' survival. They described wanting close follow-up, guidance, and explanations from professionals to help them care for their babies and correct any misunderstandings. Some mothers also reported experiencing significant mental stress during their NICU stay and in the postnatal period, which puts them at greater risk for mental health challenges.

"Because of my child's premature birth, my mind is troubled by many things, especially the issue of whether or not my child will survive. I would be happy if there was a way to get psychological support/treatment, including advice, monitoring, and support from health professionals." (Participant 9)

"Next to Allah, my husband is with me, but mainly, I need the care and support of health professionals, especially if they do everything they can to help my child survives." (Participant 8)

Subtheme 3.2 Support from family and the community

Families play a vital role in supporting mothers of premature babies during their journey. Participants highlighted the crucial role of family support in coping with stressful and unfamiliar situations. Some also expressed concern for their other children at home during their baby's NICU stay, emphasizing the need for both emotional and practical assistance from family.

"I don't have anyone close to me right now except for my husband. Since everything is new to me, I need support. It would be good if someone lived close to me, spent time with me, and help me at this time, especially my family." (Participant 4)

"Next to God, I need help from people, so that my baby doesn't get hurt. After my baby was hospitalized, I was not only worried about him but also about my children at home. I want my family to take care of them." (Participant 3)

Additionally some mothers expressed the need for greater understanding and acceptance from the communities during the challenging experience of having a premature baby. One 34 aged mother shared that; due to her baby's condition and concern for her baby's well-being, she could not prepare the traditional ceremony at her home, typically expected after childbirth. She desire the community would accept and respect her situation, rather than criticize or isolate her for not fulfilling cultural expectations.

"What I also want from the community is for them to understand my situation, rather than isolating me. I won't be having a party or ceremony where I can light a fire or burn charcoal in my house or "kesel aketatiye achachishe" and invite people over to eat, because this is not an environment where my small child can thrive. So, I want people to understand my situation and accept it without criticizing me for not doing these things."

Theme 4 Challenges faced during NICU stay

Subtheme 4.1 Inadequate counseling

Challenges reported by participants during their infants' stay in the Neonatal Intensive Care Unit (NICU) was inadequate counseling from healthcare professionals. Some participants shared that they were not clearly informed about their baby's condition or the procedures being performed. While a few healthcare providers were described as helpful and communicative, others were unapproachable and gave unclear responses when asked about the baby's condition. This lack of clear and consistent communication left a few mothers feeling confused, and emotionally distressed.

"The professionals only told me that my son was born prematurely and needed to be admitted to the Neonatal Intensive Care Unit. I am not aware of my son's current condition because they did not explain it clearly to me. My son's condition worries me because I do not understand what is being done to him and why it is being done." (Participant 4)

"Most of the professionals working in the Neonatal Intensive Care Unit were very good at understanding your concerns and explaining your baby's condition clearly. However, some of the professionals excuse me, do not want me in the room. Even when I ask them about my baby's condition, they don't answer me properly, and they disrespect me. I cried. "Crying'' (participant 1)

Subtheme 4.2 Lack of resource

Other challenges faced by participants during their infants stay in the Neonatal Intensive Care Unit (NICU) were a lack of resources, which affected both their self-care and financial

stability. Many parents faced difficulties with basic needs like lack of space for showering, washing clothes, and maintaining personal hygiene due to limited facilities. Additionally, some laboratory tests and shortage of medications at the hospital forced some of them to buy from privat pharmacy and lab test from private clinc, adding financial strain. Despite these challenges, some mothers were willing to make sacrifices for their child's well-being.

"During my time in the Neonatal Intensive Care Unit, I faced difficulties with basic needs such as taking a shower, washing my clothes, and changing into clean clothes, which affected my personal hygiene. Additionally, due to a shortage of medicine at the hospital, I am struggling to afford the medications that I am instructed to buy from private pharmacy" (Participant 6)

"My husband is a daily laborer and has had to quit his job to be with me. I have been facing financial difficulties during my stay in the hospital. Sometimes, there is a shortage of medicine in the hospital, and we are asked to buy it from outside." (participant 5)

"…….and some laboratory tests are sent to private laboratories outside the hospital, which causes financial problem for me (participant 1).

Subtheme 4.3 NICU environment

The NICU environment presented a complex experience for many participants, characterized by discomfort, worry, and feelings of hope. Several participants described the physical and emotional challenges of being in the NICU, with the unfamiliar environment, separation from their newborns, and constant concern for their babies' survival which contributing to significant mental stress. However, alongside these difficulties, some mothers also expressed feelings of hope and reassurance, particularly when observing attentive care and gradual improvements in their infants' condition.

"If I were at home as a postnatal mother, I would eat and drink whatever I could find, cover myself properly, and get enough sleep and rest. But now, it's hard to sit with my sick child because I'm constantly worried about him. Nothing feels like home here; it's uncomfortable and causing me mental stress." (Participant 9)

"I am happy when my child is treated in the Neonatal Intensive Care Unit because I feel comforted by the care provided by the professionals and the condition of the facility. I have hope that he will recover fully and remain safe." (Participant 8)

"The hardest thing for me is that my son is not with me. I would be happy if we could live together, hug him, breastfeed him, and sleep beside him…..(participant 8).

6. DISSCUSSION

This study aimed to explore the perceptions and challenges of mothers with preterm newborns in the Neonatal Intensive Care Unit. It identifies key themes such as Mothers' emotional exprience, Mothers' perception of Preterm birth, Need for support, and Challenges encountered during NICU stay. While numerous studies in our country have examined preterm birth and its effects on infant development, there is lack of research focusing on maternal perceptions and the difficulties mothers face. Therefore, this study contributes to addressing these research gaps in the study area.

The findings of this study reveal the intense emotional distress experienced by mothers. Many mothers experienced feelings of fear, sadness, and hopelessness following preterm birth and difficulty with early separation, also they perceived that a baby born prematurely might not grow or survive and they expressed uncertainty about their newborns survival. For many, the experience was described as sudden, overwhelming, and traumatic. This finding is in line with a study conducted in Bhairahawa (43), United Arab Emirates (44), Nepal (17) and Rwanda (45). In which mothers reported experiencing negative feeling due to unexpected early birth and detachments from their babies, and because of their perception of their newborns and uncertainty about their survival. This implies that mother's perception of their newborn can have a negative impact on their emotional well-being. Therefore, providing timely emotional support, clear information, and counseling through healthcare providers is essential to help them.

This study further highlights the emotional strain faced by mothers following unexpected life event and NICU admission. Feelings of sadness, worry, hopelessness, and stress were commonly experienced by mothers, particularly due to the unfamiliar NICU environment, which is highly focused on medical care and the fragile condition of their babies. Seeing their babies connected with various medical devise, breathing through oxygen machine and feeding via tube aggravated their emotional distress. Similar findings have been reported in studies from Rwanda(45), United Arab Emirates(44), Bhairahawa(43), Tribhuvan university teaching hospital in Nepal(17), and southern Ethiopia(27), where mothers expressed emotional strain linked to the unexpected birth, NICU admission and concerns about their babies' fragile

conditions. This highlights the need for healthcare providers to offer emotional support and clear communication to help mothers cope during this challenging period.

In this study the participants defined preterm baby as “a baby born early” before nine months, at seven or eight months based on gestational age. They also recognize preterm babies by physical characteristics, describing them as small in size, with low birth weight, underdeveloped organs, reduced alertness and difficulties with feeding and breathing. This was also supported by the studies conducted in Bangladesh(36), Ghana(37), Malawi(38), and Southern Ethiopia(3). In which in most regions commonly the concept of preterm birth is linked to birth occurring before the completion of a full-term pregnancy and baby is too small. In addition, the causes of premature birth, as perceived by mothers, were associated with maternal factors like illness during pregnancy, not eating good quality and enough food, doing excess household duties, family history of preterm birth, and socio-cultural and spiritual factors includes will of God and “michi”. This finding support study conducted in Western African countries(39), rural Mangoch, Malawi (15, 38) and Southern Ethiopia(3).

This study explored mothers’ perceptions of caring practices for their preterm babies, focusing on thermal care, exclusive breastfeeding, hygiene, and infection prevention. Mothers consistently emphasized the importance of keeping their babies warm, using a variety of culturally and contextually appropriate methods such as layering clothing, exposing babies to sunlight, practicing skin-to-skin contact (kangaroo mother care), closing windows and doors, placing pots of hot water in rooms, and using charcoal fires to keep the room warm. In addition, in terms of hygiene and infection prevention, mothers raise some main ideas such as hand washing/hygiene, mother’s personal hygiene, keeping baby clean, limit the number of people they interact, keep the baby away from others, and avoid taking their babies outside and praying to God to protect them. The primary reasons they mentioned were that preterm babies are very small and can get sick easily. This finding is consistent with similar studies conducted in different country including Ethiopia (5, 13-15, 36, 40, 41, 43). Overall, mothers demonstrated a strong sense of responsibility and emotional commitment to their preterm infants’ well-being. However, certain practices such as using charcoal to heat the room and placing a pot of hot water close to the baby may harm the baby if not properly managed. These

findings indicate the need for detailed health education from health professionals during the NICU stay and upon discharge.

In this study, the findings highlight the divers and complex support needs of mothers with premature babies. These needs were primarily centered on healthcare providers, family members, and the community. Mothers reported a particularly strong reliance on healthcare professionals, noting that preterm birth is often unexpected and emotionally overwhelming. As such, they emphasized the need of continued follow-up, guidance, and clear communication from healthcare providers to support them in caring for their babies and to prevent misunderstandings. Additionally, the emotional burden of the NICU stay was frequently mentioned. Many mothers expressed a need for psychological support from healthcare provider to cope with the stress and reduce the risk of mental health problem. This finding is consistent with a previous study conducted in Arba Minch, southern Ethiopia (3).

Furthermore, the role of family support emerged as essential in providing both emotional and practical help. This was particularly relevant for mothers who were concerned about balancing care between their hospitalized infants and their other children at home. Lastly, support from the community was also identified as essential, especially mother's need for understanding and acceptance from their communities rather than isolating and criticizing them due to unmet cultural expectations, due to the baby's health condition and deep concerns of their baby. This finding is supported by study conducted in urban setting in the Greater Accra region of Ghana(12). Families of premature infants should be given extra support. include education, counseling and discharge preparation by health workers (6). Similarly the participants in this study suggested that support from health care providers, family, and the community is needed for mothers with premature babies. These findings imply that achieving positive outcomes for mothers of premature infants requires a holistic support system that encompasses medical, familial, and community.

The study finding showed that mothers experiencing multifaceted challenges during their NICU stay. They mentioned inadequate counseling, lack of resources and unfamiliar and stress full NICU environment. Inadequate communication from healthcare providers emerged as a critical concern, with several participants reporting feelings of confusion and emotional distress due to unclear explanations and some unapproachable staff. This was supported by

other previous studies in which the health professional lacked compassion, were inattentive, and did not fulfill their responsibilities (1, 13, 50). This implies inadequate communication between mothers and health care providers can significantly increase maternal stress. This indicates the need for improving parent to health workers interaction and counseling protocols in NICU settings. Additionally, a lack of resources including inadequate sanitation facilities such as the lack of space to take shower, limited space for washing clothes, and challenges in maintaining personal hygiene was reported. The unavailability of medicines and laboratory tests at the hospital required mothers to purchase medications from private pharmacies and lab tests from private clinics for their baby's care. This affects both their self-care and their financial stability. Similarly, previous studies reported that mothers were challenged with inadequate facility, lack of space to take rest, lack of bath room and shortage of some Medicines and laboratory test (1, 16, 27, 45, 51).

This study further found that the NICU environment was a source of challenges for mothers. They experienced physical discomfort and emotional challenges, particularly due to unfamiliar environment which is not convenient as a home, where usual postnatal comforts eating well and resting, is not possible and separation from their newborns contributing to stress. However, moments of hope were evident when mothers observed attentive care and perceived improvement in their babies' conditions. This finding is in line with earlier studies conducted in Eastern United States, Jordan, South Africa, Iran and Ethiopia (30, 32, 33, 52, 53). These dual experiences of distress and hope emphasize the emotional complexity of the NICU journey and highlight the need to combine clinical care and emotional support in such challenging settings.

7. CONCLUSION AND RECOMMENDATIONS

7.1. Conclusion

On the base of major findings, it is concluded that mothers described their experience of having preterm birth as sudden, overwhelming, and traumatic. They experienced several challenges following preterm birth and during their NICU stay includes emotional distress, physical discomfort and financial problems. This was mainly due to unexpected preterm birth, their perception that preterm babies might not grow or survive, early separation, uncertainty about their babies survival, the unfamiliar NICU environment, and challenges with health facility and care providers including inadequate counseling, lack of compassionate care, and limited resources such as lack of bathroom, lack of space for washing clothes and maintaining hygiene, and the unavailability of some medicines and laboratory tests. Majorly stated negative feelings were fear, sadness, worry, and hopelessness which can lead to psychological stress and increase the risk of mental health problems.

Some mothers also held misconceptions about the causes of preterm birth and caregiving practices. Beyond medical care for their infants, mothers require strong support from healthcare professionals, families, and the community to reduce their stress. Hospitals should address the shortages of medications and laboratory services, as well as improve facility conditions, to reduce maternal stress and financial strain. Additionally, awareness should be raised to correct misconceptions about causes and caring practices among mothers, and the burden faced by mothers of preterm infants should be shared and supported.

7.2. Recommendations

For hospital administrative

Hospital managers and administrators should arrange a separate room for mothers of preterm babies, designated for psychological support and counseling services. This room should be staffed by healthcare professionals and provide regular, ongoing support, including a phone service that should be made available for mothers to call after discharge to ask questions or seek guidance.

Nursing staff in the NICU should improve their communication with parents, especially mothers, and provide clear and adequate counseling.

Hospitals should take action to resolve medication supply shortages and improve laboratory services, as well as enhance overall facility conditions.

For minister of health: The Ministry of Health should work to raise community awareness about preterm birth, its causes, and appropriate caregiving practices, and should discourage the criticism and judgment of mothers of preterm infants through media and health extension workers.

Establish psychological support units for mothers in each health center and create a referral link between hospitals and health centers to ensure follow-up after discharge until mothers fully recover from stress.

For researchers: A similar study using a mixed-methods approach is recommended to gain a more comprehensive understanding of the quantitative impacts and qualitative experiences of mothers with preterm infants.

Further research is needed to explore healthcare providers' perceptions of preterm birth and its impact on maternal well-being.

Further studies in community settings are recommended to explore cultural beliefs and community perceptions related to preterm birth.

Strength and Limitation of the Study

Strength of the study

As to my knowledge, this is the first study conducted in Ethiopia that explores mothers' perceptions and challenges of having preterm newborns in a Neonatal Intensive Care Unit (NICU). The study tried to provides an in-depth understanding of mothers' opinions and experience by minimizing researcher influence during each interview. The interviews included mothers from different age groups, educational levels, and occupational statuses, which provided a deeper insight into participants' perceptions.

Limitation of the study

This study included mothers of preterm babies across all categories extremely preterm, moderately preterm, and late preterm. As a result, their responses may vary depending on the degree of prematurity, which may influence the consistency of the findings.

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9. APPENDIX

Appendix A: English version of information Sheet for study participants

Addis Ababa University, College of Health Sciences, Department of Nursing and Midwifery

DD/MM/YY ___/____/_____

My name is ------------------- I am from the AAU. As a partial fulfillment requirement for an MSc degree in Neonatal Nursing, I will conduct a study on the Perceptions and challenges of mothers with preterm babies at Tikure Anbesa Specialized Hospital in Addis Ababa, you are kindly requested to participate in this study. I hope you will help me by answering the questions based on the instructions given. Your information is used only for research purposes and is kept confidential. The following is some general information about the study:

The objective of the study is to explore the perceptions and challenges of mothers having preterm newborns in Neonatal Intensive Care Unit at Tikur Anbesa Specialized Hospital Addis Ababa, Ethiopia, 2024.

Benefits, Risks, and /or Discomfort

By participating in this research project, you may feel some discomfort in wasting your time. However, your participation is important to explore the perceptions and challenges of mothers having preterm newborns in Neonatal Intensive Care Unit. There is no risk or direct benefit in participating in this research project.

Confidentiality

All information obtained from you will be kept private and will not be shared with any third parties; your name won't be recorded on the question sheet, ensuring that you won't be known for any reason

Right to Refusal or Withdraw

You have full right to refuse from participating in this research. You have also the full right to withdraw from this study at any time you wish.

I would also like to inform you that this study will be reviewed and approved by the Institutional Review Board of Addis Ababa University College of Health Sciences. If you have any questions, you can contact at any time.

If you have question about the study the address of the principal investigator is:

Name: Tihitina Mulugeta

Phone No: 0926102235

E-mail: tihitinamulugeta50@gmail.com

Would you be willing to participate in this study?

1. Yes 2. No

Appendix B: English version of informed consent

Addis Ababa University College of Health Science School of Nursing and Midwifery

Department of Neonatal Nursing

Name of Researcher: Tihitina Mulugeta

Address: Addis Ababa University College of Health Science

Phone No: 0926102235

E-mail: tihitinamulugeta50@gmail.com

Interviewer's code ______________

Name of data collector____________________ signature____________

Date of interviewing ____________month___________/2017 E. C.

Time of interview began _________________ hours________ minutes

Time of interview finished________________ hours__________ minutes

Checked on _____________date______________________month/2017 E.C.

I am informed that this study is going to be conducted to explore the perceptions and challenges of mothers having preterm newborns in Neonatal Intensive Care Unit at Tikure Anbesa Hospital in Addis Ababa, Ethiopia. I am informed that the information I give will be kept confidential, and only used for this study. I am also conscious that I have the right not to respond to any question without my interest. Hence, I agree to participate in the research voluntarily.

Signature__________ Date______________

Appendix C: English version of a Semi-structured interview guides

Part I: Background data of participants

1. How old are you? A. 18-24 ☐ B. 25-34 ☐
   C. 35-44 ☐ D. $\geq$ 45 ☐
2. What is your marital status?
   A. Single ☐ C. Widow /widower ☐
   B. Married ☐ D. Divorced ☐
3. What is your Parity A. Primiparous ☐ B. Multiparous ☐
4. What is your level of education?
   A. unable to read and write ☐ C. High school ☐
   B. Elementary school ☐ D. Diploma and above ☐
5. Where are you living?
   A. Rural ☐
   B. Urban ☐
6. What is your Religion?
   A. Orthodox ☐ B. Protestant ☐ C. Muslim ☐ D. Others (specify)_______
7. What is your occupation?
   A. House wife ☐
   B. Government employee ☐
   C. Merchant ☐
   D. Farmer ☐
   E. Other (specify) __________
8. Average income per month?-------ETB
9. At which month your baby has been delivered? ....

10. How many days you stay in NICU/hospital? _______ days

Part II: In-depth interview guides

1. What does preterm baby mean to you? Can you tell us about your feeling about it?

Probing question

I. How do you describe preterm babies? (Based on gestational age, physical characteristics, …)

II. What do you think about the causes of preterm birth?

2. Can you describe how you felt when your baby born prematurely and he were admitted to the NICU?

Probing questions

I. What emotions have you experienced while your baby admitted in the NICU?

II. How does it feel to be separated from your baby following NICU admission?

3. What are your thoughts on the care of preterm babies?

Probing question

I. Do you think that a thermal care is important to preterm babies? If your answer is yes, how do you ensure that preterm babies are kept warm and maintain optimal body temperature in your care?

II. What will you consider about feeding practice for your preterm babies?

III. What measures do you take to maintain hygiene and prevent infections for your preterm babies?

4. How do you feel about the communication between you and the NICU staff?

Probing questions

I. Have you experienced any difficulties to understand the medical care or updates about your baby?

5. What kind of emotional or social support has been most helpful to you during this time? (e.g., family, friends, hospital support groups)

6. Any experience of difficulties with the environment of the NICU? How has the NICU setup affected your comfort and ability to focus on your baby?

7. Explain or tell me your experience of any difficulties related to medical supplies or laboratory tests for your baby?
8. What has been the most challenging part of your NICU experience as a mother, and what things should be improved regarding NICU care for preterm babies?

Thank you for your Participation!

Appendix D: Amharic version of the information sheet

በጥናቱ ለሚሳተፉ የስምምነት ዉል እና አጠቃላይ መረጃ

የጥናቱ ርዕሰ ጉዳይ፡ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፓታል በጨቅላ ህጻናት ጽኑ ህሙማን ክፍል ያለጊዜያቸዉ የተወለዱ ሕጻናት እናቶች ያላቸዉ ግንዛበ እና ተግዳሮቶችን ለመዳሰስ የቀረበ ጥናት ነው፡፡

ጤና ይስጥልኝ፣ስሜ-------- ይባላል፡፡ በአሁኑ ወቅት በአዲስ አበባ ዩኒቨርሲቲ በነርሲንግ እና ሚድዋይፍሪ ትምህርት ክፍል የሁለተኛ ዲግሪ ትምህርቴን እየተከታተልኩ እገኛለሁ፡፡ የሁለተኛ ዴግሪዬን ለመጨረስ ይረዳኝ ዘንድ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፓታል በጨቅላ ህጻናት ጽኑ ህሙማን ክፍል ያለግዜያቸዉ የተወለዱ ሕጻናት እናቶች ያላቸዉ ግንዛበ እና ተግዳሮቶችን ለመዳሰስ በሚል ርዕሰ ጉዳይ ላይ ጥናት እያደረኩ እገኛለሁ፡፡ ጥናቱ በአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ትምህርት ቤት በነርሲንግ እና ሚድዋይፍሪ ትምህርት ክፍል የጸደቀ ነዉ፡፡ ስለሆነም ቀጥሎ የተዘረዘሩት የጥናቱ ዓላማዎች ይሳኩ ዘንድ በእናንተ በኩል በእውነታ ላይ የተመሠረተና ትክክለኛ የሆነ መረጃ እንድትሰጡኝ እየጠየኩ ለቃለ መጠይቁ የምትሰጡኝ መልስ ግላዊ እና ስማችሁን ያላካተተ በመሆኑ በከፍተኛ ሚስጥራዊነት የሚጠበቅ ይሆናል፡፡ ከዚህም በተጨማሪ በጥናቱ ላይ የምትሳተፉት በፍቃደኝነት ስለሆነ ካልተመቻችሁ ባስፈለጋችሁ ጊዜ ማቆም/ማቋረጥ መብታችሁ ነው፡፡ እርስዎ ጥያቄ በመመለስ ብትተባበሩኝ ለጥናቱ መሳካት የራስዎን ጉልህ ድርሻ ተወጡ ማለት ነው፡፡

የጥናቱ አላማ፡ የዚህ ጥናት ዋና አላማ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፓታል በጨቅላ ህጻናት ጽኑ ህሙማን ክፍል ያለጊዜያቸዉ የተወለዱ ሕጻናት እናቶች ያላቸዉ ግንዛበ እና ተግዳሮቶችን ለመዳሰስ የቀረበ ጥናት ነው፡፡

የዚህ ጥናት ዉጤት ያለግዜያቸዉ የምወለዱ ሕጻናት እናቶች ያላቸዉን ግንዛበ እና ተግዳሮቶችን በመረዳት ለሕጻናቶቹ የሚሰጠዉን ህክምና/ እንክብካቤ ለማሻሻል እና ለእናቶች የምያስፈልጋቸዉን ልዩ ድጋፍ ለመስጠት ያግዛል ፡፡

የጥናቱ ሂደት፡ በጥናቱ ዉስጥ ለመሳተፍ የተካተቱትን መመዘኛዎች ያሟሉ ወላጆችን ያካትታል፡፡በዚህ ጥናት እንድሳተፉ በታላቅ አክብሮት ተጋብዘዋል፡፡ ለመሳተፍ ፍቃደኛ ከሆኑ፤ በጣም ደስተኛ ነኝ እናም የዚህን ጥናት አላማ በትክክል መረዳትዎን እና ስምምነትዎን እዲያሳዩ እፈልጋለዉ፡፡ በመጨረሻም በቃለ መጠይቁ ትክክለኛ ምላሽዎን እንዲሰጡ በአክብሮት እጠይቃለዉ፡፡

ጥቅማጥቅም፤ጉዳት እና/ወይም የማይመች ነገር፡ በዚህ ጥናት በመሳተፍዎ የተወሰነ ደቂቃ ሊፍጂበዎት ይችላል ሆኖም ግን የእርስዎ ተሳትፎ ያለግዜያቸዉ የተወለዱ ሕጻናት እናቶች ያላቸዉ ግንዛበ እና ተግዳሮቶችን ለመዳሰስ እና አስፈላጊዉ መፍትሄ እንድፈለግ ያግዛል፡፡ በዚህ ጥናት በመሳተፈዎ ምንም አይነት ጉዳት ወይም ቀጥተኛ ጥቅም አይኖረዉም፡፡

ማበረታቻ/ለማበረታታት ክፍያዎች፡ በዚህ ጥናት ለመሳተፍ ማበረታቻ ወይም ክፍያ አይኖረዉም።

ሚስጥራዊነት፡ ከእርሰዎ የተሰበሰበዉ መረጃ በኮምፒተር ዉስጥ ስምዎ ሳይኖር በሚስጢር ይቀመጣል፡
፡

የመቃወም ወይም የመተዉ መብት፡ በዚህ ጥናት ዉስጥ ያለመሳተፍ ሙሉ መብት አለዎት በተጨማሪም ጥናቱን ሳያጠናቅቁ በፈለጉት ሰዓት የመተዉ መብትዎ የተጠበቀ ነዉ።

በተጨማር፡ ይህ ጥናት በአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ በተቋማት ግምገማ በርድ እዲፀድቅ ይደረጋል። ማናቸዉም ጥያቄ ሲኖረዎት በማንኛዉም ጊዜ ማነጋገር ወይም ማግኘት ይችላሉ።

የዋናዉ ተመራማር አድራሻ ከፈለጉ፡

ስም፡ ትህትና ሙሉገታ

ስልክ ቁጥር፡ 0926102235

ኢ-ሜል፡ tihitinamulugeta50@gmail.com

መጠይቁን ለመመለስ ፍቃደኛ ነሽ/ነዎት?

1. አዎ 2. አይደለሁም

Appendix E: Amharic version of informed consent

አዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ ነርሲንግ እና ሚድዋይፈሪ ትምህርት ቤት

ነርሲንግ ትምህርት ክፍል

ጥናቱን የሚሰራዉ፡ ትህትና ሙሉገታ

ስልክ ቁጥር፡ 0926102235

ኢ-ሜል፡ tihitinamulugeta50@gmail.com

የኮድ ቁጥር ___________

ጥናቱን የሚሰበስበዉ ስም_______________________ ፊርማ________________

ጥናቱ መሰብሰብ የተጀመረበት ቀን_________________ /2017 ዓ/ም

ጥናቱ መሰብሰብ የተጀመረበት_____________________ ሰዓት __________ ደቂቃ

ጥናቱ ተሰብስቦ ያለቀበት__________________________ ሰዓት __________ ደቂቃ

የተጣራበት ቀን________________ወር__________________ 2017ዓ/ም

የጥናቱ ተሳታፊዎች ፍቃደኝነት ቅፅ

እኔ የጥናቱ ተሳታፊ የሆንኩኝ ወላጅ እናት ይህ ጥናት በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል በጨቅላ ህጻናት ጽኑ ህሙማን ክፍል ያለግዜያቸዉ የተወለዱ ሕጻናት እናቶች ያላቸዉ ግንዛበ እና ተግዳሮቶችን ለመዳሰስ የቀረበ ጥናት መሆኑን አውቂያለሁ። የምሰጠውም ግላዊ መረጃዬ በሚስጥራዊነት እንደሚጠበቅ እና ለዚህ ጥናት አላማ ብቻ እንደሚውል ተነግሮኛል። ጥናቱ ውስጥ ያለፍላጎት ተሳታፊ ሆኜ መቀጠል እንደለለብኝ እና መቀጠል ባልፈለግሁ ጊዜ ማቆም እንደምችል ተረድቻለሁ። በአጠቃላይ ከላይ የተዘረዘሩትን መብቶቼን በማወቅና የእኔ በዚህ ጥናት ላይ መሳተፍ ጥቅም አለው ብዬ በማመን በሙሉ ፍቃደኝነት ለመሳተፍ ተስማምቻለሁ።

ፊርማ____________

ቀን________________

Appendix F: Amharic version of interview guides

ክፍል 1. መሠረታዊና ማህበራዊ ጥያቄዎች

1. ዕድሜሽ ስንት ነዉ ሀ. 18-24 ☐ ለ. 25-34 ☐ ሐ. 35-44 ☐ መ. ≥ 45 ☐
2. የጋብቻ ሁኔታ

   ሀ.ያላገባች ☐ ሐ. የፈታች ☐

   ለ. ያገባች ☐ መ. እመበለት ☐
3. ከዝሀ በፍት ልጅ ወልደሻል? ሀ. ወልጃለዉ ☐ ለ. አልወለድኩም ☐
4. የትምህርት ደረጃ

   ሀ.ማንበብ እና መጻፍ የማይችል ☐ ሐ. ሁለተኛ ደረጃ ☐

   ለ. አንደኛ ደረጃ ☐ መ.ድፕሎማ እና ከዚያ በላይ ☐
5. መኖሪያዎ የት ነዉ? ሀ. ገጠር ☐ ለ. ከተማ ☐
6. ሀይማኖትዎ ምንድነዉ? ሀ. ኦርቶዶክስ☐ ለ. ፕሮተስታንት☐ ሐ. ሙስልም☐ መ. ለላ (ይግለጹ) ....
7. የርስዎ የስራ ድርሻ

   ሀ. የቤት እመቤት ☐

   ለ. የመንግስት ሰራተኛ ☐

   ሐ. ነጋዴ ☐

   መ. አርሶአደር ☐

   ሠ. ሌላ.........
8. የወር ገቢ በ አማካይ----------ETB
9. ልጅዎ በስንተኛዉ ወሩ ነዉ የተወለደዉ?...
10. ሆስፒታል ዉስጥ ስንት ቀን ቆይተዋል?---

ክፍል 2፡ በከፊል የተዋቀረ ጥልቀት ያለው የቃለ መጠይቅ መመሪያ

1 ጊዜዉ ሳይደርስ የተወለደ ህጻን ማለት ለእርስዎ ምን ማለት ነው? ስለሱ ምሰማዎትን ስሜትዎ ሊነግሩን ይችላሉ?

ጥልቅ ጥያቄ

I, ጊዜያቸዉ ሳይደርስ የተወለዱ ህፃናትን እንዴት ይገልጻሉ?

II. ህጻናት ያለግዜያቸዉ እንድወለዱ መንስኤዎች ምን ምን ናቸዉ ብለዉ ያስባሉ?

2 ያለጊዜያቸው የተወለዱ ሕፃናት አያያዝ እና እንክብካበ በተመለከተ የእርስዎ አስተያየት ምንድን ነው?

ጥልቅ ጥያቄ

I. ጊዜያቸዉ ሳይደርስ ለተወለዱ ህጻናት የሙቀት እንክብካቤ አስፈላጊ ነው ብለው ያስባሉ? መልስዎ አዎ ከሆነ፣በእንክብካቤዎ ውስጥ ልጅዎ ጥሩ የሰውነት ሙቀት እንዲረው እንዴት ማረጋገጥ ይችላሉ?

II. ያለጊዜው ለተወለደዉ ሕፃን ልጅዎ ስለ አመጋገብ ልምምድ ምን ግምት ውስጥ ያስገባሉ?

III ያለጊዜው የተወለደዉን ልጅዎን ንጽህናን ለመጠበቅ እና ከበሽታ ለመከላከል ምን እርምጃዎችን ይወስዳሉ?

3 ልጅዎ ያለጊዜዉ ሲወለድ እና ወደ NICU ሲገባ የተሰማዎትን ስሜት መግለጽ ይችላሉ?

ጥልቅ ጥያቄ

I. ልጅዎ በ NICU ውስጥ ሲታከም ምን አይነት ስሜቶች ተሰምተዉታል?

II. ልጅዎ NICU በመግባቱ ምክንያት ከልጅዎ መለየትዎ ምን ተሰማዎት?

4 በእርስዎ እና በ NICU ዉስጥ በምሰሩ የጠና ባለሚያዎች መካከል ስላለው ግንኙነት ወይም ቅርበት ምን ይሰማዎታል?

ጥልቅ ጥያቄ

I. ለልጅዎ እየተሰጠ ያለውን የህክምና እንክብካቤ እና ወቅታዊ መረጃ ወይም ልጅዎ ያለበትን ሁንታ ለመረዳት ምን አይነት ችግር አጋጥሞዎታል?

5 በዚህ ጊዜ ውስጥ ለእርስዎ ምን ዓይነት ስሜታዊ ወይም ማህበራዊ ድጋፍ ያስፈልገኛል ብለዉ ያስባሉ? (ለምሳሌ፡ የቤተሰብ፣ የጓደኞች፣ የሆስፒታል ድጋፍ ቡድኖች)

6 የ NICU አካባቢን እንዴት ይገልጹታል? (ከ NICU አካባቢ ጋር በተያያዘ ችግሮች አጋጥመውዎታል?) የ NICU ቅንብር ምቾትዎን እና በልጅዎ ላይ የማተኮር ችሎታዎን እንዴት ነክቶታል?

7 ለልጅዎ ከህክምና ቁሳቁሶች እና ከላብራቶሪ ምርመራ አገልግሎቶች ጋር የተያያዙ ችግሮች አጋጥመውዎታል? መልስዎ አዎ ከሆነ ምን አጋጠመዎት?

8 እንደ እናት ከ NICU ቆይታሽ አንፃር በጣም ፈታኝ የሆነብሽ ነገር ምንድን ነው? እና ያለግዜያቸዉ ለተወለዱ ህፃናት የ NICU እንክብካቤን በተመለከተ ምን ምን ነገሮች መሻሻል አለባቸው ብለዉ ያስባሉ?

ለተሳትፎዎ በጣም እናመሰግናልን !!!