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*Original Research Article*

# Navigating Parental Knowledge, Experiences, and Challenges Regarding Post-Discharge Care of Preterm Infants

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**Abstract:** *Preterm birth remains a leading cause of neonatal morbidity and mortality globally, with heightened vulnerability persisting after hospital discharge. In resource-limited settings like Pakistan, the caregiving burden shifts predominantly to families, often without adequate preparation or support, leading to adverse outcomes despite advancements in neonatal care.* ***Objective:*** *To explore the knowledge, caregiving experiences, and challenges faced by caregivers of preterm infants after discharge from a tertiary care hospital in Pakistan.* ***Methods:*** *This descriptive, cross-sectional study was conducted in the Neonatology Department of Services Hospital, Lahore, from Nov 2024 to May 2025, following ethical approval (IRB/2025/1530/SIMS). Thirty-six caregivers of preterm infants (born <37 weeks gestation) discharged within the previous six months were recruited through non-probability convenience sampling. Data were collected through structured interviews during follow-up visits using a comprehensive questionnaire covering demographics, infant characteristics, feeding practices, kangaroo mother care practices, hygiene and temperature control, recognition of danger signs, developmental monitoring, emotional well-being, cultural influences, and access to support systems. Descriptive statistics and thematic analysis were used for data interpretation.* ***Results:*** *Most caregivers were mothers (66.7%) with a mean age of 29.94±7.22 years and 44.5% having tertiary-level education. Mean infant gestational age was 31.00±2.39 weeks with birth weight 1631.67±429.68g. Primary neonatal diagnoses included respiratory distress syndrome (30.5%), jaundice (22.2%), and sepsis (19.5%). While 83.3% of caregivers knew breastfeeding benefits, only 50% practiced exclusive breastfeeding, with 13.9% incorrectly diluting formula. Hunger cues were confidently recognized by 50% of caregivers. KMC was practiced at home by 44.4% with a mean frequency of 5.1±2.9 hours daily. Despite 83.3% receiving hygiene counseling, only 58.3% consistently practiced good hygiene. Danger sign recognition was limited, with only 27.8% identifying cyanosis, though all caregivers (100%) would seek hospital care when needed. Health concerns were reported in 72.2% of infants, primarily breathing difficulties (27.8%). Developmental concerns were noted by 30.6% of caregivers, while 38.9% reported infants achieving smiling milestones. Follow-up adherence was good (75% attending regular visits), but barriers included scheduling challenges (33.3%), transport issues (11.1%), and financial constraints (5.6%). Traditional practices were used by 47.2% of families. Emotional strain affected 55.5% of caregivers, with stress and fatigue reported by 35.5%. Post-discharge counseling was considered adequate by only 61.1%, while 38.9% received incomplete support.* ***Conclusion:*** *Caregivers of preterm infants face multifaceted challenges after discharge, including significant gaps between knowledge and practice implementation, particularly in exclusive breastfeeding, KMC continuation, and danger sign recognition. Despite relatively high educational levels, practical application of essential neonatal care practices remained suboptimal. Key challenges included feeding difficulties (58.4%), health-related concerns (72.2%), emotional strain (55.5%), and cultural conflicts with medical advice (47.2%). The study reveals urgent needs for structured, culturally-sensitive discharge education extending beyond hospitalization, enhanced psychosocial support addressing maternal mental health, community-based reinforcement mechanisms, and innovative follow-up strategies bridging hospital-to-home care transitions. These findings provide valuable insights for developing targeted interventions to improve neonatal outcomes in similar resource-limited settings.*

**Keywords:** Preterm infants, kangaroo mother care, parental knowledge, post-discharge care, feeding practices, danger signs, Pakistan

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## Introduction

Premature infants represent a significant proportion of hospital admissions and face elevated risks of both immediate and long-term health complications. Although advances in neonatal intensive care have dramatically improved survival rates, the transition from hospital to home remains a critical and challenging period for families. During this vulnerable phase, parents must independently manage complex care requirements, including specialized feeding protocols, growth monitoring, thermoregulation, respiratory support, and developmental interventions, often without the continuous guidance of experienced hospital staff (1).

The post-discharge period presents multifaceted challenges for caregivers of preterm infants. Common difficulties include feeding complications such as latching problems and inadequate milk supply, along with the management of respiratory issues, recognition of clinical warning signs, and maintenance of appropriate thermal regulation (2). Beyond these technical care aspects, parents frequently experience significant emotional distress, anxiety, chronic fatigue, and feelings of inadequate preparation for their caregiving role (3). These challenges are particularly pronounced in low- and middle-income countries, where cultural beliefs, misconceptions, and limited healthcare infrastructure compound the difficulties faced by families (4). Research from Indonesia, Uganda, and similar contexts demonstrates that while parents may possess basic knowledge of preterm care principles, they encounter substantial barriers, including financial constraints, social isolation, and inadequate follow-up services, resulting in feelings of helplessness and compromised care quality (5). The combination of insufficient discharge education, limited support systems, and these practical barriers can lead to inconsistent caregiving practices and increased risk of hospital readmission (6).

Furthermore, the psychological burden of caring for a preterm infant extends beyond the primary caregiver, affecting family dynamics, disrupting established roles, and creating substantial financial strain (7).

Despite decades of research in neonatal care, significant knowledge gaps remain regarding the comprehensive experiences of families caring for preterm infants in the home environment. Addressing these gaps is crucial for developing evidence-based interventions that enhance parental preparedness, build caregiving confidence, and ultimately improve outcomes for both infants and their families. This study aimed to explore parental knowledge and caregiving experiences for preterm infants following hospital discharge, and to identify specific challenges that impact the quality and continuity of post-discharge care.

## Methodology

This cross-sectional descriptive study took place in the Department of Pediatrics and Neonatology at Services Hospital, Lahore, from November 2024 to May 2025, after receiving ethical approval from the Institutional Review Board (IRB/2025/1530/SIMS). The research was carried out over six months following the IRB's approval. A non-probability convenience sampling method was used, and 36 caregivers were enrolled. The sample size was calculated based on a 95% confidence level, 10% margin of error, and an assumed 20% prevalence of parental health concerns after discharge, as noted in prior research (8). Eligible participants were parents or caregivers of preterm infants (born before 37 weeks of gestation) who had been discharged from the neonatology unit in the past six months. Caregivers of babies with major genetic or congenital disorders, or those who declined or withdrew consent, were excluded from the study. Data collection followed ethical protocols, ensuring confidentiality and informed consent. Caregivers attending routine follow-up appointments were interviewed privately in a supportive setting. A trained team, including neonatologists and residents, used a structured questionnaire to gather data. Topics included demographic and economic information, infant clinical details, caregiver knowledge and feeding practices, Kangaroo Mother Care (KMC) practices, hygiene and temperature control, recognizing signs of illness, daily routines and difficulties, emotional well-being, community and healthcare support, cultural influences, and barriers to follow-up care. All 36 participants provided complete responses covering feeding, KMC, hygiene, illness recognition, emotional states, developmental concerns, follow-up habits, decision-making, cultural beliefs, prior experience, and suggestions for improvement. Data were entered into SPSS version 21.0 for analysis. Descriptive statistics (frequencies, percentages, averages, and standard deviations) summarized quantitative findings. Thematic analysis was used for open-ended answers to identify common themes related to knowledge, caregiving, emotional strain, and systemic barriers. Given the small sample and exploratory nature of the study, no inferential statistical tests (such as Chi-square, t-tests, or logistic regression) were conducted.

## Results

The study included 36 female caregivers, with a mean age of 29.94 years (SD = 7.22), ranging from 20 to 45 years. Most of them were the infants' mothers (n = 24; 66.7%), while others included grandmothers (n = 7; 19.4%) and aunts (n = 5; 13.9%). A total of 23 caregivers (63.9%) identified themselves as the primary caregiver. Educational backgrounds varied: 16 participants (44.5%) had tertiary-level education, 9 (25%) had completed secondary schooling, and 11 (33.2%) had only basic or no formal education. In terms of occupation, more than half were homemakers (n = 22; 61.11%), followed by teachers (n = 7; 22.2%), and skilled or semi-skilled workers such as seamstresses or nurses (n = 6; 17.0%). One caregiver (2.8%) was a doctor. Family size ranged from 3 to 12 members, with a mean of 7.03 (SD = 2.14), and the number of children per household ranged from 0 to 6, with a mean of 3.08 (SD = 1.58). Monthly household income showed high variability, ranging from PKR 30,000 to PKR 400,000, with a mean of PKR 68,056 (SD = 62,379.98) (Table 1).

**Table 1: Caregiver demographics**

| Parameter | Value |
|---|---|
| Age (years) | Mean 29.94, SD ± 7.22<br>Range 20–45 |
| Relationship to infant | |
| Mother: | 24 (66.7%) |
| Grandmother: | 7 (19.4%) |
| Aunt: | 5 (13.9%) |
| Primary caregiver | 23 (63.9%) |
| Education level | |
| Tertiary: | 16 (44.5%) |
| Secondary: | 9 (25.0%) |
| Basic/None: | 11 (33.2%) |
| Occupation | |
| Homemaker | 22 (61.11%) |
| Teacher | 7 (22.2%) |
| Skilled/Semi-skilled | 6 (17.0%) |
| Doctor | 1 (2.8%) |
| Family size | Mean 7.03, SD ± 2.14<br>Range 3–12 |
| Children per household | Mean 3.08, SD ± 1.58<br>Range 0–6 |
| Monthly income (PKR) | Mean 68,056, SD ± 62,379.98<br>Range: 30,000 - 400,000 |

Among the 36 infants, 23 (63.9%) were female and 13 (36.1%) were male. Gestational age at birth ranged from 27 to 36 weeks, with a mean of 31.00 weeks (SD = 2.39). Birth weight varied between 1000g and 2500g (mean = 1631.67g, SD = 429.68), and current weight at discharge ranged from 1160g to 2750g (mean = 1796.11g, SD = 425.94). Postmenstrual age at discharge was 32.56 weeks on average (SD = 2.05), while postnatal age ranged from 3 to 21 days, averaging 10.19 days (SD = 4.89). During hospital stay, the most common medical diagnoses were respiratory distress syndrome (n = 11; 30.5%), jaundice (n = 8; 22.2%), and sepsis (n = 7; 19.5%) (Table 2). Caregivers reported returning for follow-ups primarily to check weight (n = 6; 16.7%) or reassess jaundice (n = 6; 16.7%), followed by sepsis monitoring (n = 4; 11.1%) and concerns about growth or infection (n = 3; 8.3% each).

**Table 2: Infant characteristics**

| Parameter | Value |
|---|---|
| Gender | |
| Female | 23 (63.9%) |
| Male | 13 (36.1%) |
| Gestational age (weeks) | Mean 31.00, SD ± 2.39<br>Range 27–36 |
| Birth weight (g) | Mean 1631.67, SD ± 429.68<br>Range 1000 - 2500 |
| Discharge weight (g) | Mean 1796.11, SD ± 425.94<br>Range: 1160 - 2750 |
| Postmenstrual age at discharge (weeks) | Mean 32.56, SD ± 2.05 |
| Postnatal age at discharge (days) | Mean 10.19, SD ± 4.89<br>Range: 3–21 |
| Top diagnoses while admitted | |
| Respiratory distress syndrome | 11 (30.5%) |
| Jaundice | 8 (22.2%) |
| Sepsis | 7 (19.5%) |
| Reasons for follow-up | |
| Weight check | 6 (16.7%) |
| Jaundice review | 6 (16.7%) |
| Sepsis follow-up | 4 (11.1%) |
| Growth-related concerns | 3 (8.3%) |
| Infection-related concerns | 3 (8.3%) |

In terms of feeding, 18 infants (50.0%) were exclusively breastfed, 8 (22.2%) were formula-fed, and 10 (27.8%) received mixed feeds. Among those using formula or mixed feeding, proper dilution was reported in 13 cases (36.1%), while 5 (13.9%) diluted the formula incorrectly. Feeding frequency ranged from every 30 minutes to 3 hours, with a mean interval of 2.15 hours (SD = 0.82). Hunger cues, such as crying or rooting, were confidently recognized by 18 caregivers (50.0%), sometimes identified by 9 (25.0%), and not recognized at all by another 9 (25.0%). Knowledge of the benefits of exclusive breastfeeding was high, with 30 caregivers (83.3%) reporting awareness. The most commonly identified benefits were improved immunity (n = 10; 27.8%), better nutrition (n = 8; 22.2%), and bonding (n = 6; 16.7%). Other less frequently mentioned advantages included growth, weight gain, emotional comfort, maternal recovery, and cost savings. Most infants (n = 25; 69.4%) were fed without any assistive device, while 6 (16.7%) used a breast pump, 4 (11.2%) used a spoon or cup, and 1 (2.8%) used a nasogastric tube. When asked about challenges related to nursing, 15 caregivers (41.7%) reported no issues, but 11 (30.6%) experienced low milk supply. Other reported challenges included oral thrush (n = 4; 11.1%), sore nipples (n = 3; 8.3%), difficulty with latching (n = 2; 5.6%), and tube feeding issues (n = 1; 2.8%). Kangaroo Mother Care (KMC) was practiced at home by 16 caregivers (44.4%), with reported frequency ranging from every 2 to 12 hours (mean = 5.1 hours, SD = 2.9) and session durations between 30 minutes and 8 hours (mean = 2.1 hours, SD = 1.9). Most (n = 13; 36.1%) reported no problems with KMC; only a few noted issues such as infant restlessness, skin irritation, or excessive sweating (each n = 1; 2.8%). Regarding hygiene, 30 caregivers (83.3%) stated they had received comprehensive guidance on handwashing and feeding hygiene. However, only 21 (58.3%) consistently practiced good hygiene, while 9 (25.0%) did so inconsistently, and 6 (16.7%) did not adhere regularly (Table 3).

**Table 3. Infant feeding practices, KMC, and hygiene**

| Parameter | Value |
|---|---|
| Feeding type | |
| Breastfeeding | 18 (50.0%) |
| Formula | 8 (22.2%) |
| Mixed | 10 (27.8%) |
| Proper formula dilution | |
| Yes | 13 (36.1%) |
| No | 5 (13.9%) |
| Feeding frequency (hours) | Mean 2.15, SD ± 0.82<br>Range: 0.5–3 |
| Recognition of hunger cues | |
| Confidently/always | 18 (50.0%) |
| Sometimes | 9 (25.0%) |
| Poorly/never | 9 (25.0%) |
| Knowledge of exclusive breastfeeding benefits | 30 (83.3%) |
| Immunity | 10 (27.8%) |

| | |
|---|---|
| Nutrition | 8 (22.2%) |
| Bonding | 6 (16.7%) |
| Feeding aids | 11 (30.6%) |
| Breast pump | 6 (16.7%) |
| Spoon/cup | 4 (11.2%) |
| Nasogastric tube | 1 (2.8%) |
| Feeding challenges | 21 (58.4%) |
| Low milk supply | 11 (30.6%) |
| Oral thrush | 4 (11.1%) |
| Sore nipples | 3 (8.3%) |
| Difficulty latching | 2 (5.6%) |
| Tube feeding issues | 1 (2.8%) |
| KMC at home | 16 (44.4%) |
| Frequency (hrs/day) | Mean 5.1, SD ± 2.9<br>Range: 2–12 |
| Duration per session (hours) | Mean 2.1, SD ± 1.9<br>Range: 0.5–8 |
| Reported KMC issues | 3 (18.7%) |
| Infant restlessness | 1 (2.8%) |
| Skin irritation | 1 (2.8%) |
| Excessive sweating | 1 (2.8%) |
| Counselled about feeding hygiene + handwashing | 30 (83.3%) |
| Practicing at home | |
| Always | 21 (58.3%) |
| Sometimes | 9 (25%) |
| Rarely | 6 (16.7%) |

Understanding of normal breathing and sleep patterns was pretty good, with 24 caregivers (66.7%) being fully aware, 6 (16.7%) somewhat aware, and 6 (16.7%) unaware. Regarding developmental milestones, 14 infants (38.9%) had begun smiling, 6 (16.7%) had head control, and 4 (11.1%) could recognize faces or respond to voices. However, 12 (33.3%) had not yet shown developmental signs. Thirteen caregivers (36.1%) felt their child's development was normal, 7 (19.4%) were satisfied, 11 (30.6%) were concerned, and 5 (13.9%) thought it was too early to assess (Table 4).

**Table 4. Sleep & breathing awareness, milestones, and development perception**

| Parameter | n (%) |
|---|---|
| Awareness of regular sleep & breathing patterns | |
| Aware | 24 (66.7%) |
| Somewhat aware | 6 (16.7%) |
| Unaware | 6 (16.7%) |
| Developmental milestones attained | |
| Smiling | 14 (38.9%) |
| Head control | 6 (16.7%) |
| Face/voice recognition | 4 (11.1%) |
| Caregiver perceptions of infant development | |
| Normal | 13 (36.1%) |
| Satisfactory | 7 (19.4%) |
| Concerned | 11 (30.6%) |
| Too early to assess | 5 (13.9%) |

Health concerns were reported in 26 infants (72.2%), with the most common being breathing difficulties (n = 10; 27.8%), fever (n = 5; 13.9%), and sleep-related concerns (n = 5; 13.9%). In response to breathing cessation, 18 caregivers (50.0%) said they would use tactile stimulation, 12 (33.3%) would try mouth-to-mouth breathing, and 6 (16.7%) offered mixed responses. Isolated cases of apneic episodes, loose stools, or failure to gain weight were reported by one caregiver each (2.8%). The remaining 10 caregivers (27.8%) noted no health issues. Temperature control strategies included the use of heaters and warm clothing (n = 14; 38.9%), a heater with KMC (n = 8; 22.2%), a heater alone (n = 4; 11.1%), and blankets or sunlight (n = 4; 11.2%). Notably, six caregivers (16.7%) used no specific method to regulate temperature. Awareness of neonatal danger signs varied. The most commonly cited signs were cyanosis or bluish lips (n = 10; 27.8%), irritability (n = 6; 16.7%), and cold extremities (n = 4; 11.1%). Despite variations in awareness, all 36 caregivers (100%) stated they would seek hospital care if danger signs appeared (Table 5)

**Table 5: Infant health concerns and caregiver response**

| Parameter | n (%) |
|---|---|
| Reported infant health issues | 26 (72.2%) |

| | |
|---|---|
| Breathing difficulty | 10 (27.8%) |
| Fever | 5 (13.9%) |
| Sleep-related concerns | 5 (13.9%) |
| Apneic episodes | 1 (2.8%) |
| Loose stools | 1 (2.8%) |
| Failure to gain weight | 1 (2.8%) |
| **Response to breathing cessation** | |
| Tactile stimulation | 18 (50.0%) |
| Mouth-to-mouth breathing | 12 (33.3%) |
| Mixed/other responses | 6 (16.7%) |
| **Temperature regulation methods** | |
| Heater + warm clothing | 14 (38.9%) |
| Heater + KMC | 8 (22.2%) |
| Heater alone | 4 (11.1%) |
| Blankets or sunlight | 4 (11.2%) |
| No specific method | 6 (16.7%) |
| Awareness of danger signs | 20 (55.6%) |
| Cyanosis (bluish lips, hands, and feet) | 10 (27.8%) |
| Irritability | 6 (16.7%) |
| Cold extremities | 4 (11.1%) |
| Would seek hospital care if danger signs | 36 (100%) |

Follow-up attendance was generally consistent, with 27 caregivers (75.0%) attending weekly or biweekly regular visits. Others had monthly (n = 5; 13.9%) or irregular (n = 4; 11.1%) follow-up patterns. Barriers to consistent follow-up included scheduling challenges (n = 12; 33.3%), transport issues (n = 4; 11.1%), financial constraints (n = 2; 5.6%), and lack of family support (n = 2; 5.6%). Support systems usually included aunts (n = 10; 27.8%) and grandmothers (n = 8; 22.2%), and half the caregivers (n = 18; 50.0%) felt that their support systems were sufficient. The infant's mother was involved in decision-making in 50.0% of cases (n = 18), followed by a family elder in 30.6% (n = 11) and the father in 19.4% (n = 7). Moreover, 69.4% of caregivers (n = 25) reported that their opinions were taken into account during the decision-making process. Traditional practices such as delayed initiation of breastfeeding, application of substances to the umbilical stump, herbal remedies, gripe water, and mustard oil massage were used by 17 caregivers (47.2%), while 19 (52.8%) used none. Sources of health information varied: most relied on clinics, family, or community health workers, while only 8 (22.2%) accessed the internet. Experience caring for infants was reported by 22 caregivers (61.1%) and was found helpful by 29 (80.6%). Emotionally, 16 caregivers (44.4%) felt confident while caring for their infant, while 8 (22.2%) reported fatigue, 5 (13.9%) experienced stress, and 7 (19.4%) reported both stress and fatigue. Twenty-two caregivers (61.1%) received satisfactory post-discharge counselling, most often from doctors (n = 27; 75.0%) and nurses (n = 9; 25.0%). At the same time, 14 caregivers (38.9%) reported receiving incomplete or partial counseling (Table 6).

**Table 6: Follow-up, support, and counseling**

| **Variable** | **n (%)** |
|---|---|
| **Follow-up attendance** | |
| Weekly/biweekly | 27 (75.0%) |
| Monthly | 5 (13.9%) |
| Irregular | 4 (11.1%) |
| Barriers to follow-up | 20 (55.6%) |
| Scheduling challenges | 12 (33.3%) |
| Transport issues | 4 (11.1%) |
| Financial constraints | 2 (5.6%) |
| Lack of family support | 2 (5.6%) |
| **Support systems** | |
| Aunt | 10 (27.8%) |
| Grandmother | 8 (22.2%) |
| Support system considered sufficient | 18 (50.0%) |
| **Primary decision maker** | |
| Mother | 18 (50.0%) |
| Family elder | 11 (30.6%) |
| Father | 7 (19.4%) |
| Caregiver's opinion considered | 25 (69.4%) |
| Use of traditional practices | 17 (47.2%) |
| **Sources of health information** | |
| Local practitioner/health clinic | 16 (44.4%) |
| Family members | 12 (33.3%) |

| | |
|---|---|
| Internet | 8 (22.2%) |
| Past infant caring experience | 22 (61.1%) |
| Experience found helpful | 29 (80.6%) |
| **Emotional state of caregivers** | |
| Confident | 16 (44.4%) |
| Fatigued | 8 (22.2%) |
| Stressed | 5 (13.9%) |
| Both stressed & fatigued | 7 (19.4%) |
| **Post-discharge counseling given by** | |
| Doctor | 27 (75.0%) |
| Nursing staff | 9 (25.0%) |
| **Counselling adequacy** | |
| Sufficient | 22 (61.1%) |
| Partial/insufficient | 14 (38.9%) |

Suggestions for improvement were diverse, including requests for better follow-up systems, home visits, feeding and emotional support, community services, and transport assistance, each suggested by 1-2 caregivers (2.8-5.6%) (Figure 1).

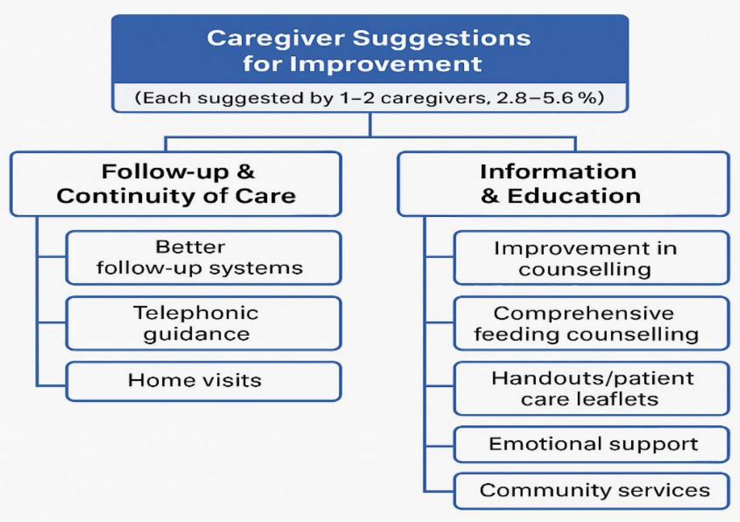

**Figure 1: Caregiver suggestions for improvement**

## Discussion

This study provides comprehensive insights into the lived experiences, caregiving practices, and knowledge gaps of families caring for preterm and low birth weight infants in a resource-limited urban Pakistani setting. The findings illuminate how the complex interplay of maternal education, cultural norms, systemic limitations, and social support structures shapes neonatal caregiving. Despite 44.5% of caregivers having tertiary education, a persistent and concerning gap existed between theoretical knowledge and practical implementation, particularly in critical areas such as exclusive breastfeeding, danger sign recognition, and thermal care management. This knowledge-practice disconnect mirrors broader trends observed across low- and middle-income countries (LMICs), where formal education, while valuable, proves insufficient on its own to drive optimal neonatal outcomes (9, 10). The stark contrast between awareness and application was most evident in feeding practices: although 83.3% of caregivers acknowledged the benefits of exclusive breastfeeding, only 50% implemented it consistently, and 13.9% reported incorrect formula dilution techniques. This disparity raises significant concerns about nutritional risks and growth outcomes stemming from misinformation or inadequate practical counseling (11). Feeding practices revealed multifaceted challenges that extended beyond simple knowledge deficits. Only half of caregivers could confidently recognize infant hunger cues, feeding intervals varied dramatically (30 minutes to 3 hours), and improper formula dilution in 13.9% of cases posed serious risks of hypernatremia, dehydration, and growth faltering (12, 13). The prevalence of feeding difficulties, including low milk supply (30.6%), oral thrush (11.1%), and latching problems (5.6%), often remained unaddressed due to insufficient lactation support and limited access to specialized counseling services (14).

Kangaroo Mother Care (KMC) implementation revealed a significant hospital-to-home transition gap, with only 44.4% of caregivers continuing the practice post-discharge despite its well-established benefits for thermoregulation, bonding, and survival outcomes (15). This low uptake likely reflects household responsibilities, family resistance, cultural misconceptions, and lack of structured community-based reinforcement, challenges consistently reported across LMICs (16). While few complications were reported among those practicing KMC, the substantial discontinuation rate suggests an urgent need for culturally adapted promotion strategies and ongoing support systems.

Danger sign recognition represented perhaps the most concerning knowledge gap, with potentially life-threatening implications. Despite universal willingness to seek hospital care when needed, only 27.8% of caregivers could identify cyanosis, 16.7% recognized irritability as a warning sign, and merely 11.1% knew to watch for cold extremities. Emergency response preparedness was similarly inadequate, with an inconsistent understanding of appropriate interventions for breathing cessation. These deficits align with findings from South Asia and sub-Saharan Africa, where post-discharge emergency readiness training remains minimal (17, 18).

Despite 83.3% of caregivers receiving hygiene guidance, only 58.3% maintained consistent practices at home, highlighting the challenge of translating facility-based education into sustainable daily routines. Temperature regulation strategies varied widely, with 16.7% employing no specific thermal management methods and others relying on potentially inadequate alternatives like sunlight exposure. The underutilization of KMC for warmth (only 22.2% combined KMC with heating strategies) represents a missed opportunity for evidence-based thermal care (19). Developmental monitoring revealed concerning gaps in both assessment and concern levels. While 38.9% of infants had achieved smiling milestones and 16.7% demonstrated head control, one-third showed no observable milestones yet generated minimal parental concern. This pattern suggests either normalization of delayed development, insufficient awareness of age-appropriate behaviors, or inadequate counseling about expected developmental trajectories. Contributing factors likely include caregiver fatigue, cultural expectations, and limited access to developmental guidance. The emotional toll of preterm infant caregiving emerged as a significant yet underaddressed concern. Over half of caregivers (55.5%) experienced stress, fatigue, or both, while only 61.1% received adequate discharge counseling support. This neglect of maternal mental health and psychosocial needs reflects broader systematic gaps in LMIC neonatal care programs (20). The isolation experienced by 50% of caregivers, combined with insufficient family support systems, compounds the psychological burden of managing medically vulnerable infants. Caregiver knowledge and experience across key themes is summarized in Figure 2.

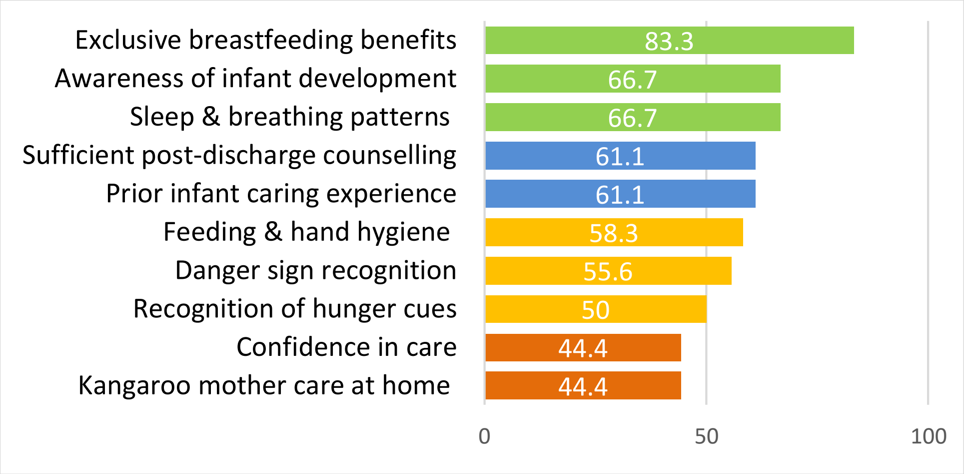

**Figure 2: Caregiver knowledge and experience across key themes**

Despite relatively encouraging follow-up adherence (75% attending regular visits), systemic barriers, including irregular scheduling (33.3%), transportation difficulties (11.1%), and financial constraints (5.6%), hindered optimal continuity of care. These findings underscore the urgent need for innovative delivery mechanisms such as mobile health platforms, community-based visits, and telemedicine support to bridge geographical and economic access gaps (21). Cultural dynamics significantly shaped caregiving patterns, reflecting the communal caregiving model characteristic of South Asian societies. While mothers served as primary caregivers, grandmothers and aunts played influential roles in decision-making and daily care practices. Nearly half of families (47.2%) employed traditional remedies, including gripe water, mustard oil massage, and herbal treatments. While culturally meaningful, these practices sometimes conflicted with evidence-based medical recommendations and required respectful, culturally sensitive guidance rather than outright prohibition (22).

The study findings reveal that post-discharge challenges were primarily health-related (72.2%) and feeding-related (58.4%), followed by follow-up barriers (55.6%) and emotional strain (55.5%) (Figure 3). These interconnected challenges emphasize the need for comprehensive, multi-dimensional interventions that address not only knowledge gaps but also practical implementation barriers, cultural considerations, and psychosocial support needs.

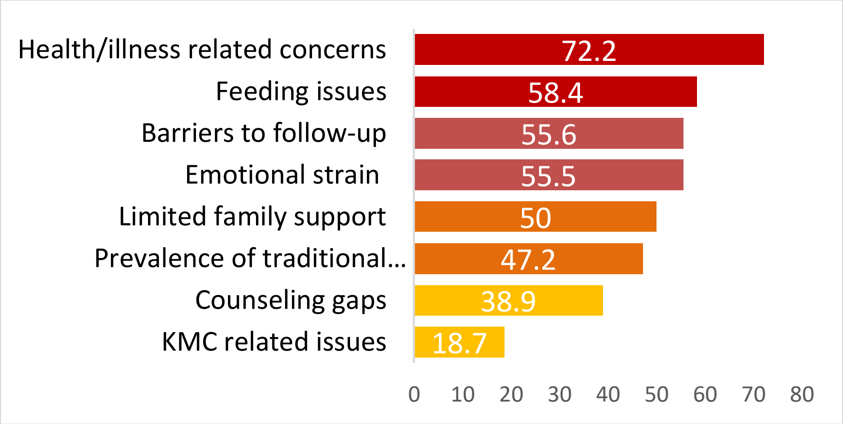

**Figure 3: Key challenges faced post-discharge**

Key areas requiring targeted intervention include: enhanced practical feeding support with hands-on demonstration and ongoing troubleshooting; culturally adapted KMC promotion strategies with family engagement; systematic emergency preparedness training with regular reinforcement; structured developmental monitoring guidance; comprehensive psychosocial support addressing maternal mental health; and innovative follow-up mechanisms reducing access barriers while maintaining care quality. This study's cross-sectional design and small sample size limit generalizability, while the single-center urban setting may not reflect rural experiences. Future research should employ longitudinal designs tracking outcomes over extended periods, include diverse geographical settings, and develop culturally adapted intervention strategies with rigorous evaluation of effectiveness and cost-effectiveness.

## Conclusion

This study reveals the complex, multifaceted nature of preterm infant caregiving in a lower-middle-income urban Pakistani context, where educated, committed caregivers nevertheless face significant challenges in translating knowledge into effective practice. The persistent gaps between awareness and implementation—particularly in exclusive breastfeeding (83.3% awareness vs. 50% practice), KMC continuation (hospital initiation vs. 44.4% home practice), and danger sign recognition (100% willingness to seek care vs. 27.8% ability to identify critical signs)-highlight the inadequacy of knowledge-only approaches to discharge preparation.

The findings demonstrate that optimal neonatal outcomes require more than individual caregiver education; they demand systematic changes addressing cultural integration, family dynamics, healthcare accessibility, and ongoing support mechanisms. The high prevalence of health-related concerns (72.2%), feeding difficulties (58.4%), and emotional strain (55.5%) among caregivers underscores the vulnerability of this population and the critical importance of comprehensive post-discharge support systems.

## Declarations

### Data Availability statement

All data generated or analysed during the study are included in the manuscript.

### Ethics approval and consent to participate

Approved by the department concerned. (IRB/2025/1530/SIMS)

### Consent for publication

Approved

### Funding

Not applicable

## Conflict of interest

The authors declared the absence of a conflict of interest.

## Author Contribution

**SH (Associate Professor)**
*Data Collection, Data Analysis, Manuscript drafting, Critical Input, and Study Design, Conception of Study, and Final Approval of Draft*
**BBM (Assistant Professor)**
*Review of Literature, Data entry, Manuscript Revision, and Final Approval of Draft*
**AS (Postgraduate Resident)**
*Development of Research Methodology Design, Conception of Study*
**AK (Postgraduate Resident)**
*Study Design, Manuscript review, and critical input.*
**FS (Assistant Professor),**
*Study Design, Critical Input*
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*Critical Input, and Review of Literature*

*All authors reviewed the results and approved the final version of the manuscript. They are also accountable for the integrity of the study.*

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