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Original Research

Stress and Coping Strategies among Parents of Preterm Infants Admitted to Three Hospitals in Nepal

Tumla Shrestha, Archana Pandey Bista, Madhusudan Subedi

ABSTRACT

Background Hospitalization in neonatal care units (NCUs) is distressing to parents. Stress and inadequate coping hinder parents' emotional health and parenting roles. Furthermore, it may impact short- and long-term developmental, cognitive, academic, and mental health outcomes among preterm infants (PTIs). This study aimed to explore the stress and coping mechanisms adopted by parents in NCUs.

Data and Methods The descriptive phenomenological study was conducted in the NCUs of three public tertiary hospitals in Kathmandu, Nepal. In-depth interviews were conducted with 15 purposively selected parents, both mothers and fathers, of preterm and low birth weight infants admitted to the NCUs. The data were descriptively analyzed employing the Colaizzi method to elucidate the stress experiences and coping strategies of parents.

Results The exploration of parents' experiences yielded two overarching themes, namely psychological distress and insecurity and coping with the support system. Parents' distress was linked to PTIs' condition, infant–parent separation, altered parenting roles, and prolonged hospitalization. Family, friends, peer parents, and NCU staff were parents' support sources. They coped with the situation by sharing experiences with peer parents, fostering closeness with the PTIs, and actively involving in care.

Conclusion Admission of PTIs to NCUs was distressing to parents. Parents valued NCU staff's support for coping and expected more support. The provision of free newborn care service is pivotal in alleviating financial burden. Opportunities for fostering infant–parent attachment, active care involvement, and peer-to-peer support are effective coping measures for parents. Improving parental support provision in NCUs considering this stress and coping mechanisms would enhance psychological well-being of parents.

Keywords stress, coping, preterm infants, parents, neonatal units, Kathmandu, Nepal

INTRODUCTION

Preterm birth (PTB) is defined as a live birth occurring before 37 completed weeks of gestation. In 2020, a Global Health estimate reported 13·4 million preterm births (9·9% of all births), which reflects a marginal reduction from 13·8 million (9·8% of all births) in 2010. The decline is primarily linked to an overall reduction in total live births rather than a reduction in preterm births.[1] South Asia has the highest preterm birth rate (13.2%).[2] In Nepal, its incidence is reported to range from 9.3% to 14%.[3,4]

Preterm infants (PTIs) face substantially higher risks of mortality, morbidity, and disability. These risks are inversely proportionate to gestational age and weight at birth. On the other side, late PTBs (34–37 weeks) are more prevalent and also have significantly higher vulnerability to morbidity, mortality, and disabilities compared to term infants. Globally, prematurity and its associated complications stand as the leading causes of neonatal and under-five mortality.[5] The survival of preterm and low birth weight (LBW) infants is paramount in achieving the Sustainable Development Goal (SDG) of reducing neonatal and child mortality and the target of Every Newborn Action Plan to end preventable newborn mortality by 2030.[6]

PTIs require special attention in the neonatal care unit (NCU) to address prematurity-related complications, often extending from a few days to several weeks or months.[6,7] Hospital-based studies conducted in India and Nepal showed higher prevalence of PTIs in NCU (28.2%, 18.4%–39.2%).[8–10] Considering the magnitude of the problem and vulnerability, expanding access to specialized NCUs for sick and small newborns is an important global priority to reduce neonatal mortality.

Quality healthcare involves not only the delivery of evidence-based clinical care to infants but also the cultivation of positive experiences for both infants and their families.[11] The World Health Organization (WHO) has recommended various evidence-based interventions which have proven effective in preventing and managing preterm births and associated complications.[6,12,13] Those interventions offer significant benefits in achieving improved neonatal health outcomes. Nevertheless, high-quality care cannot be fully achieved unless the newborns and their families have a positive experience of care.[11]

Research-based evidence in a global context highlighted that the admission of critically ill infants or PTIs in NICUs is a stressful situation for parents.[14–18] Their distress is linked to the condition and outcome of the PTIs, the separation of infants from parents, the altered parental role, and the necessary resources.[15,17,19] Such stress has the potential for a detrimental impact on both parents and their vulnerable infants during NICU hospitalization and in the post-discharge period. Early and prolonged separation resulting from the admission of PTIs in NCUs may lead to an inadequate opportunity for infant–parent bonding[20,21] and also poses challenges to the psychological well-being of parents.[15,18,20,21] Numerous studies have highlighted the risk of psychological problems among parents of PTIs admitted

to NCUs.[15,22] The establishment of a strong infant–parent bond and psychological well-being are essential precursors for the development of effective parenting roles.[20,21] Ineffective parenting roles, in turn, can increase the risk of adverse developmental, cognitive, academic, and mental health outcomes among PTIs.[18] Therefore, the emotional health and coping status of parents should be essential considerations.[23]

Several studies have demonstrated that families, friends, and parents facing similar challenges serve as significant sources of support for the parents coping with the stress associated with their situations.[19,20,24–26] The support provided by NCU staff was crucial for their coping. Parents expressed receiving both adequate and inadequate support from nurses.[27,28] In addition to religious faith, sharing experiences with parents of other admitted PTIs (peer parents), receiving timely information about their PTIs, visiting their PTIs, and engaging in PTI care promoted coping and provided emotional comfort.[23,29,30] Furthermore, reassurance and support from experienced parents have been identified as key factors in enhancing coping mechanisms.[24,26] Therefore, health personnel working in NCUs should consider incorporating these coping measures into their care practices.

Literature regarding the qualitative exploration of parental experiences is available from high[20,23,26,31] and middle- and low-income countries (LMICs).[16,28] While some quantitative and qualitative findings are available from India[17,32–34] and Nepal,[19,27,35] information is inadequate to cover the various aspects of the phenomenon, especially within specific settings. Therefore, recognizing the imperative for further exploration of the phenomenon, particularly involving both parents in the Nepalese context, this study was undertaken to explore the stress and coping strategies among parents during the admission of their PTIs to NCUs.

DATA AND METHODS

Design and Setting

This descriptive phenomenological study was conducted in the NCUs of three purposively selected public tertiary hospitals in Kathmandu, Nepal: Tribhuvan University Teaching Hospital, Paropakar Maternity and Women's Hospital, and Kanti Children Hospital. The University Hospital and Children's Hospital functioned as central referral hospitals. Preterm and sick newborns were referred to these hospitals from various hospitals of the capital city as well as various parts of the country.

The Maternity Hospital was the only public maternity center having around 70–90 births/day. A significant number of newborns born in that hospital were admitted to NCUs. The University Hospital had 19 neonatal beds: 9 in the neonatal intensive care unit (NICU) and 10 in the sick newborn care unit (SNCU). The Maternity Hospital had 40 neonatal beds: 10 in the NICU, 26 in the SNCU, and 4 kangaroo mother care (KMC) beds. The Children's Hospital was the only public tertiary-level children's hospital having 16 beds (12 functioning) in NICU and 15 beds in SNCU (neonatal intermediate care unit). The study was conducted among the mothers of the PTIs admitted to both SNCU and NICU of the study settings.

Participants

The study participants were parents, both mothers and fathers, of preterm (born before 36 weeks of gestational age) and low birth weight (<2500 grams) infants admitted to NCUs. Parents whose PTIs had no congenital malformations and metabolic or genetic disorders and those with stays in NCUs for four or more days were recruited in the study. The participants were recruited after the recovery of their infants and planned discharge from NCUs. Eligible parents willing to share their experiences were selected purposively.

Parents who provided consent for repeated interviews were recruited until sample saturation was reached. Both parents were included in the study, considering their roles during the hospitalization of PTIs in NCUs. However, more mothers were recruited as more diverse information was received from them and they were more available than fathers during data collection. Either the mother or the father of a PTI was included in the study. A total of 10 mothers and five fathers were taken as study samples from the three settings.

Research Instrument

A semi-structured interview guide, aligned with the study's objectives and available literature, formed the research instrument. The guide included directions for conducting in-depth interviews, socio-demographic questionnaires, and open-ended questions. The survey instrument was translated into simple Nepali language.

For the enhancement of the trustworthiness of the instrument, relevant literature was reviewed and consultations were held with subject-matter experts and a qualitative research expert to develop data collection tools. A pilot study was done on five mothers of NCU-admitted PTIs, and minor changes in the interview guide was done based on the feedback and suggestions of the participants.

Ethics

The study was approved by the Nepal Health Research Council. Administrative approval was secured from all three study settings. The objectives of the study and the expectated role of the participants were shared with each study participant. Written informed consent was taken from the participants for participation and interview recording. Audio records were stored in a password-protected laptop, and the transcripts were kept confidential. All personal information is carefully safeguarded when presenting the findings.

Data Collection

The lived experiences of the parents were explored through in-person in-depth interviews (IDIs). Data collection was done from December 2019 to March 2020. Eligible parents were identified from the NCUs and approached when there were plans to transfer their PTIs from NCUs after their recovery. They were requested to participate in the study after being explained about the study aim, their role, volunteer participation, and confidentiality of the information provided. Parents were treated with utmost respect, and any queries they had were addressed. Date and time were scheduled with the parents who were willing for verbal participation.

Only one parent, either the mother or the father of a PTI, was involved in the interviews. Interviews were conducted in a separate room adjacent to the mother–baby unit or the

KMC room to ensure privacy and comfort for the parents and minimal background noise for recording purposes. The first author conducted the IDIs using a semi-structured IDI guide in colloquial Nepali language. The interviewer made notes of both verbal and non-verbal expressions and moments. Conversations were recorded on digital recorders, with each IDI session lasting between 30 and 60 minutes. Each participant was interviewed for two or three sessions until data saturation was reached.

Data Analysis

Data collection and analysis were conducted simultaneously by the first author, with periodic consultations with the other authors. The recorded interviews were transcribed verbatim and translated into the English language for subsequent analysis. The consistency of the transcribed data was ensured by listening and reading repeatedly as well as comparing with the verbal and non-verbal expressions of the participants recorded in the field notes. Data analysis was done manually. The obtained data were analyzed using Colaizzi's method for the descriptive phenomenological study.[36]

Inductive coding was done, and significant statements were extracted from each transcript. Initial meanings were formulated and arranged into theme clusters. These were then combined to form distinctive constructs of sub-themes and themes. The sub-themes and themes were checked against the data by all authors to validate the emerging patterns. The themes and sub-themes were comprehensively described and contextualized with significant statements in quotes.

Trustworthiness

Lincoln and Guba's[37] criteria, i.e. credibility, dependability, transferability, and confirmability, were used to ensure the quality and rigor of this study. Credibility was maintained by expert consultations and recruiting the participants with firsthand experiences who were willing to share them. Multiple IDIs were conducted, and field notes were kept. Member checking involving five study participants (M3, M4, M9, M11, and F2) was implemented to confirm their views for the precise interpretation of the study findings.

For transferability, a comprehensive description of the research process was provided, and findings were elucidated with direct quotes. Dependability was ensured by using the same instrument in each IDI and producing transcripts promptly. For confirmability, the authors reviewed the data analysis process and the presentation of findings. All authors rigorously read and agreed upon the entire manuscript before the submission, revision, and finalization of the paper. The terms participants and respondents are used interchangeably.

RESULTS

The socio-demographic characteristics of the study respondents (parents) show that, of the 15 parents, ten were mothers, 11 were in 21–30-years age group, and eight had completed or attended some levels of up to tenth grades of schooling. Five parents were service holders; four each were engaged in unpaid work (homemaker) and business. Nine parents belonged to joint families and had a previous child or children. Eight parents came from outside the Kathmandu Valley; were referred from elsewhere (Table 1)

Table 1: Background Characteristics of the Study Respondents (Parents), Three Hospitals, Kathmandu, 2020

Background Characteristics		Number
Parental Status	Mother	10
	Father	5
Age	≤20	2
	21–30	11
	31-40	2
	Range: 18-40	
Education	Can't read and write	1
	1-10 grades	8
	11 or higher grades	6
Occupation	Homemaker	4
	Business	4
	Service	5
	Other (painter, migrant worker)	2
Family Types	Nuclear	6
	Joint	9
Parity	Primi	6
	Multi	9
Residence	Within Kathmandu Valley	7
	Outside Kathmandu Valley	8
Total		15

The characteristics of PTIs show that six were born in the 29–32 weeks of gestation, eight were delivered by cesarean section, 11 had birth weights (BW) ranging from 1100 to 1500 grams, and nine had been admitted for 15–30 days (Table 2).

Table 2: Delivery and Preterm Infants Related Characteristics, Three Hospitals, Kathmandu, 2020

Characteristics		Number
Gestational Age (in weeks)	28	5
	29-32	6
	33-36	4
	Range: 28-34	
Delivery Type	Normal vaginal	7
	Cesarean section	8
Hospitalization Duration (in days)	≤14	3
	15-30	9
	>30	3
	Range: 10-41	
Birth Weight (in grams)	1000-1500	11
	1600-2000	4
	Range: 1000-1880	
Total		15

The analysis of the IDI narrations concerning parents' experiences with the admission of their PTIs into NCUs yielded two overarching themes: (1) psychological distress and insecurity, and (2) coping the situation with the support system. The four sub-themes that emerged from the first were: (i) fear, worry, and uncertainty due to the condition and outcome of the baby, (ii) distress due to the separation, (iii) distress due to the altered and inadequate parental role, and (iv) troubles related to longer hospitalization. The two sub-themes referring to the second theme were: (a) sources

of support for coping, and (b) strategies used to cope with the situation. Themes and sub-themes are elucidated in textual form, accompanied by quotes describing each aspect of the findings. Quotes of both mothers and fathers are indicated with their case numbers (M1-M10 and F1-F5).

1. Psychological Distress and Insecurity

The majority (11) of PTIs had very low birth weight (<1500 grams) or serious health problems. During the initial days, parents, especially fathers, were briefed about the serious and unstable condition of their PTIs. Most of the parents experienced emotional anguish due to the unexpected situation of their PTIs in NCUs. They were worried about the condition, critical care requirements, and the uncertainty of survival of their PTIs. In addition, they were distressed by the separation and insufficient and altered parenting roles. Furthermore, they had hospitalization-related difficulties such as procurement of necessary medicines, financial constraints, and resource management. Some parents were worried about their elder child or children at home, along with other managerial matters. Consequently, this overarching theme has emerged from the four sub-themes mentioned above.

1.1 Fear, Worry, and Insecurity regarding the Condition and Outcome of the Infant

The occurrence of preterm birth and the subsequent admission of PTIs into NCU was an unexpected situation for parents. Parents were shocked, surprised, and extremely sad to see very small infants surrounded by specialized devices and requiring specialized therapies like ventilator support. They were deeply concerned and filled with a sense of hopelessness regarding their PTIs as they had observed and were informed. Such situations were extremely stressful for them. A father vividly captured his sentiments, "My baby was so small and sick, with tubes and devices inside the glass box (incubator). I had little hope for his survival. I was also worried for his management if he survived" (F1 -32 years, second-time father, PTI GA 28 weeks, BW 1250 grams, RDS and sepsis).

Similarly, mothers recounted their visiting experiences, describing the appearance and condition of their PTIs as both shocking and surprising. One mother said, "I was shocked to see him. I had never imagined or seen such a small baby before. I felt so sad that I wanted to cry at that time" (M2 - 28 years, second para mother, PTI BW 1140 grams, GA 28 weeks). Another mother shared, "What could I feel when my baby was in the ventilator? Very sick babies are kept in the ventilator" (M8 - 28 years, second para mother, PTI BW 1200 grams, GA 29 weeks, fetal distress, pneumonia).

The primary concern of parents during the initial days revolved around the survival of their PTIs as they were explained about the uncertainty, the observed demise of other PTIs, and comments of other parents. A father expressed his experience and emotions, stating, "Babies died there frequently. According to doctors, preterm babies might forget to breathe, and even they were unsure about them. Parents also used to comment about their heightened fear of risk. All those things made us worried and frightened that something bad (demise of the baby) might happen" (F3 - 24 years, first-time father, PTI GA 30 weeks, BW 1450 grams, sepsis, PTI referred from a rural area). Similarly, a mother shared her concerns and hopelessness, "I was deeply concerned for my baby and was constantly thinking about his survival. I can't explain now how much I cried. I used to be suspicious of any phone call from the NCU" (M3 - 40 years, second para mother, referred from a rural area for antepartum hemorrhage [APH], PTI GA 28 weeks, BW 1000 grams, respiratory distress syndrome [RDS]). Moreover, parents were deeply concerned about the pain and suffering associated with various procedures, therapies, and health problems. A mother expressed, "My baby was injected in so many places and, as a result, had injured veins. I felt very bad for his pain and suffering at such a small age" (M4 - 23 years, primi mother, PTI GA 30 weeks, BW 1470 grams, referred from a rural area).

1.2 Distress caused by Separation

All the parents were separated from their PTIs after their births. Mothers, in particular, expressed a strong desire for frequent visits and physical closeness with their PTIs. Parents shared different visiting rules across different settings. Some parents shared inadequate support for the parental visit, especially in NICUs. A mother shared, "We wished to visit our baby frequently but were allowed just once a day and only for a short duration. They did not allow us to touch and interact with the baby and asked us to leave soon" (M5 - 23 years, primi mother, PTI GA 30 weeks, BW 1300 grams, pneumonia, respiratory distress syndrome [RDS], referred from the Tarai region).

Mothers experienced emotional distress due the comments made about their situation of being separated from their PTIs. A mother shared her feelings, "In the postnatal ward, I cried a lot looking at other mothers with babies in their laps. I used to feel nervous about other parents' facial expressions towards me" (M10 - 28 years, second para mother, normal delivery, PTI GA 34 weeks, BW 1530 grams, Sepsis, RDS). However, parents seldom commented on the restricted visiting access and had accepted it as a necessary measure for the well-being of their PTIs. A father expressed, "All the babies are separated, not only ours. The attending NCU staff explained to us about the risk of infection due to frequent visits. If that's the case, we can wait" (F5 - 22 years, first-time father, PTI GA 29 weeks, BW 1700 grams, sepsis).

Some mothers experienced separation and insufficient attachment opportunities due to their health conditions and physical distance. A mother with antepartum hemorrhage shared, "I visited my baby only after 10 or 11 days despite encouragement from NICU nurses. I underwent multiple blood transfusions, had tubes applied, and was under close observation by the doctors (obstetricians). How could I visit? Moreover, the NICU was far from the postnatal ward" (M3 - 40 years, second para mother with APH, PTI GA 28 weeks, BW 1,000 grams, RDS).

1.3 Distress due to Altered and Insufficient Parental Role

During the initial days when PTIs required specialized therapies and care, parents experienced feelings of sorrow and anguish and a sense of inadequacy in their parental roles. Mothers, in particular, felt a loss of control due to their inability to fulfil their maternal roles. In addition to the conditions of the infants and mothers, unit rules played a role in restricting the parental roles. A mother stated, "It has been more than two weeks since my baby has been

separated from me. I yearn to hold him on my lap, cuddle and breastfeed him at least once, but I'm not allowed to do so. I feel so sad and eagerly am waiting for the day when I can" (M5 - 23 years, primi mother, PTI GA 30 weeks, BW 1300 grams, pneumonia, RDS, PTI referred from the Tarai region).

Mothers experienced a loss of control and voiced concerns over the discomfort of their child. A mother said, "My baby cries a lot in the baby unit. As a mother, I yearn to cuddle and comfort her, but I can't due to the devices applied to her. So, I couldn't stay in the NCU for a long time" (M10 - 28 years, second para mother, normal delivery, PTI GA 34 weeks, BW 1530 grams, sepsis, RDS). Another mother shared, "When I saw her uneasy, with her clothes misplaced, or saw something around her mouth, I wished to comfort or manage her. But I have to take permission even to see my baby. I feel so helpless as a mother" (M4 - 23 years, primi mother, PTI GA 30 weeks, BW 1470 grams).

After receiving their PTIs from the NCU, their concerns shifted to their parenting role. They grappled with the realization of their parenting responsibilities and expressed feelings of inadequacy in their parenting skills. A mother in the mother–baby unit articulated her concerns, "Now, I have to care for my baby. I am very concerned about providing proper care, which is quite difficult" (M8 - second para mother aged 30, PTI GA 34 weeks, BW 1500 grams, fetal distress). Another mother expressed deep concern regarding feeding her baby and the possibility of weight loss due to insufficient breastmilk. She said, "Doctors advised me to express breast milk in a bowl and feed it to my baby later. It's difficult to feed the baby while he is awake, especially at night. Even during the day, the baby doesn't feed on the expressed breast milk. His weight might decrease if insufficiently fed. So, I am trying my best" (M2 - 28 years, second para mother, PTI BW 1140 grams, GA 28 weeks).

1.4 Challenges Associated with Hospitalization

The PTIs required various duration of hospitalization. More than half of the PTIs (8) were referred from rural areas (five pregnant mothers were referred before delivery and three PTIs were referred for neonatal problem). Parents were engaged in the hospital, leaving their jobs or self-earning activities. On the other side, they grappled with increased expenditures related to both medical treatment and their sustenance during the hospital stay. Parents from rural areas and with little economic resources encountered heightened difficulties. Clearly, parents, especially from settings lacking free newborn care services, faced heightened challenges.

Financial and managerial matters were usually dealt with by fathers. One father said, "It is very tough. We have been in the hospital for more than one month and 15 days here. All the money we saved has been spent on the baby's treatment, our food, and other necessities. Now, I must return to work to meet further expenses" (F3 - 24 years, first-time father, PTI GA 30 weeks, BW 1450 grams, sepsis, PTI referred from a rural area). "Treatment and other expenses are exorbitant. It has been very hard on me due to the expenses on one side and managing the care of my spouse and our baby on the other. I have also been on leave for about one month and a half" (F1 - 32 years, second-time father, PTI GA 28 weeks, BW 1250 grams, RDS, sepsis).

Fathers also articulated challenges related to the availability of essential medicines, with parents from rural areas experiencing heightened difficulties. However, parents used parent-to-parent support. A father highlighted the issue, stating, "One of the great problems was the difficulty in procuring required medicines for the baby. It would be highly beneficial if such medicines were available within the hospital" (F2 - 41 years, second-time father, PTI GA 28 weeks, BW 100 grams, RDS). Another father also shared, "I couldn't find a drug named Caffeine in any of the pharmacies all over the city. Eventually, I got three packets through my brother's network and shared them with the parents of other babies. For those coming from a distance for the first time, it's even more challenging" (F4 - 31 years, second-time father, PTI GA 33 weeks, BW 1400 grams, RDS).

2. Coping Strategies Utilized within the Support System

One of the objectives of this study was to find out the coping strategies employed by parents in response to challenging situations. Parents were coping with an unfavorable situation with the available support system. The spouse and the family were the main sources of their support. Additionally, peer parents and friends having PTIs were other important sources of support. Coping mechanisms employed by parents included seeking solace through prayers, sharing experiences with peer parents, and actively engaging in infant care. Consequently, the overarching theme was supported by two sub-themes (as mentioned earlier).

2.1 Sources of Support for Coping

Both of the parents played crucial roles throughout the hospitalization period of their PTIs. In the initial days, fathers assumed responsibilities such as attending NCU calls, receiving information, and addressing the needs of their PTIs, alongside caring for their postnatal spouses. Some mothers, due to health problems or operative deliveries, required additional physical care during the initial phase. In such instances, spouses were the primary source of support for mothers. A mother highlighted this support, stating, "My husband cared for me during the initial days after the operative delivery. He attended and managed calls from the NICU, addressed my needs such as food, provided reassurance, and helped with baby care, including kangaroo care" (M1 - 25 years, second para mother referred for APH, cesarean section delivery**).**

In addition to physical care, mothers received emotional support from their spouses. One father explicitly expressed this, saying, "During parents' counseling, sometimes we were informed about the improved condition and again deterioration and that it is difficult to save the PTI's life. It was so hard to bear all those things. However, I used to act as if everything was alright in front of my wife. Otherwise, being already anxious due to the separation, coming to know about the deterioration in our baby's health condition would have made it more difficult for her to cope" (F1 - 32 years, second-time father, PTI GA 28 weeks, BW 1250 grams, RDS, sepsis).

In addition to spouses, family members, especially female members such as mothers and sisters of both parents, played a supportive role in helping parents cope with and manage the situation. A mother shared her

experience, stating, "In addition to husband, my elder sister helped me with everything I needed while I was in the postoperative period and very sick. Family and friends provided reassurance through visits and phone calls (M3 - 40 years, second para mother with APH, PTI GA 28 weeks, BW 1000 grams, RDS).

Friends with similar experiences offered considerable reassurance to the parents. A father articulated this sentiment, "One of my friends provided significant hope by sharing improved outcome of his two-year-old child, who was born preterm, with a birth weight of 700 grams and severe jaundice" (F1 - 32 years, second-time father, PTI GA 28 weeks, BW 1250 grams, RDS, sepsis). Parents valued the reassurance offered by healthcare personnel. The majority of the study participants emphasized that doctors and nurses routinely provided reassurance to them by sharing with them cases of babies having good prognoses. However, some participants stated it as inadequate. A primi mother from a rural area shared, "We are far from home and family. Our family reassures and supports us through phone calls. So far, nurses haven't shown concern about my feelings and desires nor reassured me" (M5 - 23 years, primi mother, PTI GA 30 weeks, BW 1300 grams, pneumonia, RDS, PTI referred case).

The participants from the setting with access to free newborn care services reported experiencing substantial support for timely treatment without stress and financial burden. One father provided insight into this, stating, "Our baby received timely treatment with free service. The provision of free service was the most significant support for people in situations like ours, where livelihood is a challenge. If we had to bear the expenses, our baby might not have received timely treatment. Similarly, if I had to pay for the treatment, I would have to take loans and pay for them till the baby has grown up" (F5).

2.2 Coping Strategies Employed

In the initial days, mothers often expressed distress through crying, but the majority transitioned to coping with patience, hope, and moments of hopelessness. They kept faith in gods and goddesses (almost all parents were Hindus) and worshipped for the well-being of their PTIs. A mother expressed, "During counseling, doctors informed me that the baby was in a very serious condition. Everything was in the hands of gods. We prayed to gods for the recovery of the baby, which is the only thing we could do for her" (M9 - 19 years, primi mother with normal delivery, PTI GA 29 weeks, BW 1800 grams, RDS). As the condition of the infants improved, the attachment between parents and infants deepened through parents' frequent visits and active involvement in PTI care. A mother said, "In the SNCU, we are allowed to visit and care for our baby. I provide Kangaroo mother care, change diapers, and feed the baby. The sense of love and affection has grown as we stay close, touch, and care for him. I am happier now" (M5 - 23 years, primi mother, PTI GA 30 weeks, BW 1300 grams, pneumonia, RDS, PTI referred).

In the unit, mothers used to meet each other during visits for feeding. Over time, they became close friends who were experiencing almost identical situation and felt reassured by sharing and listening to each other's feelings and problems. Parents having similar problems were the source of support for each other in various ways. A mother shared that, "Parents whose babies are here have similar pain (stress and worry about the baby). When we meet, we share our pain and reassure ourselves to some extent" (M9 - 19 years, primi mother, PTI GA 29 weeks, BW 1800 grams, RDS). "We were four mothers with babies in the NICU. We reassured ourselves by looking at each other. We became hopeful as we witnessed the recovery of other babies" (M7 - 25 years, primi mother, PTI GA 32 weeks, BW 1250 grams, RDS, NCU stay for 21 days).

Their optimism further heightened as the conditions of other PTIs improved. The novice parents experienced better coping with reassurance and sharing by experienced parents. Some of them consoled themselves, comparing their infants with those having more serious problems. Additionally, a few mothers adopted an alternative method of attachment with their babies, such as looking at the photographs of their PTIs. A mother recounted her experience, "We were happy to see the recovery and discharge of two preterm babies. Those parents provided reassurance and suggested us to stay in the hospital until our baby fully recovered" (M9 - 19 years, primi mother, PTI GA 29 weeks, BW 1800 grams, RDS).

DISCUSSION

The exploration of the emotional experiences of parents during the hospitalization of their PTIs in NCUs has highlighted two themes: psychological distress and insecurity and coping with the support system. Previous evidence also indicated that the situation is stressful for parents.[15,16,24,38] Consistent with previous studies, uncertainty about the PTIs' condition, prognosis, and survival emerged as important stressors for parents.[16,17,27] Nevertheless, unlike a few previous studies in India[17] and Ethiopia,[38] the parents in this study did not mention stress arising from inadequate information. Instead, their negative emotions emerged from information regarding the critical and unstable condition and the risk situation of the PTIs. Furthermore, parents in both the present and previous studies[16,17,19,39] experienced emotional distress due to factors such as the small size and appearance of the PTIs; the use of tubes, wires, and devices; and the need for critical care and special devices, like the ventilator. Similar to earlier findings,[16] they were also concerned about the pain and suffering of their PTIs. Although some studies[20,38] indicated stress related to the NCU environment, including equipment and noise, the parents in this study did not mention such concerns.

The findings of the present and previous studies[15,19,26,39,40] showed that separation and inadequate parental role (like holding, cuddling, and breastfeeding the infant) were important stressors for parents, especially for mothers. Parents indicated different rules for parental access in different settings. Some parents conveyed restricted visiting hours and inadequate opportunities for infant–parent attachment and maternal roles, such as touching, interacting, holding, and cuddling, as key stressors. Similar findings are reported by a previous study.[17] Their stress regarding PTI care after receiving PTIs indicates their need for guidance and care involvement in NCUs before transferring PTIs to parents. Enhancing infant–parent attachment, minimizing separation, and actively involving and partnering parents in PTI care are crucial evidence-based recommendation

for minimizing stress and fostering effective coping mechanisms among parents.[42]

In addition to the unit rule, the spatial separation between the NCU and mothers' wards emerged as a significant barrier for the mother–infant attachment. Similar findings are reported in previous studies in the Nepalese context.[19] It would be worthy to consider physical distance while constructing new units in the future. The mothers participating in the current study, as well as those from a study in Spain, revealed mothers' feelings of emptiness, distorted motherhood due to preterm birth, and PTIs' admission into NCU.[43] Mothers of PTIs cohabiting with the mothers having normal infants in a common living space reported heightened negative emotions. In light of these insights, the participants recommended keeping mothers with similar problems (having PTIs in NCUs) in the living space.

Fathers encountered numerous stressors while managing the situation of their postnatal spouses and sick PTIs. They supported their postnatal spouses in various ways, including physical care, emotional support, and situation management as necessary. They were exposed to the critical condition of their PTIs. To fulfill their responsibilities, they had taken leave from their employment. It further added to their financial burden, particularly for those who had no secure jobs. In addition, they were responsible for the management of necessary finance and resources. Fathers in both the present and previous studies expressed economic hardships attributed to higher expenses and the inability to attend work.[14,43]

The findings of this study, along with those from previous studies, underscore the financial burden on parents by the admission of their infants to NICU.[16,17,38] Study findings of Nepal and Iran showed the highest out-of-pocket expenditure and loss of economic activities among the parents of PTIs in NCUs.[45,46] However, parents in this study whose PTIs received free newborn care service reported experiencing minimal emotional burden. Some parents shared their difficulties related to obtaining some essential medicines and expressed a strong desire for the availability of medicines and supplies within the hospital. These findings were consistent with those of the previous studies.

Regarding the coping strategies, the parents in both the present and previous studies had identified several approaches, such as maintaining faith in gods, sharing experiences with their spouses and other parents with PTIs, as well as visiting and engaging in PTI care.[16,25,26,29–31,38] The evidence suggests that religious faith bolstered their hope and provided emotional comfort.[20,24,27,29] In line with findings from earlier studies, the parents in this study coped with the situation by practicing patience, maintaining hope by observing similar cases, and gathering information about their PTIs.[24,30,31] Their important coping mechanism was sharing their feelings and problems with other parents having PTIs and being hopeful. These findings align with those of the previous studies.[16,17,24,25,30] Similar to a previous study,[26] novice parents were supported and reassured by experienced parents for better coping. NCU personnel, especially nurses, can play a significant role in peer-to-peer support among NCU mothers and mobilize experienced parents for their positive experience in NCUs.[42]

While psychological distress is common during the hospitalization of PTIs, interventions such as physical proximity to their PTIs, involving parents in PTI care, adequate communication, and reassurance could be effective in promoting parents' psychological well-being.[30,41,46] Regarding support for coping, family friends and health personnel were the main sources of support, a finding substantiated by a systematic review and other studies.[20,26] Parents in the present and previous studies denoted significant support of spouses for coping and managing the challenging situation, alongside emotional support from their family and friends. Corresponding to previous evidence, parents also felt significant support for coping from the parents having similar problems.[19,24–27,29] Notably, parents reported receiving both adequate and inadequate support from nurses.[19,27,28] Interestingly, a previous study in Nepal found that the implementation of a free newborn care program did not lead to a change in out-of-pocket expenditure for sick infants.[45] However, parents who received free treatment for their PTIs reported experiencing significant support, ensuring timely treatment without the stress of financial burdens.

LIMITATION

The study was conducted among the parents of the PTIs having good prognoses. Therefore, it has limitations for generalization among the parents experiencing unfavorable outcomes for their PTIs. Despite more than half of the parents being from rural areas, the study was conducted among parents attending tertiary hospitals. The findings may not be applicable to all parents having PTIs in NCU as the current sample comprised parents of PTIs having good prognoses. Further research is needed, specifically including parents of infants with unfavorable outcomes. Some information could have been missed based on the depth of information participants were willing to share. Some meanings inherent to participants' expressions might have been lost during analysis, despite the rigorous checks performed by all authors, including measures like member checking and rigorous language translation.

CONCLUSION

The admission of PTIs to NCUs is stressful for parents. The condition and outcomes of PTIs, separation and inadequate infant–parent attachment, limited parental role, and inadequate provision of medicines and supplies are stressor for parents. In addition, hospitalization and the necessity for specialized therapies contribute to both physical and financial burdens. The availability of free newborn care service is valuable in the alleviation of financial burden and effective care management. Spouse, family, and friends were the main sources of support for their coping. Parents highly value support from health personnel, especially nurses, and express a desire for support in coping. Opportunities for being physically close with PTIs and involvement in infant care are important coping measures. Furthermore, parent support is an important coping mechanism. These findings suggest the need for enhancing neonatal care practice with provision of

parental support components in addition to competent and affectionate care for PTIs. For effective parental support, nurses and NCU team need to recognize and address the emotional feelings and coping mechanism of parents.

ABBREVIATIONS

APH	antepartum hemorrhage
BW	birth weight
GA	gestational age
IDI	in-depth interview
KMC	Kangaroo mother care
LBW	low birth weight
LMICs	low- and middle-income countries
NCU	neonatal care units
NICU	neonatal intensive care unit
PTB	preterm birth
PTI	preterm infant
RDS	respiratory distress syndrome
SDG	Sustainable Development Goal
SNCU	sick newborn care unit
WHO	World Health Organization

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AUTHOR AND ARTICLE INFORMATION

Authors Tumla Shrestha, PhD, Associate Professor; Archana Pandey Bista, PhD, Associate Professor, both at Maharajgunj Nursing Campus, Institute of Medicine, Tribhuvan University, Maharajgunj, Kathmandu; Madhusudan Subedi, MPhil, Professor, Patan Academy of Health Sciences, Lalitpur, Nepal.
Corresponding Author Tumla Shrestha, PhD
Email: tumlashrestha@gmail.com
Corresponding Author's Primary Affiliation Maharajgunj Nursing Campus, Institute of Medicine, Tribhuvan University, Maharajgunj, Kathmandu, Nepal.
ORCID ID https://orcid.org/0000-0001-5867-1286
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