

Experience of Mothers Having Preterm Newborns in Neonatal Care Units

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ABSTRACT

Background: Preterm births are vulnerable to morbidities and require hospitalization in the neonatal care unit (NCU). The situation is stressful for mothers influencing their attachment and care to the newborns. Therefore, this study was conducted to explore the experience of mothers having preterm newborns in NCU.

Methods: The qualitative study was conducted among purposively selected 13 mothers of NCU admitted preterm infants at Tribhuvan University, Teaching Hospital. Data was collected using in-depth interview. Colaizzi content analysis method was used for data analysis.

Results: Among 13 mothers, 8 were primipara, 25-30 years, homemakers; 6 had Bachelor or above education; 11 had ANC visit > 4 times. Ten infants were very preterm (< 32 weeks gestational age), 11 have very low birth weight (< 1500 gram), 9 born by caesarian section and stayed NICU for 7-14 days. Study identified 5 themes and 18 subthemes: loss of control (fear and anxiety, distress towards pain and suffering, guilt feeling, hopelessness); sense of difference (newborn's appearance, needs and problems, breastfeeding and parental roles); care of newborn (trust to nurses, confidence and emotional attachment with care involvement,), support for coping (support from family, nurses and other mothers); and difficulties faced (distance to NCU, inadequate guidance and information, and lack of supportive environment)

Conclusion: The hospitalization of preterm newborns in NCUs was usually stressful situation for mothers. Their positive experience and coping was related with provided guidance support and involvement in newborn care. Therefore, nurses working in NCU should consider these care components in their practice.

Key words: Mothers' experience; neonatal care unit; preterm infants.

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INTRODUCTION

Globally, 11.1% of births are born preterm (before 37 weeks of gestation)¹ whereas 14% in Nepal.² As born immature, they are vulnerable to morbidities and mortality. Therefore they require hospitalization for a significant period in neonatal care units (NCUs).³ Retrospective study done in 2011 in TUTH indicated hospitalization of (45%) of infants born preterm.⁴

Preterm birth and hospitalization are stressful for mothers and family.^{5,6} They experience emotions like fear, anxiety, uncertainty, distress and loneliness. Because of early and prolonged separation, and special care needs of the infant, these mothers feel powerlessness and lose their confidence for maternal roles.^{7,8} Enabling maternal role with care and support is essential to ensure proper care of newborn after NCU stay.⁹

Understanding their experience is essential to plan effective care and support to them.¹⁰ The information is limited in the context of Nepal. Therefore, this study was conducted to find out the experience of mothers having preterm newborns in NCUs.

MATERIALS AND METHODS

To explore the experience of mother, a qualitative phenomenological study was done in neonatal care units (both neonatal intensive care unit and neonate where) of the Tribhuvan University Teaching Hospital (TUTH) from June to August 2017. The population of the study were mothers of preterm newborns who were admitted in the neonatal care units. Mothers having preterm newborns in neonatal care units for more than 1 week and were willing to express their experience were selected purposively. Mothers were recruited until data saturation (total 13 mothers). The interview schedule was developed to assess socio-demographic information of the mothers and newborns. In-depth interview guide having open ended questions was developed to explore mothers' experience. Ethical approval was taken from the Institutional Review Committee (IRC) of the Institute of Medicine, Tribhuvan University. Permission was taken from the hospital authority. Written informed consent was taken from the mothers of the preterm newborns for their participation as well as for

recording of their views. Anonymity, confidentiality was maintained.

The interview was started as a simple conversation to find out the socio-demographic and health characteristics of the newborns and mothers. Conversation was gradually directed to in-depth interviews to explore their feelings and experience. Interview was conducted by the researchers themselves in the room provided in the neonatal unit during the convenient time of the mothers. Each interview was last approximately 40 to 60 minutes. Data collection was continued until there was no information and a new code of the interviews can be extracted (until data saturation).

Colaizzi's content analysis method was used to analyze the qualitative data. Following this method, audio records of each interview was transcribed, translated, read and reviewed several times to obtain general sense about the content. From the transcript, significant statements that pertain to the phenomenon under study was extracted. Those statements were recorded on a separate sheet noting their page number and line numbers. Meaning was formulated from these significant statements. Those formulated meanings were sorted into theme clusters, and finally, the main theme was abstracted at the end according to conceptual and meaning similarity. Some measures were used to ensure the trustworthiness of the qualitative data. Proposal reviewed and presented among the research experts according to the requirement of the University Grants Commission. To maintain the credibility of the data, in-depth interviews were done for around one hour (prolonged engagement). Data analysis was done involving both researchers. After formulation of the theme and sub-theme, researchers returned to two study participants to ensure the reflection of the meaning of the theme as they expressed (member checking). Similarly, findings were adequately described (thick description) and triangulation with literature was done.

RESULTS

Socio-demographic information of 13 mothers shows that the age of the mother ranged from 20-34

years, one mother was 20 years and 2 mothers were more than 30 years. Regarding educational status, 2 mothers were illiterate, others have primary to master level education. Eight mothers were home makers and remaining were daily wages worker to university lecturer. Ten mothers belonged to the nuclear family and 2 mothers had their husbands abroad. Maternal obstetric information shows that 8 mothers were primipara, 1 mother had twin delivery, 1 had previous preterm delivery. Similarly, 11 mothers had >4 antenatal check-up during this pregnancy, 9 had

operated delivery and 10 preterm birth was related to pregnancy induced hypertension (table 1).

Similarly, demographic information of the newborns shows that their gestational age ranged from 25 to 34 weeks; 7 were < 32 weeks. All the newborns had low birth weight (<2500grams); birth weight ranged from 950 grams to 2200 grams and 8 were <1500 grams. The minimum hospitalization duration was 7 days. Newborns had more than one health problem while admitted in NCU (table 2).

Table 1: Socio-demographic and Obstetric Information of the Mothers

PN	Age	Family Type	Education	Occupation	Para	Cause of Preterm Delivery
1.	28	Joint	MBA	Lecturer	Primi	PIH
2.	30	Nuclear	Intermediate	Homemaker	Second	PIH
3.	26	Nuclear	Literate	Homemaker	Primi	PIH
4.	28	Nuclear	BBA	Business	Primi	PIH
5*	26	Nuclear	Illiterate	Homemaker	Third	Twins pregnancy
6.	34	Nuclear	BBS	Homemaker	Primi	PIH
7.	24	Nuclear	Secondary	Homemaker	Primi	Spontaneous
8.	28	Nuclear	BA	Service	Primi	PROM
9.	27	Joint	BA	Service	Second	PIH
10.	23	Joint	Intermediate	Homemaker	Primi	PIH
11.	27	Nuclear	B.Ed.	Teacher	Primi	PIH
12.	25	Nuclear	Illiterate	Homemaker	Third	Prolong PROM
13.*	20	Nuclear	Primary	Homemaker	Primi	PIH

Key: PN: Participants Number, PIH: Pregnancy-induced hypertension, PROM: Premature Rupture of Membrane, *: Ante-natal check-up < 4

Table 2: Demographic, Birth and Hospitalization related Information of the Newborns

NN	G. A.	Birth weight (gm)	Sex	Type of Birth	Admission Diagnosis
1.	33	1300	female	Operated	Very LBW + NJ
2.	32	1700	female	Vaginal	RDS
3.	29	1000	male	operated	Extreme LBW, RDS
4.	32	1300	Male	Operated Birth	Very LBW
5.*	32	1500, 1600	Both female	Vaginal	1. LBW, RDS, 2. Congenital heart disease

6.	32	950	Male	Operation	LBW, RDS
7.	27	1200	Male	Vaginal	LBW, RDS, NJ
8.	28	2200	Female	Operated	Neonatal Infection,
9.	30	1500	Male	Operated	LBW,NJ
10.	34	1300	Male	Operated	LB,RDS
11.	30	1550	Female	Operation	LBW,RDS, NJ
12.	25	1300	Male	Spontaneous	LBW, RDS, infection
13.	33	1300	Male	Operated	LBW, neonatal infection

Key: NN: Newborn Number, GA: Gestational Age in weeks, LBW: Low birth rate, RDS: Respiratory Distress Syndrome,, NJ: Neonatal Jaundice, *: twins

Regarding qualitative findings, data reduced to 131 significant statements, 18 theme clusters, and further 5 themes. Five themes include: loss of control, sense of difference, care of newborn, support for coping and difficulties faced during hospitalization. Themes and subthemes are depicted in the table and described as following (table 2 and table 4)

1) Loss of control: The theme loss of control was formulated based on 4 different theme clusters: fear and anxiety, distress towards pain and suffering of the newborns, guilt feeling, and hopelessness.

Fear and anxiety: Fear and anxiety were the major emotions of the mother during newborns admitted to NCU. Mothers' anxiety was related to their perception of serious condition and uncertainty of newborns' survival. Unlike term birth, mothers also shared negative experiences of separation of newborn immediate after birth. Mothers expressed that

I was anxious about what will happen next, how will be the condition of the baby? (P2)

I extended my neck to see my baby but I couldn't.... they take away my baby' (P7).

Distress towards pain and suffering of the Newborns: In NCU, newborns are not only separated from mothers but they have to bear pain and suffering related to their health problems, various diagnostic and therapeutic interventions. Therefore, mothers expressed deep sorrow towards pain and suffering of their newborns. One mother expressed that

My baby was facing a terrible pain who was supposed to stay with mothers warmly feeding breast milk. In such a small age my baby is bearing immense pain'. I feel really sad and painful (P11).

They felt inability to minimize newborns' pain and suffering so liked to avoid exposure to a painful situation of their newborns. They expressed empathy towards newborns' pain and suffering. Mothers expressed,

At the beginning, I was unable to see my baby suffering from pain. So, I didn't go frequently there (NCU) (P10),

He is bearing all these invasive procedures ...I wish if I could take all pain from him' (P7).

Feeling Guilty: Some mothers used to self-blame for the unexpected situation and they felt that preterm birth condition may be punishment for their wrong doing. Mothers shared that

Whether it is punishment given to me by God for my wrong doing or what else. (P 2),

if my blood pressure would normal, my baby would still in my womb' (P 11)

Hopelessness: Mothers felt hopelessness frequently when they were informed about the deterioration of the newborn's health condition. Mother whose newborn in critical condition said;

The condition has not been improved but seems deteriorating so I have lost my hope' (P12)

Table 3: Thematic Matrix I Related to Mothers' Experience of Having Preterm Infants in Neonatal Care Units

Main Themes	Theme Clusters	Formulated Meanings
Loss of Control	Fear and anxiety	<ul style="list-style-type: none"> • Perception of having a serious problem • Anxiety related to uncertainty of the newborn survival • Fear of adding problems to newborns
	Distress towards pain and suffering of newborns	<ul style="list-style-type: none"> • Unwanted to see pain and suffering of newborns • Feeling sad and distress towards pain and suffering • Expression of empathy towards newborn • Desire to share the suffering of the newborns
	Feeling of guilt	<ul style="list-style-type: none"> • Feeling of preterm birth as punishment for wrong doing • Self-blaming for the situation
	Hopelessness	<ul style="list-style-type: none"> • Related to fluctuation of health status of newborns • When newborn's condition deteriorated
Theme	Theme clusters	Formulated Meanings
Sense of Difference	Newborn's appearance	<ul style="list-style-type: none"> • Very small unfamiliar appearance • Terrified/hesitated for strange appearance • Feeling uneasy to handle and hold the newborn • Fearful to see small babies with different gadgets
	Needs and Problems	<ul style="list-style-type: none"> • Suffering from serious health problems • Need various treatments, therapies and gadgets • Need of different invasive procedures • Need of expensive treatment
	Altered breast feeding role	<ul style="list-style-type: none"> • Need to provide expressed breast milk • Desire for breast feeding • Suffers from breast engorgement problems • Satisfaction with feeding other newborns • Unexpected separation of newborn • Altered mothering role and related distress

2) Sense of Difference : Mothers felt 'sense of difference' related to newborn's appearance; needs, problems and expenses; breast feeding and parenting roles.

Difference in newborn appearance: Mothers were shocked and frightened to see their newborn's appearance initially. They were scared to go near and touch the newborns. Mothers were also fearful and hesitated to see their small babies with different gadgets

like intravenous (IV) line, oxygen, monitor and many more. Some of the expression of mothers are

He looked so small like baby of rat, he was totally different from the normal baby I have seen, I was really scared to touch him (P 9, P11), 'his head fitted on my hand' (P9).

My small baby was with tubes, oxygen, monitor in incubator. Seeing all these, my feet trembled with fear (P9).

Difference in needs and problems: Newborns were very small up to 950 grams at birth. Mothers felt that their newborns were suffering from serious health problems like

respiratory problems, infection, jaundice. Some mothers expressed difficulties related to the expenses required for the treatment. They perceived that their newborns required extra therapies and intervention. Mothers' expressions like

My baby had difficulty in breathing and many problems, he was given saline, injections, oxygen' (P8).

Immediately after delivery my baby was given injection which costs around NPR. 11000. The cost and expenses are like flowing water in the river. We have taken a loan to manage the situation' (P5).

Altered breastfeeding: All the mothers felt the difference in their breastfeeding role. Newborns were unable to suck breast milk and fed with expressed breast milk (EBM) Therefore, mothers' role was

to supply EBM for their newborns. Some mothers suffered from breast engorgement as their newborns were unable to feed initially. While separated from their infants, the mother breastfed other normal newborns in the postnatal ward. Mothers shared

My baby couldn't feed on my breast. After the third day of birth, he was given expressed breast milk (EBM). So, I am providing EBM for my baby (P5, P9).

I used to breast feed other babies and felt satisfied feeling like feeding my baby' (P7).

Altered parental role: They felt distress towards their passive role compared with the mothers having normal newborns. Mothers who were in the ward together with mothers having normal newborns felt more distress. Mothers shared that

All the mothers have their baby with them but I haven't' (P6).

I wanted to hold my baby on my lap, feed her breast milk. But I have no baby at hand so feeling bored (P12)

Table 4: Thematic Matrix II Related to Mothers' Experience of Having Preterm Infants in Neonatal Care Units

Theme	Theme cluster	Formulated Meanings
Care of New-born	Trust to nurses	<ul style="list-style-type: none"> Feeling good to observe competent care like feeding, hygiene Appreciation of care with affection
	Care confidence with Care involvement	<ul style="list-style-type: none"> Guidance before involvement Involvement in newborn care Able to perform caring Care confidence and care transition
	Emotional attachment	<ul style="list-style-type: none"> Feeling of attachment, love Emotional pleasure
Theme	Theme Clusters	Formulated Meanings
Support for Coping	Family support	<ul style="list-style-type: none"> Husband main source of support and reassurance Support from sisters and in-laws Support from family members to manage the elder child at home Family members unable to arrive to support due to unexpected preterm birth Inadequate family support among mothers residing from outside the valley Difficult in coping with inadequate support
	Nurses support	<ul style="list-style-type: none"> Good communication & polite manner Informational support Emotional support
	Hope & support from other mothers	<ul style="list-style-type: none"> Positive hope from progress among similar cases Feeling reassured by sharing situation

Theme	Theme clusters	Formulated Meanings
Difficulties Faced	Distance of mothers' room and NCU	<ul style="list-style-type: none"> • Difficulty to visit and care newborn, frequently • Difficulty for mothers having operative delivery • Difficulty to visit at evening, and night
	Need for information and guidance	<ul style="list-style-type: none"> • Guidance for care and identification of illness signs • gradual providing negative information • Information to mothers about danger signs and their management
	Lack of supporting environment in NCU	<ul style="list-style-type: none"> • Negative behavior among few nurses • Unable to get response from nurses • Scolding for risk of infection

3. Care of Newborns : As newborns were separated, care of the newborn was the main concern for the mothers. Therefore, care of newborn theme included three subthemes: trust to nurses for newborn care, care confidence, and emotional attachment through care involvement.

Trust to Nurses for Newborn Care: Mothers were worried and in doubt about the newborn care provided in NCU in the beginning. Later when they saw the newborn care provided by nurses with competency and affection, they appreciated care provided to their newborns. Mothers shared their experiences like

There is no place to feel doubt about the care they have given to our baby (P4)

They cared for our babies as like they were their own babies (P8).

Care confidence with involvement in infant care: According to mothers, nurses guided and involved the mothers in newborn care like feeding, KMC, hygiene care before shifting newborns in general ward. They felt confidence in newborn care with involvement in newborn care. According to mothers, newborn care ability was one of the criteria to get their newborns with them from NCU.

At the beginning, I was not known to even hold my baby. They guided me for feeding, KMC and now I am doing it myself. (P7)

At first, they made sure that I can take care of my baby like feeding then after, they shifted my baby out form NCU (P2).

I have learned KMC and practicing it now (P4).

Emotional Attachment through care involvement: Mothers were scared to touch and hold the baby in initial visit(s), they felt feeling of love, attachment and emotional closure with care involvement. One primi mother expressed that

Today, I cared for my baby myself. Touching my baby was quite scaring but while holding, there was immense love flowing to my baby. There was a feeling of intimacy. I am really happy with caring. (P7).

4. Support for coping : During hospitalization of their newborns, mothers felt support from their spouse and family and health personnel including nurses to cope with the situation. They also felt support from mothers having similar problem.

Family Support: Husbands and family members were the main source of support and reassurance during a stressful situation. Some mothers had their husband far for the work. Such a situation, near family members like sisters, in- laws were taking care of them. Family support was important for the mothers in hospital, as well as for managing older children if any. Mothers who had no family support to look after elder children had difficulty coping. One mother who had left 2 older children far in the village expressed

My only concern is my elder daughters who are staying alone at home, nobody is there to look after them so I want to go home as earlier as possible (P5).

Mothers who were residing Kathmandu from far

(outside the valley) had inadequate family support compared to local residents as delivery was occurred before the expected time.

Nurses' Support: Mothers felt comfortable with polite manners and supportive behaviour shown by nurses. Nurses' providing Information and emotional support helped them to cope the situation. The mother expressed

They talk in a polite manner. I feel comfortable being with them' (P4).

Staffs are supportive, they usually suggest me not to worry much, suggest to have food on time, they have done everything for my baby (P6).

Hope and Support from Other Mothers: Mothers felt reassured by sharing with other mothers having similar problem. Similarly, prognosis of the similar cases created positive hope for them.

Their babies were improved and they went home similarly my baby will also be alright one day and I will also go home with my baby' (P7).

4. Difficulties Faced : According to mothers, they experienced difficulties related to distance between mothers' room and NCU, guidance and information need and lack of supportive environment in NCU.

Distance between mothers' room and NCU: Most of the mothers expressed difficulty related to distance between mothers' room and NCU. Difficulty was more prominent among mothers having operated birth. Most of the mothers suggested managing NCU and mothers' room nearby. Some of their expressions are

Sometime, lift may be non-functioning. Climbing up to 4th floor is very difficult for us' (P6), (P11),

It would be better to arrange the mothers' room nearby NCU. (P10); 'It would be better to look after our babies time to time without any stress' (P6), (P4).

Need for information and guidance: Some mothers felt the need for guidance for newborn care especially for danger sign identification and management. They also expressed unprepared to receive negative information. Mothers expressed that

It would be better to inform the parents about illness

signs of the baby... and how to manage and prevent them' (P8).

The doctor told me that my baby will not survive hearing this I was shocked. If I have counseled earlier it would be better' (P11).

Need of Supportive environment in NCU: Although the majority of the mothers indicated supportive behavior of the nurses in NCU, few of them indicated receiving negative behavior, felt inadequate response from them due to engaged in work or personal behaviour. Mothers shared that'

Among whole staffs, two are very rigid and rude' (P1

They are always engaged with their work and usually have not much time to stay and talk with us even sometime can't respond to our question (P2).

DISCUSSION

Mothers in this study experienced fear, anxiety, hopelessness, feeling of guilt, and hopelessness. Anxiety was related to the appearance, condition, and outcome of the newborns, altered maternal role. Mother expressed that their newborns were different and in a serious condition requiring extra treatment, care, and expenses. Systematic reviews and the qualitative study revealed similar findings.^{5,6,10} Similar to previous studies, mothers in this study were distressed for pain and suffering of their newborns and helpless to protect from pain and suffering.^{6,11}

Similar to the study by Sarapat et al., 2017, mothers of experienced altered breastfeeding roles characterized by providing EBM for their newborn.¹³ Supporting the study finding of Russel et al., 2014, mothers in this study felt secured when they saw care provided by nurses with competency and affection to their newborns. Mothers appreciated the nurses' guidance, encouragement, and support for their involvement in newborn care.¹² Their involvement in newborn care was related to emotional comfort, and attachment with their newborns.^{5,12} The main source of support to cope with the situation was supported in various forms from their husband and family. Likewise, supporting previous studies, they felt reassured and supported by sharing with parents having a similar problem.¹³

Mothers in this study desired minimum distance from their room to NCU for more frequent visits and involvement in newborn care. Some mothers felt inadequate response and support by nurses because of the busy work schedule and personal attitude. They expected the supportive environment in NCU with positive behavior by nurses and other health personnel, adequate response for their queries in such stressful periods. Mothers expressed the need for adequate guidance and support for learning preterm newborn care including identification of illness signs. The findings of the previous studies reported the need for adequate information, guidance, and involvement for mothers to be prepared for preterm newborn care.⁹ Mothers also anticipated receiving information especially negative information related to newborns timely and gradually with preparation by health professionals.^{6,14}

CONCLUSION

Having the preterm newborn in NCU was a stressful experience for mothers. The stress and anxiety were the result of exposure to different stresser related to the condition and survival of the newborns; therapy requirements and their expenses; and alteration in maternal caring roles. Their positive experience was related to nurses' emotional, informational support as well as guidance and support for involvement in newborn care. Therefore, nurses should deal with supportive behaviour and provide adequate information. Mothers should be guided, and supported for involvement in newborn care in NCU to minimize their negative experience and for better neonatal and maternal outcomes.

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