

Parental Experiences in Neonatal Intensive Care Unit at Felege Hiwot Comprehensive Specialized Hospital, Bahir Dar, Ethiopia: A Phenomenological Study

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Abstract

Background: Neonatal intensive care settings are important to save the lives of sick neonates; however, parents are challenged by many stressful conditions during their stay outside the rooms of intensive care units. Therefore, this study aimed to explore the lived experiences of parents in a neonatal intensive care unit at Felege Hiwot Comprehensive Specialized Hospital, Bahir Dar, Northwest Ethiopia.

Methods: In this study, a phenomenological qualitative approach was used to explore parental experience and data were collected using in-depth interviews from purposively selected parents. In addition, a thematic approach was used to analyze the data using Open Code Software Version 4.02.

Results: In this study, parents found to developed psychological problems like anxiety, stress, worry, hopelessness and state of confusion. Emotional related conditions were anger, crying, sadness, frustration, dissatisfaction, regret, disappointment, feeling bad, self-blaming, nervousness, disturbance and lack of self-control. Parents expressed that health care providers showed indiscipline, lack of commitment and not cooperative at all.

Conclusion: Parents of neonates in the intensive care unit were challenged due to a shortage of money and traveling a long distance. Psychological and emotional factors were identified as major stressors of parents during their stay in the NICU. Hence, providing psycho-emotional supports, strengthening parents–healthcare providers' interaction, and scale up neonatal intensive care unit service into the primary health care unit are recommended.

Background

Parents experienced many challenges in the neonatal intensive care units (NICU) due to neonates' health status, inadequate information and lack of support from healthcare providers (HCPs) (1–4). They also suffered from socio-economic, psychological, emotional and physical health problems(5).

NICU parents experienced a number of stressful psycho-emotional conditions like anxiety, worries, shock, fear, dissatisfaction, anger and post-traumatic stress during admission and after discharge(2, 6–8). Undesirable feeling of HCPs towards parents also identified as stressful events for them (9). Additionally, parents explained that prematurity, low birth weight, severity of illness and poor prognosis of a child were common causes for stress. They were stressed when the HCPs told about worsened medical conditions such as irregular breathing patterns and attached medical devices to their baby (10–14). Other studies showed that poor parents-HCPs interaction (15–17), limited counseling and inconsistent information obtained from HCPs led to parental stress (4, 17–19). However, parents whose neonates admitted in the NICU had low level of stress and high level of support from HCPs (20).

Parents had main role in neonatal care in the NICU(8, 21) and need supportive measures to relief from stressful conditions(22, 23). They witnessed that HCPs tried a lot to save their severely ill neonates (24, 25) but, their support was minimal(13, 26). Understanding the emotion of parents is essential to improve neonatal health conditions (5, 22). This helps to design stress relieving measures like counseling, education and support (27).

Parents whose neonates subjected to severe medical problems experienced feeling of exclusion and lack of belongingness to the NICU (6, 8, 28, 29). Likewise, parents felt that the care provided in NICU is compromised due to HCPs' work overload, disease oriented nursing care, longer hospital stay, shortage of healthcare providers, lack of beds and medical equipment (30, 31). However, they had a sense of encouragement, empowerment and empathy when the HCPs felt their feelings(8, 32).

Although parental experience in the NICU was explored in different countries (2, 5, 32–34), there are variations in, accessibility of health facilities, parent-HCPs and parental involvement in the care due to socio-cultural differences, nurses' working culture and the hospital setting (35–38). And also, it is not well explored in Ethiopia. The information generated from this study is essential to the hospital to improve the services by facilitating NICU resources. In addition, it would help programmers to formulate strategies targeted the NICU and scale up the service to the periphery level. Therefore, the aim of this study was to explore the lived experiences of parents whose neonates were admitted into a NICU.

Materials And Methods

Study area and period

This study was conducted at Felege Hiwot Comprehensive Specialized Hospital (FHCSH), Bahir Dar, Northwest Ethiopia from August 1 to 15, 2020. The hospital was established in 1961 and currently provides service for about seven million people. The hospital has seven wards including the NICU. It also has 859 HCPs (133 physicians, 438 nurses and 56 midwives) specifically; six physicians and 31 nurses were working in the NICU and there were 75 beds with its supportive machines. The 2019 six months report of FHCSH showed that 1296 neonates were admitted in the NICU. The NICU ward were crowded and no space to take rest for family attendants and visitors, no waiting rooms and chairs, most visitors and attendants sat on patients' bed. In the neonatal side, more than six babies were admitted within one room and more than two babies were under one radiator warmer or phototherapy. In the maternal side, more than ten mothers per room were observed. The building lacks a special provision for disabled parents and the elevators were not functioning properly at the time of the study.

Study design

We used a phenomenological qualitative study design to explore the lived experience of parents when their neonates were admitted to NICU.

Sample and recruitment

A total of 18 parents (9 mothers and 9 fathers) whose neonates received healthcare in the NICU were included in the study. Parents were illegible to participate in the study regardless of mode of delivery and health status of the neonates. To recruit the NICU parents, first we registered details of different medical characteristics of admitted neonates such as low birth weight, prematurity, sepsis, perinatal asphyxia, meconium aspiration syndrome, respiratory distress syndrome, jaundice and twins. Based on the information obtained, parents were selected purposively.

Data collection method and tools

Data were collected by experienced experts using semi-structured interview guide and audio recorder in nurses' duty rooms. The research team prepared and reviewed in-depth interview (IDI) guide and translated into the local language Amharic. The English versions of the guiding questions have been included in the supplementary file (S1 File). Data collection was continued until adequate, complete and little new information came from the interviewees.

Trustworthiness

Trustworthiness was verified to address the dimension of credibility, transferability, dependability and conformability. The credibility of the study was ensured by having prolonged engagement in the field and persistent observation to obtain in-depth data the data. Transcribed and translated data were verified by inviting experienced researchers and by repeated engagement of authors in the transcription, translation and coding. Thick description of the data was done to increase transferability of the study. Data transcription; translation and interpretation were done using scientific procedures. Finally, conclusions were clearly drawn from the data.

Data analysis

The recorded interview was transcribed verbatim and translated into English language for the subsequent analysis. Consistency of the transcribed data was checked by listening and reading repeatedly. When there were variations in translation, discussions were made and results explained after the consensus reached. Data coding was done sentence by sentence to create themes that have similar ideas. Thematic analysis was used to describe the data obtained from interviews. Open Code Software Version 4.02 was used to analyze the data.

Results

Socio-demographic characteristics

In this study, 18 parents of neonates admitted to NICU were interviewed. All of parents were Orthodox Christian while 17 of them were married and eight parents were farmers. Seven parents had secondary and above educational level and 12 parents were from rural area. Of the total parents, four of them were traveled more than 100 kilometers to arrive at FHCSH (Table 1).

Table 1
Socio-demographic characteristics of interviewed parents at
FHCSH, Bahir Dar, Ethiopia, 2020

Variables	Categories	Frequency
Mean(39) age(years)		30.6(± 7.3)
Age range(years)		20–41
Sex	Male	9
	Female	9
Educational status	Cannot read and write	5
	Can read and write	2
	Primary	4
	Secondary and above	7
Residence	Urban	6
	Rural	12
Marital status	Married	17
	Unmarried	1
Occupational status	House wife	4
	Farmer	8
	Government employee	3
	Priest	2
	Student	1
Distance in Km	< 15	4
	15–49	5
	50–100	5
	> 100	4

Description of parental experiences

Parents whose neonates admitted into the NICU were exhausted and bored due to prolonged stay and financially insecure to fulfill their daily living expenses. They could not access a space to take physical rest and shortage of water to keep their hygiene. Additionally, they were suffered from longer separation with their neonates due to limited visiting time that regulated by the hospital. They were uncomfortable with the care given to their neonates because they were restricted to engage the care of neonates. Regarding the health condition of the neonates, parents have a fear that their neonates might die. Parents also concerned with seasonal occasions that might compromised the care of their neonates as a result of the fear of COVID-19 transmission. At the same

time, parents who are farmers were emotionally unstable because they were come during farming season, due to this reason they were highly interested to return to their home.

Themes

In this study, six main themes were identified. These include socio-economic factors, health facility related factors, parents-healthcare providers' communication, maternal and child health related factors, psycho-emotional factors and current occasions (Table 2).

Table 2

Summary of Themes, sub-themes and codes of parental experiences in the NICU at FHCSH, Bahir Dar, Ethiopia, 2020

Themes	Theme-I	Theme-II	Theme-III	Theme-IV	Theme-V	Theme-VI
	Socio-economic factors	Psycho-emotional factors	Parents-Health care providers communication	Health facility related factors	Maternal and child health factors	Current occasions
Sub-themes	<ul style="list-style-type: none"> • Social factors • Economic factors 	<ul style="list-style-type: none"> • Psychological factors • Emotional factors 	<ul style="list-style-type: none"> • Communication • Parental involvement 	<ul style="list-style-type: none"> • Resource related • Health workers related factor 	<ul style="list-style-type: none"> • Maternal health condition • Child health condition 	<ul style="list-style-type: none"> • Seasonal factors • COVID-19
Codes	<ul style="list-style-type: none"> • Long distance • Shortage of money 	<ul style="list-style-type: none"> • Confusion • Hopeful • Hopelessness • Stress • Worries • Angry • Complain • Cry • Sadness • Disappointment • Dissatisfaction • Fear • Bad felling • Happiness • Self-control • Nervousness • Rerate • Self-blaming 	<ul style="list-style-type: none"> • Communication • Health information • HCPs cooperation • Commitment • HCPs Support 	<ul style="list-style-type: none"> • Absence of HCPs • Availability of foods • Comfortable with services • Eger to discharge • HCPs Delay • Unavailability of medicines • Lack of space • Lack of water • Limited visiting time • Long stay • No free bed for admission • Uncomfortable setting 	<ul style="list-style-type: none"> • Improvement child health • Poor suck reflex • Maternal illness 	<ul style="list-style-type: none"> • Fear of COVID-19 • Farming season

Theme I: Socio-economic factors

Health service delivery in the NICU was free of charges, however, some parents suffered from shortage of money during their stay. A 35 years old father described as:

Since I am not expecting that we will stay for several days, now I am running out of money. Hence, I faced problem in shortage of money". And also, another study participant said that "the ambulance and medicines are available by them [health facilities]. We have been here [NICU] since last week; as a result, we have finished our money. We are staying here by the support of health professionals.

According to this study, travelling long distance from home to health facilities affected parental experiences in NICU. The distance from home to health facilities which had NICU service ranges from 5 to 240 km. As a 23 years old mother explained as:

I feel a fluid [flow of amniotic fluid from the uterus] three days before my delivery. When I went to the nearby health center on next day, they [health care providers] told me that it [amniotic fluid] starts to clear the canal for delivery. However, they [HCP from health center] referred me on the third day to hospital and I delivered my baby at 12:00 Am in the hospital. After delivery, they take the neonate in to the NICU, because the neonate is weak due to staying in labor for several hours.

Theme II: Psycho-emotional factors

Psychological factors

In this study, majority of parents experienced anxiety, stress, worry, hopelessness and confusion. For instance, a 30 years old mother explained as:

I was coming to this health facility by referring from the health center. My babies [twins] are born at seven months [gestational age] and I have a little bit trouble. I am worrying if I will go to my home with loss of my babies.

Additionally, she added that

...my husband left me, and he does not call me. I am worried about what would happen to him. I also frustrated something may be wrong to my husband when he comes back to home. So, I feel hopelessness since I am not sure whether my husband arrives safely or happened something.

Another 25 years old mother explained her experience as: "...when I see my neonate assisted by machines [nasal cannula and other materials], I feel hopeless". And also, a 23 years old mother added as: "I am stressed. The only thing what I can do is giving everything to God to help us".

Similarly, a 35 years old teacher (father) described his experience as: "the presence of my neonate in NICU makes my social life more difficult. My families are too much confused. In addition, as the health status of my wife is not good, I am worried too much about her".

However, some parents are happy and hopeful when the health condition of their neonates has improved. A 40 years old farmer described as: "I am praying. As I expect, my neonate health status has improved from day to day and able to suck breast. I am really happy and hopeful"

Emotional factors

This study revealed that emotional factors like being angry, crying, sadness, frustration, dissatisfaction, happiness, regret, complain, disappointment, feeling bad, self-blaming, nervousness, disturbance and lack of self-control play great influence on the parental experiences in the NICU.

The majority of parents whose neonate health condition had gotten worsen expressed their extreme sadness, disappointed, bad feeling and angry. For instance, 30 years old mother described as: *"I was expressed in deep feeling, angry and sadness. Also I was disappointed, disturbed and crying a lot"*.

Furthermore, a 27 years old father had experienced that: *"... I was nervous and experienced lack of self-control, especially, when the health care providers told me that the neonate is seriously ill"*.

Besides, a 23 years old mother said: *"I feel sad and blame myself because I had to give my breast feed as soon as my baby was born. She also added: "... the current health condition of my neonate becomes deteriorated which makes me feeling bad. In general, it was frustrating and dissatisfaction moment for me"*.

Moreover, a 36 years old mother also described it as:

It is a difficult moment to me. I feel bad when I see my neonate is critically sick. But, other parents give me hope that the neonate's health status will be improved. To be honest, I did not expect the neonate would have such kind of health problem because of neonate's normal gestational age.

Theme III: Parents-Health care providers communication

Communication

In this study, parents-HCPs communication influenced parental experiences in NICU. Parents expressed that they have good communication with HCPs during their neonates stay in the NICU.

A 33 years old mother described her experience as:

When I need an information about the progress of my neonate health condition, I can talk directly with the HCPs. I am satisfied with the interaction that I had with them. The HCPs are good in providing health information.

In addition, a 26 years old parent said: *"I am very satisfied with the HCPs' communication and they are cooperative"*. A 40 years old priest parent also explained: *"the health team is very kind and cooperative. We have good communication with the health teams. ... like wisdom is given for King Solomon, I wish them, God may give long live and grow in their profession"*.

Parental involvement

This study indicated that parental involvement contributed to the improvement of critically sick neonates.

A 24 years old mother described as: *"I am keeping the medical equipment to prevent detachment from the neonate's body. Also, I have other roles like: breastfeeding, keeping the personal hygiene"*. On the other hand, a 40 years old father said: *"My role in the NICU is not beyond facilitating medicines and laboratory requests"*.

Theme IV: Health facility related factors

Resource related

This study showed that parents experienced unavailability of some medicines, shortage of water for toilet and hygiene, lack of spaces to take rest and limited time to visit their neonates.

Majority of the parents described that the time to visit their child was limited. According to their experience, they visited their neonates only as per the schedule of the hospital in the morning and evening; however, they wanted to visit frequently. A 40 years old father said:

I would be happy if I had a chance to visit my child three times a day. Here, I am not farming, I am not keeping cattle. It is good if they [healthcare providers] allow me to visit my child frequently as far as I am here to support them [the mother and the child].

Some parents have also complained that the service given to their neonates at health facilities was delayed. This delay might cause the neonates to develop birth asphyxia, meconium aspiration syndrome, and other birth related complications. For instance, a 27 years old father said:

We went to the health center at evening and stayed there up to midnight. Then, the night duty midwife goes and other provider handover my wife. While the fluid flows from the uterus [premature membrane ruptured], but no sign of labor seen for several hours. She was only shouted [ehe, ehe, ehe...] without down ward pushing. In the next day, early in the morning, something is happened either the fetus is breathlessness or sucking amniotic fluid. Then, they refer us to this hospital.

In addition, shortage of space to take a rest mentioned as a barrier for parents during their stay in the hospital. A 35 years old father described as: *"I faced a physical problem since I do not get a proper space to take a rest or sleeping within these two weeks"*.

Furthermore, parents complained that staying in the hospital was longer than their expectations. Although they expected that they return to their home within few days, they stayed more than a week in the hospital. This increased their expense and puts them in financial trouble.

Health workers related factor

Even though there were supportive HCPs, some of them lacked discipline, commitment and not cooperative to support parents. As parents explained, laboratory investigations were not done as a result of absence of healthcare providers. For example, a 36 years old father explained as: *"X-ray was ordered but the experts were absent for the whole day and I am disappointed as a result of their absence"*.

Some parents explained that HCPs do not respect parents. A 27 years old father described as: *"The HCPs have several gaps, for instance, they cannot understand others' problems, and they are negligent so that my baby is harmed. During labor, the midwife annoy her [my wife] and said do not shout. They [HCPs] stay a long time on social media. I am very upset since my baby has injured although he could be born healthy. They do not consider us human; undermine and forced us to go out, but I do not say these are a problem of all health professionals"*.

Theme V: Maternal and child health factors

The severity of child health illnesses such as poor sucking reflex of the neonate contributed to parental stress in NICU. A 40 years old parent said:

...the child cannot take the expressed breast milk. I have a strong need and effort to survive my child, but when I see the child, he is weak and no improvement.

A 30 years old mother explained her experience as: *"...what can I do mister, my babies are seriously ill. Doctors try to help them [twins] but they are not improved from their illness and I am too worried to their illness"*.

In NICU, most of the time, parents worried about the status of their neonates. However, in some instances when both the mother and the neonate get severely ill, the father experience high stress and give more attention to the mother than the neonate.

Theme VI: Current occasions

The context of current pandemic infection [COVID-19] and seasonal situation (farming season) influenced parental stay in the hospital.

A 35 years father explained as: *"Because of the current problem [COVID-19] HCPs in the NICU do not give a positive response. They [HCPs] are not happy to give their professional support as expected from them"*.

A few of parents explained that the neonatal admission time during farming season influences their stay in NICU. A 36 years old parent said: *"the time now is June, which is the most important period for us as a farmer since it is our farming season. So, staying here for me is so challenging."*

Discussion

This study was conducted to explore the experiences of parents in the NICU. The major identified themes were socio-economic, health facility related, parents-health care providers' communication, maternal and child health related, and psycho-emotional factors and current occasions.

Financial constraint was one of the parental challenges presented in the NICU. These challenges include long stay in hospital and extra costs for buying stock out medicines and their daily expenses like transportation and food. The previous study supported that additional costs challenged NICU parents (26). This agreement might be linked with long time hospitalization and other expenses outside of the NICU.

In addition, parents complained that travelling long distance from home to health facilities affected their experiences in NICU. Consistent with this study, parents faced hardships associated with traveling long distances from their homes to the health facilities(26). This might be related to inaccessible NICU setting for parents.

Anxiety, stress, worry, and confusion were the common psychological problems that parents experienced in the NICU. Not only the parents, but also the whole family disturbed *"my families are too much confused"*. Comparably, the anxiety level of parents was high and had unforgettable moments (40). Most parents were depressed and stressed due to the NICU atmosphere (2, 41, 42). The more likely explanation of this similarity could be due to unfamiliar parents with NICU medical equipment.

In this study, sadness, crying and lack of self-control were emotional problems that felt by parents in the NICU. Other study revealed that parents felt broken heartedness, disappointment and fear. They perceived that "oxygen was bad because oxygen kills children"; it caused fears and worries for parents(22). Furthermore, the NICU

fathers expressed that the situation was out of their control (23, 27). Others also found that the most stressful events for parents were attached medical equipment and continuous noise of alarms in the NICU(29).

Even though parents wanted to visit their child frequently, the hospital had limited visiting schedule. In line with this findings, reports showed that parents were challenged by strict visiting hours(26, 43). The service provided in NICU for neonates was delayed which might increase neonatal morbidity and mortality. Regarding the facility resources; shortage of space and sanitary situations of the facility were often overwhelming. Similarly, other studies showed that there were no private family rooms and lack waiting area(3, 26).

This study indicated that lack of compassionate and respectful care and unsupportive HCPs had negative consequences on parents, which mean the HCPs were not disciplined, lack of commitment and cooperative while they gave care in NICU. Other studies also showed that HCPs were unsupportive, careless and negligent(2, 3).

Although parents had no clear role and limited engagement to care the child, the interaction between HCPs and parents was good and supportive. Providing holistic information on the progress of the neonates' health status for the parents had a positive impact on reducing their stress. This enhances parental service satisfaction in NICU. Other reports also substantiated that parents had gotten updated information about their infants' health condition and their engagement also optimal(3, 13, 22, 26, 27, 43–46). In contrast, other studies reported that parents were not received adequate information from HCPs about their babies' progress(26, 41).

Poor medical condition of the neonates contributed in aggravating parental stress. This situation made them worried if the life of their child ends up with complications and death due to poor medical progress. In accordance with this finding, the progress of infants' medical condition influenced parental feeling (2).

The current situation, particularly COVID-19, threatens the parents and their family in terms of getting optimal care for severely ill neonates. It was related to poor HCPs approach. Other evidence showed that during the COVID-19 pandemic occasion, parents experienced higher stress than the usual time. And also, COVID-19 contagion had negative impact on parent–infant relationships(47).

This study has its own limitations; the interviews were conducted in the NICU, study participants might hide their feeling since they may perceive the care given to their child will compromise. This study also limited to include the health care providers perspective particularly in the parent- provider interaction.

Conclusions And Recommendations

Parents whose neonates admitted to NICU were challenged due to shortage of money and travelling a long distance. Psychological and emotional factors were identified as major stressors of parents during their stay in the NICU. On the other hand, unavailability of some medicines, shortage of water for toilet and hygiene, lack of spaces to take rest and limited time to visit their neonates were the concern of many parents. Likewise, some HCPs were not cooperative to provide information. Poor medical condition of both maternal and neonate as well as the current situation, particularly COVID-19, threatens the parents and their family in terms of getting optimal care in the NICU.

Based on the study findings, we recommended that accessibility of NICU service should be scale up into the primary hospitals and health centers to avoid unnecessary expenditure of money and travelling long distance from their home. The health team staff should provide ongoing education for the parents to minimize the risk of developing both psychological and emotional related stress. The HCPs in NICU should involve parents to improve care given to the neonate and alleviate negative emotions. The hospital should provide training on compassionate and respectful care for healthcare providers to enhance parent-healthcare provider communication and supports.

The supply chain management system of the health facilities should be strengthened to avoid unavailability of medicines. And also, sufficient waiting area and space for the care of the neonates should get due emphasis. The NICU setting should be designed in a way that HCPs and parents can manage their personal hygiene.

In addition, counseling services should be designed to promote psychological health of NICU parents. Increase the access of personal protective equipment to prevent the transmission of contagious pandemic disease (COVID-19) in the hospital. Finally, further studies with longitudinal qualitative design should be considered.

Abbreviations

FHCSH: Felege Hiwot Comprehensive Specialized Hospital

HCPs: Health Care Providers

IDI: In depth interview

NICU: Neonatal Intensive Care Unit

COVID-19: Corona virus disease 2019

Declarations

Ethics approval and consent to participate:

All procedures were performed accordance with the ethical standards of the institutional review board's guidelines and regulations and with the Helsinki declaration ethical standards. The institutional review board of Bahir Dar University, college of medicine and health sciences was approved the study (Ref.No.00255/2020). Support letter was written from the ethical review committee to FHCSH administrators to allow data collection in their hospital and permission was obtained from them. Prior to data collection, the objective of the study was clearly stated to study participants. The informed consent was obtained from each participant based on ethical committee's guidelines and in order to maintain the confidentiality of information, researchers were used anonymous codes.

Consent for publication:

not applicable

Availability of data and materials:

all data was presented in the manuscript

Competing interests:

The authors declare that they have no competing interests

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Authors' contributions:

EWM and DAZ participated in conception, proposal writing, data collection, data analysis, report writing and manuscript writing and approval. LSA, MT and MBD participated in conception, proposal writing, data analysis, report writing and manuscript writing and approval. FA participated data analysis and manuscript writing and approval.

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