

Acceptance And Adherence Of Parent-Centered Early Intervention Program For Preterm Infants: A Mixed Methods Study Approach.

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Abstract

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- Preterm infants
- Early intervention, family-centred care
- Parental perceptions

Background: Early intervention programs have emerged as an effective strategy to enhance developmental outcomes in preterm infants. Although family-centered care is widely recommended, its implementation in India is limited. Acknowledging the pivotal roles of parents as active facilitators in their child's development, this study aimed to explore the acceptance and adherence to parent-centred early intervention program for preterm infants in the Indian context.

Methods & Methodology: A mixed-methods design was adopted, consisting of two phases. Phase 1 of the program included therapist-led demonstrations and parent training sessions conducted in the Neonatal Intensive Care Unit (NICU), focusing on skill transfer and parental empowerment. Phase 2 consisted of a structured four-week home-based early intervention program implemented by parents. A total of 21 parents of preterm infants were recruited. One month post program initiation, semi-structured interviews were conducted to explore patterns of acceptance. Adherence was recorded through review of logbooks maintained by the participants.

Results and Conclusion: Telephonic interviews of 15 parents were thematically analysed. Four themes derived from this analysis were *Integrating Early Intervention into Daily Routine*, *Enhancing Parental Confidence*, *Parental Beliefs and Attitude*, and *Barriers*. 10 parents (47.6%) returned logbooks, of which 9 demonstrated consistent practice for ≥ 21 days. This study highlighted that parents adopted various strategies to incorporate early intervention practices into their daily caregiving routines, enhancing their confidence and engagement in infant care. However, challenges such as time constraints, lack of extended family support, and competing responsibilities affected consistent participation. These findings suggest that although parent-centered programs successfully extend developmental care beyond the NICU, the substantial dropout rate highlights the need to modify program delivery and follow-up strategies to align with family needs and enhance long-term engagement towards the program.

Introduction:

Early Intervention (EI) plays a crucial role in improving neurodevelopmental outcomes for preterm infants.^[1,2] Approximately 10% of infants are born preterm worldwide each year, with India accounting for 13% of live births.^[3,4] Despite advances in newborn care that have reduced mortality rates, many preterm infants continue to experience neurodevelopmental problems, which are attributed to interrupted brain maturation and early exposure to the extrauterine environment.^[5] Initiating EI programs within the Neonatal Intensive Care Unit (NICU) and continuing them in early infancy is associated with improvements across motor, cognitive, sensory, and socio-emotional domains. This can be attributed to the developing brain's neuroplasticity.

Traditionally, EI programs for preterm infants have relied on therapist-led models delivered in hospital or clinical settings. While these models have proven to be effective, they are difficult to implement on a long-term basis due to restricted accessibility, financial constraints, and the inability to offer continued care post-discharge.^[6] To address these difficulties, high-income countries are increasingly adopting Family-Centered Care (FCC) model. This model positions the parents as active partners and primary facilitators of their infants' development, encouraging ongoing involvement beyond the hospital setting.^[7,8] Several structured, parent-mediated programs, such as the Supporting Play, Exploration, and Early Development Intervention (SPEEDI) and COPing with and CARing for infants with special needs (COPCA) programs, have shown significant improvements in infant motor and cognitive outcomes, enhanced parental confidence, and strengthened parent-infant bonding. Importantly, these programs enable caregivers to continue developmental interventions at home, ensuring continuity of care from NICU discharge to early childhood.^[9,10]

Despite mounting evidence, adoption and implementation of FCC-based EI models in

low- and middle-income countries (LMICs), like India, remain limited. Existing research among LMICs has generally focused on clinical outcomes, with minimal consideration for parental acceptance, adherence, and sociocultural factors that influence participation.^[11,12] Understanding these determinants is critical for tailoring FCC interventions to the healthcare system among LMICs, which differs from high-income nations in terms of health literacy, family dynamics, and access to EI programs. Therefore, this study aimed to assess parental acceptance and adherence to a parent-centered early intervention program for preterm infants.

Materials & Methods:

Study design:

This study was conducted between July 2024 and May 2025 at a tertiary-level NICU in Bengaluru, India. Ethical clearance was obtained from the institution. A mixed-methods design was used to comprehensively assess both parental acceptance and adherence to a structured home-based EI program. A sample size of 12–15 infants was estimated, reflecting anticipated NICU admissions and logistical feasibility for recruitment and follow-up. This range was adequate for the planned qualitative exploration and adherence monitoring.

Participants:

Parents of preterm infants admitted to the NICU were screened for eligibility using convenience sampling. The primary investigator recruited eligible participants, who were then enrolled in the EI program after providing written informed consent. Parents of medically stable preterm infants admitted to the NICU, able to read and communicate in English, residing within Bengaluru were included. Preterm infants with severe CNS injury (e.g., intraventricular haemorrhage or periventricular leukomalacia), musculoskeletal or congenital abnormalities, bronchopulmonary dysplasia, or sepsis, undergone any major surgery, and NICU stay beyond term age were excluded. The recruitment and follow-up process is illustrated in

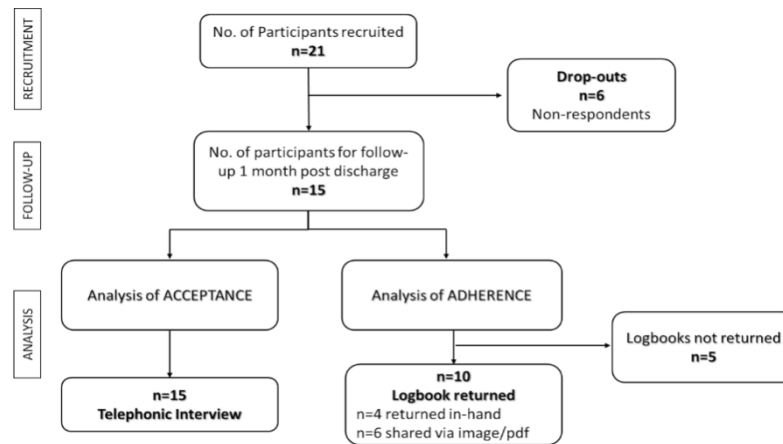


Figure 1 illustrating STROBE flow diagram of participants

Intervention:

The intervention consisted of a structured EI program delivered in two phases: during the NICU stay and for four weeks post-discharge at home. A schematic representation of the intervention is presented in Figure 2. The program was designed to be administered once daily for approximately 20 minutes. The intervention included oromotor stimulation (gentle oral and perioral stimulation), visual and auditory stimulation (age-appropriate tracking activities), tactile and kinesthetic

stimulation (graded touch and passive range-of-motion exercises, including cycling movements of the limbs), and supervised tummy time and swaddling. These EI activities were developed based on current evidence and aligned with established recommendations, including the Indian Academy of Pediatrics (IAP) guidelines for high-risk infants and evidence-based frameworks such as SENSE (Supporting and Enhancing NICU Sensory Experiences) and NIDCAP (Newborn Individualized Developmental Care and Assessment Program)^[13,14].

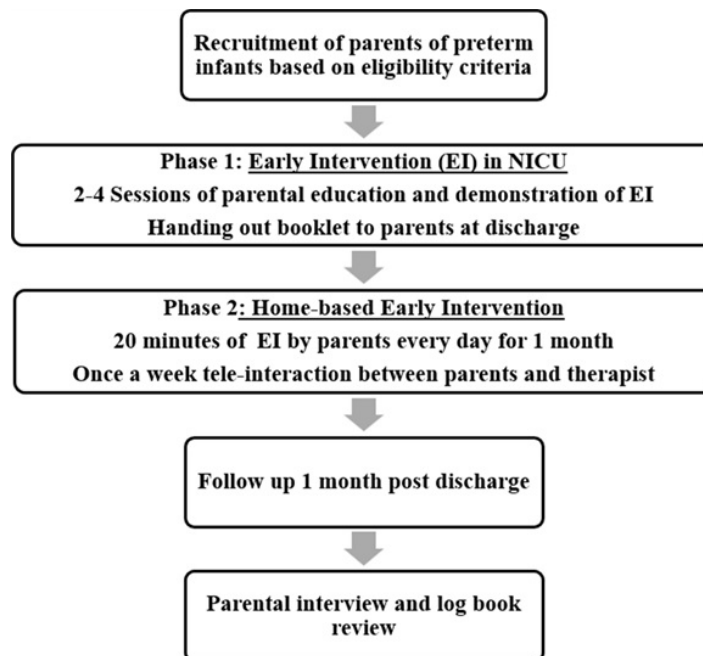


Figure 2 illustrating the study procedure

Parents were given one-on-one demonstrations of EI techniques in the NICU by the primary investigator. Parents were also given a structured, illustrated booklet outlining the daily exercise protocol and a log section for recording home practice. During the four-week home-based phase, weekly telephonic follow-ups were conducted by the therapist to address concerns and reinforce program adherence.

Outcome Measures:

Parental acceptance was assessed one-month post-discharge through semi-structured interviews conducted by the primary investigator. The interview guide was developed based on existing literature on parent-mediated EI and reviewed by experts in the field to ensure content validity. All interviews were audio-recorded with consent. Interviews were transcribed verbatim and cross-verified. The transcripts were further ratified for accuracy by external reviewer. Parental adherence to the intervention was recorded through caregiver-maintained logbooks, in which parents documented daily completion of activities over the four weeks. Adherence was categorized operationally as good (≥ 21 days), moderate (14–20 days), or fair (< 14 days) based on program engagement duration, adapted from general adherence guidelines.^[15]

Data Analysis:

Qualitative and quantitative analytical methods was employed. Interview transcripts were analysed using Braun and Clarke's six-phase thematic analysis framework.^[16,17] Coding was performed manually by the primary investigator and themes were developed using word cloud. Themes were finalized based on reviewer consensus. The COREQ (Consolidated Criteria for Reporting Qualitative Research)^[18] checklist was applied to enhance methodological transparency. Adherence data via logbook were quantitatively analysed using SPSS version 27. Descriptive statistics were used to report participant demographics and adherence categories.

Results:

Of the 21 preterm infants recruited, 6 participants were lost to follow-up after phase 1 of this program. 15 participants continued with phase 2 and were analysed for acceptance of the program. For the adherence component, data of all 21 participants was analysed to maintain data transparency. Demographic profiles including maternal and infant characteristics are summarised in Table 1.

Table 1 Represents the Demographic Characteristics of Participants and Preterm Infants

PARTICIPANT CHARACTERISTICS (N=21)	FREQUENCY
Age of Mother (in years)	29.90 $\pm$ 3.145 (25 – 36)
<u>Education Qualification</u>	
Higher secondary	2 (9.5%)
Undergraduate	13 (63.9%)
Post graduate & above	6 (28.6%)
Twin Births	6 (28.6%)
Multipara	7 (33.3%)
<u>Gestational Age</u>	
28 to < 32 weeks	6 (28.6%)
32 to < 37 weeks	15 (71.4%)

<u>Birth Weight</u>	
<1000g	1 (4.8%)
1000-1499g	8 (38.1%)
1500-2499g	10 (47.6%)
≥2500 g	2 (9.5%)

Table 2 Represents the Sub-Themes and Reference Quotes

<u>THEME</u>	<u>SUB-THEMES</u>	<u>REFERENCE QUOTES</u>
Integrating Early Intervention into Daily Routine	Support from family and follow-up	“My mother helped me at home.” “The tele-follow-ups helped me correct any mistakes I made.”
	Routine-based integration	“Yes, I adjusted my routine and made sure to do the exercises every day.”
	Caregiver adaptation towards EI program	“Initially, I was anxious to do them alone, but over time, I could perform the exercises every day.” “Booklets were very useful. I learned a lot.”
Enhancing Parental Confidence	Gaining Confidence to perform the EI	“Very confident and comfortable after performing the exercises for almost 1 month”
	Ease of Exercises	“It was a good experience. The exercises were simple and manageable”
Parental Beliefs and Attitudes	Understanding the Importance	“Recognized the benefits and expressed that performing the exercises leads to significant improvement.” “Considered the exercises essential and believed they must be done.”
	Sustaining Motivation	“Motivation fluctuated – some days were easy, others were challenging.” “Stayed motivated by performing exercises during the baby's awake time.”
Barriers	Maternal exhaustion and competing priorities	“I missed follow-ups because I was busy with my older child's exams and didn't check the phone much.”
	Infant health issues and variable sleep patterns	“The baby's altered sleep schedule affected mine too.” “I haven't started the exercises due to my baby boy's ongoing health issues. I couldn't focus on either of the twins.”

Qualitative data obtained from the 15 semi-structured telephonic interviews were analysed using thematic analysis. A total of 9 sub-themes and 4 themes emerged: Integrating Early Intervention into Daily Routine, Enhancing Parental Confidence, Parental Beliefs and Attitude, Barriers. (Table 2) Twenty-one participants were included for adherence analysis. Ten parents (47.6%) returned duly filled logbooks, of which 9 demonstrated good practice.

Prior awareness of EI programs was reported to be low (30%) amongst the study participants. Parents reported booklets and telephonic follow-ups to be useful. 73.3% found both helpful, 20% reported only booklets to be useful, and 6.7% valued tele-interactions alone. Suggestions for additional training included hands-on support (13.3%) and video-based resources (6.7%), while 80% reported existing support was sufficient. (Figure 3)

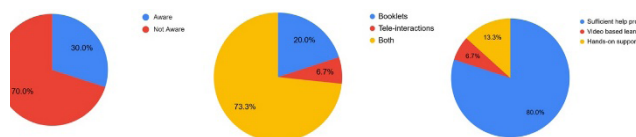


Figure 3 illustrating Program Awareness and Feedback on Educational tools

Discussion:

Our study is one of the first study in the Indian context to examine parental acceptance and adherence to a structured early intervention program for preterm infants. Overall adherence was reported as 47.7% with 9 participants demonstrating good adherence. Parental interview led to the emergence of four themes: integration into daily routines, parental confidence, beliefs and attitudes, and barriers to implementation, which provided crucial insights into the facilitators and challenges to implementation of the home-based EI program.

Integrating Early Intervention into Daily Routine:

This theme captures parents' perspectives on how they managed to provide home-based EI for their infants. Parents reported that aligning EI exercises with the baby's sleep-wake cycle, after bathing, during massage, or during awake hours, made the

intervention a part of their everyday caregiving and felt less like a task. Active involvement and support from family members, especially the grandmother, helped mothers to stay consistent with the EI program. This is supported by a qualitative study conducted in India, which highlighted that caregiving is often shared within extended families and this cultural practice among LMICs provided mothers with both physical assistance and emotional support.^[19] Education and guidance by the therapist in the NICU, a structured booklet at discharge, and regular tele-interactions enhanced parental engagement. These findings indicate that culturally sensitive, routine-integrated EI programs are more likely to be accepted by parents.

Enhancing Parental Confidence:

This theme emerged from parents' descriptions of their experiences during home-based EI delivery. Despite receiving structured guidance and training in the NICU, parents initially expressed hesitation in performing EI independently. Confidence improved over time as they observed positive changes in their infants—such as improved movement patterns, greater alertness, and more interactive behaviors during awake periods. Parents reported that ongoing therapist support during homebased EI program enhanced their confidence levels. Most parents described the exercises as simple and feasible, though activities like tummy time were challenging, thus expressing the need for individualized guidance and video demonstrations. These patterns align with McCubbin's Family Adaptation Model, which suggests that families adjust through the interaction of internal motivation and external supports such as professional guidance and family involvement.^[20]

Parental Beliefs and Attitudes:

This theme reflects parents' views regarding their prior awareness about the EI program and the motivation they maintained throughout the study period. Existing literature suggests that parental knowledge and health literacy strongly influence attitudes towards developmental care.^[21] However, in our study, only 30% of the participants reported prior awareness of EI, despite most having higher

educational backgrounds. This finding suggests that general education does not necessarily translate to awareness of developmental interventions. Parents consistently emphasised that understanding the purpose of early intervention enhanced their motivation to participate. Structured guidance provided by therapists played a key role in maintaining engagement and reinforcing the intervention.

In our study, most mothers (66.7%) were first-time parents, explaining initial uncertainty and hesitation in implementing the exercises. In contrast, those with previous infant-care experience adapted more readily, aligning with the findings of Bryanton et al. (2008), who reported that familiarity with caregiving tasks enhances parental confidence.^[22] A recent systematic review and meta-analysis on healthcare-based interventions to improve parenting outcomes in LMICs reported significant gains in parental knowledge, responsiveness, and stimulation practices following targeted education and support.^[23] These findings underscore the importance of providing structured education to enhance parental motivation and adherence to the EI programs.

Barriers:

Despite the presence of multiple facilitators, parents reported several barriers. Implementation was affected by both infant and parent-related barriers. Unpredictability of preterm health in terms of gastroesophageal reflux, feeding intolerance, respiratory instability and fluctuating alertness were the most reported infant barriers.^[24]

Parent-related barriers were equally significant. Mothers reported emotional fatigue and competing domestic responsibilities. These findings are consistent with Guillaume et al.'s observations that psychological burden experienced by mothers during this period can make the transition both emotionally and physically demanding.^[25] For mothers in nuclear families, the absence of additional caregiver support placed the entire responsibility of the EI program on them. Mothers identified this as a major drawback, noting that limited shared caregiving, restricted their ability to

maintain continuity. Evidence from LMICs similarly highlights that when extended family support is limited, the caregiving burden on mothers increases substantially.^[26] Addressing these barriers is essential when designing parent-centered early intervention programs.

Parental Adherence Patterns:

Overall adherence towards the home-based intervention was found to be 47.6%. Several parents informally reported performing exercises but were unable to record them consistently due to time constraints or caregiving demands. This is supported by a study conducted by Raghupathy et al., in an Indian setting which also highlighted challenges of capturing adherence in the home environment, using the traditional logbook method.^[27] Thus, it is recommended to use simplified, parent-friendly monitoring tools such as digital logs which could reduce reporting fatigue and enhance data capture.

Strengths and limitations:

A key strength of this study lies in its valuable insights into parental perceptions, experiences, and challenges in implementing EI in the LMICs. Consistent tele-follow-ups maintained continuity and motivation after discharge, while interviews one-month post-intervention enabled reflective feedback. However, some limitations must be noted. Adherence was assessed through caregiver-maintained logbooks, which may be subject to reporting bias. Logistical constraints prevented in-person interviews or focus group discussions, which could have enriched the data by capturing more detailed parental perceptions.

Conclusion and future implications:

This study highlights that a parent-centered early intervention program can facilitate parents in transitioning from initial apprehension to active participation in their infants' development. Despite a family-centered framework, implementation relied mainly on mothers, highlighting a gap between intent and practice. Future initiatives should encourage shared caregiving, modifying delivery methods and simplified adherence tools.

Conflict of interest:

Authors declare no conflict of interest.

Ethical considerations:

The study was approved by the Institutional Ethics Committee(Ref. No. MSRMC/EC/PG-16/08-2024) and registered with the Clinical Trials Registry of India (CTRI/2024/11/077481). All procedures were conducted in accordance with the ethical standards of the institutional research committee and the principles of the Declaration of Helsinki. Written informed consent was obtained from all participating parents. Participation was voluntary, and parents were informed that they could withdraw from the study at any time without any effect on their infant's clinical care. Data confidentiality was ensured by anonymizing all responses and coding transcripts and records.

Data availability:

The datasets generated and analysed during the current study are not publicly available due to confidentiality of audio transcripts, but are available from the corresponding author on reasonable request.

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Author contributions:

NP, KJ, NN, and PG conceptualized the study. NP, KJ, and NN developed the methodology. Data collection was performed by NP, with PG providing support for participant recruitment and medical clearance. NP, KJ, and NN conducted data analysis. Validation was performed by KJ and NN. NP drafted the manuscript, and KJ and NN reviewed and edited it. Supervision was provided by KJ, NN, and PG. All authors read and approved the final manuscript.

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