

Experiences of Mothers with Premature Babies in Neonatal Intensive Care Unit in Gauhati Medical College and Hospital (GMCH), Kamrup (M), Assam: A Qualitative Study

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Abstract: ***Background of the study:** Preterm birth is an important issue in public health and is a major part of worldwide neonatal mortality and morbidity. **Objectives:** To describe the experiences of mothers with premature babies admitted in NICU. **Methodology:** Qualitative phenomenological research design was used. Data were collected from a total of 30 participants until the data saturation was achieved. Sample were selected by non-probability purposive sampling technique. Socio-demographic data were collected by administering self-structured questionnaire and semi-structured interview schedule was used conducted and the probing questions of the interview were open-ended. Participants verbatims were recorded. Records were transcribed and thematic analysis was made. **Results:** The findings of the study revealed 6 major themes and sub-themes. 1) Lack of knowledge, 2) Emotional and psychological experiences of having a premature baby, 3) Maternal newborn interaction, 4) Feeding challenges, 5) Financial challenges, 6) Maternal-health care provider's interaction and expectations. **Conclusions:** The feelings and needs of mothers with premature baby admitted in NICU were varies from mothers to mothers in this study. Some mothers expressed negative feelings such as sadness, fear and anxiety, depression. While others expressed positive feelings and had faith on supreme power. Mothers expressed their feelings regarding feeding and financial challenges.*

Keywords: WHO- World Health Organization, Kamrup (M)- Kamrup Metropolitan, ICU- Intensive Care Unit, KMC- Kangaroo Mother Care, R- Research sample

1. Introduction

Preterm birth is an important issue in public health and is a major part of worldwide neonatal mortality and morbidity. Though most pregnancies last 40 weeks, but the incidence of premature or pre-term baby i.e., born before 37 weeks of pregnancy is also not less. It is estimated that globally, 15 million babies are born preterm each year (WHO, 2018) i.e., more than 1 in 10 newborn babies.

Studies shows that prematurity is associated with higher rates of neurodevelopmental morbidity, sensorineural impairments and other complications. Approximately 1 million children die each year due to complications of preterm birth. Many survivors face a lifetime of disability, including learning disabilities and visual and hearing problems. Globally, prematurity is the leading cause of death in children under the age of 5 years.

In 2020, preterm birth affected 1 of every 10 infants born in the United States. The preterm birth rate declined 1% in 2020, from 10.2% in 2019 to 10.1% in 2020. However, racial and ethnic differences in preterm birth rates remain. In 2020, the rate of preterm birth among African-American women (14.4%) were about 50 percent higher than the rate of preterm birth among white or Hispanic women (9.1% and 9.8% respectively).

In India, among the total 27 million babies born annually (2010 data), 3.6 million babies are born preterm, and over 300,000 of these preterm babies die each year because of associated complications.

A study was conducted by Ms. K. C. Malsawmtluangi M.Sc. (N), Mrs Nirmali Gogoi Associate Professor Department of Pediatric Nursing SMCON, Assam down town University in selected hospitals, Guwahati, Assam (2018). The result showed that the prevalence of preterm baby was 27(45%). Out of which majority 20(74.1%) were moderate to late preterm, 5(8.5%) were very preterm and 2(7.4%) were extremely preterm.

From birth, the child has an ability to respond to the environment, which influences the interaction between mother and child. As suggested by Flacking et.al., (2012), the feelings of separation and exclusion could be related to the lack of physical and emotional closeness which are important factors in the early relationship between parents and the newborn infant. During hospitalization of their baby, mothers may experience several and often contradictory emotional reactions, such as grief, sadness, guilt, fear, anger, loss of self-esteem, and sense of failure.

A very few studies were conducted regarding experiences of the mother with premature babies admitted in NICU, in Gauhati Medical College and Hospital (GMCH),

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Kamrup(M), Assam. Besides this, the researcher had observed during her clinical posting in NICU, GMCH that most of the premature babies with associated complications were getting admitted in NICU for a prolong time. Having interaction with the mothers as well as the parents, the researcher felt that, most of the parents undergone lots of fear, anxiety, depression, shame guilt, failure, uncertainty regarding the status of health, improvement and future perspective of their children. Hence, keeping in mind the above experience, the investigator felt the need of conducting a study titled: Experiences of Mothers with Premature Babies in Neonatal Intensive Care Unit in Gauhati Medical College and Hospital (GMCH), Kamrup(M), Assam: A Qualitative Study.

2. Literature Survey

Acharya S, Bhandari S, Bhattarai S and Gaire H (2020) had conducted a study on experiences of mothers having preterm infants admitted in neonatal intensive care unit: a qualitative study in Nepal. Mothers experienced contradictory emotions while holding their preterm for first time. They felt emotional detachment due to the emergency NICU admission. Mothers were anxious about unpredictable life span of baby and blamed themselves for early delivery. To deal with these emotions, mothers adopted coping strategies like acceptance of the situation, devotion towards God, attachment with family. Hence, the study concluded that health professionals need to pay more attention to reduce anxiety of mothers by providing continuous communication about baby's progress.

Mengesha E W, Amare D, Asfaw L S, Tesfa M, Debela M B and Getahun F A (2020) had conducted a study on parental experiences in neonatal intensive care unit in Ethiopia: A phenomenological study. Parents complained of psychological problems like anxiety, stress, worries, hopelessness, and a state of confusion. In addition, anger, crying, sadness, frustration, dissatisfaction, regret, disappointment, feeling bad, self-blaming, nervousness, disturbance, and lack of self-control were major emotional problems raised by the parents. Researchers recommended that health care providers should support parents with psycho-emotional problems, strengthen parents–healthcare workers' interaction, and scale up neonatal intensive care unit services to the primary health care centres.

Namusoke F, Sekikubo M, Namiro F and Nakigudde J (2020) had conducted a study on "What are you carrying?" Experiences of mothers with preterm babies in low-resource setting neonatal intensive care unit: a qualitative study. This study explored the lived experiences of mothers with preterm babies admitted to NICU in a low-resource setting. Researchers included mothers who delivered and were caring for preterm babies at the NICU of Mulago National Referral Hospital. There were six themes on the experiences of mothers of preterm babies in NICU: constant worry and uncertainty about the survival of their babies, baby feeding challenges, worries of discharge, communication gaps between mothers and nurses, community acceptability and disdain for preterm babies, and financial challenges. Mothers of preterm babies admitted to NICU in a low-resource setting still need a lot of support other than the medical care given to their babies.

3. Methods/ Approach

The study aimed to assess the experiences of the mothers with premature babies admitted in Neonatal Intensive Care Unit (NICU) in Gauhati Medical College and Hospital (GMCH), Kamrup (M), Assam. In order to achieve the objectives of the study a qualitative approach was found appropriate and selected for the study. As the study aimed to assess the experiences of mothers with premature babies admitted in NICU, the research design selected for the study was phenomenological research design. Purposive sampling technique was used to select 30 mothers of premature babies admitted in NICU who met the inclusion criteria of the study. Data collection was done in the month of May and June, 2022. The approximate duration of the interview was between 25-30 minutes. Interview was conducted as per convenient language i.e., Assamese language and data provided by the participants were recorded using an audio recorder with their consent. Data were collected until the data saturation was achieved. The audio recorded interview was transcribed to English language manually. Accuracy of the transcribed data were checked by listening to the recorded interview and corrected the minor mistakes. Each transcript was read several times to enable the researcher to engage with the emerging data. Codes were generated from the transcribed interviews and were grouped into sub-themes and themes. Direct quotations from the participants were used to support the themes.

4. Results/ Discussion

The findings of the study revealed 6 major themes and sub-themes.

1) Lack of knowledge: The mothers of premature babies admitted in NICU expressed their knowledge regarding premature babies and NICU. "Premature baby means birth of the baby before time, if the mother is having illness.....and NICU means the baby must have some serious illness." (R1)

2) Emotional and psychological experiences of having a premature baby:

a) Expression of emotions and faith on supreme power: Though the situation in NICU is worrisome for the mothers and family members, but faith in God may bring comfort and cheer, even in the midst of stress and crushing difficulties.

".... baby was kept in ventilator for 24 hours in ICU in Barpeta Medical College. After 9 days the medical personnel referred the baby to GMCH through ambulance by providing oxygen. I was very much scared at that time." (R21)

"I have delivered twin babies, but one of my baby died 4 days ago in NICU, now I have only one baby with me. We are planning to take the baby home once he is fully recovered. We are praying to God so that we can take the baby home soon." (R22)

b) Vacillation between hope and hopelessness: The mother felt insecure, attentive and vigilant, oscillating between hope and hopelessness "At first, I was very much sad. I was

wondering what will happen now, whether I would get my baby back from NICU, whether I could see him or take him in my arms.”(R9)

3) Maternal newborn interaction:

a) Looking after their own child and lack of self-confidence:

Parents talked about the importance of being allowed to help with looking after their own baby, for example cleaning, massaging and nappy changing as well as being able to touch or hold their baby. “When I first saw my baby, I felt very sad. At first, I was afraid to hold such a tiny baby. But now I can hold my baby without any fear as the baby’s weight and size is gradually increasing and I have been able to take care of my child inside the ICU. After giving KMC inside the ICU for 3 days, they have allowed me to provide KMC in KMC room.” (R13)

4) Feeding challenges:

a) **Challenges of expressing breast milk:** maintaining expressed breast milk during preterm infants’ treatment period in NICU may increase stress and difficulties for some mothers. “... lesser amount of breast milk is secreting and it is not sufficient for my baby. Expressed breast milk was given to NICU staff, and they feed my baby.” (R20)

b) **Lack of sucking skills:** Premature babies sometimes aren’t born with mature sucking skills. “The baby wants to drink but as the baby is small so he can’t suck properly.” (R10, R18)

c) **Interruption of feeding due to medical interventions:** Premature babies are at risk for other conditions that can make it hard for them to breastfeed or bottle-feed in regular intervals. “At first the baby was fed through pipe. They removed it today and told me to feed the baby through spoon and if the baby can’t drink expressed breast milk through spoon, then they will insert the pipe again.” (R23)

5) **Financial challenges:** Financial difficulties are common in families of hospitalized children “We are facing financial problem. We are poor people. We are staying in hospital for so many days. All blood tests are free except one, we have done that blood test in private lab. We are buying medicines also.” (R17, R19)

6) Maternal-health care provider’s interaction and expectations:

a) **Effective communication:** The mothers are expressing their expectations from health professionals as encouraging to take care of their babies. “As I have twin baby, nurse didn’t allow me to stay with both the child at the same time. They gave me only one baby i.e., the second baby for breast feeding. They didn’t allow me to see the first baby till now. Today when I asked them to show the baby, they told me come after some time” (R19)

“We have a good communication with the health care staff. They allowed me to give KMC inside the ICU.” (R20)

b) **Psycho-social support:** Serious child illness and hospitalization is a major family crisis that can have a lasting negative impact on families. “Health care staff

helped us psychologically. I can express my concerns with them. They taught me to breast feed the baby properly. And told me that if my baby’s weight will increase then they will discharge us from hospital. It makes me happy to hear that from health care staff.” (R6, R13)

c) **Feeling like an individual:** Staff knowing parent’s names and remembering details from previous conversations made parents feel like they are high on a list of priorities and receiving personalized care. “They recognized me and my baby by my face only. It makes me feel very happy. They recognized me by my name also.” ((R1-R30) “..... ma’am and ma’am helped me a lot.ma’am had given a name (Jiban) for my child, as the baby fight with critical disease and still alive.” (R20)

5. Conclusion

This study describes the experiences of mothers with premature babies admitted in NICU in GMCH, Kamrup (M), Assam. The feelings and needs of mothers with premature baby admitted in NICU were varies from mothers to mothers in this study. According to the mothers, health care providers in NICU had to play essential role for accomplishment of early maternal-newborn bonding. In this regard, mothers must be given adequate support by NICU staff in order to solve their emotional problems and to ensure early bonding with their babies.

6. Future Scope

Similar study may be conducted among the mothers of newborn child admitted in Neonatal Intensive Care Unit (NICU), Paediatric Intensive Care Unit (PICU), similar study may be conducted among the mothers of under five children admitted in Paediatric Medicine Ward, similar study may be conducted among the mothers of children admitted in Paediatric Surgery Ward.

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