

## Experience of Mothers towards Hospitalization of Preterm Infants in Neonatal Intensive Care Units

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### ABSTRACT

**Introduction:** Hospitalization of the preterm infant (PTI) in the neonatal intensive care unit (NICU) is a stressful situation for mothers requiring nurses' care and support for adjustment and coping. Understanding mothers' experience is valuable for enhancing care and support for them. Therefore, this study was conducted to explore mothers' experience regarding hospitalization of PTIs in NICUs.

**Methods:** The qualitative pilot study was conducted among purposively selected 5 mothers of NICU admitted PTIs in a public academic hospital of Bagmati province from May to July 2019. After obtaining ethical approval, in-depth interviews were conducted using interview guideline. The data were analyzed using the content analysis method.

**Results:** Exploration of mothers' experience has identified 4 themes: worry and uncertainty regarding the condition and outcome of the PTIs; altered attachment and maternal roles; attachment, and care enabling with care involvement; mixed experience of care, and support.

**Conclusion:** Hospitalization of PTIs in NICUs was distressing to mothers related to inadequate and altered attachment, and maternal roles. They experienced mother-infant attachment, contentment, and care enabling with involvement in PTI care. They valued nurses' PTI care and care guidance and expected more guidance, communication, and emotional support. Considering study findings might be worthwhile for enhancing care status in NICUs.

**Keywords:** *Mothers' experience, Neonatal care unit, Preterm infant, Care and support*

### INTRODUCTION

Each year around 14.8 million infants are born preterm globally and 81,000 in Nepal.<sup>1,2</sup> Preterm birth increases the biological risk for morbidities and mortalities requiring special care in the NICUs for survival and development. Studies done in the global and national context showed a higher prevalence of PTIs in NICUs (28.25%, 14%, and 20%).<sup>3-5</sup> The treatment needs and hospitalization duration depend on the degree of prematurity and related health problems of the PTIs. Mothers of NICU admitted PTIs experience more emotional distress related to the condition and progress of the PTIs as well as separation, and inadequate and altered maternal role.<sup>6-9</sup>

Because of early and prolonged separation, and special care needs of the infant, these mothers lose their self-confidence and feel incompetency in playing their maternal roles.<sup>10,11</sup> Previous studies showed mothers' appreciation for nurses' competent and compassionate PTI care.<sup>12,13</sup> They also valued nurses' guidance and support for adjustment and care confidence.<sup>10-12,14</sup> Nevertheless, they indicated inconsistencies in healthcare team communication and reported receiving limited emotional and practical support.<sup>13,15</sup> They also expressed the need for adequate guidance and support for coping as well as for care enabling.<sup>13,15,16</sup>

Enhancing care and support considering the experience of mothers is important for their coping and care enabling. So that, mothers can provide better care to their PTIs for better short and long-term outcomes. Nevertheless, a dearth of information is available regarding the experience of mothers of PTIs in the Nepalese context. Therefore, a study was conducted to explore the maternal experience regarding hospitalization of their PTIs in NICUs. So, that findings might be useful for improving the care and support in neonatal care.

### METHODS

A qualitative exploration was part of the mixed-method pilot study. The study was done among purposively selected 5 mothers of NICU admitted PTIs of a public academic hospital of Bagmati province of Nepal. Ethical approval for the study was obtained from the Nepal Health Research Council. Administrative permission was obtained from the study site. Written informed consent was obtained from the mothers for participation and the audio recording of the interviews.

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To collect the data in-depth interviews were conducted by the first author (scholar) using open-ended and probe questions. The interviews were conducted after the transfer of PTIs from NICU to the neonate unit and before discharge. Interviews were conducted considering convenient time for mothers when they were free of baby care and family members were available to look after the PTIs. Interviews were conducted considering the comfort and privacy of the mothers. The quiet environment was considered also for the recording purpose. Each mother was interviewed 1-2 times for about 20-50 minutes. The interviews were recorded and field notes were taken.

The qualitative data were analyzed using the content analysis method. Audio records were transcribed and translated into the English language. After reading the transcripts, meaning units were identified and coded. Initial codes were copied in another sheet, grouped, and formulated sub-categories. Combining subcategories and categories main themes were formulated. The formulated themes and categories were reviewed with generated codes and the entire data set. Finally, themes were developed.

Measures were used for the trustworthiness of the qualitative data. To maintain credibility, mothers having adequate experience who were interested and willing to share their experience were included in the study (purposive sampling). The member check was done with two mothers (M1, M5). To maintain dependability co-author checked the analysis process and study findings. For conformability, a description of the research process was done. For transferability study context, and research process described. The findings were reported with the quote expressed by the mothers.

**RESULTS**

The socio-demographic information of PTIs showed that four were born normally with gestational age 30-32 weeks (very preterm), and birth weight 940-1820 grams (low birth weight) (Table 1). The hospitalization duration ranged from 14 days to two months. Mothers' age ranged from 23 to 29 years. They were secondary level or above educated. Four of them were primi mothers, homemakers and three of them belonged to the joint family.

Table 1: Socio-demographic Information of the Mothers and Preterm Infants

P.N	Mother's			Infants'		
	Age (Years)	Education Level	Gestational Age (weeks)	Birth Weight (grams)	Sex	Hospitalization Duration (days)
1	23	Higher secondary	31	940	Female	61
2	25	Bachelor	30	1300	Male	53

3*	29	Secondary	32	1600	Male	14
4	27	Secondary	32	1820	Female	27
5#	26	Secondary	31	1135	Female	31

PN: Mother number \*: Operative birth, twins, one stillbirth  
#: Multi Para

Analysis of the qualitative data related to the experience of mothers in NICU has identified 4 themes and 10 subthemes (Table 2).

Table 2: Subthemes and Themes regarding Mothers' Experience

Themes	Sub-themes
Worry and uncertainty	Fear, stress, and worry for the condition of the PTI
	Insecurity about the PTI's health outcome
Altered attachment and maternal role	Inadequate attachment and maternal role
	Lack of confidence in PTI care
Attachment and care enabling with care involvement	Challenging breastfeeding role
	Nurses' guidance and support for PTI care
	Attachment with care involvement
Mixed experience of care and support	PTI care confidence with self-care
	Satisfied with PTI care
	More expectation for maternal support

**Worry and Uncertainty**

Mothers were worried about the unexpected preterm birth, admission of PTIs in NICU, and day-to-day health condition. They had fear and concern regarding the survival of their PTIs. They were eager to attend the parent's counseling about the PTI's condition and also stressed the possible negative information like deterioration or added problems. Mothers less participated in the counseling with fear and inadequate decision authority. Following verbatim explicit it.

*"There were 2-3 preterm babies in NICU. Not all babies are discharged with recovery. Today one baby died, so feeling very bad. We wait eagerly for counseling about the baby's condition and also be worried about the information about getting worse. Sometimes, there may be the need to discuss conditions and treatment. So, my husband attends the counseling." (M4)*

### Altered Attachment and Maternal Role

Mothers were allowed to visit their PTIs in NICU once a day during visiting time for a while according to unit rules. They were eager to meet their PTIs frequently, be close, touch, and hold on to their lap. Sometimes, their visiting schedule was influenced by the unit's busy schedules, baby's condition, mothers' health conditions like operated birth, and the distance between the NICU and the post-natal ward. They could see their PTIs without touch and being close. A mother stated, "During visiting time, they allowed seeing our baby from the glass window. We couldn't see our baby while going to provide expressed breast milk (EBM) as the room is separate." (M2)

They had controlled their desire as they were explained about infection risk to their PTIs. On the other side, they were distressed correlating the unfavorable situation of similar cases with their own. Following verbatim clarify it.

*"They (health personnel) explained to us about infection risk. So, we visit rarely despite a strong desire for it. However, if something happened bad (death), feeling guilty for not seeing him would occur. Therefore, I felt a strong desire to see him."* (M2)

Furthermore, mothers had limited PTI care roles like providing expressed breast milk (EBM). They perceived providing EBM as a significant contribution despite an unexpected, and relatively difficult role. Gradually with the improved condition of their PTIs, mothers were involved in PTI care like kangaroo mother care (KMC) and feeding EBM for a few episodes or days as the preparation for shifting the PTI from NICU. After shifting the PTI from NICU, they were responsible to provide all care. They experienced PTI care as different and difficult. Following verbatim clarify it.

*"I used to go there from early morning to late evening to give the EBM that much I could do for her. Now I am feeding her. It is very difficult and time-consuming as she is always drowsy. I have to try it again and again. Otherwise, her weight will decrease the next day."* (M4)

*"As a mother, it is my responsibility but I feel quite different and difficult to care for such a small baby. He has such a small neck, body. I feel fear that something wrong may happen while handling or changing clothes."* (M1)

### Attachment and Care Enabling with Care Involvement

Mothers were caring for their PTIs with the guidance of the nurses and using their idea. They experienced attachment and, and contentment with PTI care. Providing care was

the means for being close with their PTIs when their PTIs were separated. Mothers said,

*"After many days, they called me in NICU for keeping my baby on my chest (KMC) and feeding breast milk. I felt being close with him, immense love towards him, and I was so happy."* (M5)

*"After receiving my baby, I am caring for him myself like feeding, KMC, changing cloth. Now, I feel I can care for and understand his behavior. I am feeling nice and being a mother."* (M2)

In addition to attachment, they experienced a gradual increase in care confidence with involvement in PTI care. A mother shared, "For the first time when I kept him for KMC, I was nervous that he may fall. Nurses assured and encouraged me and I continued it. Now I am doing it well." (M3)

### Mixed Experience of Care and Support

Some mothers appreciated the nurses' PTIs' care based on their observation while providing KMC to the baby in NICU. The other few expressed their satisfaction relating to the improvement of the PTIs' condition. A mother shared, "In NICU, babies are kept clean, cared for, and well-fed. Like mothers, they cared for our babies very well. I felt satisfied with their care for the babies." (M3).

According to another mother,

*"I went to NICU just 2-3 times for KMC and breastfeed before shifting the baby from NICU. I haven't seen how they cared for my baby. So, I can't say about it. However, I am satisfied as the baby recovered with their care."* (M1)

Mothers valued nurses' guidance for initial PTI care like EBM feeding and KMC. A mother shared "Sisters were helpful, they fed the baby, and guided how to express and feed the baby. I learned to feed the baby with their guidance." (M2)

Another mother said, "Initially, I was unknown about KMC, sisters explained me about it, and, showed the technique. Then I am performing it." (M5)

However, they felt inadequate guidance, especially for general PTI care like handling, clothing, and so forth. A mother expressed, "One sister showed me bathing and changing cloth. I couldn't keep that in mind. They guide us once, then what to say to them. I feel uneasy to ask them again, though they mightn't feel bad." (M1)

Mothers appreciated the nurses' concern for their health condition and physical need in addition to PTI care. According to a mother, *"They asked about my health condition, advised for adequate food for milk secretion. They were very helpful, guided us for baby care and now I am caring."* (M3)

Furthermore, a mother conveyed her expectation about emotional support, *"Mothers have worries and anxieties related to their baby's condition. Mothers' worries and anxieties would minimize with nurses' care and concern."* (M5)

Some mothers shared their concern regarding inadequate attendance of their PTIs' needs and timely response due to nurses' responsibility for many infants in NICUs. They have non to very few expectations for their care considering the situation. Mothers expressed that

*"In NICU, one sister looked after many babies. While caring for one baby, another baby cries. They can't attend to both babies at a time. At that time, I feel, if I was allowed I could take care of my baby"* (M1)

*"They were every time busy looking after the babies, how they could provide time to mothers. They have no time to respond to us."* (M2)

## DISCUSSION

Similar to previous studies mothers in this study experienced worry and uncertainty regarding the condition and survival of the PTIs. Their worry increased knowing the deterioration in the condition of their PTIs.<sup>7,8,11,17</sup> Consistent with studies of South Africa and China, mothers also expressed worry about the death of the other PTIs in the unit.<sup>10,11</sup> Mothers in present and previous studies experienced separation and inadequate attachment with their PTIs.<sup>7,8,18,19</sup> They also shared about limited visiting time and lack of opportunity to be close and hold their PTIs. Evidence of systematic review and other studies also indicated an inadequate conducive environment for mother-infant attachment.<sup>11,20,21</sup> Nevertheless, other studies in England and Malawi reported adequate opportunities to visit, be close and hold their infants in NICUs.<sup>14,22</sup> Studies from Thailand and South Africa reported the provision of the scheduled visit and involvement in infant care during the visit.<sup>11,17</sup>

Consistent with a systematic review and other studies<sup>10,13,19</sup>, mothers experienced the loss of normal maternal roles like cuddling, holding, breastfeeding during the separation of their PTIs in NICUs. When there was time to care for

their PTIs after transfer from NICU, parents identified new anxiety concerning assuming primary responsibility for caring for their infants.<sup>8,10,17,19,21</sup> The mothers in this study experienced challenges in the breastfeeding role. Nevertheless, they perceived it as a significant contribution and means of attachment with their PTIs. Studies among mothers in China and Tanzania also reported breastfeeding PTIs as natural but physically and emotionally challenging situations requiring support.<sup>23,24</sup>

Mothers' of present and previous studies experienced care involvement like providing KMC, breastfeeding as a positive, pleasant, means of attachment, and understanding their infants.<sup>8,12-14,25,26</sup> Furthermore, the mothers reported that their involvement in PTI care like touching and interaction with their PTIs, feeding, changing nappies was useful to develop mother-infant attachment, emotional comfort, and caring ability before discharge.<sup>8,12,14,15,27</sup>

Like previous findings, mothers were satisfied with the affectionate care by nurses to their PTIs.<sup>11-13</sup> They also appreciated nurses' guidance for breastfeeding and KMC instead of the busy schedule of the nurses.<sup>10,12,13,15</sup> Like study findings of South Africa, mothers were concerned about the inadequate attention to their PTIs related to lower nurse-infant ratio.<sup>11</sup> They desired support in care management with their involvement in PTI care. Mothers in present and previous studies expected more guidance for the PTI care and emotional support by nurses in NICUs.<sup>8,10,11,15</sup>

## CONCLUSION

Mothers experienced worries and uncertainty during the hospitalization of PTIs in the NICU. Their distress was related to the condition and survival of their PTIs, inadequate and altered attachment, and maternal role. Involvement in PTI care like KMC and breast milk feeding was useful for mother-infant attachment, emotional comfort, and care enabling. They appreciated nurses' PTI care in NICU, and valued guidance for PTI care like breast milk feeding and KMC. However, they expected more guidance, communication, and emotional support from nurses.

For the enhancement of the neonatal care practice, it would be beneficial to consider the enhancement of maternal support in the NICU in addition to competent PTI care. Mothers' support needs expectations include support for mother-infant attachment by allowing mothers to visit, interact and be close with their PTIs; guidance and encouragement for PTI care and communication, and emotional support.

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