

What mothers go through when the unexpected happens: A look at challenges of mothers with preterm babies during hospitalization in a tertiary institution in Nigeria

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Abstract

Context: Preterm babies require special care, including immediate hospitalization after delivery. Mothers of preterm babies may be required to stay in a hospital for a longer period and may be anxious about the treatment outcome and health of their babies. These may be stressful for most parents.

Aims: The purpose of the study was to explore the challenges of mothers with preterm babies during hospitalization in a tertiary institution in Nigeria.

Setting and Design: The qualitative study was carried out at the special care baby unit (SCBU) of the University of Abuja Teaching Hospital using a phenomenological approach.

Materials and Methods: Data were collected through semi-structured interviews from 12 mothers with their preterm babies on admission. Only mothers who met the inclusion criteria were interviewed.

Statistical Analysis Used: Content analysis was used to analyze the data.

Results: Six themes emerged from the challenges the mothers faced, namely limited access to baby, strange SCBU environment, inadequate spousal support, high costs of treatment, lactation problems, and informational challenges.

Conclusion: The results of the studies showed that mothers of preterm babies face enormous challenges when caring for their hospitalized preterm babies such as need to emotional and financial supports and educational needs. The health team should help mothers overcome these challenges by strengthening the support structures that exist. Mothers who are able to overcome their challenges can become collaborators in the provision of care, while the babies are on admission.

Keywords: Infant, Intensive care units, Mothers, Needs assessment, Neonatal, Premature

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Received: 29 July 2019; **Accepted:** 07 September 2019; **Published:** 27 December 2019.

INTRODUCTION

Delivery can occur preterm, early term, full term, late term, or postterm depending on the number of gestation

weeks completed.^[1,2] Those deliveries that occur pre- or postterm may have negative consequences on the health of the baby as well as the mother, hence a major concern

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How to cite this article: Abeasi DA, Emelife B. What mothers go through when the unexpected happens: A look at challenges of mothers with preterm babies during hospitalization in a tertiary institution in Nigeria. *J Nurs Midwifery Sci* 2020;7:22-9.

Access this article online

Quick Response Code:



Website:

www.jnmsjournal.org

DOI:

10.4103/JNMS.JNMS_39_19

for global health. Preterm birth is defined as delivery prior to 37 weeks following the onset of the last menstrual period.^[2,3] The prevalence of preterm birth has been reported to be high affecting 5%–18% of pregnancies^[1,4] in which it is estimated that globally about 15 million babies are born prematurely yearly. The lowest preterm birth rates are found in Europe.^[5] About 15% and 18% of pregnant women are likely to deliver preterm babies in the US and UK, respectively.^[6] The survival rate of preterm babies delivered in high-income countries is better than those in low-income countries. High rates of preterm birth are recorded in South Asia, Africa, and North America,^[7] although most developing countries such as Nigeria do not have data that are available and reliable in terms of its prevalence.^[7,8] It is, however, estimated that the prevalence of preterm birth is 7.4% in Africa.^[9]

High morbidity and mortality rates are associated with preterm births, which is a cause for concern because of the increasing prevalence, especially in African and Asian regions.^[10] Globally, almost half of all newborn deaths are attributable to preterm accounting for 1 million deaths in 2015 and are the leading cause of death in children under five;^[11] unfortunately, majority occur in low- and middle-income countries. Nigeria follows India and China to be the 3rd country with the highest number of preterm births of 773,600 and the 2nd highest rank for death due to complication of preterm.^[7] Preterm babies are usually admitted to the neonatal intensive care unit (NICU) immediately after birth because they may need support due to immature organs. This is usually a source of trauma and distress for most parents,^[10] especially for the woman who cannot visualize herself as a mother, though she is no longer pregnant. Parents may also experience the fear of the unknown, thus being uncertain about the present and the future.^[12] It is also likely to hamper the transition process to parenthood.^[13] Consequently, these can have both short- and long-term effects on the preterm baby.

The above impact of having preterm babies on mothers and to a large extent, the family has led many researchers to explore issues pertaining to caring for the preterm baby. Several studies have mostly concentrated on the experiences of caring for their preterm babies in the NICU.^[14-18] Few studies done in Nigeria have looked at other variables but not challenges, such as characteristics and predictors of outcome of caring preterm babies,^[19] incidence and outcome of preterm deliveries,^[20] and prevalence and risk factors for postpartum among women with preterm and low-birth-weight infants.^[21] In Nigeria, there is the paucity of data on the challenges faced by mothers of preterm babies, while their babies are still on admission at the NICU. The

current study makes three key contributions to the literature on the subject matter. First, it is the first study to explore the challenges of mothers of preterm babies in Nigeria and also adds to the few studies that have looked at the challenges of preterm mothers in other countries. This is significant because contextual and environmental factors are likely to influence what mothers of preterm babies view as challenges. Second, it focuses on the challenges of the mothers, while their babies are still on admission not after discharge. Most studies have examined the challenges mothers of preterm babies face post discharge. It is important to identify the challenges early enough and the necessary interventions done before being discharged home. This can in the long term decrease the challenges these mothers face after discharge. Third, it is among the few studies that have considered the challenges of mothers of preterm babies in a tertiary hospital. The aim of this research was, therefore, to explore challenges of mothers with preterm babies during hospitalization in a tertiary institution in Nigeria.

MATERIALS AND METHODS

Design

To explore the challenges of mothers with preterm babies in the special care baby unit (SCBU) in Nigeria, a phenomenological approach was used for this study in 2019. The aim was to gain deeper understanding of the nature or meaning of everyday experiences,^[22] thus providing in-depth knowledge that is holistic, incorporating contextual influences.

Setting and participants

The study was conducted at the SCBU of the University of Abuja Teaching Hospital (formerly Gwagwalada Specialist Hospital) which is a government tertiary/referral hospital in Gwagwalada area council of the Federal Capital Territory, Abuja, Nigeria. The SCBU manages a range of neonatal conditions, especially those that require intensive care. A total of 12 mothers participated in this study; this number was arrived at after saturation of data. Inclusion criteria were as follows: a mother who had delivered a baby before 37 completed weeks of gestation, her baby had been in the hospital for >5 days, the baby's condition had improved if the baby had been very ill, and the mother was not too anxious for an interview. Mothers who did not meet the above criteria were excluded.

Sampling procedure

The purposive sampling method was used. This nonprobability sampling strategy is common to qualitative research and based on the premise that the researchers' knowledge of the topic area enables them to identify

individuals who can be informative and can contribute meaningfully to the objectives of the study.

Data collection

A semi-structured interview guide was used to collect in-depth information from each participant. It permits participants to respond freely to questions and also enables the researcher to get participants to describe and explain situations in a way that provides rich descriptive data. In-depth interviews were conducted until saturation was reached.^[23] Saturation is the stage when no new information (themes) is emerging during the interviews.^[23] Some questions included in the interview were; What in the neonatal unit is challenging for you?; how do you feel about your baby?; what forms of support do you get?

Trustworthiness

It is the way of assessing the quality of the measurement procedure for collecting data in a qualitative study. It consists of credibility, dependability, confirmability, and transferability.^[24]

Credibility was ensured by making the participants comfortable before the interview began and also throughout the interview. When participants are anxious, they may provide information which is not credible. They were also allowed adequate time to narrate “their stories” and to express their in-depth understanding of the phenomenon under study. Certain phrases and words mentioned by the participants were repeated in order to clarify exactly what the participants meant.

Dependability means data stability over time and over conditions; thus, it includes the aspect of consistency. This was achieved by the researcher ensuring that the analysis process was in line with the accepted standards for the research design which was used in this study.

Confirmability refers to the degree to which the findings of the research can be confirmed by other researchers. The researchers’ feelings, ideas, and professional views were separated from those of the participants. To ensure confirmability, the researchers kept an audit trail (which is the detailed recording of the research interview transcripts; raw data field notes including the date and the time of interview, how consent was obtained, and the process of the interviews) so that others can follow to confirm the findings.

Transferability is the extent to which the findings from the data can be transferred to other settings or groups yet preserving the meaning and the inferences. The researchers

ensured transferability through thick detailed descriptions of the research design so as to make replicability possible. Thorough descriptions of the research setting or context and other processes were given.

Data analysis

The five steps for qualitative data analysis, namely familiarization and immersion, inducing themes, coding, elaboration, and interpretation and checking, were followed.^[25] The audiotaped data were played and transcribed. The transcribed data were read over and over again in order to get in-depth meaning. This allowed the researchers to put ideas, thoughts, and words together to help come out with categories which were further organized into themes. Concepts, ideas, and words identified within the data were noted. The most common and similar phrases were copied and pasted in different files, and the files were named according to the codes. The whole texts were read repeatedly till no new insights emerged. Finally, a written account of the phenomena being studied was done.

Ethical consideration

Ethical approval for the study was obtained from the Ethical Board of the University of Abuja with approval number UATH/HREC/PR/2019/06/002. In addition, adequate information regarding the research was given, and the respondents were made aware that they can either choose to participate or decline to take part in the study without incurring any penalty or prejudicial treatment before data analysis. All participants gave verbal consent before being enrolled in the study. Data collected were kept confidential and anonymity ensured, but coding systems were developed so that sources of various data could be identified only by the researchers.

RESULTS

Demographic and obstetric characteristics of the respondents

Twelve mothers between the ages of 24–36 years participated in the study. They were all married. All the 12 mothers were literates. Most of them delivered through cesarean section. The gestational ages ranged between 30 and 35 weeks, and the birth weights of the preterm babies range between 1.8 kg and 2.2 kg. The period of stay in the hospital ranged between 7 and 35 days [Table 1].

Challenges faced by mothers of preterm babies in caring for their babies

Six themes emerged from the study were as follows: limited access to the baby, strange SCBU environment, high cost of treatment, inadequate spousal support, lactation difficulties, and inadequate information [Table 2].

Theme 1: Limited access to the baby

The hope of having limitless access to their babies appears to be short lived as mothers in the current study complained that they do not have access to their preterm babies as would have happened when they were at home and not in the hospital. Mothers who have had the experience of carrying a term child felt it was not the same as the preterm baby. They stated that with term children, they could be carried anywhere and anytime unlike preterm babies. Two mothers had this to say:

“With my previous child I use to carry her and play with her even if she is not crying. But with this one because they said the temperature outside is not good for her so I am unable to carry her from the incubator... Sometimes I wish, but all the same I want the best for my baby.” J. A. 32 years.

Table 1: Demographic and obstetric characteristics of mothers with preterm infant

Variables	Frequency, n (%)
Marital status	
Single	0
Married	12 (100)
Age	
20-25	2 (16.7)
26-30	4 (33.3)
31-36	6 (50.0)
Educational background	
Tertiary	5 (41.7)
High school	7 (58.3)
Neonate’s age (weeks)	
<28	0 (0.0)
28-32	5 (41.7)
32-37	7 (58.3)
Type of birth	
Vaginal delivery	4 (33.3)
Cesarean section	8 (66.7)
Period of stay in the hospital	
7-14	4 (33.3)
15-21	3 (25.0)
22-28	4 (33.3)
29-35	1 (8.3)

Table 2: Examples of the categories and themes

Themes	Categories
1. Limited access to baby	Inability to carry baby Instructions from staff on when to carry baby
2. Strange SCBU environment	Sophisticated equipment in the unit Rules in the SCBU
3. High cost of treatment	Cost of medications Cost of incubator space
Inadequate spousal support	Blaming by the spouse A sense of rejection from the spouse Spouse appearing confused
Lactation difficulties	Difficulty expressing milk Inability to feed by self
Informational challenges	Inadequate information Source of information Timing of receiving information

SCBU: Special care baby unit

“The thought of always carrying your baby is not like that here.... sometimes the baby is crying during injection or something and you cannot carry him.” I. O. 24 years.

In this study, mothers felt as if they were being overly restricted in taking care of their children, especially when one had to be given the order before. One mother stated that:

“You cannot just touch your baby when you want to, you have to be given the go ahead from the staff. It feels someway but I am helpless. You know you cannot go against the instructions of the staff. They are taking care of your baby so you have to respect them at all cost” S. Y. 36 years.

Theme 2: Strange special care baby unit environment

The SCBU has a lot of equipment to support babies with all sorts of issues to recover. Critical neonatal care is timely and accurate monitoring. Mothers mentioned that the sophisticated equipment and how they operate was also a challenge to them because it was a constant reminder that the baby is still at risk. One mother indicated that:

“Every single thing here is actually challenging if you ask me. New environment with lots of sophisticated equipment’s like the incubator.” I. Z. 31 years.

They also mentioned that there were so many rules that one had to comply with before entering the unit and also in touching the babies. This appeared to be stressful for mothers. One mother said:

“The whole set up appears stressful. We were asked to remove our slipper before we can enter the area were babies are kept, you need to wash your hands, generally there are a lot of rules” N. U. 27 years.

Theme 3: High cost of treatment

Mothers stated that it was financially tasking taking care of the preterm baby. This is because they have to buy medications, pay for an incubator space, and pay for oxygen for some babies. They believed even if they would spend a lot of money and their babies are able to make it, it is worth it. Two mothers indicated as follows:

“The doctors said my child has another condition, so I buy a lot of drugs which are very expensive. I have seen people lose their babies after all the money spent, I just pray mine gets well” M. A. 26 years.

“It’s just generally expensive, but it’s worth my baby’s life though” O. O 24 years.

Theme 4: Inadequate spousal support

Another theme that emerged from the study was the role of the spouses supporting their wives or partners, while

their babies are still on admission. The mothers in the study mentioned that they did not receive adequate support. This appeared to be mainly emotional support. There were elements of being blamed, confusion, and rejection:

"It hurts a lot that my husband is blaming me for having a preterm baby. Only God knows what I did wrong." S. Y. 36 years.

"I cannot really tell, but my husband appears confused about the whole situation just as I am also confused. He does not visit as I expected to him, always giving excuses..." Y. O. 33 years.

"You know it is not easy when you need someone and he turns his back on you. I cannot tell why he is behaving like that, before I delivered, he was very excited about the whole thing, suddenly the excitement has vanished in to the thin air. I really feel rejected" T. O. 27 years.

Theme 5: Lactation difficulties

Another challenge mentioned by mothers during the course of the interview was some difficulties with lactation at the initial stage. Mothers stated that they were not able to produce enough milk for the baby and inability to feed by self. Two of the mothers lamented as follows:

"At the early stage, milk was never enough. Like, I am always expressing with little success. I was told to take a large amount of liquid but it did very little. So that was really challenging for me". I. Z. 31 years.

"I had to express breast milk for the nurses to feed him with, meanwhile I had read a lot about breastfeeding and was really looking forward to having that experience". O. O 24 years.

Theme 6: Informational challenges

Mothers received some amount of information from the staff in the unit, but to them, it was inadequate since they had a lot of unanswered questions. One of the mothers indicated that:

"The nurses and doctors are seen going around and it's difficult to get a lot of information regarding what is really happening to your baby. You know you cannot blame them, they are busy but there should be a way around it... I sometimes wish I have more information, something like an update every now and then." R. A. 29 years.

Again, the timing of the information did not appear to suit the mothers. One mother had this to say:

"They, I mean the staff, try just that some of times they try to provide the information are not appropriate. They can be speaking but because you are thinking about other things you don't listen, so at the end of the day you end up having no information". J. B. 36 years.

In addition, some mothers were also critical on where they received the information. It appeared they had a preferred source of information. One mother said:

"I try to read online, but most often because I am not a medical person, I do not understand and would have wished to get more information from the staff, especially the nurses. I believe the staff can explain things to me at my level by excluding all those big words" M. A. 26 years.

DISCUSSION

Mothers in the current study reported that they had limited access to their babies unlike they would if their babies were term babies. In spite of the importance of granting mothers' frequent access to their preterm babies, the need to undergo some invasive procedures such as intubation and catheterization^[26] may not permit mothers in this study to carry their babies as they would have wished. In consistent with the current study, some studies have identified the contact with the preterm baby as a major need of the mothers.^[27-32] Limited access of mothers to their preterm babies has several implications. Several studies have shown that the limited contact affected the mother–child relationship.^[33,34] Thus, inability to have frequent access to the preterm baby is likely to induce negative emotions from the mother which are likely to cause higher levels of stress, subsequently leading to less interaction with their infants in the NICU.^[35] Having frequent access to the preterm baby can also be a coping mechanism.^[29] It would, therefore, be good if mothers of preterm babies are allowed to connect to their babies by performing parental duties, thus taking on the identity of parents.^[29,36,37]

The findings of the current study highlight that the SCBU environment was a challenge to most mothers. The key stressors had to do with the monitoring equipment some of which produce different sounds to alert the staff on the physiological happens of the baby, tubes, and other wires connected to the babies. In a meta-analysis of 12 qualitative studies about the experiences of mothers with preterm, one of the themes that emerged was coping with turbulent neonatal environment.^[18] The NICU environment has been reported to impact families, especially mothers who assume the role of caregiving.^[38] Studies have reported that the NICU environment remains stressful for parents.^[39,40] The physical environment thus can play a critical role in easing parental stress and producing satisfaction. Other mothers also commented on the numerous rules at the NICU which is consistent with a study by Williams *et al.*^[41] NICU rules have been found to be a significant source of conflict between nurses and parents.^[42]

The high cost of treatment was another challenge expressed by mothers in the current study. The above study is consistent with other studies. An earlier study indicated that 35% of all expenditures for newborns and approximately 10% of all medical expenditure for children are associated with preterm.^[43] Similarly, recent studies have found that the cost for hospital stay for premature newborns was much greater and cost also corresponded to newborns birth weight; thus, the lower the birth weight, the higher the cost.^[38,44]

Another theme that emerged from the study was the inadequate support received from the spouses. On the contrary to the findings of this study, several studies have reported that fathers provide support for their wives, which is mostly emotional.^[39,45] It is possible that fathers in the current study were dealing with their own anxiety and depression and were also faced with the need to play multiple roles which may be overwhelming for them. It could also be due to the different cultures in different population where men are required to cope with stressful events without expressing it. Significant levels of anxiety and depressive symptoms have been reported in fathers of preterm babies.^[46-49] Having a preterm baby does not only affect the mother but also affect the father's relationship and other facets of their lives.^[50]

In the current study, though mothers acknowledged that they received some amount of information from the staff, they mentioned that it was inadequate. Mothers expressed that they wanted to get more information from the staff which corroborates a study,^[46] though their study was conducted on fathers of preterm babies. This is also consistent with a study which reported that the amount and quality of communication with medical staff was not adequate.^[41] One study reported that parents preferred and relied on personal communication from the medical team as opposed to using the internet.^[51] This is similar in the current study where one mother stated that though she reads from online, she would have preferred receiving the information from the staff, particularly nurses. Nurses play a major role in dissemination of information.^[51] However, in a study majority (56%), preferred source of information received from a neonatologist as opposed to 49% preferring nurses.^[52] Mothers reported that sometimes the time they received the information was not appropriate. Parents go through four stages: prenatal, acute, convalescent, and discharge, and the informational needs of parents may change as they evolve through the stages.^[52] For optimum outcomes during provision of information, it is important to identify the right time to disseminate information as well as identify the informational needs of the mothers.

The findings of this study indicated that mothers had a challenge expressing breast milk and they were also under pressure by the staff. The initiation and maintenance of lactation has been noted as a challenge for many mothers,^[53] especially for preterm mothers,^[16] which is similar to the findings of the current study. The fragile nature of the baby and the stressful NICU environment may be key contributing factors. In mothers who deliver at term, it is expected that the mammary glands have been fully developed by them; however, it remains uncertain whether the shortened gestation due to prematurity will have any effect on the synthesis and ejection of milk.^[54] Several studies have found that transferring the preterm babies to the breast is a challenging task.^[55,56]

The study has two limitations; the researchers did not determine the fathers' challenges in caring for preterm babies at the NICU. Recruitment of participants was done in only one center; participants in different centers might have had different challenges.

CONCLUSION

The study explored the challenges faced by mothers of preterm babies during hospitalization at the NICU. The findings indicated six main areas in which mothers had challenges, namely limited contact with baby, inadequate support from spouse, increased cost, lactation difficulties, and inadequate information. Each of the challenges is equally important and needs to be addressed by the health team through collaborative efforts. Based on the above, the researchers make the following recommendations.

Sufficient informational support should be given to mothers of preterm babies as well as their spouses. In providing information, mother's psychological state should be assessed to know the right time to provide information. An information protocol should be developed by the unit in ensuring that the right amount of information is given to the right person by the right professional at the right time.

Proper orientation should be performed for the parents of the preterm babies, especially mothers, which will help them familiarize with the NICU environment. This is likely to decrease the anxiety response to the environment and also better under what constitutes the NICU environment.

The fathers of the preterm children should not be isolated and should be offered the same support as the mothers. When they understand the concept of prematurity, they are less likely to blame or reject their partners as well as being

confused. Thus, they can provide emotional support to the mothers which will buffer the challenges they go through.

Further studies should aim at a comparative investigation into the challenges of mothers of preterm babies in the NICU and at home. The unique challenges of fathers caring for their preterm babies in the NICU can also be explored.

Conflicts of interest

There are no conflicts of interest.

Authors' contribution

All authors contributed to this research.

Financial support and sponsorship

Nil.

Acknowledgments

The authors of this work wish to express their profound gratitude to mothers of preterm babies at the special baby care unit of the UATH for their support during the data collection. The authors acknowledge the support of Dr. Paul Adjei Kwakwa.

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