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# Experiences of mothers of preterm neonates following discharge from Neonatal Intensive Care Unit (NICU) - A qualitative content analysis

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## Abstract

Preterm birth brings with it stress that requires separation from their parents, acute care, prolonged hospitalization, rigorous medical interventions with more technological contact. A preterm neonate in the neonatal intensive care unit, not only places the parents in emotional turmoil, but it also makes them experience physical, social, financial and spiritual stress. This study retrospectively explored the experiences of parents of Neonatal Intensive Care Unit (NICU) graduates (neonates who are discharged from NICU) in dealing with preterm neonates and identified their coping mechanisms. **Methodology:** Data was collected through a telephonic interview from six mothers of preterm infants discharged from the NICU using a qualitative descriptive design. A retrospective analysis of the experiences of mothers during hospital stay was assessed. A qualitative content analysis was used to analyze the interviews. **Results:** In the study, it was observed that parents experienced fear, anxiety and uncertainty, lack of control and feeling of low self-esteem. The major concerns were that their neonate would be discharged without developing complications and difficulty understanding medical jargons. The mothers seemed to believe that the stay of their baby in the NICU accelerated their coping skills and emotional strength and they also became very courageous and confident in taking care of their babies. **Conclusions:** The results of the study would help health professionals recognize families suffering and expectations from the medical community in reducing the burden. The study would serve as a base for future research studies and evidence-based practice.

**Keywords:** Preterm birth, experiences, parents, NICU graduates (neonates discharged from the NICU)

## Introduction

Maternal infant bonding is one of the most important steps among all primates. It is the first step towards a lifelong attachment in the developmental process of a neonate, as well as also as a parent. Preterm birth,

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whether imminent or not, hinders the bonding process and possibly distorts the personality of the parent, the neonate or the parent-infant relationship dyad. Preterm birth has an associated string of complications that places significant stress and focused attention on the neonate and the parent's stress and expectations are often overlooked. Knowingly or not, the parent's stress, needs and expectations are pale when compared to that of the neonate in everybody's perspective, including the parents. Even the parents would agree that caring for the needs of their neonate is the priority and that thinking of solutions to their problems would be selfish. Seldom is it realized that by caring for the parent, the health of the neonate is indirectly promoted.

Mothers are overwhelmed and frightened by the Neonatal Intensive Care Unit (NICU) environment, the complex equipment, the sounds, the number

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of personnel and the appearance of their baby. The premature birth of a baby requires a NICU environment with its numerous medical interventions required for the baby's survival and well-being. However, the NICU environment separates the parents from their child and this causes emotional pain to the parents. Parenthood is synonymous with bonding and when hindered, parents are deeply affected, which further stresses their parent-infant relationship. Along with the emotional turmoil the parents go through, they must also manage physical, social, financial and spiritual stress. "*What did we do wrong, to deserve this?*" is commonly asked by parents (Obeidat, Bond, & Callister, 2009).

Fathers have expressed concern primarily about familial responsibilities and were interested in new information (Russell et al., 2014). Parents have verbalized powerlessness to protect their neonate from pain and distress, making them question the fundamentals of parenthood. They have also expressed fear over the outcome of their neonate upon discharge from the NICU. They wonder whether their baby would be similar to other babies; would he/she even survive; and what would his/her life be like are the common questions in a parent's mind. With significant progress in medical technology and the increased chances of survival of a preemie, the family of the preemie assumes more of a concern in this era (Schappn, Wijnroks, Venema, & Jongmans, 2013)

It is also noteworthy that the numbers of preterm neonates are increasing. This is true even in developing countries, which still have a long way to go in terms of medical advancement (Gondwe, Munthali, Ashorn, & Ashorn, 2014).

Parents of a preterm baby in the NICU often learn how to cope with these challenges and demonstrate resilience. This paper aims to discover the difficulties of parents and their coping strategies. Acquaintance with these details can help health professionals discover both the most significant struggles of parents and identify their coping strategies to help them realize their greatest expectations as parents.

Being aware of parental experience to meet the needs and concerns of the parents and enhance their satisfaction (Obeidat, Bond, & Callister, 2009) and discover the myriad of thoughts, feelings and,

expectations of a parent of a preemie is an added responsibility for the health professional. It is also the responsibility of the health professional to help the mother through uncertain motherhood towards achieving the self-concept of real motherhood (Aagard & Hall, 2008) Mothers in Northern Sweden verbalized that physical separation from the neonate is among their leading causes of stress. It also depicted that mothers were anxious and had difficulty feeling like a mother as they were not prepared to have premature infants. Mothers expressed that separation from the child was stressful as they considered being close to the child was important. Even though the family life was affected, mothers felt that handling the situation is possible with the support of the spouse and hospital staff. They also expressed that the knowledge of birth and care of a premature infant is essential and mothers wanted to be involved in their infants' care (Lindberg & Ohrling, 2008).

Parents of premature babies often feel powerless, helpless, and more stressed than a parent with a full-term baby during the initial period in the ICU (Ionio et al., 2015). In addition to the regular stress of parenthood, the stress and distress of the NICU are primarily due to the adaptation with a sick infant, the NICU environment, and their separation from the neonate. While many such studies have revealed similar findings, they often represent small sample sizes in which parents have been recruited based on convenience sampling and most of the time lack a control group of non-preterm neonates (Carter, Mulder, & Bartram, 2005). Hence, additional studies in this area are required to gather evidence. After discharge from the NICU, parental support is often deficient, especially when compared to the amount of attention and support parents receive daily during the NICU hospitalization. Neonatal nurses play a pivotal role in fostering and nurturing the parent-infant relationship. To that end, this paper aims to identify and recognize parental experiences of dealing with preemies after discharge and how they handle significant issues of parental expectations in a more empirical manner (Lindberg & Ohrling, 2008).

Numerous studies report parents with babies in the NICU experiencing several forms of stress - physical, mental, spiritual, and financial. This results in parental fear and anxiety, but may hopefully contribute to their

own maturing, evolving, and becoming a stronger individual. There exists a gap in terms of what, and to what extent, parents expect assistance from health professionals. This data indeed varies from parent to parent, and from country to country. Therefore, several studies on this topic are required to generate a working knowledge of a variety of those expectations.

A meta-synthesis was done in Jordan to assess the parental experience of having an infant in the NICU. The literature search covered in this report was for the period between 1998-2008 and utilized major databases. Fourteen articles were selected to meet the purpose of the literature review. The findings of the study addressed the themes of the feeling of stress, pain, despair, shock, ambivalence, frustration due to separation, and also found an oscillation between hope and hopelessness. The overall experience of the parents was overwhelming, and the findings suggest the promotion of parental roles, independence, and the possible value of family-centered care (Obeidat *et al.*, 2009). A descriptive qualitative study was done to assess the experience of mothers having a premature birth in northern Sweden. Narrative interviews were conducted with six mothers. The mothers had feelings of anxiety, fear, uncertainty, a desire for closeness and open communication with the health professionals (Lindberg & Ohrling, 2008). Stress was more prevalent in less educated and low-income groups (Patel, Muley, & Patel, 2015). A quantitative survey from Rwanda was conducted among 110 parents in a NICU to investigate a parent's perception of stress when their infants were admitted to the NICU. The data collected using the Parental Stress Scale showed that parents experienced stress from having their infants cared for in a NICU (Musabirema, Brysiewicz, & Chipps, 2015).

A study from the United Kingdom assessed the views of 32 mothers and seven fathers on care of their babies in NICUs in interviews conducted between June 2011 and November 2011 in tertiary NICUs in England. The parents were posed with 12 open-ended questions and thematic analysis was done. The themes identified were in terms of parental involvement, staff proficiency and competence, and communication skills of the staff. The parents ultimately wanted lot of support in the care of their neonates (Cinar, Kuguoglu, Sahin, & Altinkaynak, 2017).

A qualitative study done in Turkey assessed the experiences of fathers having premature infants in the NICU. The study data was collected using in-depth narrative interviews which extended up to 50 minutes. The findings of the study were centered on the themes of being in surprise situations. The paternal concern was primarily around the neonate, the desire to be in contact with the neonate and being involved in the care of their baby. They also were concerned about familial responsibility and always seemed to have a never-ending thirst for knowledge with matters of their neonate's concern (Russell *et al.*, 2014).

A correlation between negative conditions at birth and higher scores in some scales of the impact of event scale, profile of mood states and post-partum bonding questionnaire were found in an Italian study. Soon after birth, higher levels of stress were reported by mothers than the fathers. The study demonstrated that the NICU might be a stressful place for both mothers and fathers. Poor conditions at birth such as low gestational age, low birth weight and longer hospitalization were found to have a link to higher levels of stress and more negative feelings such as anxiety, depression, and anger both in mothers and fathers (Ionio *et al.*, 2015).

The strengths of all these previous studies included the involvement of several standardized questionnaires and tools, a large sample size and the data being collected from both the parents.

These studies were conducted in different countries. While these studies made available a lot of quantitative data, they failed to gather qualitative evidence of the experience and feelings of the parents. Further, these studies gathered data from the parents within a few days after delivery of the baby which would make these studies very reliable as it depended on the recent memory of the parents.

The data collected within a short period after delivery would also mean that the answers on the scale could be due to the early stress that the parents would have been facing in the new environment of the NICU. For these reasons, the current study data was collected retrospectively to understand the true experiences and feelings of the parents in a non-threatening atmosphere.

### Objective of the study

1. To examine the experience of parents of NICU graduates.
2. To discover common issues of concern when the neonate is in the NICU.
3. To explore issues with the growing preterm after discharge from the NICU.
4. To identify coping mechanisms in dealing with neonates admitted in NICU

### Methods

A qualitative content analysis was employed for this study. The goal of qualitative descriptive studies is a summarization of specific events in everyday terms as experienced and expressed by individuals or groups of individuals. Qualitative descriptive studies tend to draw from naturalistic inquiry, which is aimed at studying something in its natural state to the extent that is possible within the focus of the research area (Lambert & Lambert, 2020). A list of mothers whose babies were preterm (24-34 weeks) and whose age at the time of recruitment was between 18 months to 5 years of age were included in the study. Data was collected between December 2017- May 2018.

### Participants

Convenient sampling was employed for the study and mothers of NICU graduates, who satisfy the inclusion criteria, were chosen, which included preterm babies (24-34 weeks) who were admitted and discharged from the NICU and whose babies were in the age group of 18 months to five years of age, currently. The study required a detailed conversation with mothers retrospectively, after a long duration of discharge; therefore, this required a convenient selection of samples with a purpose. This sampling technique also provided the researcher with a lot of opportunities to draw the required data within the existing resources. The final sample size was six and data was collected until thematic saturation was achieved.

The researcher chose a retrospective collection of data, as no research studies in this particular topic have collected data retrospectively. Hence, this study would provide a new perspective to the experiences of the mother. The retrospective collection of data is not influenced by the emotional turmoil when the baby is in the NICU. The primary investigator (MRH) identified

the participants after getting a list of the NICU graduates from the Neonatology office after seeking due permission from the Head of the Department of Neonatology (HOD). Suggestions from the HOD regarding the communication ability of each parent who could be part of the study were sought. All parents of NICU graduates who had been admitted to St. John's Medical College Hospital, Bangalore who were ready and available to participate were included in the population of this study. Parents of the neonates born between 24 – 34 weeks who were successfully discharged from the NICU and who were currently between 18 months - five years of age were included. Parents of neonates, with congenital anomalies, were excluded from the study.

### Procedure

After permission from the Institutional Ethics Committee (IEC) (IEC 372/2017) and concerned authorities, participants were identified from the list of NICU graduates. All potential participants were contacted by telephone and the purpose of the study was explained to them. Permission to participate in the study and convenient timing of such calls to them for data collection was sought. Informed written consent was obtained to participate in the study as well as written permission to audiotape the in-depth interview and conversation was taken.

However, once consent was taken, participants preferred telephonic conversations, due to the difficulty in terms of time and energy to participate in a face to face interview. The mothers were contacted by telephone and six of the mothers agreed to participate in a telephonic interview. A series of two to three telephonic conversations ranging between 30-45 minutes were made to the mother at a time of their convenience. Thematic saturation was achieved by repeated telephonic conversations. The six mothers also belonged to the mother's support group and were the only active members. Since the sample frame was limited, a convenient sampling technique was employed and data was collected from the existing samples until thematic saturation was reached.

While collecting data, the primary investigator made sure that the participants were comfortable in discussing and answering the questions and respect the emotional

and sensitive issues which they would not like to discuss. The participants were also made comfortable for the interview by MRH being warm and friendly, and a good listener. The primary investigator paid careful attention and was prepared for strong emotions. She was capable of managing a potential crisis and strived for a positive closure, should such be encountered. However, none of the mothers had strong emotional outbreaks. All answered every question positively.

An interview guide with semi-structured questions was used. The type of questions included those addressing maternal experiences, feelings and knowledge while in the NICU and after discharge. The questions were also directed towards the type of coping mechanisms that were employed when the baby was in the NICU. Open-ended questions were also presented in order to understand maternal experiences and to probe further as the conversations progressed. The questions were validated by three experts, which included three neonatologists and a nurse. Specific prompts and probing were used as required. The conversations on the mobile phone were recorded and the data was transferred to the laptop and hard drive and stored, the same evening of the interview. A notebook was used to maintain field notes, which was later typed into Microsoft word.

**Result**

Table 1:  
*Profile of Participants*

Demographic variables	Frequency	Percentage (%)
N=6		
<b>Age in years:</b>		
20-30	2	33.33
30-40	4	66.66
<b>Gender:</b>		
Female	6	100
<b>Occupation:</b>		
Professionals	4	66.66
Nonprofessionals	2	33.33
<b>Gestational age in NICU:</b>		
24-28	1	16.66
28 <sup>+1</sup> -34	5	83.33
<b>Current age:</b>		
18 months- 3 years	4	66.66
3 years-5 years	2	33.33

**Theme 1**

*Perplexed and shocked! Lost as parents:*

The mothers of preterm babies were worried, anxious and became apathetic. To some of them, it came as a shock. They were afraid and worried. They verbalized a difficulty to adjust to terms used in the NICU (jargon), ignorance, fear, and some of them expressed being hyperalert to what the health professionals communicated. The mothers often felt terrified and helpless when they experienced their first encounter with their neonate. One mother said, *“It’s only when someone is admitted in the hospital, do we realize, how ignorant we are regarding our health care and the system in our country.”* Another mother verbalized, *“It was terrifying!! I felt terrible and helpless.”*

*“It was difficult to process the entire thing”* voiced another mother. *“I was blank; I was shocked to see my baby. She was small, 18 to 19 cm long. I was scared to touch her.”*

*“She seemed to be like a little chicken with no feathers!! Is this my baby? She has a lot of tubes,”* was the expression of another mother.

*“I went totally blank,”* said another mother. *“I kept doing things like a machine, but I felt my heart was made of stone and I could feel nothing,”* was the verbalized feeling of another mother.

These parents also verbalize their inability to protect their neonate from pain and meet his or her needs. They were filled with uncertainty, fear and worries about the outcomes of their neonate, in terms of discharge.

All the mothers seemed to go through the same set of emotions. Their primary concern seemed to be centered on the neonate’s present health status. But some parents worried about the future of the neonate as well.

*“How will my child’s future be?! Would he be alright physically, mentally?!”*

The mothers seemed to be anxious about the future of the child in terms of normalcy, but it was few mothers, who were concerned about the child’s future.

**Theme 2**

**Quest for knowledge**

The mothers were highly alert but becoming more familiar with medical terminology was the greatest challenge.

They seemed to be vigilant and were hyper-alert, often picking up terms quickly. They seemed to be aware not only of the medical condition and progress of their neonate but also about the other neonates in the NICU, who were around the same age. One mother said, “I used to Google and read the prognosis.” Mothers felt the need for daily counseling and reassurance from their doctors. They also wanted their doctors to communicate the overall progress of the neonate rather than only stressing on the problem areas. These parents seemed to want in-depth enlightenment of their baby’s condition from treating health professionals.

*“I want to know everything about my baby, good and bad, how he is progressing and about his total well-being, not just the problem areas,”* was the plea of one mother. *“We need to be informed,”* was another mother’s concern. They wanted to be aware. However, the mothers seemed satisfied with the promptness of the doctors in answering the questions of the parents.

*“When the neonatal doctors used to call us for counseling, we would get scared. Some doctors were good, but some were harsh. It would have been great if they were a little more co-operative. The hospital caters to a mixed population, some doctors talk to us like we are totally ignorant, and we need to know only, what they say. It’s their verbal tone and attitude in dealing with us, which sometimes made us sad.”*

### **Theme 3** **Acceleration of emotional stability, patience and a sense of accomplishment.**

These mothers verbalized a strong sense of emotional stability and strength. Though the initial few days took a huge emotional toll on them, in later days, they became strong like warriors. *“I eventually learnt practicality, patience, positivity and also felt there was no use or point of cribbing”* said one mother. *“I gained firsthand experience in becoming hard working, resilient, in being confident, courageous and full of hope even when the chances seemed bleak.”* It was as if positivity flowed with each negative incident. The confidence as a parent and as the neonate’s care-taker increased rapidly, even in one week’s time. *“I was able to handle my baby, calm my baby, understand the complexity of the readings on the machine and at a point, I was able to reach out to help other mothers going through the same situation”*, was the expression of one mother. *“Patience and the covert ability to care came to the surface, when I had to take care of my neonate,”* said another.

*“Today, when I see my kid, I realize that no one could have done it better than me!”* proudly exclaimed yet another mother.

### **Theme 4** **Understanding gaps in care and accepting human frailty, and sometimes NOT!!:**

Though parents were going through tough times, they became very observant and were quick to identify gaps in care or negligence. But surprisingly they all seemed to be very non-judgmental about such gaps and generously quoted that, *“it’s understandable, the physicians and nurses are overworked and sometimes another baby would need more of their attention than mine.”* Some nurses seemed to be rash and rude. The attitude of certain nurses was that parents are not capable of comprehending the neonate’s condition.

Examples of perceived negligence in care that mothers observed at times were included.

*“I used to always hang around the NICU because at one point of time I experienced negligence in the care of my baby, where my baby’s oxygen was disconnected to help another baby, though the nurse was aware of the dependency of my baby on oxygen,”* observed one mother.

*“Sometimes, during shift changes and in the evening and nights, there would be a delay in administering medications or feeds, but I used to fill in for them during problem times.”*

### **Theme 5** **Volunteering to help other parents**

A trait that all mothers demonstrated was one of volunteering to be helpful. An innate desire to reassure others seemed to blossom once the mothers were able to cope. *“After a week, I became an expert. I used to motivate them and help them,”* verbalized one mother. *“I became bolder, stronger and filled with confidence and it was because of other mothers support when I was a newbie, so, I, in turn, would do anything to help the other mothers.”*

*“The mothers’ support group was my greatest reassurance, it gave birth in me new hope and optimism that kept me going,”* said one mother.

*“The mothers who stayed with me, held me through my most difficult times, only a person who experienced the same would be of the greatest help,”* said yet another.

## Theme 6

### Health professionals not as supportive as they should be

Mothers in this study observed that most of the doctors and nurses seemed supportive and sympathetic. They were clear and helpful, and they motivated the parents. However, some others found that certain doctors were not as empathetic as they should be. They also verbalized that some doctors told them forthrightly that they should discontinue care. One mother verbalized this, saying, *“I was ready to fight, and she was ready to fight, and I was not willing to give up on her, then why did doctors communicate in that way to me.”*

*“It’s not just the problem areas that we want to know, we want to know everything about our baby”*, said one mother. This shows that there is a need for the health professionals should be clear, direct, reassuring, and polite when dealing with the parents.

## Theme 7

### Strengthening support services for mothers

All the mothers felt that mothers in the NICU needed a lot of support and encouragement, and they all wanted psychological counseling made available daily. They also wanted their doctors and nurses to be proficient in many languages, so communication would not be difficult. They desired to be helped and encouraged daily, believing that if mothers were supported well, their neonates would improve. Amidst all of this, they also wanted some rest to be facilitated. Some verbalized a need for music therapy, *“It would be great, if the health professionals were proficient in all languages or at least a translator should be available. Already everything is Greek and Latin to us, I mean the medical jargons and if the health professional does not know the language, it is even more difficult,”* verbalized a mother.

## Theme 8

### Common issues and coping

The common issues that the parents experienced included a myriad of health issues their neonates experienced, a never-ending list of medications, and the numerous therapies and surgeries that their neonates had to go through. The most common medical concern being respiratory distress, the requirement of prolonged ventilation and other breathing issues. The concern for weight gain, feeding issues, lack of milk, or

an excess of milk coupled with an inability to feed the baby were significant issues that complicated the wait for a discharge date.

Mothers noted that as the neonate was growing, they focused upon feeding issues; throwing up after a feed; a baby who was irritable most of the time, especially at night; constipation; thinking that their baby was weaker than other babies of the same age, or smaller in size, or perceiving their infant was slower in matters of infant development than other babies. All these matters brought concerns and stress to these mothers, even when their babies were affected by the smallest of symptoms.

As days went by and discharge was near, parents turned their concern towards how adequate they felt in caring for the baby, identifying any concerning issues, the distance of the health facility in case of an unanticipated problem, and the burden of the entire responsibility for the baby being on the mother who would be alone at home during the day.

Speaking after NICU discharge, parents also feared the long-term development of the child. *“My kid is slow in her physical development and her speaking skills,”* said another mother.

*“I feel they are weaker than the kids of their age, who were born when they were full-term,”* was the complaint of another mother.

Most mothers reflected that their coping was mostly facilitated by familial support and the constant reassurance and counseling that came from their family, doctors and nurses. The mothers seemed to get a lot of solace by just staying in the NICU all day long. Reading about their baby’s condition also helped them through. Nevertheless, the value was seen in speaking with health care professionals. *“Another coping skill of mine was frequenting the hospital every single week, I would not be satisfied until I spoke to a health professional,”* were the words of one mother.

All the women demonstrated a lot of faith and spiritual belief in supernatural power. *“It was God and my family that helped me through”* were the words of nearly all the mothers.



Some of them verbalized that power naps helped them through. Each positive goal attained by their neonate seemed to keep the mothers strong.

## Discussion

The current study was conducted on mothers who had their preterm babies admitted in the NICU and had graduated from the NICU successfully. The study conducted interviews with mothers telephonically to gather data retrospectively about their experiences in dealing with preterm babies, their expectations from health professionals and their coping mechanisms in dealing with the babies. The current study was done among six mothers from the same geographical region.

The methodology employed in the current study was different from the majority of published reports on parental stress in the NICU. It was qualitative and involved intense long telephonic conversations with a semi-structured interview schedule about the feelings, experiences and, expectations of the mothers – looking back at the journey they traversed. The answers given by the mothers were (the shock, the mother's quest for knowledge, the progressive strengthening of emotions, understanding gaps in care, volunteering to help other patients, need for supportive health personnel and the coping mechanisms applied) not based on the stress that they were going through currently. The mothers were able to speak truthfully and with a lot of insight without the fear of being judged or the care to their baby being jeopardized, which could be stated as the strength of the current study. As seen in the previously reported literature, most prior studies examined the stress and experiences of both the parents quantitatively, using a series of validated questionnaires and tools and their sample sizes were larger. The data was collected within a few days after the delivery or before the discharge of the babies from the NICU. The authors of the current study believe that such timing more likely than not introduced different stresses which failed to capture other important perceptions that could only be elaborated in a qualitative study.

A study was done in the UK identified themes of parental involvement, staff proficiency and competence and, the communication skills of the staff, which was similar to the themes of the current study where the mothers expected the health care professionals to be

competent and communicate regularly (Cinar et al., 2017). Findings of a quantitative study done in Milan, depicted that the NICU was a stressful place for parents, which is similar to the findings of the current study (Ionio et al., 2015). The appearance of the baby was a concern, which was similar to the findings of the study done in Rwanda (Musabirema et al., 2015). A correlation between negative conditions at birth and higher scores in some scales of the impact of event scale, profile of mood states and post-partum bonding questionnaire were found in a 2016 Italian study (Ionio et al., 2015). In administering the Parental Stressor Scale: Neonatal Intensive Care Unit, the Impact of Event Scale Revised, Profile of Mood States, the Multidimensional Scale of Perceived Social Support and the Post-Partum Bonding Questionnaire to 40 mothers and fathers of premature infants, and also to 40 mothers and fathers of term infants, it was demonstrated that the NICU might be a stressful place for both mothers and fathers. This study was quantitative in design and its strengths lay in its use of numerically and objectively quantifying the stress of both parents, using multiple scales, and using a control group of parents of term infants. This contrasted with the current study which involves only qualitative analysis.

A qualitative study done in Turkey assessed the experiences of fathers having premature infants in the NICU. The study data was collected using in-depth narrative interviews which extended up to 50 minutes. The findings of the study were centered on the themes of being in surprise situations; the paternal concern was primarily around the neonate, the desire to be in contact with the neonate and being involved in the care of their baby. They were also concerned about familial responsibility and always seemed to have a never-ending thirst for knowledge with matters of their neonate's concern (Russell et al., 2014). The thirst for knowledge was a common factor in the current study as well, though the study samples consisted of only the mothers.

A descriptive qualitative study was done to assess the experience of mothers having a premature birth in northern Sweden. Narrative interviews were conducted with six mothers. The mothers had feelings of anxiety, fear, uncertainty, a desire for closeness and open communication from the health professionals.

They also verbalized that separation from their infant was among the leading causes of stress and they expressed the need for support from the family to help them perform their maternal duties well (Lindberg & Ohrling 2008). This study is like the current study in terms of the methodology and results. However, the current study interviewed mothers over the telephone with a minimum of two to three phone calls lasting between 30-45 minutes.

A quantitative survey from Rwanda was conducted among 110 parents to investigate their perception of stress when their infants were admitted to the NICU. The Parental Stress Scale was used to achieve the data. The results indicated that parents experienced stress from having their infants cared for in a NICU. What was most stressful for these parents was the appearance and behavior of the baby. The study also depicted the association between parent's age, educational level, occupation and infant birth weight. The study brought out quantitatively the various factors responsible for parental stress. It also brought out that communication with the staff was a challenge for the parents, which was like the findings of the current study (Musabirema, Brysiewicz *et al.*, 2015).

This study served as a platform for the mothers to speak openly about their experiences and share their insights for the benefits of other NICU babies in a non-threatening atmosphere. It demonstrated the fact that these mothers were keen on helping other NICU mothers and in increasing the support services for the mothers during their neonate's hospital stay.

It is noteworthy that this study, which explored the feelings, experiences and insights of NICU mothers, has produced data that corroborates the findings of other studies. The data that was achieved was immense and depicted the true expectation of a mother in an Indian scenario.

### Strengths

The study helped the primary investigator (MRH) to gain insight into the experiences, the coping mechanisms and the expectations of parents of preemies.

### Limitations

The study was completed by MRH in a short period and many of the parents preferred speaking on the phone

rather than speaking in person. As such, non-verbal cues or reactions were not captured. Though the study was intended to identify the experiences of parents, the six interviewed subjects all happened to be mothers. If the sample contained both fathers and mothers, the unique way of the response of both parents could be assessed.

### Conclusion

This study identifies the difficulties mothers experience during their stay in the NICU, and their expectations from healthcare professionals. The mothers were anxious, worried, apathetic, vigilant, observant and were searching for knowledge. As days progressed, they felt a sense of emotional stability and strength. The mothers expected the health professionals to be more sensitive, supportive, encouraging and communicate proficiently, regularly and clearly in all languages. Mothers also verbalized a need for music to soothe them and time for rest.

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