

# “The Lived Experiences Of Mothers In Neonatal Intensive Care Units Having Newborns: A Phenomenological Study”

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## Abstract

**Background:** The admission of a newborns in a Neonatal Intensive Care Unit (NICU) is an emotionally devastating event to mothers. It interferes with maternal expectations, disrupts the bonding process and in most cases, evokes anxiety, guilt, and helplessness. These experienced emotional experiences should be understood to deliver comprehensive and compassionate nursing care. **Purpose:** The purpose of the study was to examine and narrate lived emotional experiences of mothers with newborns that were admitted to the NICU through a phenomenological approach. **Methods:** A qualitative phenomenological research design was used. Through purposive sampling, fifty mothers whose newborns were taken to the NICU of a tertiary care hospital were selected. The data were gathered by using semi-structured in-depth interview in a private environment. The audio-taped interviews were transcribed word-to-word and analysed under Colaizzi method to determine the emerging patterns and themes of emotional experience. **Findings:** The analysis showed that there were 5 key themes namely: (1) Emotional turbulence-feelings of fear, anxiety, and helplessness; (2) Disrupted maternal identity-sense of inadequacy and guilt; (3) Hope and faith as coping strategies; (4) Need to communicate and have support by the healthcare professionals; and (5) Emotional adaptation and resilience over time. According to mothers, emotional distress was significantly decreased by empathy, clear information and participation in infant care. **Findings:** The results point to the fact that mothers of infants in the NICU experience a complicated emotional process with distress, uncertainty, and slow adjustment. Introducing family-centred care, emotional counselling, and regular communication in NICU units is able to significantly improve maternal well-being and encouraging positive coping.

**Keywords:** Phenomenology, maternal emotions, neonatal intensive care unit, lived experience, coping, qualitative research.

## Introduction:

The birth of a child is a life-changing event that is usually viewed as a happy and satisfying experience to a mother. Nevertheless, in cases when a baby needs to be admitted to Neonatal Intensive Care Unit (NICU) this experience can be both emotionally troubling and psychologically traumatizing to mothers<sup>1</sup>. The NICU setting, including its complicated medical equipment, alarms, and limited access to their children, results in fear, anxiety, and helplessness among the mothers<sup>2</sup>. The process of natural bonding between mother and child is disrupted by separation at birth and increases maternal stress levels even further<sup>3</sup>.

In a case of mothers who have given birth to newborns through NICU, they are burdened with the uncertainty regarding the survival and health conditions of the baby, which causes an emotional

exhaustion and loss of perceived maternal role<sup>4</sup>. The novel medical environment and reduced contact with healthcare workers are also additional factors leading to the feeling of alienation<sup>5</sup>. Research has indicated that these experiences may predetermine mothers with depression, post-traumatic stress, and dysfunctional family functioning<sup>6</sup>.

It is imperative to comprehend the emotional experience of the life of these mothers in order to develop helping interventions to meet their informational and psychological needs. A phenomenological method is especially suitable, as it is possible to deep dive into the subjective meaning and emotional realities that mothers attribute to their NICU experience<sup>7</sup>. Such studies can also provide insights that help the nurses and other healthcare professionals to offer caring and supportive family-driven care that can be used to support maternal health and improve neonatal outcomes<sup>8</sup>.

Thus, the paper aims to identify and describe the emotional experience of the mother of a child in the NICU once it is put there to understand their emotional experiences and coping techniques in a deeper manner.

### **Background of the study:**

Psychological distress occurs high among the parents of newborns in the Neonatal Intensive Care Units (NICUs) around the world. A meta-analysis and systematic review of 6,822 parents (5,083 mothers, 1,788 fathers) revealed that the combined rate of anxiety in mothers was approximately 51 (95% CI 41-61%) and depression 31 (95% CI 24-38%). The levels of stress in mothers in NICU units were found to be 41% (95% CI: 31-51%).<sup>9</sup>The identical study demonstrated that the level of stress, anxiety and depression were significantly greater in mothers than in fathers.

A second meta-analytic report of 53 studies in various countries based on the Parental Stressor Scale: NICU (PSS:NICU) established that alteration of parental role (i.e., failure to play their expected role of mother) was always the most important source of stress among both mothers and dads.<sup>10</sup> In addition, physical environmental factors particularly sight and sound in the NICU were highly ranked as causes of parental stress across the world.

Stress and emotional disturbance of mothers of newborns admitted to Neonatal Intensive Care Unit (NICU) is significant in India and has not been studied. In Eastern India, in one cross-sectional study, out of 100 NICU parents (mothers and fathers) 60.8% were found to be severely or highly stressed as assessed by Parental Stressor Scale: NICU (PSS:NICU), the most significant stressor being the visuals and auditory stimuli in the NICU.<sup>5</sup> The average of the total stress was 3.71 (0.70).<sup>6</sup> In a second study involving 74 mothers whose newborns had at least five days in the NICU, 45% of the mothers were moderate stressed, 24% were highly stressed and 31% were lowly stressed; the perceived stress was moderate (mean 3.36 +0.67) on the PSS:NICU scale.<sup>11</sup> These records indicate that in diverse environments in India, emotional stress among mothers in NICU is not rare and frequently acute, particularly in areas of parental role change and physical environment.

In addition to that, it is not only stress that impacts the mothers but can also be experienced in terms of quality of life and the level of anxiety. As an illustration, in a study of 135 mothers whose newborns had spent at least 48 hours at the NICU, there was moderate negative correlation ( $r=0.467$ ) between parental stress in relation to NICU condition (appearance, behavior of the newborn, environment, etc.) and the quality of life of the mothers in terms of SF-36.<sup>10</sup> In another descriptive study, using a standard anxiety rating scale, the authors only included mothers of preterm newborns ( $n=50$ ) who lived in Vadodara, they identified the following prevalent results: very severe anxiety (58%), severe anxiety (22%), moderate (10%), and mild (10%) anxiety.<sup>12</sup> The results highlight the intense emotional load and the necessity to investigate the emotional experiences of mothers in NICU settings in more depth, to be able to develop culturally sensitive ways of providing support.

## **Methods and Materials**

### **Study Design and Rationale**

This paper adopted the descriptive phenomenological methodology to describe the lived emotional experiences of mothers whose newborns were placed in the NICU. Such a method is appropriate to comprehend individual and subjective experiences without giving them meaning so that the researchers can explain the feelings of the mothers, coping mechanisms, and difficulties in taking care of their hospitalized newborns. The design focuses on the consciousness deliberateness and deliberate setting the preconception of the researchers so that the results can reflect the genuine experiences of the participants.

### **Studying Team and Reflexivity.**

The study was carried out by a group of maternal and neonatal health professionals who had wide experience in qualitative research. There was no relationship between the researchers and the participants before. Prior to data collection, each individual member of the team recorded his and her assumptions and beliefs about the maternal experiences in NICU settings, which contributed to reducing bias and guaranteeing objectivity in recording the views of the participants.

### **Setting**

The research took place at a NICU of a Narayana Medical College Hospital located in Nellore, Andhra Pradesh, India, a State with high-risk neonatal care referral center. The facility was selected because it has a large number of patients with diverse needs, it is specialized in neonatal care and all mothers irrespective of their socio-economic backgrounds are accessible.

### **Participants**

Mothers in the study population had to be 18 years and older with newborns spending over five days in the NICU to be included in the study. Mothers who had serious medical or psychiatric conditions were eliminated. The involvement was voluntary and informed consent was provided before the data collection.

### **Sampling and Sample Size**

Purposive sampling strategy was adopted to select mothers who would have a profound understanding of the phenomenon. The collection of data was done until data saturation was achieved and 50 participants were realized.

### **Data Collection**

The interviews were done individually and in a semi-structured format, and in a private room within the vicinity of the NICU. A guide on the interview was made using the goals of the study and available literature on maternal stress in NICUs. All the interviews took about 40-45 minutes and were tape-recorded. The participants were free to discuss their experiences and clarifying questions were used to examine the emotional and psychological side of experience in the NICU.

### **Data Management**

Interview transcription was done verbatim and all the interviews in local languages were translated to English through back-translation process to maintain the intended meaning. Pseudonyms secured the identity of participants, and all electronic data were saved in a safe place with passwords.

### **Data Analysis**

The analysis of the data was conducted with the help of the phenomenological approach of Colaizzi that implied several readings of transcripts, distinguishing important statements, deriving meanings, grouping them with the help of themes, and creating a comprehensive description of the phenomenon. Participant feedback was used to validate the themes to make them credible. The analysis was performed in an iterative manner, that is, as the data was being collected to understand and interpret it.

## Results

### Demographic Characteristics

The study involved fifty mothers. Table 1 shows the length of stay of their babies in the NICUs. The minimum stay was 5 days and the maximum stay was 60 days with the mean length of stay coming to about 21 days ( around 3 weeks).

**Table 1. Demographic characteristics of participating mothers**

Mother	Number of days on admission
1	12
2	25
3	7
4	30
5	21
6	45
7	10
8	28
9	14
10	35
11	19
12	8
13	22
14	16
15	40
16	9
17	18
18	27
19	12
20	33
21	15
22	26
23	7
24	38
25	20
26	11
27	24
28	17
29	13
30	50
31	12
32	22
33	9
34	31
35	14
36	29
37	16
38	21
39	10
40	44
41	18
42	27

43	15
44	36
45	12
46	23
47	9
48	20
49	8
50	55

The statistics indicate that on average, mothers spent three weeks of NICU, which is indicative of both short-term and long-term hospitalization.

Themes and Sub-Themes of The Parable of the Invisible Gardener.

The transcripts of the interviews disclosed the existence of five key themes that were related to the emotional experiences of mothers when they were admitted to the NICUs. These themes embody the mental, social and realistic sides of life coping with a hospitalized newborn.

**Table 2. Summary of themes and sub-themes**

No.	Themes	Sub-themes
1	Emotional turbulence	Fear, anxiety, helplessness
2	Disrupted maternal identity	Feelings of inadequacy and guilt
3	Hope and faith as coping mechanisms	Religious faith, positive thinking
4	Need for communication and support	Empathetic staff, information sharing
5	Emotional adaptation and resilience over time	Gradual adjustment, strengthened coping

### **Emotional Turbulence**

This theme represents the high emotional reactions of mothers after their birth of a baby that is admitted in the hospital. The general feeling was anxiety, apprehension of the unknown, powerlessness:

I felt afraid that I will lose my baby; each beep of the monitor was awful. (Mother 7)

There are days when I was optimistic and days when I was totally helpless the situation is emotionally exhausting (Mother 19).

The NICU experience was said by mothers to have been overwhelming with highs and lows of hope and despair experienced when their infants are at the hospital.

### **Disrupted Maternal Identity.**

Most mothers said that they felt inadequate and guilty and frequently they doubted their capability of taking care of a vulnerable baby:

I believe that I did not do a good job as a mother because I did not manage to take the baby home safely. (Mother 12)

I am always anxious whether I am doing enough to make my baby recover. (Mother 35)

A sense of interrupted maternal role was brought about by the distance between them and their newborns, as well as dependence on the care providers.

### **Coping Mechanisms of Hope and Faith.**

Hope, optimism, and religious or spiritual faith were commonly employed by the participants in overcoming stress:

Praying helps me to have the strength to enter into every day. (Mother 21)

I continue to remind myself that my baby is in the best care and things are going to improve (Mother 5).

This theme shows the defensive nature of internal beliefs and optimism in dealing with emotional distress.

**Healthcare Professionals Communication and Support Requirement.**

Mothers highlighted the need of sensitive communication and regular information sharing with the NICU employees:

The nurses explain everything properly and that is why I feel like I am a part of the care that my baby obtains. (Mother 8)

There are those members of staff who are kind and supportive, and those who are distant, and this causes me to be anxious (Mother 44)

Availability of information and supportive contacts was a great way of alleviating maternal anxiety and encouraging a sense of confidence in caregiving.

**Later Adaptation and Temporal Resilience, Emotionally.**

During the hospitalization, mothers stated that they were slowly adjusting to the NICU setting and they became resilient:

Initially I was very much scared but I am feeling more secure now with my baby and am involved in the care. (Mother 30)

I have also been able to learn how to be calm and concentrate on what I can do to my baby. (Mother 50)

Involvement in care and support provided by the staff and seeing changes in their babies made mothers feel in control again.

**Difficulties in Maternal Involvement.**

Even though the experience was positive, mothers encountered obstacles, such as inadequate staff interaction and unavailable facilities:

In some cases, I have been motivated to assist, but there are those instances when nurses do not engage me at all. (Mother 17)

We lack a decent place to sleep hence, it is quite stressing to stay here.

These issues highlight the importance of systematic family-based practices and positive NICU settings.

## **Discussion**

The research question that was addressed in this investigation was what emotional lives mothers undergo after giving birth to preterm infants and being hospitalized in a tertiary care NICU. Interpretation of interviews found five significant themes: (1) emotional turbulence, (2) disrupted maternal identity, (3) hope and faith as coping strategies, (4) need of communication and support of healthcare professionals, and (5) emotional adaptation and resilience with time. The results shedding light on the close relations between maternal feelings, roles in care giving, and the NICU environment.

### **Maternal Anxiety and Emotional Turbulence.**

The women in this study expressed intense emotional distress right after they had given birth to preemies. Fear, powerlessness, anxiety, and sadness were prevalent and many participants often put their experiences as an emotional rollercoaster. These responses indicate the interference of the expected maternal functions and the abruptness of a high-intensity care setting. In line with other researchers who

have earlier carried out their studies in Kenya, Colombia, Spain, and Ghana, preterm birth had been linked to increased maternal anxiety, stress, and susceptibility. These results highlight the need to acknowledge maternal emotional needs as part of the neonatal process since the emotional distress may influence the well-being of mothers and the outcomes of infants.

### **Hope, Faith and Coping Mechanisms.**

The respondents mentioned that hope, optimism, and faith were the key coping strategies in the face of the uncertainty of NICU admission. Religious beliefs and optimism were especially significant to deal with emotional stress. Other previous international studies have noted similar observations, and they have established that negative psychological impacts of preterm birth and hospitalization can be alleviated by internal coping strategies.

### **Maternal Involvement and Family-Centered Care (FCC).**

The FCC method proved to be one of the most important aspects to relieve maternal distress. Mothers noted that involvement in the care of their infants, access to information and advice by NICU staff helped create a feeling of confidence, reassurance and control. These results are similar to those in Iran and Uganda where FCC had a positive influence on maternal involvement and neonatal outcomes. Mothers considered the ability to carry out the most important caregiving practices like skin-to-skin contact (SSC), support with breastfeeding, and involvement in pain management. Repetition of SSC, specifically, led to the decrease of fear and the rise of confidence to work with fragile newborns, which contributes to the importance of SSC in preterm care.

### **Mothering Roles of Preterm Care.**

Mothers recognized their pivotal role in infant health promotion initiative by SSC, breast feeding, and pain management. Nurse-led education was used to inform mothers about the indications of discomfort, comfort, and appropriate nutrition. The findings are supported by the studies carried out in China and Colombia, and the fact that mothers need to be provided with the knowledge and skills to deliver active neonatal care. Importantly, mothers in this research were less concerned with the physical and emotional requirements of breastfeeding, which could indicate a robust support of the healthcare staff and family members, as well as the resilience that occurred during the period of hospitalization.

### **Difficulties with Maternal involvement.**

Although the experiences were positive, some of these mothers mentioned some barriers to complete involvement in care, such as the attitude of the staff to them, a lack of accommodation, and a lack of resources. Other orderlies and nurses were also viewed as non-supportive, and this was detrimental to maternal interaction. Such results are contrary to the previous research in Ghana in which maternal involvement was more facilitated regularly, so the staff training, workload, and infrastructure could impact the implementation of FCC. The inability to have adequate rest and accommodation facilities by mothers also added to the stress and reduced their capacity to participate in the full caregiving activities. The systemic interventions based on the staff attitudes and hospital infrastructure are thus necessary to improve the maternal involvement and the total experience in the NICU.

### **Implications for Practice**

The article highlights how psychological support, structured FCC, and parent education need to be incorporated into the NICU protocols. Medical workers are expected to expect maternal demands, communicate in a non-judgmental manner, and empower mothers by giving them a prominent role in care. Personalized interventions targeting emotional, informational and practical needs can help reduce distress and improve maternal-infant bonding and eventually lead to better neonatal outcomes.

### **Conclusion**

This paper emphasizes that the mothers of the newborns admitted to the NICU undergo a complicated and multidimensional emotional process. A thematic analysis showed that five key themes were identified, which are emotional turbulence, characterized by fear, anxiety, and helplessness, disrupted

maternal identity, which manifests itself in inadequacy and guilt, hope and faith as coping strategies, the necessity to communicate and receive support in healthcare workers, and emotional adaptation and resilience in the long term.

The mothers have made claims that empathic communications, comprehensible information, and active participation in taking care of the baby minimized the emotional distress and gave them confidence in the process of care giving. The findings highlight the relevance of organized family-centered care, continuous emotional counseling and regular communication in the NICU environment to care about maternal welfare.

Through these emotional challenges recognition and encouragement of the mother involvement, the healthcare providers may promote maternal resilience, maternal-infant bonding, and better overall outcomes among the mothers and the babies. Individualized interventions which meet the psychological and informational needs of the mothers are thus necessary in alleviating stress levels of NICU hospitalization and promoting positive maternal coping.

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**Mothers and public intervention:** The design, conduct, reporting, and dissemination plans of this research did not involve mothers and/or the public.

**Availability of data:** This study data will be available by a reasonable request of the first author.

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