

Lived Experience of Mothers Having Preterm Newborns in a Neonatal Intensive Care Unit at Wolaita Sodo University Comprehensive Specialized Hospital Southern Ethiopia: A Phenomenological Study

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Background: Following hospitalization of a preterm infant, mothers experience unexpected and stressful events. In Ethiopia, specifically in the study area, the experiences of mothers with preterm babies, the difficulties they face during their hospital stay, as well as the types of support available to help them deal with the difficulties have not been thoroughly investigated.

Objective: To explore the lived experiences of mothers having preterm newborns in a Neonatal Intensive Care Unit at Wolaita Sodo University Comprehensive Specialized Hospital (WSUCSH), Wolaita Sodo, Southern Ethiopia.

Methods and materials: A qualitative design with phenomenological approach was used. Twelve mothers were selected purposively to explore their lived experiences. Data were collected using in-depth interviews and field notes from Apr 27-Jun 3, 2022. The interview transcripts were analyzed using inductive thematic analysis following Colaizzi's 7 steps approach. Data were coded by using Open Code Software Version 4.02.

Results: Four themes were identified, namely: mothers' emotional experience, care and support to cope with the situation, difficulties encountered during NICU stay and sense of difference. Shock, fear, worry, and anxiety were mothers' major negative emotional experiences. They complained about the lack of medicine and laboratory tests at the hospital and issues with some facilities, such as a lack of space for showering, overcrowded rooms, being in multi-bed rooms, and an inconvenient toilet. Despite difficulties in communication, they appreciated the care and support of health professionals.

Conclusion and recommendation: Mothers with preterm babies in the NICU experienced both negative and positive emotions. The unavailability of medicine, inadequate hospital facilities and the negative experience with some HCPs affected mothers' stay. Hence, HCPs' effective communication and understanding of mothers situations to better reflect their needs and the hospital's paying close attention to the difficulties of resource constraints was recommended.

Keywords: mothers' experiences, newborn, neonatal intensive care unit, phenomenology, Ethiopia

Introduction

Preterm birth is defined as a baby born before 37 full weeks of pregnancy. According to the WHO report, estimated 15 million babies are born prematurely worldwide, and the rate of preterm birth is rising year after year. The more significant share of this preterm birth was attributed to Sub-Saharan Africa and South Asia, which accounts for more than

60% of the cases worldwide¹ {, #46;, #46}. In Ethiopia, Premature births account for approximately 10.48% of all births.²

Admission of premature new-borns to a hospital's NICU for stabilization purposes is expected. Following the preterm new-born's admission, for various reasons, including infection, noise, and privacy, the mother is kept from visiting the NICU, preventing her from getting closer to her newborns.^{3,4}

Mothers of premature babies experience an unexpected and stressful event when their babies are admitted to a hospital's NICU for nursing care, mainly due to interruption of contact between the mother-newborn following the birth of a preterm baby.⁵

Worldwide initiatives such as kangaroo mother care,⁶ the Baby-Friendly Hospital Initiative,⁷ and the Humane Neonatal Care Initiative⁸ aim to reduce mother-child separation, promote infant wellbeing, and improve maternal coping abilities. This relieves the mother's anxiety and also promotes confidence in the healthcare team.^{9,10}

Mothers who give birth to a baby who needs to be admitted to a NICU have a unique and often terrifying birth experience, and this experience impacts the mental health of the mother.¹¹ Premature birth can have a detrimental effect on a mother's ability to cope, which can alter how she takes care of the infant, resulting in the child's poor growth and development or even death.¹² Despite the overwhelming support received from their families, friends and professional appropriate care and support, which is crucial in helping them cope with the emotional challenges, the available professional support, such as counselling, support group, and professional support, was inadequate. If proper aid is not provided, it might have a lasting impact on mother-child attachment.¹³ Understanding the experience of mothers with preterm babies is essential to plan effective care and support for them.¹⁴

Mothers experience post-NICU psychological trauma for months or years after the new-borns' NICU stay, and it can have a long-term effect on the functioning of mothers of premature babies.¹⁵ And also has an impact on the normal attachment process; adequate bonding is the foundation for healthy mother-child relationships, which is also the basis for premature babies.¹⁶

Researchers' findings show that in the current system, taking care of hospitalized preterm infants is mainly focused on the infant, but caring for the parents of these infants, especially mothers who are encountered with a variety of stressors, is often overlooked and sometimes ignored. In addition, despite research in other countries on this topic, various studies report differences in the socio-cultural environment, hospital setting, access to health services, parent-healthcare provider interaction, and family involvement in the care of their newborn.^{4,17-19} Furthermore, in Ethiopia, specifically in the study area, the experiences of mothers with preterm babies, the difficulties they face during their hospital stay and the types of support available to help them deal with the difficulties have not been thoroughly investigated. To bridge the literature and neglect gap (the current weaknesses in taking care of mothers with preterm newborns in the NICU) a research is needed. Therefore, this research was aimed to explore the lived experiences of mothers having preterm newborns in a Neonatal Intensive Care Unit at Wolaita Sodo University Comprehensive Specialized Hospital, Wolaita Sodo, Southern Ethiopia.

Methods and Materials

Study Context and Period

This research was conducted at Wolaita Sodo University Comprehensive Specialized Hospital. It is found in Wolaita Sodo town, Wolaita zone, South Nation Nationalities People Region (SNNPR), Ethiopia. Wolaita Sodo town is the capital city of the Wolaita zone and is located 330 km southwest of Addis Ababa, the capital city of Ethiopia. The Obstetrics and Gynecology department is one of the seven departments and has six wards. Eight Gynecologists, 12 Medical doctors, 72 Midwives, and 31 Nurses are currently working in the department. Antenatal care, postnatal care, delivery, family planning, EPI, comprehensive abortion care, gynecological surgeries and procedures, post anaesthesia care unit, gynecology OPD, cervical cancer screening, and NICU service are among the services provided by the obstetrics and gynecology departments. The NICU is a ward in the Obstetrics and Gynecology department. There were 7 physicians and 20 nurses working in the NICU. The 2021 report of WSUCSH showed that about 8520 mothers gave birth at the hospital, and 1123 neonates were admitted to the NICU. The research was conducted from April 27-June 3, 2022.

Study Design and Approach

The constructive philosophy of science was adhered to because; it is based on observation and scientific study. It says that people construct their own understanding of the world through their experience and reflection.

A phenomenological qualitative descriptive approach was used to gain an in-depth understanding of mothers' lived experiences of having a preterm newborn admitted to the NICU. This method describes the common ordinary meaning of people's everyday experiences of a phenomenon.²⁰

Participants' Selection (Recruitment)

Mothers whose preterm newborns were admitted to the NICU at WSUCSH for at least one week (a hospitalization stay of more than one week was deemed adequate and it is easier for mothers to share their NICU experiences).^{12,21} Before recruiting study participants, we reviewed all of the newborns' clinical situations on their profiles with the assistance of NICU staff to select appropriate mothers for the in-depth interview. Those mothers with early-born premature infants who were willing to participate and provide detailed information about their experience to answer the research question were purposively included. After selecting the participants, we scheduled a convenient time for the mothers to share their experiences.

Eligibility Criteria

Mothers who gave birth before the 37th gestational week and whose babies were hospitalized in the NICU for at least one week were included in the study whereas, mothers who had a history of mental illness (because of their condition, their ability to comprehend and make an informed decision to provide information about the phenomenon and provide consent remains controversial)²² were excluded from the study.

Sampling

Purposive sampling was used to recruit 12 mothers willing to share rich information about their experiences with premature newborns admitted to the NICU for in-depth interviews. A homogeneous purposive sampling technique was used to recruit mothers with preterm newborns.

Data Collection Methods, Tools and Procedures

Interviews were conducted by using a semi-structured interview guide with open-ended questions to allow participants to describe their experiences having a preterm newborn, from the birth of the preterm baby through admission to the NICU. Probing questions like (tell me more about that. Would you elaborate more on it? I do not hear you. Would you repeat it? What do you mean when you say.? And so forth) were asked according to the mothers' responses for clarity and in-depth understanding of the phenomenon under investigation. The interview guide was written in English and translated into Amharic and Wolaitigna to conduct the interview. The interview was conducted both in Amharic and Wolaitigna. After two days of training on qualitative research methods and the research to be done, one second-year master's student interviewed the mothers together with the main PI. LAN audio tape recorder and a field note were used to conduct the interview. Data were collected until data saturation occurred. We stopped interviewing 12 mothers because we did not get any new information from the respondents, which indicated the saturation of the ideas. The effort was made to ensure bracketing throughout the research. Each participant's interview lasted between 30 and 40 minutes.

Data Analysis

Data collection was carried out simultaneously with the analysis. The participants' audio-recorded interviews and all expletives, behaviours, and actions, such as laughter or crying, were transcribed to be immersed in the data and translated verbatim into English by the PI. The transcription interviews were coded using Open Code Software Version 4.02. The interview transcripts were analyzed by using inductive thematic analysis following Colaizzi's descriptive phenomenological framework analysis method;²³ Step 1: Familiarization, step 2: Identifying Significant Statements, Step 3: Formulating meanings, step 4: Clustering theme, step 5: Developing an Exhaustive Description, step 6: Producing the

fundamental structure of the phenomenon, and step 7: Seeking verification of the fundamental structure. Finally, data analysis has resulted in comprehensive descriptive summaries that accurately reflect the meaning participants attributed to their lived experiences.

Trustworthiness

Guba's trustworthiness criteria were applied to ensure the study's rigour, focusing on the study's credibility, transferability, dependability, and confirmability. To ensure Credibility Prolonged engagement was done; first by establishing a good rapport and building trust with the participants, we recruited them in order to elicit information about the phenomena under scrutiny. A semi-structured interview was guided by an interview question and persistent observation to obtain in-depth data. Peer debriefing was done with a similar status colleague during data analysis to confirm findings by other peers by presenting the study findings to them and receiving their comments to improve its quality. Some of the available study participants were invited to review the findings by reading the transcripts if they correctly represented their views and ideas. Additionally, a negative case analysis was carried out, in which we deliberately looked for data both in the already-existing data and in the planned data collection that do not support the working hypothesis. To enhance the study's transferability, the research design, data collection, and analysis processes were clearly outlined, and we provided a thick description in which we described the study context in sufficient detail to allow judgment about transferability to be made by the reader. To ensure dependability of the study, after listening to the audio recordings of the interviews, both verbal and non-verbal data were recorded and the transcribed verbatim was saved properly to cross check the whole process of the study and maintain the consistency of the interpretation. And also, to enable readers of the research report to develop a thorough understanding of the methods and their effectiveness, the text included section devoted to the research design and its implementation, describing what was planned and executed on a strategic level.

To minimize our preconceived personal bias, the whole process of the research, data collection, data analysis, and reporting of the findings were done clearly using scientific procedures.

To assure bracketing, a literature review was conducted after data collection and analysis in order to avoid leading the participants to what had already been discovered about the phenomena. We also kept a reflexive diary by examining our consciousness and thoughts and prompting ourselves to write down our assumptions, opinions, and ideas about the phenomenon under investigation. An audit trial was also carried out by senior supervisors.

Result

Sociodemographic Characteristics of the Participants

In this study, twelve mothers whose preterm newborns were admitted to the NICU took part in an in-depth interview. The ages of the mothers ranged from 18 to 30 years. Regarding educational status, 4 mothers completed primary school, 4 completed secondary, 3 were diploma holders, and the remaining 1 had a BSc degree. All mothers were married and protestant religion followers; 6 were housewives, 5 were employed, and 1 were a student. Seven of the mothers were from urban areas while the other 5 were from rural areas. Among the participants, nine were given birth through SVD and seven were primiparous. The gestational age of the newborn at birth ranges between 31 and 34 weeks. The time spent in the NICU during the interview was between 14 and 26 days. For further details, (Table 1).

Mothers' Experiences of NICU

In this study, 81 codes, 9 subthemes, and, in the end, 4 themes were identified regarding the lived experience of mothers with preterm newborns admitted to the NICU. The themes extracted were: Mothers' emotional experience, sense of difference, care and support to cope with the situation, and difficulties encountered during the NICU stay. The themes and subthemes are shown as follows (Table 2).

Theme I: Mothers' Emotional Experience

Mothers go through many negative and positive emotional experiences when their newborns enter the neonatal intensive care unit for care and support. Mothers' emotional experiences are organized around three subthemes: fear, anxiety,

Table 1 Socio-Demographic Characteristics of the Participants and Preterm Infants in Wolaita Sodo University Comprehensive Specialized Hospital, Southern Ethiopia, 2022 (n=12)

Participant ID	Age	Educational Status	Ethnicity	Occupation	Residence	Parity	Mode of Delivery	Type of Pregnancy	Newborn Age at Birth (Weeks)	Time Spent in the NICU During Interview (Days)
IDIP01	23	Diploma	Wolaita	Employed	Urban	Multipara	SVD	Singleton	32 wks	15 days
IDIP02	24	Secondary school	Wolaita	Housewife	Rural	Primi	SVD	Twin	31 wks	17 days
IDIP03	26	Diploma	Wolaita	Employed	Urban	Primi	SVD	Singleton	34 wks	14 days
IDIP04	22	Secondary school	Wolaita	Employed	Urban	Primi	SVD	Singleton	32 wks	18 days
IDIP05	20	Secondary school	Wolaita	Housewife	Rural	Primi	C/s	Twin	33 wks	16 days
IDIP06	25	Diploma	Wolaita	Employed	Urban	Primi	C/s	Twin	31–33 wks	16 days
IDIP07	18	Grade 12th student	Wolaita	Student	Urban	Multipara	SVD	Singleton	33 wks	14 days
IDIP08	22	Primary school	Sidama	Housewife	Urban	Primi	C/s	Singleton	32 wks	26 days
IDIP09	24	Primary school	Wolaita	Housewife	Rural	Multi	SVD	Twin	32 wks	18 days
IDIP10	28	Degree	Wolaita	Employed	Urban	Multi	SVD	Twin	31 wks	15 days
IDIP11	30	Primary school	Wolaita	Housewife	Rural	Multi	SVD	Singleton	33 wks	15 days
IDIP12	25	Primary school	Wolaita	Housewife	Rural	Primi	SVD	Singleton	31 wks	16 days

Table 2 Presentation of the Themes and Sub-Themes of Mothers' Experience with Preterm Babies in the NICU at WSUCSH, Southern Ethiopia, 2022

Themes	Sub-Themes
Mothers' emotional experience	Feelings of shock, fear, anxiety, and worry Being between hope and despair Feelings of happiness on baby's health improvement and faith in supreme power (God)
Sense of difference	Newborn's appearance Altered breast feeding role and separation from their infant
Care and support to cope with the situation	Care and support from the HCPs and Hospital Family care Support and hope
Difficulties encountered during the NICU stay	Stressful NICU environment Unavailability of medicine and inadequate facilities

shock, and worry; being between hope and despair, the feeling of happiness as their baby's health improves and faith in a supreme power (God).

Subtheme 1.1: Feelings of Shock, Fear, Anxiety, and Worry

The untimely delivery of a baby without the mother being prepared creates a variety of stress, and it is a challenging event for mothers. The main sources of stress were: the small physical size and fragile appearance of the baby; the

stressful NICU environment; the instruments used in the NICU to care for the baby, such as the oxygen machine, feeding tube, and incubator; the unreliability of improvement in the newborn's health condition, the money spent for the newborn's treatment, and her family suffering because of her. In this study, almost all mothers described that they were shocked and feared when their babies were born prematurely and were told the baby to be admitted to the NICU. They were rarely prepared for emotional stresses. Mothers shared that;

Since I had an operation at that time, I was unconscious at all. When I woke up after the operation, I lost the children next to me. I was shocked and asked my family, and they told me that they [babies] had been there (4).... I was shocked when they were born because it was my first time, and I thought they were missing something due to their premature birth. (P6, 25 years old mother)

Fear, worry, and anxiety were the mother's major negative emotional experiences during their hospital stay due to baby's NICU admission. Many mothers reported feeling worried and anxious when they saw their newborns in the NICU, breathing on oxygen machines and feeding by tube, and when their babies stopped breastfeeding. Mothers expressed their emotional experiences as;

I felt anxious when I saw them [twin babies] on oxygen; I was relieved to see them moving in the middle, but I was concerned about what would happen to the babies when I saw them breathing on oxygen. (P2, 24 years old mother)

Also, mothers expressed their perception that not being sure if their newborns would survive was another source of worry and distress. They feared that the baby would be born prematurely and not grow. They also thought and feared that the baby might not have survived or that they might not have found the baby again. This situation overwhelms mothers, and they experience grief. Mothers expressed;

I was shocked the first day. What if she was born prematurely and did not survive? What would I be like if I had suffered so much? I'm worried. When they took her to the heating room (4), I worried that she would not be saved. I was worried that this girl might not survive. Will this child survive or not? I was worried that the professionals would just trouble or save the baby. (P4, 22 years old mother)

Even when mothers saw their newborns' health improving, they became concerned and anxious about what other mothers were saying about the fate of the newborns once they were admitted to the NICU, as well as when they saw other mothers losing their babies and crying. This worsens their stress.

...But that is what everyone is talking about; I mean the patient or whatever he is referring to is frustrated. There are a lot of rumors from the patients that the baby is going to die and that he will not be able to get out of there once and for all. It is a problem. That is to say, our baby is there too (4) and we are sitting here, and what they are talking about is shocking. (P3, 26 years old mother)

The admission of a preterm baby to the neonatal intensive care unit is not only a phenomenon for mothers but is also for families. Their families were concerned and terrified about the mother and newborn situation. As a result, mothers become stressed more when seeing their families suffer because of them.

They [family] also felt bad and were very sad for me. They were so worried and said that after she carried the baby for this long and gave birth prematurely, it would hurt her if something went wrong with the baby. My first child was born like this, and he died nine months later; I was shocked at that, and they were scared that this would hurt her. They were terrified but did not want to hurt me, so they smiled at me. They were in anguish and sorrow, but when I saw their faces, they just smiled so as not to grieve me... he [her husband] left work for me; He is on leave. This situation worries me (P1, 23 years old mother)

Subtheme 1.2: Being Between Hope and Despair

Hope is another emotional experience expressed by mothers, whose emotions are ups and downs because of the fluctuating health condition of their babies, and they oscillate between hope and hopelessness. Mothers described that they became hopeful and confident when their babies' health improved, like when they started breastfeeding, and when

they were out of the machine and breathing independently. At the same time, they felt hopeless when their babies' health conditions worsened or the newborn's problems were deteriorating.

When I first saw him in that big machine, I had given up hope that he would not survive. What happened was a coincidence, not something we bring up; what has happened is that we take this misfortune and think about the future... He is getting better. At first, his breathing was not good, but now he is back to normal and I hope he (her baby) recovers now. (P3, 26 years old mother)

Subtheme 1.3: Feelings of Happiness on Baby's Health Improvement and Faith in Supreme Power (God)

Even though mothers experienced several negative emotions, they also felt positive ones, such as joy/happiness and thanksgiving to God when their newborns started breathing independently and breastfeeding. Moreover, mothers reported they were afraid at first, but when their babies got good care and as a result, they became happy when they saw their babies' health condition improving. They expressed their experience as;

I was thrilled to see him [the baby] get out of the machine and start breathing on his own. I convinced myself that he would never die again, so I had the baby come to me, and they brought him to me and told me to breastfeed. "I convinced myself that I am no longer sad" because he started properly breastfeeding and I accepted the baby. (P1, 23 years old mother)

...Now they have taken the babies out of the big oxygen machine and put them in the little one. I'm glad to see that. (P2, 24 years old mother)

Theme 2: Sense of Difference

Many mothers reported their experience of feeling of a sense of difference. Their sense of difference is in the newborn's appearance, altered breastfeeding role, and separation from their infant.

Subtheme 2.1: Newborn's Appearance

Some mothers described that they were shocked and scared when they first saw their baby and feared touching him/her due to his/her small physical size and strange appearance. Moreover, felt worried and frightened when they saw the tiny baby breathing on the oxygen machine. They thought the baby would not grow and become a human being due to its small physical appearance.

I was terrified when I first saw him; I didn't think he'd become a human being because he was my first child; I'd never seen a man's son like this. This has been a miracle for me. (P8, 22 years old mother)

Subtheme 2.2: Altered Breast Feeding Role and Separation from Their Infant

Breastfeeding encourages mothers to bond with their children. However, when their babies are born prematurely and admitted to the NICU, they only see them twice a day and do not contact them as often as needed. This has become a new situation for them, and being separated from their children reduces their breastfeeding role and relationship.

Mothers expressed their experience as;

...I said I would not go in and I would not give any milk to the baby. They [HCPs] brought the bottle here, and after the milk was milked, my husband took it and gave it to her [to the baby]... To this day, they [HCPs] are taking breast milk in bottles and giving it to the baby. I just took him [the baby] today, 15 days later. (P1, 23 years old mother)

Another mother described separation from her infant as:

I am a little worried when my family comes for a visit because I am embarrassed if they ask where the kids are when they are not with me. (P6, 25 years old mother)

Theme 3: Care and Support to Cope with the Situation

When mothers give birth prematurely and their babies are admitted to the NICU, they go through a variety of emotional experiences and challenges. To cope with these situations, they require care and support. In this study, mothers reported

receiving care and support from healthcare providers, the hospital, and their families. These made an impression on them, and they were pleased. The support they received is categorized into two subthemes: care, support from the HCPs and hospital, and family support and hope.

Subtheme 3.1: Care and Support from the HCPs and Hospital

Healthcare providers are the primary source of support and care for mothers. The mother stated that healthcare providers are very supportive; they care for the babies very well. They also provide appropriate informational and emotional support and guidance on how to milk the breasts using a breast pump and feed them using a bottle. Their overall support and care during their stay in the hospital play a vital role in strengthening their relationship with the and making them have a positive attitude towards them. Moreover, trust them, and their encouragement boosts their hope of getting their baby healthy and developing good experiences.

Mothers expressed their experience with HCPs as;

They [HCPs] are very supportive. My children could not have survived that day without them next to God. I came here with weary children. When I came here, their life was returned [babies' health]. Without them [health professionals], their health might not have returned. They do their own thing. There are very good doctors. (P10, 28 years old mother)

However, this mother also pointed out that sometimes HCPs had negative interactions with them and sometimes there were difficulties in communication that made them stress.

...There was something wrong with the professionals. As soon as I gave birth, I mean, my children were born with three days left for eight months. I gave birth at about six o'clock in the afternoon; then they had [the babies] to enter the heating room (4), but they didn't. When they [babies] were tired at three o'clock in the evening, I shouted, "Take them" [the babies], and they took me back at ten o'clock. They gave me a piece of paper saying you can go in the morning. When I got home, they were tired. They were born one month early; this type of person should be kept in the heating room (4). They said it is not what you say. ... The doctors use bad words on people; I really feel like they put a lot of pressure on people, I cried. (P10, 28 years old mother)

Subtheme 3.2: Family Support and Hope

To overcome distressing events for mothers, family members supported them when their babies were admitted into the NICU. Family support greatly aids a mother's ability to cope with the circumstances. They visited them regularly, shared their feelings, and comforted, and encouraged them by giving hope and praying to God. Mothers expressed their families' support

They [her family] are constantly calling and asking me how the baby is doing. My husband does not want to offend me either; he is doing what he can, even though he is sad. At home, there is a five-year-old boy; he [her husband] is taking care of both of us while he is with me and with him. (P1, 23 years old mother)

Theme 4: Difficulties Encountered During the NICU Stay

Mothers whose newborns were admitted into the hospital NICU due to prematurity faced various difficulties. They reported many problems during their stay in the hospital. They also said that these problems exacerbated all the negative emotional feelings, such as anxiety and worry, as well as other uncomfortable situations that had already happened due to the baby's being born prematurely. The major difficulties that emerged as the subtheme were the stressful NICU environment, unavailability of medicine and inadequate facilities.

Subtheme 4.1: Stressful NICU Environment

During their hospital stay, the NICU environment was stressful for mothers. The mothers were concerned about the overcrowded NICU room, noise, the overwhelming heat caused by the room's crowdedness, midges caused by the heat, and the mothers' inappropriate use of the toilet. In particular, the overcrowded NICU room was the major concern of the mothers. Because of the overcrowding and suffocating conditions of the room, mothers reported the baby's weight had

decreased and feared that it might cause another illness for their babies and that this would make them stay longer in the hospital. Mothers shared their NICU environment experience as:

Sometimes, when there are too many people in this room, the baby becomes overwhelmed; you know, he vomits. In this room, only one person is allowed to visit, but when there are four or five people sitting there, the room is crowded and the baby is overwhelmed, and at that time I go and tell the doctors because they [visitors] do not hear me. When the doctors come and get them out, the baby feels fine. I am happy when people go out, and I get anxious when there are too many people. When too many people are here, the baby loses weight and his breathing is not normal. There were so many people yesterday that I cried all day long because the doctor said that this child would die because of man. Therefore this is being done today [oxygen]. And I am overwhelmed by this. If they [HCPs] can, I would like to have a room for myself... due to overcrowding; our days here are getting longer as the baby loses weight. (P8, 22 years old mother)

As another mother described the stressful situation of the NICU environment, many mothers slept in one room and disturbed each other, so they could not sleep. This condition is stressful for them. And they expressed as:

...there are so many people in one room because the breath of other adults is difficult for them [newborns]. It would be nice if they could reduce the number of beds and people and put the newborns to bed far away, and also, it is good that they do not let anyone else enter. The other thing is that, because of the heat, midges are a nuisance here. When a person sleeps tired, they [Midges] bite and sting unintentionally. You take care of these so that they do not cause another illness and that the services and care they provide for children continue. (P1, 23 years old mother)

Subtheme 4.2: Unavailability of Medicine and Inadequate Facilities

Although some support was provided by the hospital, all mothers reported a lack of medicine and laboratory tests at the hospital, as well as issues with some facilities such as a lack of space for showering, space for cooking their food, being in multi-bed rooms, and an inconvenient toilet. Due to a lack of medicine and laboratory tests for the baby's care, they are forced to purchase medicine from a private pharmacy and laboratory tests from a private clinic at a high cost. This situation overwhelmed them and put their economic potential at risk.

Support is definitely missing. Previously, mothers were treated at the hospital for free. However, we no longer have all of this; we no longer receive gloves, medicine, or anything else from the inside; everything is purchased from the outside. In the past, after a person gave birth, he was treated free of charge and went home safe and cured, but now he spends a lot of money. (P10, 28 years old mother)

In addition, other mothers described their experience with the hospital's shortage of medicine and supplies needed for the baby's care in the following way.

It is just professional help here, nothing else. Including gloves, you bought everything from outside (private pharmacy). This is another problem....look, there is medicine that they send us to buy from outside (private pharmacy), and there are other things, so it would be nice if we could get it here, at least with the extra money. For example, they send us out at night to come make laboratory results. How do we get out tonight? It's scary. (P3, 26 years old mother)

Another source of stress for mothers was that their families did not have a place to rest when they came to visit, especially at night. This experience led the mother to worry about their family, and they felt guilty that this troubling situation in her family was because of her and thought they were responsible for the circumstance.

When my family and husband come, they spend the night outside because there is no room for them here. That creates another anxiety. I sleep here, and think something will happen when they spend the night there; you are worried (P6, 25 years old mother)

Discussion

This study was aimed to explore the lived experience of mothers having preterm newborns in the NICU. Mothers narrated all their life experiences of having premature newborns in the NICU, from admission through their stay in the hospital.

In this study, mothers described they were shocked and feared when their babies were born prematurely and were told that the baby would be admitted to the neonatal intensive care unit. They stated worry, anxiety, and sorry when they saw their newborns in the NICU and breathing on oxygen machines and feeding by tube, and they were also worried when their babies stopped breast-feeding. This study is consistent with a study conducted in Rwanda in which parents reported experiencing negative emotional feelings like fear and anxiety when they were told that their newborn needed admission to the NICU and as a result of the look at the different tubes and wires attached to the newborns inside the incubators and the sound of the equipment.

In addition, mothers' stated they were scared that the baby would be born prematurely and would not grow. This supports other findings in Tribhuvan University in Nepal, which found that mothers' anxiety was related to their perception of their newborns' serious condition and uncertainty about their survival.¹² In Rwanda, mothers were stressed by thinking that their babies would not survive.²⁴ Moreover, the finding is in line with a study conducted in Botswana that reported it was difficult for the participants to believe that the tiny, frail and vulnerable Infant would survive, making investing in the new relationship even more challenging.²⁵

The study's findings showed that mothers felt torn between hope and hopelessness. They became hopeful, confident, and happy when they saw their babies getting good care and hope from HCPs and their health conditions improved; they started breastfeeding; and were out of the machine and started breathing on their own. Whereas they felt hopeless when their babies' health conditions were worsening or the newborn's problems were deteriorating. This finding supports previous studies conducted in, South Africa,²⁶ Iran,¹⁴ Tribhuvan University in Nepal,¹² and Jordan.¹⁶ This implies that the mothers are very worried and stressed due to the perception of being not sure that the baby would survive.

Moreover, when their babies are born prematurely and admitted to the NICU, they only saw them twice a day and did not get in touch with them as often as needed. This has become a new situation for them, and being separated from their children reduces their breastfeeding role and relationship. This finding aligns with previous literature where mothers disliked the maternal baby unit policy of only allowing them to visit their newborns at set hours. This regulation prevented them from having access to their babies whenever they wished, resulting in a sense of separation and loss of control, which could harm the wellbeing of mothers.^{12,16,27} However, in contrast to these literatures, in this study, even if mothers were given limited time to visit their babies, none of them complained. The difference might be that mothers trusted the healthcare providers more in this study, or they might have chosen to remain silent for fear of the NICU regulations. Mothers should be allowed to have frequent visits with their babies in order to increase their relationship with them, and that will contribute to their hope of survival of their babies.

In this study, mothers expressed healthcare providers are their major source of support and care. They also provide appropriate informational and emotional support, breastfeeding support, and guidance on how to milk the breasts using a breast pump and how to feed them using a bottle. This finding is in line with other studies where mothers considered nurses as their major support source and felt more secure when they saw competent and affectionate care for their newborns provided by health workers. Moreover, the nurses support the family by reassuring them that they would be updated with any changes in the infant's condition and strengthening maternal responses to their infants.^{12,14,21,26,28} This suggests that the care and support provided by HCPs to mothers would be beneficial in allowing mothers to discuss their shared experience. So that HCP support should be encouraged and maintained.

Earlier studies conducted in Bahirdar in Ethiopia, Ghana, South Africa, Botswana and Jordan reported that although the healthcare providers were supportive and appreciative of their support, some mothers perceived that some of the nurses were unfriendly, and they expressed having had bad experiences with NICU staff where the nurses lacked discipline, commitment, interest, and were not cooperative to support them, which increased mothers' anxiety and frustration.^{11,16,25,29,30} This implies that there is a gap which should be taking into consideration that the HCPs should communicate effectively to understand their situation.

Similar to the literature, one mother reported a mix of healthcare provider attitudes in this study. Even if there were good and supportive doctors, there were times when communication was difficult and they used bad words towards them, which was another source of stress. This implies that the situation is having a negative impact on the mother. HCPs that have disciplinary issues should improve their unfriendly attitude and communicate effectively with mothers in order to discuss their concerns and help them cope with unexpected events.

Family members provided social and psychological support from pregnancy through childbirth; visited them regularly; phoned them; shared their feelings; comforted and encouraged them by praying to God, enabling them to cope with the stressful situation. This finding is consistent with the findings of other similar studies in which mothers mentioned that they received support from their family and relatives. This reduced the participants' isolation and enabled them to focus on the infant's care.^{25,30,31} This implies that the continuous support they received helped them to go through the unexpected event of hospitalization due to preterm delivery.

Our study found that mothers faced many difficulties during their hospital. One of the difficulties mentioned by mothers was that while the hospital provided some support, all mothers reported a lack of medicine and laboratory tests at the hospital, as well as issues with some facilities, such as a lack of space for showering, space for cooking their own food, being in multi-bed rooms, an inconvenient toilet, and a lack of space for families to rest when they came to visit, especially at night. Due to a lack of medicine and laboratory tests for the baby's care, they are forced to purchase medicine from a private pharmacy and laboratory tests from a private clinic at a high cost. This situation overwhelmed them and put their economic potential at risk. Previous research in Bahidar in Ethiopia, Ghana, and Tehran discovered a lack of adequate facilities and equipment used for the care of preterm newborns in the NICU, such as medicines being unavailable; a lack of water for toilets and hygiene; a lack of a bathroom to take a shower; a lack of space to take rest; and a lack of time to visit their neonates. And also, they were concerned and worried about the financial aspect of care in the NICU.^{11,24,29,32,33} This might be because mothers spend a long time in the hospital and often do not get medicine and other laboratory tests in the hospital, instead purchasing them from private pharmacies and clinics. If the medication issue is resolved, mothers will be relieved of the financial burden of medication costs.

Our study further identified that mothers stated the NICU environment was stressful for them, which is another challenge they faced. The mothers were concerned about the overcrowded NICU room, noisy environment, the overwhelming heat caused by the room's crowdedness, midges caused by the heat, and the mothers' inappropriate use of the toilet. In particular, the overcrowded NICU room was the major concern of the mothers. Because of the suffocating room due to overcrowding, mothers feared that it might cause another illness for their babies and that this would make them stay longer in the hospital. Similarly, previous studies reported that mothers were dissatisfied with the inadequate accommodation of the room and reported problems with hygiene and cleanliness of the ward, lack of proper ventilation, lack of bathrooms for mothers, lack of comfortable chairs, and poor quality of the hospital food.^{10,11,29,32} This implies that there is a need to improve accommodation of NICU room so as to reduce the stress of mothers and their families. Mothers wished all these problems to be fixed and wished to have a private room.

Strength of the Study

As far as we know, this study is the first to examine the mother's viewpoint on her lived experience of having preterm newborns in NICU in Ethiopia and our study area.

Limitation of the Study

Despite the study's strengths, this research has its limitations. Even if every effort was made to improve the study's transferability, there is still inherent researcher bias in the study, which must be considered when transferring the current study's results.

Even though data were collected until saturation and some of the participants were contacted to validate their interpretations of the phenomenon, the interpretation of the lived experience is not entirely free of the researchers' interpretation because complete bracketing is never possible.

Conclusion

The findings from this study confirm that the experiences of mothers whose preterm newborns were hospitalized in the NICU were diverse and complex. The untimely delivery of a baby without preparation and an unknown NICU environment due to the admission of the newborn to the NICU a potential implication of negative and positive emotional experiences. Care and support provided by healthcare providers and hospital has a significant positive impact on mother-child bonding and empower mothers. Also to better understand the needs of mothers and their families and lessen their worries and stresses, HCPs working in the NICU should communicate effectively. To minimize the stressful experience of hospitalization, every effort should be made to address resource-constrained issues like medical issues, multiple beds in one room that cause overcrowding, hygienic facilities in the room, and a place for the family to sleep at night. The hospital should pay close attention to the lack of medications and laboratory tests because, as mothers frequently mentioned, they and their families were burdened financially by paying for medications and laboratory tests from a private health facility.

Abbreviations

C/s, Cesarean section; HCPs, Healthcare Providers; IDIP, In-Depth Interview Participant; NICU, Neonatal Intensive Care Unit; PI, Principal Investigator; SVD, Spontaneous Vaginal Delivery; WSUCSH, Wolaita Sodo University Comprehensive Specialized Hospital.

Data Sharing Statement

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Approval and Consent to Participate

We obtained ethical clearance for the study from the Institutional Review Board (IRB) of Wolaita Sodo University, College of Health Science and Medicine, and School of Public Health prior to the commencement of the study with approval number CRCSD 86/02/14. In addition, an institutional approval letter was also obtained from Wolaita Sodo University Comprehensive Specialized Hospital to conduct the study. After the reason for conducting the study was explained before each individual interview, written informed consent was obtained from the mothers for their participation and to record their views. The information shared on was kept private and anonymous. The interview was conducted in a quiet area near to the NICU room during the most convenient time for the mothers. All study participants were informed that their participation was entirely voluntary and that they had the option to leave the interview whenever they felt uncomfortable. Above all, this study was entirely conducted as per the Declaration of Helsinki ethical principles for medical research on human subjects.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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