




BMJ Open Torn between two worlds: parental experiences of neonatal follow-up for infants with hypoxic ischaemic encephalopathy in India—a qualitative study using interpretative phenomenological analysis

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ABSTRACT

Objective This study aimed to understand the barriers and facilitators of a neonatal follow-up programme, as perceived by parents of infants born with hypoxic ischaemic encephalopathy (HIE).

Design This study applied a qualitative study design using interpretative phenomenological analysis. It included focus group discussions, face-to-face in-depth interviews and telephonic interviews. Data were analysed using thematic content analysis.

Setting Neonatal follow-up clinic of a tertiary hospital in South India. The study was conducted between March and December 2020.

Participants Five fathers and eight mothers of infants with HIE.

Results Parents of children with HIE are torn between two worlds—an atmosphere of support and one of criticism. Three main themes were identified: (1) neonatal intensive care unit (NICU) stay: distressful versus reassuring experiences; (2) parenthood: supportive versus unsupportive environments; and (3) neonatal follow-up: adherence versus non-adherence.

Conclusion Parents of children with HIE experience sociocultural barriers in the NICU, after discharge and during the follow-up period. These lead to a complex array of emotional and physical consequences that affect parenting and follow-up care.

INTRODUCTION

Neonatal mortality in India has reduced in the past 5 years after the launch of India Newborn Action Plan.¹ However long-term sequelae of infants born with hypoxic ischaemic encephalopathy (HIE) are still high. Of 1.2 million infants with moderate to severe disabilities in India, 40% of children have a history of HIE.^{2–3} This large number necessitates early detection and intervention of infants through regular neonatal follow-up

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study explored the follow-up experiences of parents from varied sociocultural backgrounds.
- ⇒ The multimethod qualitative approach using interviews as well as focus groups supported data triangulation.
- ⇒ The interviewers, being the therapists who cared for the child in the follow-up clinic, might have inhibited the participants from expressing negative experiences.
- ⇒ The interviews were conducted a few years after the neonatal intensive care unit stay, which could have led to recall bias in participants.
- ⇒ Telephonic interviews could have limited the interviewer's ability to interpret emotional expressions while recounting experiences.

programmes. Studies in India have shown that the compliance to neonatal follow-up is moderate (50%–60%) resulting in low participation and reduced effectiveness of early intervention programmes.^{4–6}

Neurodevelopmental difficulties of infants with HIE include abnormalities of vision and hearing, and cognition, communication, speech, language, and motor problems that present as feeding disorders, gait abnormalities, motor planning problems or cerebral palsy (CP).⁷ Following HIE, at 2 years of age, 36% of children have adverse outcomes like CP, hearing loss and intellectual disability.⁸ Symptoms of hyperactivity and autism spectrum disorder have been reported at 5 years of age. Adverse neurodevelopmental difficulties that interfere with daily life tasks are seen at adolescence, emphasising the need for long-term follow-up.⁹



Neonatal follow-up and early intervention play a key role in the child's development in physical, social, emotional, language and cognitive domains.^{10–12} In India, we have no systematic database of outcomes or follow-up of at-risk infants.^{7,13} Factors affecting treatment adherence include inaccessible healthcare systems, parents' poor understanding of the child's condition, maternal educational levels, long distance from rural areas to the hospital, lack of communication facilities, varying ability of healthcare providers to meet linguistic and cultural needs of families, and low socioeconomic status.^{14,15}

In India, mothers face blame and guilt due to stigma and superstitious beliefs during the time of delivery, neonatal intensive care unit (NICU) admission, post-discharge and early years of parenting. The severity of stigma increases when the infant is known to have a medical condition at birth like HIE and is at risk of disability.¹⁶ To ensure good compliance to neonatal follow-up, we need to understand the societal and cultural barriers that parents face from admission through discharge and beyond.^{17,18}

Barriers and strengths in each culture may differ and require a different approach to mitigation. To our knowledge, there are few studies done in low/middle-income countries that explore the barriers and ways to overcome them from the parent's perspective. This study aims to understand the barriers and facilitators for neonatal follow-up as perceived by parents of infants with HIE.

METHODS

Study design

This study used a qualitative study design based on interpretative phenomenological analysis, with constant analysis of data for emerging themes.¹⁹ The use of a combination of focus group discussions (FGDs), face-to-face in-depth interviews and telephonic interviews allowed for rich information about personal experiences.^{20–21} This method was chosen for its ability to respond to the research questions derived entirely from the perspectives of parents rather than from preconceived hypotheses from the authors.²² We initially planned to do only FGDs and face-to-face interviews, but subsequently included telephonic interviews for those who did not have access to the hospital during the lockdown period of the COVID-19 pandemic. There is good evidence to support telephonic interviews.^{23,24} The first author and second author (SAC and HBJ) are female occupational therapists trained in paediatric occupational therapy, working at the NICU. RS is a female occupational therapist who works at the Department of Psychiatry.

Setting

The study was conducted in the neonatology department of a tertiary care hospital in South India, with level 3 facilities. During the NICU stay, educational sessions are routinely held for parents addressing the child's condition and ways of caregiving. At the time of discharge from the NICU, the parents are instructed and given a

booklet about breast feeding, developmental milestones, early stimulation, physical growth charts and schedule for the follow-up visits. Parents are advised to follow up every 3 months until 1 year of age, following which standardised assessments are done at 1 and 1 ½ years of age, respectively. Assessments are done in the follow-up clinic by the doctors, nurses and occupational therapists, who discuss a home programme with parents as part of the intervention. Children with developmental delays and disabilities are referred to the developmental paediatric unit of the institution. Parents are taught to do therapy for their children in three to five training sessions. Children are then reviewed quarterly; goals and activities are adjusted as required.

Participants

The study was conducted between March and December 2020. The inclusion criteria were infants with HIE who were admitted in the NICU for a minimum of 5 days. We included parents of children aged 4–7 years, as we thought it would be the right age to target parents with some experience in parenting, and at the same time remembered their NICU experience. The exclusion criterion was parents who were unable to give informed consent. Using purposive sampling, the research team accessed hospital medical records to identify parents eligible for the study and contacted them by telephone for participation. The parents who consented were included in the FGD and face-to-face interviews. Telephonic interviews were conducted for parents who consented but could not attend the FGD due to travel restrictions related to the COVID-19 pandemic. We contacted 20 families, out of which 13 consented to participate. Parents completed a demographic questionnaire before the FGD and interviews. They were each assigned a pseudonym to ensure anonymity. Only the researchers and the participants were present for the interviews and FGD.

Data collection

We conducted one FGD (three mothers and one father), five face-to-face interviews (two mothers and two fathers) and four telephonic interviews (three mothers and two fathers). One of the investigators (RS) certified in qualitative research methods moderated the FGD. A primary investigator (SAC) conducted the face-to-face and telephonic interviews. The FGD and interviews were 1.5–2 hours long and conducted in Tamil. We obtained written informed consent from participants for the FGD and face-to-face interviews, and audio consent using a consent script for the telephonic interviews. The first two authors had built rapport and established a relationship while they came for follow-up to the NICU. The parents were encouraged to talk freely about their experiences and were told that there is no right or wrong answer. Probing was done through preplanned follow-up questions. Field notes including facial expressions and actions of the participants were recorded.

Box 1 Interview guide

- ⇒ How did you feel when your baby was in the neonatal intensive care unit (NICU)?
- ⇒ What were the joys and challenges of parenting after discharge from the NICU?
- ⇒ How did you cope with the experience?
- ⇒ How has your follow-up experience been?

The interview and FGD guides were reviewed by all members of the study team and consisted of four semi-structured questions. The interview questions were broad, so as to accommodate inductive, data-driven thematic analysis. These questions were translated from English to Tamil to be used in the interviews and FGD (box 1). To deepen the narrations, follow-up questions were asked, ‘Can you tell me more? Can you give any further explanation? Can you give me an example?’

Sample size was finalised when saturation occurred with no new data emerging from participants’ accounts. The interviews and FGD were audio-recorded, translated from English to Tamil by a translator fluent in both the languages. All the authors involved in the analysis were fluent in Tamil and used both the transcripts as well as audio-recordings during analysis.

Data analysis

We used the Consolidated Criteria for Reporting Qualitative Studies checklist to guide the reporting of the methodology and results.²⁵ Data were analysed using standard qualitative analysis methods²⁶ and Quirkos V.1.6 qualitative software.²⁷ The transcribed interviews and FGD were imported into the software for analysis. HBJ, RS and SAC familiarised themselves with the transcripts and listened to audio-recordings multiple times. They noted down early observations and met weekly to discuss these. Each investigator prepared first, second and third-level codes using the Quirkos software, where they had access to each other’s data. Codes were then examined for patterns across the dataset, and overlapping codes were collapsed. Codes thus agreed upon were promoted to provisional themes. Each investigator proceeded to form their thematic maps. Distinct themes were reviewed for alignment to the research question. These themes were integrated into a final thematic map. Rigour was thus addressed by repeated coding of transcripts by different team members, by constant comparison between current literature and new data and discussion of final themes with all authors.

Patient and public involvement

We were unable to involve participants or the public during various phases of the study due to the sensitive nature of the topic and also due to restrictions faced during the COVID-19 pandemic.

Table 1 Demographic characteristics of parents and children

Parents’ characteristics	n (%) n=13
No of fathers and mothers	
Fathers	5 (38.5)
Mothers	8 (61.5)
Nuclear and extended families	
Nuclear families	3 (30.0)
Extended families around initial years of parenting	7 (70.0)
Paternal education	
School graduates	2 (40.0)
College graduates	3 (60.0)
Maternal education	
School graduates	5 (62.0)
College graduates	3 (37.0)
Paternal working status (employed)	5 (100)
Maternal working status	
Employed	2 (25.0)
Homemaker	6 (75.0)
Socioeconomic status*	
Upper lower	4 (40.0)
Lower middle	3 (30.0)
Upper middle	3 (30.0)
Children’s characteristics	n (%) n=10
Mean age in years (SD)	4.54 (1.5)
HIE stage	
1	4 (40.0)
2	6 (60.0)
Main disability perceived by the parent	
Cerebral palsy	3 (30.0)
Intellectual disability	2 (20.0)
Speech delay	1 (10.0)
Writing difficulty	1 (10.0)
Hemiparesis	1 (10.0)
Typical development	2 (20.0)

*Socioeconomic status was scored using Kuppaswamy Socioeconomic Scale 2021.
HIE, hypoxic ischaemic encephalopathy.

RESULTS

The characteristics of parents and their children are outlined in table 1.

The results are presented in three themes (table 2): NICU stay—distressful versus reassuring experiences; parenthood—supportive versus unsupportive environment; and neonatal follow-up—adherence versus non-adherence. In the following verbatim accounts, the mother is denoted as M and the father as F for the

Table 2 Themes, subthemes and illustrative quotes

Theme	Illustrative quotes
NICU stay: distressful vs reassuring experiences	
Blame on the mother	"It happened because my wife did not take adequate nutrition during pregnancy. She didn't eat well and that is why this happened." (F3)
Restrictions on the mother	"During the last months of pregnancy we usually go the mother's place. For that also they said there is some "kettanachathram" ('bad star'- inauspicious sign) towards my mother's city side and I should not go there. They did not allow me to go to my mother's house till the end which put a lot of stress on me..." (M3)
Hope beyond suffering	"...My husband left me after I had this child but I remember what the nurses told me that this baby is God's gift. So I keep telling myself that though my child has a disability, my child is still a gift and I will take care of him. He will be my priority..." (M5)
Parenthood: supportive vs unsupportive environments	
Uncertainty at discharge	"The doctors told us that 90%, the baby can get well and 10%, he might not. Some problem will be there and we cannot say what problem now. The baby will be in the High Risk Infant follow-up group. We cannot guess what problems might arise in future, you have to make an appointment and see us regularly for the next year." (F2)
Challenging parenting experiences	"My son did not sit in the balvadi (government pre-school) for almost one year as he had problems speaking and understanding. I used to sit along with him even when I was pregnant with my second one. I had him on my lap for 2 hours continuously. Then slowly after a year he got adjusted to his teachers. That was very difficult for me as I had to come home and do the entire house work alone." (FGDM1) "My son bites our hand when he gets angry. We have to keep looking out or else he will bite." (FGDF1)
Unsupportive social milieu	"He was alright till 6 months of age while I was breast feeding him. People tell me he got fits because we started using a bottle. From then on, he gets fits at the beginning and end of the month. So I used to blame myself for his condition..." (FGDM3) "I struggle financially as I am unable to work after marriage and because I have to take care of a 5 year old child with severe Cerebral Palsy. I have no support from friends and my husband's family. The money the Government gives is not even enough for the needs of my child." (M5)
Emotional reappraisal of the situation	"As a mother I want him to do what he thinks. So whatever he is interested in, like drawing, I will let him do that. I don't force him at all in studies. So whatever he is interested in, he can pursue." (M2)
Support from family and HCPs	"When we started to come for the monthly check up and the doctors told us he is fine we started feeling better. Then our fear reduced because anyways we were coming every month for the first one year." (F3)
Neonatal follow-up: adherence vs non-adherence	
Attitudinal barriers	"The doctor did everything for us and gave us the right suggestions. The doctor we visited regularly for one year left the institution. After that we didn't know who to see and then we stopped coming there." (F3)
Barriers to compliance with therapy	"...They (family) used to tell me not to move the legs and do exercises for the baby now... So, I have to close my door at night and then do when everyone is asleep..." (M5)
Environmental barriers	"He is four years old and he has not even developed head control. It is not easy to carry and bring him to therapy. But as a mother I am responsible for him and I try to do it as much as I can." (FGDM3)
Sociocultural barriers	"My neighbors told us to take him to a temple for nine weeks and that it would heal his disability. We took him there for nine weeks as it is a special temple." (FGDM4)
Supportive family and work environment	"I feel a joint family is good because even if I have to go somewhere like to the hospital they take care of my child. If I am alone, then I would have to do everything. Before he wakes up I should finish all the work and then have to be with him after that." (M4) "I am a teacher. My workplace is very supportive. They accept medical slips in the office and in the school. They don't give permission for other reasons but if it is for treatment they usually grant leave." (F1)
HCPs, healthcare professionals; NICU, neonatal intensive care unit.	

interviews. For the FGD, mothers are denoted as FGDM and fathers as FGDF (figure 1).

Overarching theme: impact of sociocultural factors on parenting and follow-up experience

The impact of sociocultural factors on parenting and follow-up was the core theme. Sociocultural factors are the larger scale forces within cultures and societies that affect thoughts, feelings and behaviours. Positive sociocultural factors are a strong sense of family belonging, community support, good education and healthcare, availability of recreational facilities and exposure to the arts.²⁸ Our study identified factors such as superstitious beliefs, discrimination and stigma in the community with regard to children as well as the parents. Parents' accounts

consistently identified various familial and sociocultural factors that affected their parenting.

Theme 1. NICU stay: distressful versus reassuring experiences

Blaming the mother

Parents expressed the birth as the most difficult phase. The family blamed the mother and her behaviour for the unexpected admission of the infant in the NICU. The mothers reported blaming themselves for the situation, since they were blamed by relatives causing maternal anxiety and confusion. According to M3, "My family didn't want me to get admitted for birth when the doctors told us to. They repeatedly said it is "ammavasai" (new moon night—considered inauspicious) and I should not

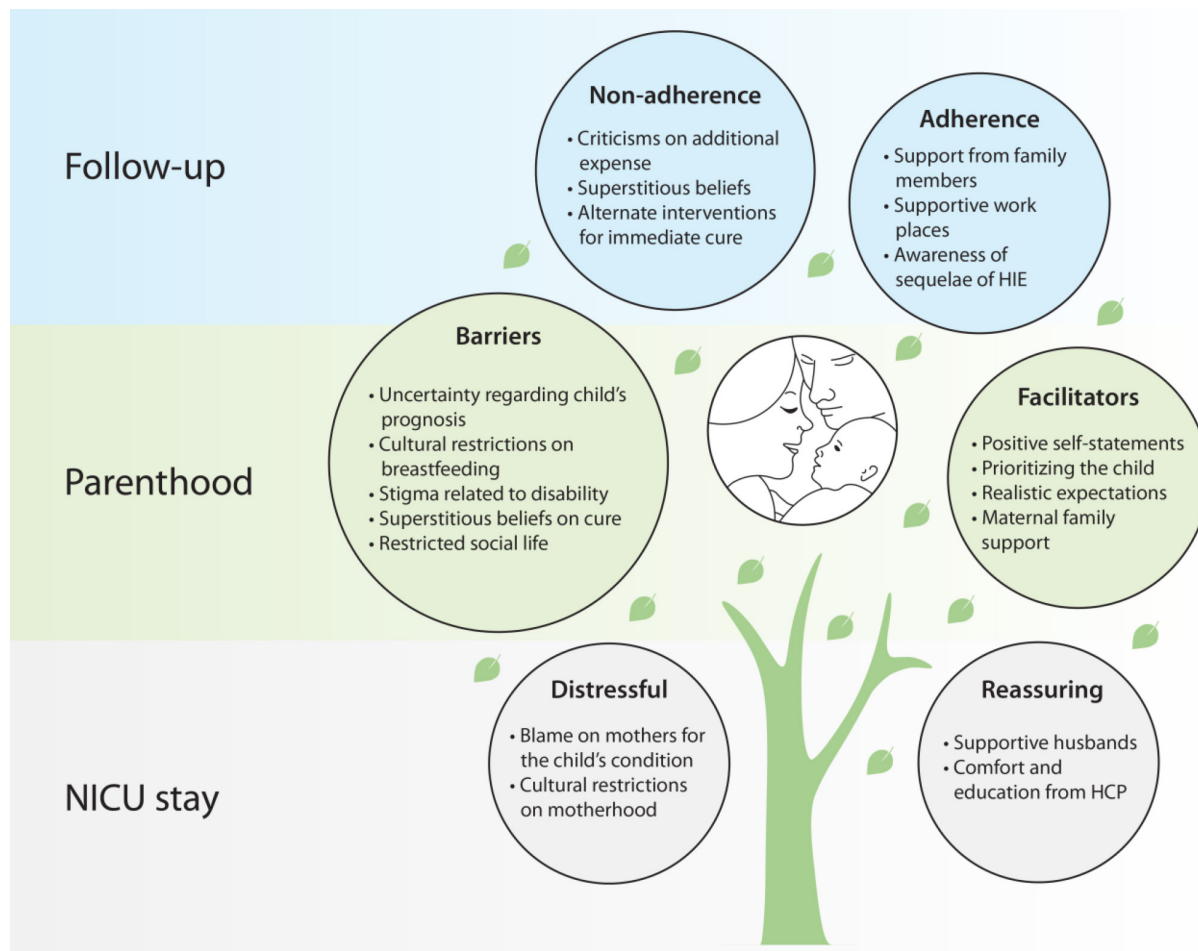


Figure 1 Thematic map showing the themes and subthemes. HCP, healthcare professional; HIE, hypoxic ischaemic encephalopathy; NICU, neonatal intensive care unit.

get admitted on that day. They blamed me saying that the child is in this condition because I didn't listen to them."

Some mothers took independent decisions when the labour pain began and were blamed for doing so. FGDM2 said, "Everyone at home wanted me to deliver at home as my pain started at night. They told me not to go to the hospital. I went to the hospital all by myself against their wishes as I thought it would not be safe at home. They all blame me for going to that hospital. They say I am the reason he (son) is like this."

Restrictions on mother

The mothers faced stress from family members due to cultural practices, in addition to adjusting to motherhood in the NICU environment. M4 said that she was not allowed to take a bath during her NICU stay since her family believed it would cause the infant to become sick. She said, "I used to take a bath while my relative was sleeping. Around early morning, 2 am to 3 am."

Hope beyond suffering

Despite being blamed and restricted, parents identified some factors that helped them to cope with the NICU stay. Mothers identified their spouses as a major source of support. Fathers played multiple roles: protecting the

mother from accusations, supplying basic needs of food, water and accommodation, balancing work–life and being the contact person for healthcare professionals (HCPs) in the NICU. M3 said, "No one was there to support me. It is only my husband who supports me. He says not to feel bad, not to think anything and let them talk whatever they want. You do not worry." Some HCPs provided comfort and guidance to the parents throughout their NICU stay. As expressed by F4, "The doctors all told me not to be scared and that they will save him. He will be alright. After three to four days we became relaxed. Once the doctors told us that he would be fine we felt better. We knew we would go home soon."

Theme 2. Parenthood: supportive versus unsupportive environments

Uncertainty at discharge

Parents reported uncertainty with information given about the child's condition by the HCPs at discharge. Parents were told that their child's condition can be fully evaluated only at future follow-up visits. "When we got discharged they (HCPs) told us that he has got fits and it might come again also. They do not know. When we enquired about the baby's condition, they said the baby's

brain had mild damage. They had taken an MRI for him, so after the results, they said there was no big variation but we will have to wait and check his milestones regularly for precautions. We will have to come for one and a half years for regular checkups.”

Challenging parenting experiences

After an uncertain NICU stay, parents looked forward to a new beginning at home with their child. But parenting experiences were challenging due to sequelae of HIE and pressure from family members. F2 said, “We went home confused, after going home, every time we kept checking. It had been two months, he had not rolled over. Will it become delayed or will he do it on time? We were always in constant fear.”

As children grew, problems related to their disabilities started to increase. Parents complained about their child’s assaultive behaviour as the main stressor in early parenting years. F4 expressed his frustration saying, “My child was very adamant. When he wants something he has to get it. He does not care who that person is. He even tries to hit his teachers and talks back to them. We used to get a lot of complaints about him. If we ask him to write he will throw his slate.” Due to irregular follow-up, parents were unaware on how to manage behavioural problems. Some used punishments as a way to deal with the tantrums. F4 expressed helplessness when he said, “No, nothing else works with him. We have tried to talk to him, but finally we have to hit him.”

Unsupportive social milieu

Parents felt they received no support from society related to their child’s disability. They felt rejected, isolated and blamed for their child’s current condition. Parenting was stressful as criticisms from others continued. M5 reported saying, “...If it was up to us, we would have searched for a solution to the problem but they will keep telling us you didn’t listen to us, that’s why this happened...” M6 also said, “Yes, everyone in my village talks about the condition of my baby and sees us differently. I have felt so bad many times.” Parents received many superstitious suggestions from people on how to treat their child’s condition. M5, mother of a child with motor difficulty, said, “They tell he has to stand for a while with his legs buried knee-length in the sand. One day we made him stand like that, he cried so much. Then, they tell us to make him play outdoors at 11 am; he will get vitamins (from sunlight). Or they ask us to make him play in the hot sand after 3 pm.” Due to the child’s problems and the stigma, the parents had a restricted social life. During family gatherings, people had their opinions and criticisms regarding the child. M5 mentioned, “Some say maybe he does not have enough blood in his body that is why he is like this.”

Emotional reappraisal of the situation

Parents used a variety of internal coping mechanisms to deal with the difficulties they faced while parenting. The internal strategies included focusing on the positives,

developing realistic expectations and using positive self-statements. Most mothers resorted to internal coping mechanisms as they were homemakers and lived with their husband’s families. They did not have much contact with friends/colleagues or family. M6, mother of a child with a severe disability, said, “Whether the child is normal or not, he is my life. Those children who are normal will grow up and when they are 12 years of age will leave the parents and go. The ones who are not well will stay with us forever.” M3 said, “A doctor once told us one thing. He said don’t look at your child as a problem. Look at him as a normal child and then you will know whether he has a problem or not. So that is the point I always remember.”

Support from family and HCPs

Parents received external support from HCPs, colleagues, family and spouses. For mothers who continued to work, it was the grandparents who were the primary caregivers. F4 mentioned, “The grandparents look after him one step more than us. They will not scold him. Whatever wrong he does, they say that he is a child and let him do it, you should not scold him.” Some fathers played a major role in the parenting process while others supported the mother in the process. Some fathers were supportive of the mother joining back work after childbirth, by taking care of their children during their early childhood. As F2 said, “My son became attached to me very well. I didn’t expect it would be like this. But till today, he is my best friend. For the past four-five years, he has stayed the most time with me. When I started taking care of him, I started feeling like a mother to him.”

Theme 3. Neonatal follow-up: adherence versus non-adherence

Attitudinal barriers

Parents knew the importance of long-term follow-up, but faced many challenges in adherence. They overcame issues related to distance from the hospital (>20 km), financial barriers and work commitments. However, they struggled with familial and attitudinal barriers in the community. In extended families, the finances and household work are shared; hence, mothers were not allowed to take independent decisions regarding their children’s treatment process. M6 described her stressful follow-up experience, “They used to scold us many times saying we cannot take our child in bike to the hospital as the ‘Kaath-upata’ (a ghostly wind believed to cause illness) will strike him. They say we spent a lot of money on this child and we should not risk him falling sick again. Every time we come for a follow-up we fight at home.”

Barriers to compliance with therapy

Parents who brought their children regularly for follow-up encountered difficulties in continuing therapy at home. FGDM4 said, “My family doesn’t understand at all. At the hospital, they used to tell us to take the baby outside to show visuals. She (HCP) tells us to read stories to him, talk to him. They will wonder why we have to do all this.

Anyway, he will grow in a usual way, why do we have to do all this?”

Environmental barriers

For parents of children with disabilities, follow-up became harder as the child grew, either due to behaviour problems or motor skill difficulties. In India, wheelchair use is difficult due to environmental barriers like steps, thresholds and inaccessible public transport; mothers usually carry children and come for follow-up. FGDM3 said, “When I take him for therapy on the bus, I have to carry him all the way to the hospital. He is 4 years old. Adding to this, he is also adamant, cries and everyone stares at me (mother starts crying). So I started to do exercises for him at home by myself as it was difficult to bring him to therapy. Now I have come to the hospital after 4 years as there is no improvement. Here also, he doesn’t cooperate for exercises. I am the only person who is involved in his home exercises.”

Sociocultural barriers

Some mothers who wanted to bring their child for long-term therapy could not do so due to other responsibilities at home. In extended families, the daughter-in-law is generally responsible for most of the household chores. FGDM4 said, “I have finished all my work in the morning. I prepared lunch for my elder son and my husband. I washed all the clothes. I kept food ready for my father-in-law. I gave a bath to both my children. I fed my younger son. Now I have come here. I have to get back home before 7 pm to cook dinner.” Also, the family wanted to see immediate improvement in their child and perceived the therapy process as slow and ineffective. They had difficulty accepting the long-term nature of the disability and the need for lifelong therapy. Parents were asked to turn to religious activities that might heal their child or other interventions. FGDM2 resorted to acupuncture and diet modifications to prevent seizures and stopped medicines. She said, “I take him for acupuncture. He is not supposed to eat idly and dosa (fermented rice cakes) as the batter gets sour. It has chemicals. No outside food, only natural food. I have to give him the correct quantity of drumstick soup and pumpkin soup. It was a short treatment and they will do the treatment for us. So I did that.”

Supportive family and work environment

Extended families were perceived as facilitative when siblings needed to be taken care of. M5 reported, “His (husband) elder brother’s wife, younger brother’s wife are there. We have been a joint family for the past fifteen years. All of us live together. So all the work at home the others will do. We don’t have to do anything on hospital appointment days. We leave home at 7 in the morning.” For mothers who did not have much family support, they considered their husbands to be huge support balancing relationships between them and other family members. The fathers were responsible for taking leave from work, follow-up expenses in addition to the cost for the

treatment taken during NICU admission, (which is usually paid off with a loan) and travel to the hospital. M3 felt strong support from her husband; she said, “My husband is really good. He has a clean character. He supported me so much. Because of his support only, I overcame all this. If he had not helped, I might have gone backward. Who can take me to the hospital? Who can do all this for me? Nobody can do.”

DISCUSSION

Parents of children with HIE are torn between two worlds—an atmosphere of support and one of criticism. They face reassuring and distressing experiences during the NICU stay, post-discharge and early parenting years. Parents were torn between their desire to follow post-discharge advice and barriers in the familial and socio-cultural milieu. Parents eventually developed ways of coping with negative experiences. Our findings expose the adverse impact of the environment on an already stressful parenting experience and on adherence to medical advice.

The first finding of this study is that during NICU stay, mothers faced disproportionate attribution of blame by family, society and even spouses. Experiences of self-blame, anxiety and depression by parents while in the NICU have been described in developed countries.^{29–32} This study found that parents experienced additional blame by family members and strangers. The negative experiences in extended families were reported more frequently when the child had impairments than when the child had near normal development. A study on parenting children with burn injury similarly found that parents suffered twice the trauma of their child’s burn and the blame. They went through a process of ‘enduring the blame’.³³ A local cultural belief exists that mothers who do not take extra precautions during pregnancy are more likely to give birth to children with disabilities.³⁴ Mothers face restrictions due to traditional practices that are part of the childbirth process.¹⁶ The Indian culture gives prominence to family values over individuals—elders over younger persons. In this context, it is hard for new parents to transgress existing support systems. Mothers in the NICU, burdened by uncertainties of their infant’s prognosis, had to surmount these restrictions and discrimination. Parents in this study reported getting emotional and psychological support from their spouses as well as HCPs, similar to findings of other studies.^{35 36}

The second finding in this study is the challenge of the transition of parenthood from the NICU to the home environment. Parents experience anxiety regarding their child’s health status post-discharge.^{15 37} The first year of parenting is reportedly the most stressful for parents of children who have been in the NICU due to constant fear of their child becoming ill again.³⁸ Parents in this study reported that information on what to expect and regular follow-up visits in the first year helped them with this transition. This is similar to findings of other studies.¹⁵



Similar to other aspects of human behaviour and socialisation, parenting is influenced by social and cultural factors.^{16 39} Parents living in an extended family had less control over the antecedents and consequences of their child's behaviour, which increased the parents' sense of helplessness.⁴⁰ Although some parents identified maladaptive behaviour patterns as arising from developmental difficulties, they did not actively seek interventions. Parents eventually learnt to cope with their child's condition by focusing on positive aspects of parenting, taking pride in their child's achievements and accepting the child, as also reported in other studies.⁴¹⁻⁴³

Our third finding was that neonatal follow-up compliance was influenced by several factors. Many studies have explored the contributions of maternal, paternal, child-related and environmental factors as facilitators or barriers to neonatal follow-up compliance.⁴⁴ Facilitators included a greater sense of control over the child's prognosis, having adequate resources,⁴⁵ higher mean maternal stress scores, higher perceived risk of developmental difficulties in the child,⁴⁵ longer NICU stay and presence of chronic lung disease.⁴⁶ Barriers included fear of bad news, feelings of vulnerability, perception of not needing follow-up until problems arose, distance from the hospital and lower maternal age.¹⁸ In this study, parents perceived sociocultural factors to help or hinder follow-up irrespective of the extent of the child's disability. Beliefs and rituals around childbirth act as opportunities and barriers to the healthcare providers.⁴⁷ The cultural barriers that include mothers not being allowed to make independent decisions in extended families add challenges to existing difficulties of caring for an infant with HIE.^{40 41}

Support from spouses, grandparents, extended family members and healthcare workers helped parents cope post-discharge. Traditionally, for a few months after childbirth, the mother and the baby are sent to live with the maternal family. Fathers visit the baby occasionally and play a role in nurturing the baby.^{48 49} This study found that the unexpected NICU admission brought fathers closer to the parenting role. Subsequently, they took more responsibility in helping the mother in childcare, supporting her return to work, and balancing between the child and his family. This was also seen in another study.³⁶ Some parents were grateful for the practical help received from the extended family in looking after siblings and sharing of household work during follow-up visits.

The adverse sociocultural factors identified were low awareness of disability, leading to stigma and subsequent focus on alternative forms of 'healing'. Earlier studies found that the social life of parents of children with disabilities is affected by stigma and superstitions related to disability.^{41 42} Similarly in this study, many mothers avoided social gatherings for fear of being criticised. Suggestions by community members to try traditional healing methods caused indecision in the parent's minds. Parents were advised to seek interventions that would 'cure' the disability and not spend money on medical

treatment that they believed was ineffective. Some parents were unwilling to come to the hospital until hopes pinned on prayers to particular deities had been exhausted.

Many parents faced criticisms from family members related to the extra cost, travel time and necessity of follow-up. Mothers were unable to come for follow-up by themselves since most were dependent on the husband's family for financial support. As children who had motor impairments grew older, bringing them for regular therapy sessions using public transport became challenging. These findings have been reported in studies exploring the effect of culture on disability in India.^{34 50}

Parents identified institutional barriers like long distance to the hospital, long waiting time and loss of a day's wage when coming for follow-up. Despite these challenges, most parents brought their children regularly to follow-up and therapy, making the child the utmost priority in their lives. This is contrary to other studies done in India that found parents to be insensitive to the needs of their children with disabilities.⁴⁰

The following individual and population-based strategies might improve the follow-up compliance for parents belonging to a collectivist culture. Individual-based strategies include empowering parents in extended families to make independent decisions regarding the child's care. Family education about milestones in cognition, emotion, language and self-care in addition to motor abilities is required for early identification and intervention. Psychosocial support for parents should be provided from the NICU stay and continued as children grow as parenting challenges and expectations from therapy change over time.⁵¹ Population-based strategies include improving awareness of the risk of disability when follow-up is compromised, reducing stigma related to disability and expanding the support system for parents of children with disabilities. This could be done through creating easier access to the government-provided disability benefits, developing support groups for parents in their respective villages and regular home visits from the HCPs to assess community barriers. Support groups are a crucial part of NICU in other countries.⁵² Social cultural influences need to be evaluated and considered as an additional risk factor while making policies regarding educational interventions post-discharge and follow-up care for High Risk Infants. Additionally, including extended family members in the sessions wherever possible could help to improve the support for parents.

LIMITATIONS

This study has some limitations. The interviewers, being the therapists who cared for the child in the follow-up clinic, might have inhibited the parents from expressing negative experiences. The interviews were conducted a few years after the NICU stay, which could have led to recall bias in participants. Telephonic interviews could have limited the participants' ability to communicate

their feelings and the interviewer's ability to interpret emotional expressions while recounting experiences.

CONCLUSION

This study makes an original contribution to the scant literature on sociocultural influence on parenting and follow-up experience of parents of children with HIE. The study throws light on the various challenges faced by parents in dealing with children with disabilities in India. Parents struggle between the conflicting advice given from HCPs versus their communities. Mothers in our study considered fathers' support crucial as it was easier for parents to cope with stigma and superstitions together. Including fathers and extended family members in every aspect of follow-up would result in a family-centred approach to children with disabilities. Parents of children born with HIE need long-term ongoing psychosocial support from the HCPs. This study helps the HCPs to understand better the contextual factors that modify the adherence to therapy goals or follow-up. This might result in better neonatal follow-up compliance in the long term.

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