



Original Article

Exploring the Experience of Mothers of Premature Babies: A Phenomenological Study

Sobia Gulshan¹, Kabir Ozigi Abdullahi¹, Adnan Yaqoob¹ and Afsar Ali¹¹Lahore School of Nursing, The University of Lahore, Pakistan

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*Corresponding Author:

Sobia Gulshan
Lahore School of Nursing, The University of Lahore,
Pakistan
sobiagulshan314@gmail.comReceived Date: 23rd January, 2023Acceptance Date: 14th February, 2023Published Date: 28th February, 2023

ABSTRACT

Premature birth of babies is a one of the major public health problems all around the world. **Objective:** To explore the experience of mothers of preterm babies when their baby is admitted in a tertiary care hospital of Lahore. **Methods:** This study was conducted in the Neonatology department of Children's Hospital, Lahore, Tertiary Care Hospital, Pakistan from June 2022 to December 2022. Semi structured face-to-face individual interview was used to obtain data from the 12 participants who were purposively selected for the study. The audio recorded data collected was translated into English and transcribed verbatim. Analysis was done with the help of computer assisted software called NVIVO-12. By using the Coliazzi's method of phenomenological analysis the codes generated from NVIVO-12 were organized into sub-categories, categories, sub-themes and themes. **Results:** Three themes emerged with sixteen subthemes. The themes are: Mixed emotional feelings of the mothers; Mother's satisfaction about care and support from Health Care Professionals; Mother-baby interaction in NICU. Mothers were worried due to unexpected emergency premature delivery and baby's status and had uncertainty related to delivery outcome and the baby's life. Participants have good interaction babies while the Kangaroo Mother Care and Breast Feeding and they applaud HCPs. **Conclusions:** Mothers were concerned about the survival of premature babies admitted to the NICU. They showed different emotions like fear, anger, sadness, worry, tension, lack of confidence, hope, gratefulness, courage and spiritual faith in Allah. They expressed the feelings of satisfaction about care, treatment counseling and teaching by HCPs.

INTRODUCTION

Preterm birth is a major cause of perinatal and neonatal mortality and morbidity worldwide., it contributes to 75% of the neonatal mortality all around the world. Premature baby is defined as the baby who is born before 37 weeks of gestation. It is the single most important cause of poor infant outcomes in relation to survival and good quality of life [1]. Preterm birth is associated with many psychosocial complications and stressful experiences in mothers [2]. Parents of premature babies start their journey of parenthood in a stressful environment of the Neonatal Intensive Care Unit (NICU) [3]. According to the World Health Organization (WHO) report (2020), it is estimated that 15 million preterm babies are born every year and 1 million premature babies die due to the complications of

prematurity [4]. Globally the prevalence of preterm birth is estimated at 15 million per year. In Pakistan 900000 premature babies are born each year and the neonatal mortality rate is 42 per thousand live births [5]. Additionally, preterm birth of a baby and admission in NICU is a traumatic experience for parents [6]. Mothers are primary caregivers of their babies and they provide care to their babies in a highly technical, strange and terrifying environment of NICU. It may be resulted as an acute grief and anxiety, depression and posttraumatic stress in mothers [7]. The birth of a premature baby is high among Pakistani Mothers and neonatal mortality rate is also high in Pakistan, still no research conducted in Lahore Pakistan to explore the emotional response of mothers while their

babies are being admitted in hospital. Birth of a premature baby and admission in NICU tremendously affect the parents, especially mothers. Parents having diverse experiences in NICU. These experiences have long lasting effects on the mental health of mothers, premature babies and eventually the society where they live. Our health care system has more focus on care and treatment of a sick premature baby. There are multiple challenges for preterm baby's mothers which is the subject of the study. What is being faced by mothers of premature babies in NICUs during admission of their baby is still unclear in developing countries which are overburdened and have limited facilities. To fill this gap, this study aimed to explore the experience of mothers with preterm infants admitted to the NICU. This is very important for understanding the challenges faced by mothers and the appropriate strategies for intervening to reduce these challenges. The findings of this research will help to make interventions for caregivers of premature babies especially for mothers and reduce neonatal mortality.

METHODS

A qualitative research was conducted with a descriptive phenomenological approach. Phenomenology can help us learn from experience. It is not just a description of human experience. All participants were fully informed and provided written informed consent. The Institutional Review Board of Lahore University and Allied Health Sciences of Children's Hospital Lahore has granted the approval letter of IRB to conduct this study. Descriptive phenomenological research design was employed in this research. This study was conducted in the Neonatology department of Children's Hospital, Lahore (CHL), Tertiary Care Hospital, Pakistan from June 2022 to December 2022. All mothers of premature babies born before 37 weeks of gestation and in stable condition and mothers who have previous experiences of baby's admission in the neonatology department and were willing to participate in this study were included. Mothers whose preterm babies were critically sick or on ventilators and mothers whose babies had any congenital anomaly due to the peculiar demands of those conditions on them were excluded from this study. Twelve participants were purposively sampled. Eligible participants were selected with the support of specialist nurses in the NICU and invited to participate in the study. Face-to-face interviews were conducted from each participant by using a semi structured interview guide. Probing questions were also used to find out more information and in-depth knowledge of the phenomenon. Confidentiality of interviews was assured and recorded interviews of the participants were kept in a safe and secured place. Memo notes were made during and after

interviews on the basis of observations made by the researcher on the participants' non-verbal cues. Demographic data were obtained in the first part of the interview. Sample size was determined when data saturation reached. After that the data was transcribed into English Language. Then the transcribed data was converted to text files and imported to NVIVO-12 computer software and cods were generated. Qualitative data set was analyzed by using the Colaizzi's method by following the seven steps read the entire content of the interview extract important statements, formulate the meaning, organize a collection of meanings into a cluster of themes, developing an exhaustive description of cluster of themes, establish the basic structure of the phenomenon identified by a clear statement, go back to the participants for validation and data was organized in sub-categories, categories, sub-themes and themes. Rigor means the reliability and trustworthiness of research studies. It was established by focusing on four criteria, primarily credibility that is the same as internal validity, confirmability dealing with presentations, dependability which related to the reliability, and transferability that can be like external validity. Credibility is defined as the confidence in the truth of the data and its interpretation. In the current study, the researcher made sure the credibility of participants' data by collecting data from those mothers who were still experiencing the phenomenon or those that have previous experience being studied. Participants were selected with different backgrounds to gain multiple perspectives. Data was collected from mothers of premature babies while they were still nurturing preterm infants in the NICU of Children's Hospital Lahore, which helped them to think about it and they explained their experience when they happened as it is. Researcher during data collection process continued to ask detailed questions or probes if needed to gain insights into the participant's experience to increase the reliability of data. Prolong engagement with participants was made to ensure credibility. The researcher increased confidence in the truth of research data by using two methods of data collection that are in-depth interviews based on comprehensive literature review and observations. Member check was also done as research work was evaluated by the supervisor on a regular basis. Member check was also done by contacting three participants of the study. They were invited to review and comment about the findings through a face to face meeting. At the end of data collection, interviews were transcribed and summary was shared with the participants, in this way the facial expressions were observed again to check whether the participants told the true data. Reliability of research work is known as dependability. It is the ability of researchers to maintain it

and provides reliable data. For achieving dependability, researcher ensured that the research process is logical, easy to understand, and clearly documented. If the reader will examine the research work, they can easily evaluate the dependability or reliability of the research process. Research audit trial is one of the important ways to demonstrate dependability. Reliability is based on dealing with bias, triangulation of data, and reflexivity. Reflexivity is a process of self-diagnosis and an important aspect of dependability during qualitative research and was attained by bracketing as identified by Edmund Husserl to recognize and acknowledge the prejudices, assumptions, or criticisms by discussing with her supervisor. Dependability determines that the findings of the study could be repetitive if the research is replicated with the same participants in the same setting. An audit of research work is required to achieve dependability. The audit of research work was being done by the researcher's supervisor. Confirmability is the proof that a researcher's interpretations and results have been clearly derived from the data, and the researcher needs to demonstrate how the conclusions and interpretations have been reached. Confirmability is achieved when credibility, transferability, and dependability all are established in research work. In this study the researcher included markers such as the rationale for theoretical, methodological, and analytical decisions throughout the study so that others can understand how and why the decision was made. The researcher's supervisor then provided feedback further to enhance or develop stronger, clearer and more dependable results. It significantly showed that the researcher has expressed the real participants' data in the study not any biases or a prejudice of the researcher's imagination or researcher experience in neonatology. Transferability means that the results of qualitative data can be transferred to other settings. The researcher made sure that this criterion of trustworthiness was met by purposive sampling of the participant, which were able to provide sufficient and rich data. Accurate, sufficient and thick description of the mother's living experience related to the care of hospitalized premature babies has been given in data analysis and interpretation. The research report allows other researchers or policy makers to evaluate its applicability to other settings.

RESULTS

Twelve mothers of premature babies have participated in the study. Majority of the participants (80%) were young adults from which job holders were 58.33% and house wives were 41.66%. All the participants were educated and 66.66% have delivered the baby via cesarean section and 33.33% by normal delivery as for the gestational age of

babies, most were delivered between 28-32 weeks of gestation (66.66%) and 33.33% between 33-37 weeks and 16.66% babies has <1.5kg of body weight, 58.33% between 1.5kg-2kg and 25% babies has body weight between 2.1-2.5kg. 41.66% babies admitted in NICU <20 days, 41.66% between 21-30 days and 16.66% babies admitted for >30 days. Three themes emerged with sixteen subthemes. The themes are: Mixed emotional feelings of the mothers; Mother's satisfaction about care and support from Health Care Professionals; Mother-baby interaction in NICU. Birth and admission of a premature baby in the NICU for special care triggered an emotional crisis in the parents, especially mothers. Participants expressed different kinds of emotions depending on the situation they faced. They showed both negative and positive emotions influenced by thoughts which started from the birth of the premature baby to the admission in NICU. Feelings of worry, fear, anger, tension, depression, these are the negative feelings expressed by the participants related to unknown outcome of the delivery and admission of the baby in NICU. Feeling worried or anxious may be due to an actual or potential problem. In the present study participants were worried and afraid for emergency delivery and for their babies' status which is the potential problem for the participants, they communicated about this for instance: "I was worried because labor pains were increasing, not under control and increasing. But I was too worried during all this situation because my days were not completed." (P4), "Mother can cross anything for their babies. Definitely we can scarify everything for our baby" (P6), "I was also very uncertain and scared about the health and life of my little baby" (P8) and "When pain started earlier I was afraid of losing my babies. I said to my husband "I need my 3 living babies. I never want to lose anyone" (P9). Feelings of anger by the participants is a secondary emotion that basically arise from experiences such as loss, disappointment, fear, worry, etc. Feelings of anger was expressed by the participants as "I started weeping bitterly and said to my family members that you people are making me much more. I was angry for myself" (P4). Participants were also angry due to lack of accommodation facilities for them it was reported as: "I felt very angry as already our babies are sick and there is no proper place to stay in NICU with our babies" (P1). Depression is a persistent feeling of sadness and may be caused by a stressful life event like in the present study due to premature delivery and admission of their babies in NICU. Some participants accentuated like this: "My baby born before time I was unable to feed him in NICU I was very depressed" (P8) and "I am very depressed that he born before the time and admitted in CHL, I was very depressed to see my baby in NICU" (P10). Participants were scared to see heavy machinery in NICU attached with their babies.

They described these feelings like that: "I am afraid while looking on heavy machinery of NICU my baby was also attached with many kinds of machines she also remained on manual ambo bagging. Some other babies are attached with pumps" (P12). Spiritual believe in ALLAH, courage and hope for the recovery of the baby these were the positive feelings which were experienced by the all the participants throughout all the interviews. Participants described it as: "I prefer to recite DAROOD E PAK and pray for my baby" (P11), and "I also got hope that one day my baby will also be healthy and discharged like others IN SHA Allah" (P2). Participants experienced the positive feelings of satisfaction related to the care of their premature babies and support being provided by HCPs in NICU and good facilitated neonatology department. They depicted it as: "I felt very good in government hospital. This is a special hospital for children, it is well facilitated. For the treatment it is the best hospital" (P9) and "They are very nice and loving and taking great care of our baby, if I asked anything from them they replied very nicely they didn't get angry" (P3), "If I told you collectively in short words about my experience that after GOD, they (HCPs) are everything for us. According to me frankly this the definition for them (HCPs) of CHL, NICU. They survive my baby when my baby shifted here on his last breathes, after ALLAH PAK they are everything for my baby. ALHUMDULILLAH, they (HCPs) don't allow us to touch our baby without using hand sanitizer. Everyone attended us very well" (P6). Participants were also encouraging and supporting each other they described about this in the following way: "Mothers take care of each other as we people came from far away for the treatment of our sick babies. We all mothers are here in this hospital due to in dire necessitation. It is a good experience that we are helping each other. We care each other we discuss in this way we encourage each other. If one sees the other person in the same problem, then the other must be encouraged" (P5). Participants also wanted more information and counselling to look after their babies: "There must be a proper schedule for mothers counseling by doctors. But the there is a shortage of doctors also" (P2). Majority of the participants conveyed their positive experience of interaction with their premature babies in NICU in terms of Kangaroo Mother Care (KMC), Breast Feeding and body massage. they reported it as: "KMC is very effective. It is very effective in a sense that baby becomes more active, HCPs in NICU provided me the proper place and privacy for the provision of KMC still I felt shy, When I put him in incubator after the provision of KMC my baby became more active I was very happy, he cried very well. KMC was very good. My breast milk also improved after KMC" (P2), "I felt very happy when I started breast feeding to my admitted baby in NICU. It was a good experience to feed my baby" (P9), and "I notice. MA

SHA ALLAH when first day I have given body massage to my baby he didn't respond well. But when second day I have given body massage to my baby, firstly baby's body was not relaxed then he relaxed his body and respond well. At the end of massage my baby put his both hands on my hand" (P6). Participants wanted to stay with their babies and unrestricted visitation in NICU: "I wish to have a healthy full term baby. I again wanted to put him attach with myself my chest. I wanted that mothers never be restricted to see their babies" (P10).

DISCUSSION

The present study was conducted with the aim to explore the experience of mothers of preterm babies when their baby is admitted in a tertiary care hospital of Lahore. The results showed that mothers have encountered several obstacles related to the NICU which provided important and useful information to improve quality of care in NICU, areas that need improvement include emotional aspects of mothers of premature babies and information sharing by the HCPs. Unexpected premature birth is traumatic experience for mothers in this study mothers experienced predominantly negative emotional feelings such as fear, anxiety, and sadness are all consistent with previous qualitative studies [8-11]. Concurring with some other studies participants also explained about the positive feelings of courage, power and hope [11, 12]. Consistent with previously conducted studies the participants of the present study shared that the HCPs of NICU were very competent, good source of knowledge with nice behavior and provide excellent care to the babies instead of their shortage [13-15]. Similarly, like other studies the participants were satisfied and happy to in involve in their baby care by KMC, breasting and body massage. Participants were agreed that involvement in baby care is effective for themselves and their babies [16-18]. Counselling with respect, and clear timely information helpful to maintain a good interpersonal relationship between the mothers of premature baby and health care providers [19, 20]. Adequate accommodation facilities must be provided to post-natal mothers so they can sleep comfortably and give proper care to their babies [21].

CONCLUSIONS

The birth of the premature baby is unexpected and cause different emotional reactions in mothers like worry, fear, anger and depression. Mothers unable to interact with their hospitalized babies as they wish. Mothers were satisfied by the care provided to their babies. Involvement of mothers through information exchange, education, about baby care and proper hospital policies are essential. Cordial interacting with HCPs and mothers and providing support

in areas such as Breast Feeding and KMC empowers the mothers their physical and mental well-being. A comfortable and spacious place to stay in NICU is important for mothers to ensure adequate rest to cope with unpleasant premature birth and post-natal period.

Conflicts of Interest

The authors declare no conflict of interest

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