

Stakeholders' Experiences and Perspectives on Home Program Provision and Adherence for Preterm Infants of First-Time Mothers in India: A Qualitative Study

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Research Article

Keywords: adherence, early intervention, home, occupational therapy, sociocultural factors

Posted Date: May 19th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-9247305/v1>

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Additional Declarations: No competing interests reported.

Abstract

Background

In resource-constrained settings, home programs are crucial, especially for first-time mothers who lack prior caregiving experience, to ensure continuity of care of preterm infants post-discharge. There is limited literature on home program provision and adherence to support early intervention of pre-term infants in the Indian context. Therefore, this study aimed to examine the experiences and perspectives of all stakeholders, including first-time mothers, family members, and healthcare providers, regarding the provision of home programs and adherence to them for preterm infants in the Indian context.

Methods

The study employed a descriptive qualitative design. Semi-structured interviews were conducted with ten first-time mothers, seven family members, and 15 healthcare professionals, including neonatologists, occupational therapists, physiotherapists, and nurses.

Results

Three main themes emerged. The first theme, “Current practices and factors impacting home program provision,” described inadequate delivery, siloed services, and limited emphasis on early intervention. The second theme, “Implementation of the home program by first-time mothers,” described challenges, including mothers’ inadequate knowledge and confidence, lack of family support, and socio-cultural factors. The third theme, “Felt Needs and Recommendations,” outlined strategies to improve home program provision and adherence, including the need for structured programs, family involvement, enhanced interdisciplinary coordination, and follow-up services.

Conclusion

The findings identified practice gaps, felt needs, and factors influencing the continuity of early intervention for preterm infants after discharge among first-time mothers. The findings highlight the need to strengthen existing practices in home program provision by incorporating strategies that bolster mothers' personal resources and self-efficacy while integrating family support and community services.

BACKGROUND

Preterm birth continues to be a major global health issue, with approximately 13.4 million infants born prematurely in 2020. Nearly 15% of these births occurred before 32 weeks of gestation, necessitating specialized neonatal care to support survival and enhance long-term developmental outcomes [1]. The burden is especially high in low and middle-income countries (LMICs), which account for nearly 60% of global preterm births [2]. India alone accounts for a substantial portion of this total, with approximately 3.02 million preterm births each year, more than 23% of all preterm births worldwide [1, 3]. Preterm infants require early intervention to support their developmental progress [4, 5], which begins in the Neonatal Intensive Care Unit (NICU) and extends beyond discharge [6–8].

The transition from the NICU to home is a critical component of ensuring continuity of care. In developed countries, the transition from NICU to home is more streamlined, supported by a structured, well-resourced transition care pathway that includes coordinated follow-up, education, early intervention services, home visits, and automatic referrals to early intervention services [9, 10]. However, in developing countries such as India, continuity of care appears fragmented due to

resource constraints [11–13]. Home programs are a cost-effective alternative, especially in limited-resource settings, where accessibility issues and economic hardship prevent parents from continuing formal early intervention after discharge [14]. The mother is usually the primary recipient of the home program [15, 16]. Research indicates that mothers who provide consistent sensorimotor stimulation via a structured home program in the first year significantly support the developmental progress of their preterm infants [17]. However, mothers are often emotionally overwhelmed and fearful after NICU discharge [18] and have difficulty carrying out the home program [19, 20]. The situation is especially challenging for first-time mothers who lack prior caregiving experience [21, 22].

In India, first-time mothers are usually young, with an average age of 21.2 years [23, 24], and may not be well educated [25], which may further affect their ability to comprehend the complexities of caring for high-risk infants. We identified only two studies in the Indian context that examined first-time mothers' experiences of caring for preterm infants. The study by Sahoo, Lewis, and Dsouza [26] involved first-time mothers, whereas the study by Raghupathy et al. [16] included parents of preterm infants, with 70 percent of mothers being first-time mothers. In both studies, first-time mothers appreciated the care and support provided by health care professionals, but also described several challenges in service delivery, including an overwhelming NICU environment and care processes, and felt that the time and information provided were inadequate to meet the complex and critical demands of caring for a preterm infant after discharge. They reported difficulty following all components at home, especially early intervention, due to fear of handling their fragile infants, low confidence, time constraints, and disrupted routines. The mothers also reported that their husbands were afraid to handle the baby. With limited personal and spousal competencies for infant care, first-time mothers relied on more experienced family members. While mothers described families as a valuable source of support, they also reported challenges, including family members' insistence on carrying out unsafe and contraindicated but culturally prevalent practices such as burning coal in infants' proximity and traditional oil massage [27, 28]. Thus, the provision and adherence to home programs that support early intervention depend on several stakeholders, including the first-time mother, family members who are service recipients, and health care professionals who serve as service providers to the mother and family.

In a resource-constrained setting such as India, home programs offer a feasible way to provide ongoing early intervention for preterm infants and are especially important for first-time mothers. The long-term outcomes for preterm infants in India are poor, including delays in motor and mental development [29]. Studies suggest that adherence to early intervention programs is around 59.2% [30], underscoring the need to improve home program provision, especially to reduce infant morbidity. This would require understanding current practices and the factors influencing the provision and adherence to home programs. The two available studies in the Indian context [16, 26] have captured only the experiences and perspectives of mothers and fathers. A comprehensive understanding of home program provision and adherence would require input from all stakeholders, including extended family members and health care professionals. Therefore, this study aimed to understand the experiences and perspectives of all stakeholders, i.e., service recipients (first-time mothers and family members) and service providers, regarding home program provision and adherence for first-born preterm infants in the Indian context.

Research Questions:

1. What are the perceptions and experiences of first-time mothers and family members about home program provision and adherence for preterm infants?
2. What are healthcare professionals' perceptions and experiences concerning home programs for preterm infants of first-time mothers?

METHODS

Study settings

The study was conducted in NICUs at three hospitals in South Karnataka, India: two tertiary teaching hospitals, one in Udupi and another in Mysore, and a corporate hospital in Bangalore. These sites represented diverse healthcare environments with varying early intervention and follow-up services for preterm infants. In the teaching hospitals, multidisciplinary teams provided specialized neonatal care and follow-up, whereas the Bangalore hospital had a NICU mainly staffed by neonatologists and nurses, lacking in-house therapy and follow-up services. When early intervention was needed, infants were referred to other hospitals. All participating mothers and family members were recruited from these settings; however, because the number of healthcare professionals in these hospitals was limited, the study setting for this group of stakeholders was expanded to include professionals practicing across various parts of India.

Study design

This study employed a qualitative descriptive design to explore stakeholders' experiences and perspectives on how home programs were delivered and implemented to support early intervention continuity for preterm infants. This approach was chosen to gain insight into participants' experiences and to provide a clear, detailed description of the phenomenon, thereby facilitating an exploration of the "what," "how," and "why" of stakeholder experiences [31]. It captures straightforward, comprehensive accounts, especially when knowledge is limited [31–33].

Study participants and sampling strategy

For healthcare professionals, both purposive and snowball sampling techniques were employed. Neonatologists, nurses, occupational therapists, and physiotherapists with a minimum of two years of experience in the NICU or early intervention settings were identified and invited to participate. Subsequently, snowball sampling was used to recruit additional professionals based on recommendations from the initial participants.

For mothers and family members, purposive sampling was used. The study included English or Kannada-speaking first-time mothers and family members of preterm infants with a history of NICU admission, who had cared for their infant at home for at least one month but not more than six months following discharge. Mothers with significant medical conditions such as postpartum psychosis, neurological disorders, or cognitive impairments were excluded. Similarly, mothers whose infants had severe congenital anomalies or other serious health conditions were excluded. Family members were included if they had been directly involved in caring for the preterm infant at home. In total, 16 mothers were approached, of whom six declined to participate due to scheduling conflicts, lack of time, or reluctance to engage in extended interviews. Of the 11 family members approached, four declined to participate due to household responsibilities or lack of time. Of the seven recruited family members, only two dyads were present (F01 and F02, who were the spouses of M01 and M02, respectively). For healthcare professionals, 15 individuals were approached, and all agreed to participate in the study.

Data collection

The study was conducted from October 2021 to August 2022. This study was approved by the Ethics Committee of Kasturba Medical College and Kasturba Hospital (318/2020). Data were collected through semi-structured interviews, using separate interview guides for mothers, family members, and healthcare professionals. The interview guides were developed based on the literature and our experience working with mothers and healthcare professionals in the NICU. The interview guides served as a reference, enabling open-ended exploration of participants' experiences without imposing structure. Table 1 presents the interview guides, including sample questions and probes. To assess the clarity of the questions, the interview guides were pilot-tested with one mother, one family member, and two occupational therapists. They were finalized based on the feedback received. Additionally, the interview guide for mothers and family members was translated into Kannada.

Table 1
Interview guide

Interview Questions for mother/ family members		Interview Questions for Healthcare Professionals	
1	Could you describe how you were advised to take care of your baby at home after discharge from the NICU?		Could you please describe the provision of home programs in your setting and your experience of the same?
2	Could you share your experience with following the home program instructions for your baby after discharge from the NICU?		Could you describe your experience with how mothers follow the home program instructions?
3	In your opinion, what else could have been done to improve home program provision?		From your perspective, what else could have been done to improve home program provision?
Sample probes			
	• How did you go about providing the home program at home? • Can you give an example of the kind of support you received at home while caring for your baby? • What challenges or difficulties did you face while carrying out the home program? • How are you continuing the home program at home, and how are you managing it day to day?		• How is the home program usually explained or delivered to families in your setting? • Can you share specific examples of barriers you have encountered while supporting families with the home program? • Specific approach or strategies implemented to help families stay consistent with the home program.

[Insert Table 1 here]

Interviews were conducted in English/ Kannada based on the participants' preference. Interviews in Kannada were conducted by a bilingual research assistant to ensure data quality. Interviews were conducted either in person or by phone. Due to COVID-19 restrictions, most interviews were conducted by phone to comply with safety protocols. However, whenever possible and safe, in-person interviews were conducted at the hospital or other convenient locations. First-time mothers and family members were approached during routine follow-up visits at the selected hospitals. Using hospital records and follow-up registers, eligible participants who met the inclusion criteria were identified. After confirming eligibility, they were approached in person and invited to participate in the study. Healthcare professionals were identified through purposive and snowball sampling and contacted directly at their workplaces or through professional networks. The purpose of the study was explained to all potential participants, and those who agreed provided written or verbal informed consent prior to participation.

After obtaining the consent, participants were interviewed either in person or by phone, at their choice. Interviews took place in quiet settings to minimize distractions. Field notes were also taken during the interviews to capture contextual details and nonverbal cues. Interviews lasted 25 to 45 minutes, and all interviews were audio-recorded with participants' prior consent. All recordings were anonymized, transcribed, and translated into English within a week of the interview. To ensure accuracy and cultural relevance, a bilingual expert reviewed the translations, and a native Kannada speaker verified the transcripts. Data collection continued until no new themes were identified, indicating saturation.

Data analysis

The study used thematic analysis [34] to analyze the data. The analysis was conducted manually using printed transcripts. First, all authors read the transcripts and field notes multiple times to become familiar with the data. Two researchers (the primary and corresponding authors) independently identified initial codes relevant to participants' experiences. In cases of coder disagreement, the second author was consulted to resolve the issues. These codes were grouped into categories, which were then refined into overarching themes. An iterative process of discussion, review, and refinement took place during several team meetings to ensure the themes accurately captured the participants' experiences.

Research team and reflexivity

The primary author (PA) is an occupational therapist with experience working in the NICU and has good knowledge of conducting qualitative research. The corresponding author is an occupational therapist with expertise in qualitative research, while the second author is a leading and experienced Neonatologist working in the NICU. Additionally, throughout the analysis, the authors maintained a reflective journal to document the research team's thoughts, interpretations, and decisions during the coding process. This helped to ensure alignment between the data and the study objectives.

RESULTS

Characteristics of the 32 participants are presented in Table 2 (mothers of preterm infants), Table 3 (family members of mothers of preterm infants), and Table 4 (healthcare professionals). Only two mother–family member dyads were part of the sample: Mother 1 with Family 1 and Mother 2 with Family 2.

Table 2
Demographic Characteristics of Mothers of Preterm Infants

Participant	Age (years)	Location	Interview Mode	Educational Level	Occupation	Family Structure	Residence at the time of the interview	Support System
M01	31	Udupi	In-person	Higher secondary education	Homemaker	Joint Family	Mother's house	Sister-in- law and other family members
M02	26	Udupi	In-person	Higher secondary education	Homemaker	Joint family	Mother's house	Own mother
M03	25	Udupi	Telephone	Higher secondary education	Homemaker	Nuclear Family	Husband's house	No support
M04	25	Mysore	Telephone	Secondary education	Homemaker	Joint family	Husband's house	Mother- in-law, husband, and family members
M05	24	Mysore	Telephone	Higher secondary education	Homemaker	Joint family	Mother's house	Mother
M06	26	Bangalore	Telephone	Higher education	Staff Nurse	Nuclear Family	Mother's house	Paid worker
M07	24	Udupi	In-person	Higher secondary education	Homemaker	Nuclear Family	Mother's house	Mother
M08	30	Udupi	Telephone	Higher secondary education	Homemaker	Joint family	Mother's house	Mother
M09	40	Udupi	Telephone	Higher education	Homemaker	Nuclear family	Husband's house	No support
M10	30	Udupi	In-person	Higher secondary education	Homemaker	Joint family	Mother's house	Mother

Table 3
Demographic Characteristics of Family Members of Mothers of Preterm Infants

Participant	Age (years)	Location	Interview Mode	Occupation	Relationship with mother
F01	32	Udupi	Telephone	Software Engineer	Spouse (Family member of Mother1: Dyad 1)
F02	30	Udupi	Telephone	Welder	Spouse (Family member of Mother2: Dyad 2)
F03	34	Udupi	Telephone	Homemaker	Sister-in-law (Individual: no dyad)
F04	28	Mysore	In-person	Security Guard	Spouse (Individual: no dyad)
F05	32	Udupi	Telephone	Staff Nurse	Sister-in-law (Individual: no dyad)
F06	48	Udupi	Telephone	Homemaker	Elder sister (Individual: no dyad)
F07	28	Udupi	Telephone	Salesman	Spouse (Individual: no dyad)

Table 4
Demographic Characteristics of Healthcare Professionals Interviewed

Participant ID	Age (years)	Location	Interview Mode	Profession	Experience in Early Intervention
HCP01	27	Delhi	Telephonic	Occupational Therapist	6 years
HCP02	31	Bangalore	Telephonic	Occupational Therapist	4 years
HCP03	29	Kerala	Telephonic	Occupational Therapist	3 years
HCP04	32	Mysore	Telephonic	Physiotherapist	4 years
HCP05	28	Bangalore	In-person	Physiotherapist	3 years
HCP06	28	Udupi	In-person	Physiotherapist	3 years
HCP07	32	Bangalore	In-person	Nursing professional	5 years
HCP08	36	Udupi	In-person	Nursing professional	11 years
HCP09	29	Udupi	In-person	Nursing professional	4 years
HCP10	46	Mysore	Telephonic	Nursing professional	13 years
HCP11	41	Bangalore	In-person	Neonatologist	10 years
HCP12	42	Mangalore	Telephonic	Neonatologist	11 years
HCP13	42	Mysore	Telephonic	Neonatologist	11 years
HCP14	37	Udupi	In-person	Neonatologist	4 years
HCP15	45	Mysore	Telephonic	Neonatologist	14 years

[Insert Table 2 here]

[Insert Table 3 here]

[Insert Table 4 here]

Based on the analysis, three overarching themes emerged: (1) current practices and factors impacting home program provision, (2) Implementation of home program by first-time mothers, and (3) Felt Needs and Recommendations. Figure 1 represents the themes and categories of the study.

[Insert Fig. 1 here]

Theme 1: Current Practices and Factors Impacting Home Program Provision

This theme describes the practices related to the content and delivery of the early intervention home program, as well as the hospital system-related factors that influence its provision in the NICU. The content of the home program varied with the NICU setup, including the availability of healthcare providers and the presence of an early intervention unit or a therapist. Typically, it covered the medical management of high-risk preterm infants, which included information about medications, infection control, and breastfeeding of the infant. However, if the unit had an early intervention unit or therapist, the program then extended beyond medical care to include early intervention to support the infant's developmental pattern. Most participants received their home programs through verbal instructions, a combination of verbal and written materials, or demonstrations, based on mothers' preferences and the availability of HCPs. Two family members explained, *"At the time of discharge, they (HCPs) told us medicine to be given on time and breast milk should be given to the child"* (F03). A few participants also reported receiving written materials (a printed pamphlet) and training demonstrations on implementing the early intervention program at home. The mothers and family members appreciated these strategies and found them helpful in ensuring the continuity of the early intervention program at home. As one mother explained, *"They (HCPs) told what to do at home"* (M01). The home program content was usually modified during follow-up sessions based on the infant's developmental milestones and the specific concerns expressed by the parents. One occupational therapist explained, *"After three months of age, we work on developmental milestones, the musculoskeletal system, and neurobehavioral organization. Before that, we focus on all domains of development-gross motor, fine motor, visuospatial, and social"* (HCP01).

Home program provision was also influenced by the hospitals' system and processes. The participants identified siloed services, weak referral pathways, inconsistent information, and a lack of coordination among HCPs as factors that influence home program provision. One family member explained that *"even now there is a lot of confusion about how to burp the baby...the doctor told me how to burp after feeding. But other staff (HCP), a different way. I do not know which one is right"* (F01). In addition, mothers and family members were dissatisfied with the way information was communicated to them in the NICU. As one spouse narrated: *"We are first-time parents, they (HCPs) should tell us the information properly, not keep us in the dark. We(parents) get panicked"* (F01). The parents felt that the information provided was incomplete and not clearly understood due to medical terminology, and that it could have been delivered more sensitively, given the parents' emotional state. The study found that neonatologists placed greater emphasis on medical management and less on early intervention. This focus on medical management was a concern as neonatologists were the primary point of contact in the NICU. As one physiotherapist explained, *"Unless the doctor does not tell them (mother/ family member) that it (early intervention) is important, they will not come"* (HCP04). These challenges resulted in limited referrals for early intervention services. HCPs also reported inadequate coordination and communication among professionals, which hindered the consistent implementation of early intervention services and follow-up care. A physiotherapist mentioned that *"As a team, I do not think we work together well. We often work in silos"* (HCP04).

Theme 2: Implementation of Home Program by First-time Mothers

This theme covers multiple interrelated factors influencing home programs, including mothers' knowledge and confidence, family involvement, and sociocultural factors.

Subtheme 2.1: Mother's knowledge and confidence

Preterm infants' fragile condition caused fear and anxiety in first-time mothers, especially during the NICU-to-home transition. The mothers worried about providing proper care and not harming their infants. Unclear guidance left them feeling unprepared, which reduced their confidence in home care. To bridge these gaps, some mothers and families sought supplementary resources, such as mobile apps (e.g., Mylo), to reinforce their caregiving at home. HCPs also acknowledged that mothers lack confidence and struggle to follow proper home programs due to fear of harming their infants. As one nurse explained, *"Some mothers hesitate to handle the baby at home due to fear of hurting them. They lack confidence in handling the baby"* (HCP 8). Moreover, one mother also stated that *"I had a fear of doing exercises for my child at home. My child was very small... I was also scared to hold him"* (M07).

Subtheme 2.2: Family involvement and sociocultural influences

First-time mothers reported not having enough time to care for their preterm infants at home because of other household chores and responsibilities. HCPs also acknowledged the challenges that mothers encountered at home. *"Mothers say they have other household chores, so they may not get time"* (HCP03). In such situations, involving family members was helpful. Most first-time mothers relied heavily on family members with prior motherhood experience, particularly their own mothers, for infant care and household support. This family support often alleviated the mothers' burden and facilitated a smooth transition from hospital to home care. However, like the first-time mothers, family members, particularly husbands, also expressed concerns and lacked confidence in caring for the delicate pre-term infants. One husband stated, *"I am very scared to lift the child...she is very small. Even my wife gets scared to hold the baby"* (F01).

Family involvement also presented challenges to implementing home programs recommended by HCPs. For instance, many mothers and family members favored traditional practices handed down through generations by their ancestors, who deemed these rituals vital for infant health and safety. Consequently, traditional practices heavily influenced caregiving at home. One family member explained, *"We are village people, we follow certain customs for a newborn baby, like keeping a fire spark under the cradle and briefly holding the baby in its smoke. These are our rituals"* (F06). And the family member added, *"We are village people, we know what to do...we trust our own ways"* (F06).

Narratives also revealed that family members had misconceptions about what caused preterm birth. They believed that the infant's condition resulted from the mother's negligence during pregnancy and thought it could have been avoided had the mother cared for herself better or listened to their advice. Consequently, the mother was often blamed for the infant's premature birth. Also, some family members believed that looking after the infant was solely the mother's responsibility. One family member (sister-in-law) said, *"Mother should be responsible for the baby's care... Mothers seem to be more careless these days... I felt that she had eaten properly, this (having a preterm) would not have happened"* (F03).

Theme 3: Felt Needs and Recommendations

Participants offered several recommendations to improve adherence to the home program following NICU discharge. They expressed a need for structured, standardized education to better prepare first-time mothers and families for home-based care after NICU discharge. HCPs highlighted the importance of providing step-by-step information to improve understanding, while mothers expressed a desire for written guidance and hands-on training prior to discharge to enhance their confidence in caring for their infants at home. As one healthcare professional stated, *"We need to have a structured way of educating parents—something that tells them step by step what they need to do once they go home. A standard educational program would ensure no important information is missed"* (HCP12). Similarly, a mother said, *"More training should be given before discharge, like what exactly we have to do at home, even if it is small things. That should be taught in the NICU itself. And if they give us something in writing while discharging, we can look at it and follow the instructions at home more properly"* (M01).

In addition to education, participants underscored the importance of developing systematic follow-up and monitoring mechanisms to support continuity of care. Suggested strategies included home visits for families living in remote areas, the use of parent diaries to document adherence to home programs, and digital platforms such as WhatsApp video calls or

mobile applications to enable real-time guidance and developmental tracking. As one neonatologist explained, *“There should be a provision to do a WhatsApp video call, so parents can do a WhatsApp video call and show us what’s going wrong at home. Then we can guide them immediately and tell them what to do”* (HCP14), and another professional (Physiotherapist) stated, *“I think we should have a system to track our baby after discharge. Like some app which can track the development, and at the same time, we can provide therapy through that.... It might work”* (HCP06).

Regarding post-discharge follow-up care, neither first-time mothers nor their families reported using public or government-funded facilities or being advised to do so by HCP at discharge. HCPs recommended community-based government-funded early intervention services and training of community workers to support adherence after discharge. One healthcare professional stated, *“If we could have a robust neurodevelopment program where occupational therapy, physiotherapy, and other professionals work together, which is handled by the government... that would have made a difference, the outcome would have been better”* (HCP11). And another healthcare professional stated, *“This early intervention program could be taught to ASHA workers (Accredited Social Health Activist is a community health worker) in all the Primary Health Care centres. I believe they are the best people to teach the families and encourage them to follow up with us. They could also ensure that the interventions are being carried out at home”* (HCP04).

DISCUSSION

This study aimed to understand current practices in home program provision and adherence to early intervention for first-born preterm infants in the Indian context. The findings suggest that adherence to early intervention following discharge was influenced by how the home program was provided in the NICU. In a previous study, first-time mothers reported that the home program provided at discharge was inadequate and did not support adherence at home, as they could not recall all instructions [26]. Similar concerns were reiterated by first-time mothers and endorsed by family members in the present study. The present study found that the home program predominantly focused on infection control, infant weight management, and breastfeeding, while early intervention was less emphasized. Therapists participating in this study reported that referrals for rehabilitative or early interventions were limited. These findings suggest that home program provision in study settings was focused on medical management. This could be attributed to the practice context and reflects the predominant medical model of practice in NICUs across India [35]. Of the three study settings, only the teaching hospital followed the Kangaroo Mother Care (KMC) guidelines, a nationally recommended protocol known to support neurodevelopment, physiological stability, and parent–infant bonding [36–38]. These findings highlight significant practice gaps in NICU care, particularly in integrating early intervention and aligning clinical practices with national guidelines.

A previous study reported that healthcare systems, including environment, workflow processes, and communication practices in the NICU, contribute to parental stress and anxiety [26]. The present study describes inconsistencies among healthcare professionals as another NICU-related factor influencing service provision. For example, first-time mothers reported confusion about the different feeding techniques described by nurses and physiotherapists. Conflicting information among healthcare professionals indicates a lack of coordination [39] and could be attributed to several factors. First, NICU team members have varying skill levels. HCP attrition is typically high due to high demand and limited availability of skilled professionals in specialized areas, such as neonatal care [40]. Due to limited specialized NICU training in India [41, 42], most HCPs gain knowledge and experience while working in the NICU. They often learn skills informally, resulting in inconsistent practice [43]. In complex, intensive NICU environments with multiple HCPs and varying skill sets and expertise, it may be challenging to adhere to standard or evidence-based guidelines, which can contribute to coordination gaps among team members. Second, conflicting information among HCPs suggests overlap or duplication of service provision, resulting in the inappropriate use of time and resources in already-constrained, challenging NICU settings. Involving multiple professionals in care can lead to parental confusion about whom to contact for information about their infant [39] and may erode first-time parents' trust and confidence in HCPs, undermining adherence to early intervention at home.

The home program was primarily conveyed to first-time mothers through verbal instructions, a finding also reported in a previous study [26]. Verbal instructions alone may hinder understanding, retention, and accurate implementation of the home program, particularly among first-time mothers who are often overwhelmed, anxious, and inexperienced in infant care. This approach does not provide mothers with alternatives for recalling information from the NICU after discharge, whether from family or written materials. The present study also identified effective practices for home program delivery in one of the study settings, which employed multiple methods, including verbal instructions, written pamphlets, and demonstrations, and were appreciated by first-time mothers.

At home, the implementation of the home program was further influenced by multiple interrelated factors. Only mothers were involved in delivering home programs, with little or no involvement from spouses or family members. These findings were consistent with earlier studies [16, 26]. However, as reported in previous studies, first-time mothers felt ill-equipped to care for their infants and to provide early intervention as instructed at discharge due to limited knowledge, skills, and confidence. To bridge the information gap, some first-time mothers used supplementary resources such as mobile applications. However, these apps may not always be accurate or specifically designed for preterm infants. With limited personal resources and access to healthcare services, the first-time mother relied on family members. In India, it is common for first-time mothers to return to their maternal home after childbirth, where they receive postnatal support and are encouraged to rest [44]. This practice was reflected in the present study, as the majority of mothers stayed at their mothers' houses following post-discharge. Among family members, spouses were often reluctant to help with infant care due to limited confidence in handling a fragile baby, but they offered support with other responsibilities [26]. The present study further reveals that other family members also exhibited similar hesitation in providing infant care. Thus, first-time mothers had to rely on older, experienced family members for support and guidance in infant care, who often preferred to follow traditional, culturally valued child-rearing practices that conflicted with medical advice. This is especially a concern in rural areas, where young parents also valued traditional practices over medical advice due to sociocultural norms, as seen in the present study. This pattern has been noted in earlier studies highlighting tensions between medical guidelines and culturally embedded caregiving practices in Indian households [28, 45]. This finding contrasts with that of Sahoo, Lewis, and Dsouza [26]. However, in that study, the participating mothers were better educated and closely adhered to clinician recommendations, whereas in the present study, the mothers had lower educational levels. Maternal education has been shown to influence caregiving practices and health-related decision-making [46] significantly. This challenge creates a significant gap in the provision and adherence to home programs. All the stakeholders in this study also recommended that receiving training and hands-on practice in early intervention before discharge would be beneficial and could boost the mother's confidence in delivering early intervention at home [26, 47].

Family and HCP narratives in the current study revealed that infant care was largely perceived as the mother's sole responsibility. As a result, HCPs directed most instructions to the mother. These practices continued after discharge, when family members also felt that the mother was primarily responsible for infant care from admission to the NICU through discharge at home and even during follow-ups. These practices reflect deeply rooted gendered caregiving norms prevalent in the Indian sociocultural context and imbibed by most people, even HCPs, albeit unconsciously [48]. On the one hand, first-time mothers are entrusted with full responsibility for caring for an infant with special needs. While on the others, they have limited autonomy to do so. NICUs are generally provider-driven in India, with limited autonomy or voice for service recipients, especially vulnerable first-time mothers [49]. At home, due to the patriarchal culture, women already have limited independence and say in salient matters. Inadequate education, limited earning capacity, young age, and family living arrangements further exacerbate this power imbalance, leaving mothers with limited autonomy and the remaining power in the hands of older family members [50].

Additionally, taking full responsibility for the infant for the first-time mother can be challenging because preterm infants need continuous, 24×7 care, and it could be an overwhelming demand. Mothers following pregnancy are also known to be at higher risk of falling ill due to temporary changes in the immune system, delivery-related factors, fatigue, and infections [51, 52]. In addition, first-time mothers are at higher risk of postpartum depression [53, 54]. In the event of a mother falling

ill and being unable to care for the infant, adherence to early intervention can be compromised if other family members are also ill-equipped or uninvolved. In addition to limited physical support, the present study findings suggest that mothers did not get adequate emotional and social support from family members. In previous studies, first-time mothers have reported social stigma and insensitive remarks from family and community members, which often lead them to withdraw socially [26]. In this study, some family members, especially in-laws, explicitly blamed the mothers for the infants' medical condition. This highlights the harsh and stigmatizing realities that vulnerable first-time mothers must confront in caring for their infant. Such insensitive and accusatory gestures can heighten emotional distress for first-time mothers, increasing their vulnerability at home and hindering the effective implementation of the home program. This is especially a concern when first-time mothers return to their in-laws' or husband's home, where they are expected to take up household and other responsibilities in addition to caring for an infant with special needs [26, 55]. Inadequate follow-up was another factor influencing adherence to the home program. Follow-up visits are essential for ensuring ongoing compliance with the early intervention home program after discharge. During these visits, HCPs track developmental progress, reinforce caregiver education, and customize home interventions to the child's developmental stage. These strategies collectively support long-term neurodevelopmental outcomes [56]. In some settings, practices like KMC have been supported by healthcare professionals through home visits and integrated follow-up [57, 58]. However, the present study revealed significant limitations in both the provision and utilisation of follow-up services after hospital discharge. The two teaching hospitals offered follow-up services, but these were underutilized by mothers and families. HCPs in the current study reported that many families missed follow-ups because mothers, especially those from rural areas, depended on family members to travel to the hospital, and because of financial constraints. Most mothers in this study hailed from rural areas, aligning with existing research that access to rehabilitation and follow-up care is often restricted by distance, transportation issues, and costs, particularly in rural communities [59].

The HCPs also suggested community-based government-funded services to support adherence after discharge. This suggestion aligns with the National Health Mission (NHM), which has several programs to support families after hospital discharge, with Primary Health Centres (PHCs) serving as operational hubs for follow-up care. These centres provide medical and nursing services and also have community or ASHA workers who serve as liaisons between the centres and the community. These programs include Home-Based Newborn Care, Home-Based Young Child Care, and screening and intervention programs for high-risk infants, such as Rashtriya Bal Swasthya Karyakram, which refers cases to District Early Intervention Centres (DEICs) [60, 61]. The current study findings indicated that mothers and families did not use these government-funded services. HCPs may be aware of the national programs in general, but may not know the actual availability of these services in the family's locality, especially in remote regions, and may not have referred the families to the PHCs at the time of discharge. Underutilization of government schemes has been attributed to poor coordination between facilities and primary care, inadequate discharge counselling, inconsistent training of community health workers, and weak integration across care levels [62]. These challenges in service provision may create a significant gap in the provision of continuous care for preterm infants. Follow-up at PHCs would be very useful for families residing in remote or rural regions. HCPs' suggestions for flexible follow-up methods, including both offline and online options such as mobile apps and video conferencing, align with several studies that recommend technological solutions to improve access [63, 64].

Implications of the Study:

The study has several implications. First, the study highlights the need for HCPs to be cognizant of first-time mothers' unique needs when considering the discharge of preterm infants from the NICU and to adopt a more person-centred approach aligned with the biopsychosocial care model as recommended by Sharma et al [65]. Second, in addition to medical management, home programs need to emphasize early intervention strategies. However, to support adherence, mothers and families also need to value and embrace early intervention. Early intervention is crucial for infants' development and should be introduced promptly in the NICU through practices such as KMC. However, KMC adoption is hindered by space, staffing, and protocol issues [66], necessitating context-specific adaptations and better implementation. Besides KMC, early referrals to rehabilitation professionals would also facilitate early adoption of early intervention by

mothers and families [67]. In the NICU, teamwork is vital since many professionals are involved in infant care [68]. There is always room to improve NICU processes and care coordination. In-house interprofessional education (IPE) may also improve role clarity, collaboration, and communication [69]. Different care models, such as multidisciplinary, interdisciplinary, and transdisciplinary, may be explored based on available resources and the setting's feasibility.

Thirdly, the study's findings underscore the importance of empowering first-time mothers by strengthening their personal resources to prepare them for home by improving discharge readiness. This involves providing mothers with education and training to identify infant needs, respond appropriately, and adapt care. Home programs should be structured, incorporate multimodal strategies, and be tailored to the needs of mothers and infants [26]. Additional support is essential for mothers after NICU discharge and can be provided by involving salient family members, especially the spouse, in infant care. Therefore, education and training can be extended to family members to alleviate the burden on first-time mothers [70]. Discharge readiness programs should also address prevalent socio-cultural stigmatizing attitudes and unsafe child care practices that may compromise mother and child health.

Lastly, the current study underscores the need to strengthen follow-up care for continuity of early intervention. Families should be encouraged to follow up regularly, in person, at the hospital or setting. However, if accessing the parent setting is difficult, families should be directed to the local PHC with a formal referral. HCPs may need to make additional efforts to identify such centres for families from very remote or distant places, or advise families to seek services available in their communities. Another strategy to ensure continuity of care is home visits by professionals to provide ongoing training to mothers [47]. Digital solutions could also be explored to support adherence.

Strengths and Limitations:

A key strength of the study is data triangulation. Participant triangulation was achieved by including multiple stakeholder groups, namely first-time mothers, family members, and HCPs, including neonatologists, occupational therapists, physiotherapists, and nursing professionals involved in early intervention for preterm infants. Contextual triangulation was further ensured by collecting data across diverse settings, including two educational institutions and one corporate NICU hospital. Additionally, researcher triangulation was employed by involving multiple researchers in the data analysis process, thereby enhancing the rigor and credibility of the findings.

The study is not without limitations. First, the interviews were conducted in both online and offline formats, which may have influenced the depth of responses. Telephone interviews limited the ability to observe non-verbal cues, and privacy could not always be ensured, potentially restricting participants from sharing sensitive experiences. To address this, interviewers used probing questions, allowed extra time for elaboration, and ensured confidentiality to the extent possible. Second, using two languages for interviews and transcription raises the possibility of minor nuance loss; however, this was minimized through back translation and peer review. Third, due to contextual factors, the transferability of the findings to other settings is limited. However, a detailed description of the study context has been provided to allow readers to assess applicability.

CONCLUSION

The study provided comprehensive insights into practice gaps, felt needs, and factors influencing continuity of early intervention for preterm infants by first-time mothers after discharge. The findings highlight the need to strengthen existing practices in home program provision by incorporating strategies that bolster mothers' personal resources, self-efficacy, and skills in early intervention, while integrating family support and community services. Addressing these interconnected levels of support may sustain early home-based intervention services for preterm infants.

Abbreviations

ASHA

Accredited Social Health Activist
DEICs
District Early Intervention Centres
HBNC
Home-Based Newborn Care
HBYCC
Home-Based Young Child Care
HCP
Healthcare Professional
IPE
Interprofessional education
KMC
Kangaroo Mother Care
LMIC
low- and middle-income countries
NICU
Neonatal Intensive Care Unit
NHM
National Health Mission
PHC
Primary Health Centre
RBSK
Rashtriya Bal Swasthya Karyakram

Declarations

1. Ethics approval and consent to participate:

Ethical approval for this study was obtained from the Kasturba Medical College and Kasturba Hospital Institutional Ethical Committee; IEC:318/2020. All methods were carried out in accordance with relevant guidelines and regulations. Written informed consent was obtained from all participants prior to data collection.

2. Consent for publication:

Not applicable.

5. Funding:

This research was supported by a grant from the Indian Council of Medical Research (ICMR) for a project (file no 5/7/76/MH/Adhoc//2020-RBMCH). This publication is one part of that project. The funder had no role in the design of the study; collection, analysis, and interpretation of data; or in writing the manuscript

Author Contribution

1. R.S. worked on conception, design, data acquisition, collection, interpretation, and analysis. She has drafted and critically revised the manuscript for important intellectual content alongside the corresponding author. 2. L.E.L. worked on the conception and data analysis parts whenever his help was needed, and he contributed intellectually to revise the manuscript. 3. S.A.D. (Corresponding author) worked on conception, design, data interpretation, and data analysis. She has

contributed to drafting and critically revising the manuscript. Each author has reviewed and approved the final version for publication.

Data Availability

Data will be shared on request.

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Figures

Figure 1: Themes and categories

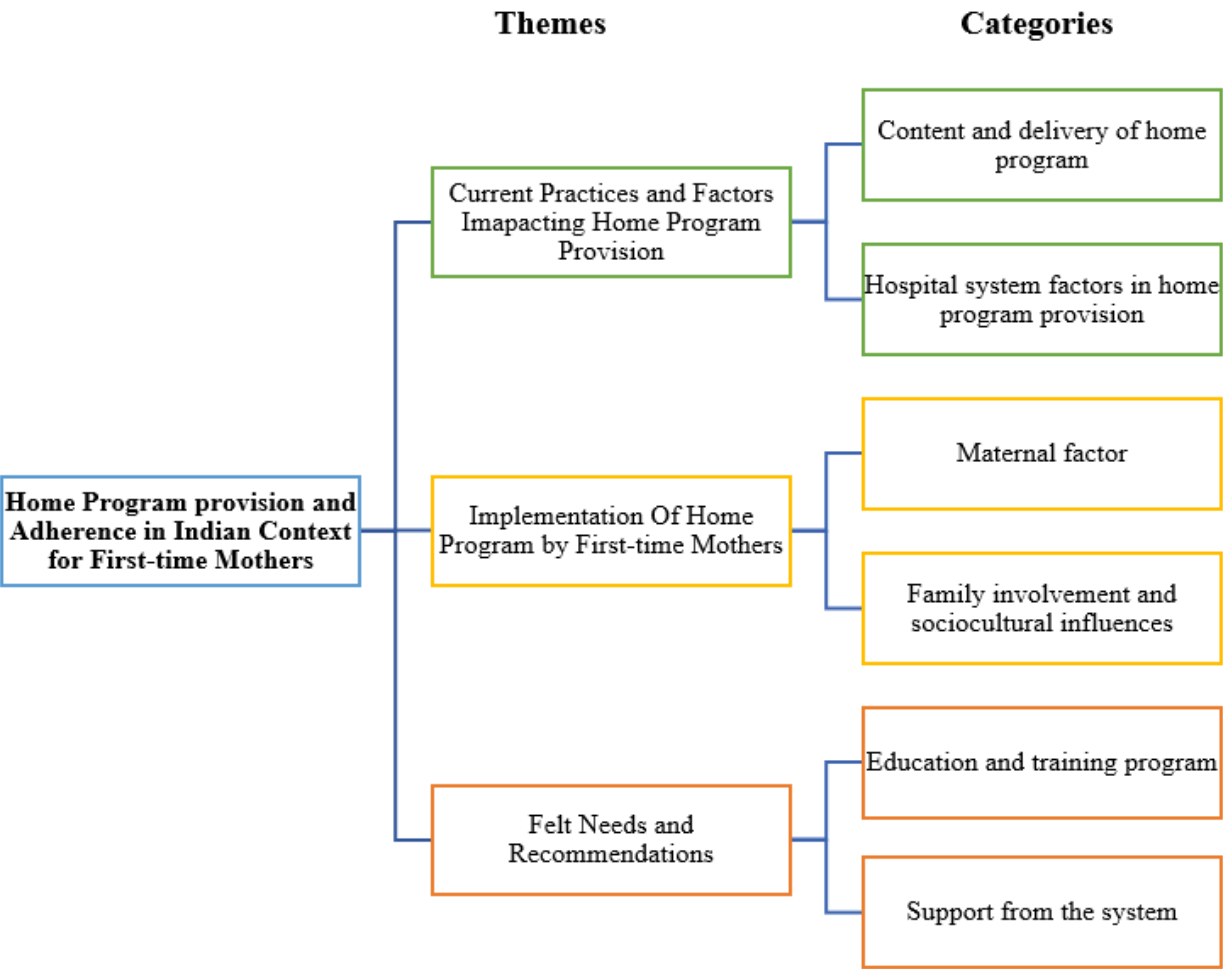


Figure 1

See image above for figure legend.

