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EMPIRICAL RESEARCH QUALITATIVE

Experiences of parents whose school-aged children were treated with therapeutic hypothermia as newborns: A focus group study

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Abstract

Aim: To describe parents' past and present experiences of their newborn infant's therapeutic hypothermia (TH) treatment after perinatal asphyxia 10–13 years after the event.

Background: Newborn infants are treated with TH following perinatal asphyxia to improve neurodevelopmental outcomes.

Design: A qualitative descriptive design using focus groups (FGs).

Methods: Twenty one parents to 15 newborn infants treated with TH between 2007 and 2009 participated in five FGs. The FGs were transcribed verbatim and analysed using framework approach. The SRQR checklist was followed for study reporting.

Results: Two main categories were identified: hardships and reliefs during TH treatment and struggles of everyday life. Both categories include three subcategories, the first: (1) concern and gratitude for the unrecognized treatment, (2) insufficiency of information and proposed participation and (3) NICU nurses instilled security and hope. The second with subcategories: (1) unprocessed experiences of the TH treatment, (2) later challenges at school and (3) existential and psychological challenges in everyday life.

Conclusion: TH of their newborns affected the parents psychologically not only during the treatment, but lasted months and years later. Information and communication with health care professionals and school management were inefficient and inadequate. The parents' concerns could be prevented by an improved identification and understanding of the problems and the needs of the infants and their families before discharge.

Relevance for Clinical Practice: Through more personalized and efficient preparation and communication by the nursing staff before discharge, many of the parents' worries and problems could be reduced. Check-up of parents' needs of psychosocial support before and after discharge and offering counselling should become routine. Also, nurses at Well-Baby Clinics and in school health care should receive knowledge about TH treatment and the challenges the children and the parents experience.
1 | INTRODUCTION

Perinatal asphyxia (intrapartum-related complications) occurs when the placental blood flow is disturbed or interrupted before childbirth or if there are insufficiencies of the blood gas exchange in the newborn infant leading to hypoxia. Several different causes can result in asphyxia: maternal haemorrhage or anaemia, umbilical cord complications, birth positioning of the infant, blockage or malformation of infant’s airways or difficult resuscitation. The incidence of perinatal asphyxia in high-income countries is about one to three per one thousand live births, whereas in low-income countries perinatal asphyxia is much more common (Kurinczuk et al., 2010). Globally, the annual mortality in perinatal asphyxia is estimated to approximately 26% out of 2.7 million deaths within the neonatal period (Liu et al., 2016).

1.1 | Background

In surviving infants, perinatal asphyxia may result in hypoxic ischaemic encephalopathy (HIE), a condition of cerebral impairment caused by biochemical processes with risk of permanent damage to the brain. The diagnosis of HIE is based on low Apgar scores and metabolic acidosis alongside neurological symptoms. The Apgar scoring is used to assess the condition and prognosis of the newborn infant regarding heart rate, respiratory effort, muscle tone, reflex irritability and colour at 1, 5 and 10 min after birth (The American Academy of Paediatrics, 2015). The neurological symptoms of the HIE are divided into three stages based on the Sarnat score: mild, moderate, and severe (Sarnat & Sarnat, 1976). Moderate and severe HIE increases the risk of acute complications to vital organs and long-term complications such as neuro-developmental disorders and cognitive impairment (Jacobs et al., 2013). Asphyxia may also occur postnatally during the infant’s first hours of life.

Besides the routine neonatal intensive care, therapeutic hypothermia (TH) is standard of care since 2007 for full term infants suffering moderate or severe perinatal asphyxia, if the infant fulfills the criteria for the treatment. To be effective, TH must be initiated within 6 h from birth, with a target core temperature of 33.5°C, and continue for 72 h followed by a rewarming process to regain normal body temperature (Azzopardi et al., 2009; Jacobs et al., 2013). Infants born in hospitals not providing neonatal intensive care or not providing TH, are transported to a hospital with those facilities. However, TH for perinatal asphyxia in low-income and middle-income countries has been shown not to reduce mortality or disability in follow-ups of outcome. Instead, TH increased mortality and lacked neuroprotection compared to the control group (Thayyil et al., 2021).

In a literature review of nursing care in TH in newborn infants with HIE, it was identified that the different nursing tasks during treatment require specific skills (Solaz-García et al., 2021). The authors listed three main blocks summarizing nursing care during TH: general care for the stabilization of the infant during the entire process and in collaboration with other multi-disciplinary staff members, the responsibility of preparing material needed, medical equipment and administration of medical treatment, and finally, emotional support to parents to reduce stress and to encourage parents coming close and getting involved in the daily care of their newborn infant (Solaz-García et al., 2021).

1.2 | Parental experiences of TH

Parental experiences of TH in their newborn infants have been explored in some studies since the treatment became standard of care for perinatal asphyxia (Backe et al., 2021; Heringhaus et al., 2013). Parents often describe the childbirth as traumatic and chaotic, and express fear that their infant will not survive (Backe et al., 2021). During the 72h of TH, parents are living through an emotionally exigent time of hope and despair (Heringhaus et al., 2013). Their infant’s stay in the neonatal intensive care unit (NICU) is characterized by parents trying to cope with the situation and the treatment surrounded by technical equipment that their infant is receiving (Nassef et al., 2020). Parents worry about the prognosis and find the given information about long-term outcome vague and uncertain (Cawley & Chakkarapani, 2020). Adequate and regular information about medical decisions and care is desirable, but sometimes overlooked or missed by health care professionals (Lemmon et al., 2016). Participation in medical rounds is beneficial, but parents have reported face-to-face communication to be the most effective way for information (Sagaser et al., 2022). TH also affects parent-infant bonding, which is delayed by physical and psychosocial separation since skin-to-skin contact during the treatment is not possible in most NICUs (Thyagarajan et al., 2018).

Implementation of the caring philosophy of family-centred care (FCC) in NICU has proven to be beneficial during TH through a gradual transitioning into parenthood by the close everyday prerequisites for effective communication and mutual trust with staff as well.
as physical closeness to the infant (Nassef et al., 2020). In order to increase the emotional closeness and physical touch between infant and parents during TH, experimental interventions to cuddle the newborn during TH or during rewarming have shown sufficient physiological stability in the infant (Odd et al., 2021). Parents have reported that the possibility to hold or to cuddle their infant during TH gave them the opportunity to feel closeness and a sense of normality (Ingram et al., 2022) as well as facilitating the parent–infant bonding (Craig et al., 2019).

Although several studies describe parental experiences during and for some time after TH in their newborn, we have identified the knowledge gap of parental experiences of TH in their newborn when the child has reached school age. This study was conducted to start filling out this research.

2 | METHODS

2.1 | Aim

To describe parents’ past and present experiences of their newborn infant’s TH treatment after perinatal asphyxia 10–13 years after the event.

2.2 | Design

This is a qualitative descriptive study with focus groups (FGs) as method for data collection. FGs promote interaction and sharing of experiences between the parents. Kitzinger suggests that FGs, can create a collective synergy of experiences that the participants are either aware or unaware of (Kitzinger, 1994).

2.3 | Setting and sample

Parents of 51 children treated with TH following perinatal asphyxia between 2007 and 2009 in two level III NICUs in Stockholm, Sweden, were eligible for study inclusion. In addition to the two hospitals with the two NICUs providing TH, the infants could have been born at one of the three other obstetric departments in the same region. The newborn infants in the NICUs were cared for by multidisciplinary teams consisting of neonatologists, nurses, nurse assistants, nutritionists and social workers.

The rationale for choosing FGs over individual interviews was that parents, during follow-ups of their infants, started talking to each other about their experiences when they met in the waiting room. From what we saw in the waiting room, we anticipated that parents not only would be able to talk about their experiences with other parents, but also that they could benefit reflecting upon their experiences with other parents who had similar experiences.

Parents of 21 of the children did not answer the request or could not be reached, leaving parents of 30 children to be asked to take part in the study. Mostly, the PhD student contacted only one parent to the remaining 30 children, that is, the first author (S.K.N.) who gave oral information about the purpose of the study. For some children both the mother and the father were contacted when the first parent referred the decision of participation in the study to the other parent. During this stage, parents of 11 children declined participation, leaving parents of 19 children initially accepting participation. Parents who agreed to participate, and parents who were hesitant but did not decline participation, were sent a letter with information and purpose of the study. After four FGs had been completed, stricter restrictions due to the pandemic outbreak of SARS-CoV-2 infection COVID-19 were introduced in November 2020 and fifth FG was cancelled. At this stage, 17 parents to 13 children had participated in the study. The fifth FG was held a year later with the participation of four parents to two children. In summary, 21 parents, eight fathers (38%) and 13 mothers (62%) of 15 children participated in the FGs since not all parents that initially accepted to take part in the study came to the planned FG. The median age of the parents was 44 years, and the mean age was 45 years, with a range of 33–57 years (Table 1). Fourteen parents were first-time parents, and 11 parents subsequently had siblings.

Four children were born in 2007, eight were born in 2008 and three in 2009. The mean and median age of the children was 12 years.

### Table 1 Focus groups’ (FG) and informants’ characteristics, \(N = 21\)

<table>
<thead>
<tr>
<th>FG 1</th>
<th>Informants</th>
<th>n=3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/Female</td>
<td>1/2</td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>46 years</td>
<td></td>
</tr>
<tr>
<td>Mean age of infant</td>
<td>12 years</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FGI 2</th>
<th>Informants</th>
<th>n=7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/Female</td>
<td>3/4</td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>45 years</td>
<td></td>
</tr>
<tr>
<td>Mean age of infant</td>
<td>12 years</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FGI 3</th>
<th>Informants</th>
<th>n=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/Female</td>
<td>2/3</td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>49 years</td>
<td></td>
</tr>
<tr>
<td>Mean age of infant</td>
<td>11 years</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FGI 4</th>
<th>Informants</th>
<th>n=2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/Female</td>
<td>0/2</td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>49 years</td>
<td></td>
</tr>
<tr>
<td>Mean age of infant</td>
<td>12 years</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>FGI 5</th>
<th>Informants</th>
<th>n=4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male/Female</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>38 years</td>
<td></td>
</tr>
<tr>
<td>Mean age of infant</td>
<td>13 years</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 2 Maternal and infant characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N = 15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal</td>
<td></td>
</tr>
<tr>
<td>Prima gravida</td>
<td>9</td>
</tr>
<tr>
<td>Delivered by caesarean section</td>
<td>4</td>
</tr>
<tr>
<td>Delivered by instrumental assistance</td>
<td>7</td>
</tr>
<tr>
<td>Partus normalis</td>
<td>4</td>
</tr>
<tr>
<td>Infant</td>
<td></td>
</tr>
<tr>
<td>Mean gestational age: weeks + days (range)</td>
<td>39 + 6 (35 + 3 – 41 + 6)</td>
</tr>
<tr>
<td>Mean birth weight: kg (range)</td>
<td>3.546 (2.380–4355)</td>
</tr>
<tr>
<td>Male/Female</td>
<td>9/6</td>
</tr>
<tr>
<td>Mean 1-min</td>
<td>Apgar 3</td>
</tr>
<tr>
<td>Mean 5-min Apgar</td>
<td>3</td>
</tr>
<tr>
<td>Mean 10-min Apgar</td>
<td>4</td>
</tr>
<tr>
<td>Ventilator support: HFO or IPPV/CPAP (n = 14)</td>
<td>8/3</td>
</tr>
<tr>
<td>aEEG background activity [n = 13]</td>
<td>8</td>
</tr>
<tr>
<td>Suspected clinical seizures/verified electrographic seizures</td>
<td>9/5</td>
</tr>
<tr>
<td>Sarnat score at 24 h: moderate/severe</td>
<td>14/1</td>
</tr>
<tr>
<td>Total stay at NICU, days: mean (range) [n = 13]</td>
<td>14 (7–33)</td>
</tr>
</tbody>
</table>

Abbreviations: aEEG, amplitude integrated electroencephalography; CPAP, continuous positive airway pressure; HFO, high-frequency oscillatory ventilation; IPPV, intermittent positive pressure ventilation; NICU, neonatal intensive care unit.

The study was approved by The Swedish Ethical Review Authority (reference number 2014/1175-31/1, on 20 August 2014) which was an approval of the whole PhD project consisting of four different studies. Since there was a delayed start of this study, it became possible to interview parents about their experiences when their child had started school. Due to the changes in research questions, aim and data collection method, an amendment was needed, applied for and approved 6 years later (reference number 2019-01447, on 5 March 2020). Initially, at least one parent of each eligible infant was invited to participate in the study. Written and oral information was given, and informed consent was provided by the participating parents, as well as permission for the audio recording of the FGs. Parents were told that they could withdraw their participation at any time. If participation in the FG would raise any questions or other issues for parents, before or after the FG, the researchers could refer them to adequate help.

2.5 | Data analysis

The recorded FGs were transcribed verbatim by external service resulting in 174 single-spaced pages of text. The transcriptions were analysed using framework approach which is suitable for large sets of qualitative data (Gale et al., 2013). The transcribed FGs were read through several times for familiarization by the first and the last author. In the next step, concepts in the data were marked and coded. The codes in the matrices were compared between the participants in the same FG, as well as in between the different FGs (Ritchie & Lewis, 2003). The first author sorted and indexed the codes into a framework matrix which was discussed and confirmed by the last author before it was applied on all the FGs. The first and the last author analysed and discussed the data until consensus of the final categories and subcategories was obtained.

2.6 | Ethical issues

The study was approved by The Swedish Ethical Review Authority (reference number 2014/1175-31/1, on 20 August 2014) which was an approval of the whole PhD project consisting of four different studies. Since there was a delayed start of this study, it became possible to interview parents about their experiences when their child had started school. Due to the changes in research questions, aim and data collection method, an amendment was needed, applied for and approved 6 years later (reference number 2019-01447, on 5 March 2020). Initially, at least one parent of each eligible infant was invited to participate in the study. Written and oral information was given, and informed consent was provided by the participating parents, as well as permission for the audio recording of the FGs. Parents were told that they could withdraw their participation at any time. If participation in the FG would raise any questions or other issues for parents, before or after the FG, the researchers could refer them to adequate help.
or counselling to their health centre's general practitioner or first-line psychologist. The contact information of the researchers was written in the parental research information sheet, and they were reminded of the possibility to call or send a message after their FG was completed. Each parent received two cinema tickets for their participation in the study.

2.7 | Rigour

The backgrounds and expertise of the research team (S.K.N., M.B.B., M.J.) are in nursing, neonatal intensive care, research and medical science. The first and the last authors are experienced in qualitative research and conducted the interviews, as well as the data analysis. Trustworthiness was achieved by disclosure and audibility of the data collection and the data analysis. Recognition of the reflexivity of two of the authors, who are former neonatal intensive care nurses, reduced the risk of internalization between the researchers and the participants and made them aware of unconscious presumptions.

3 | FINDINGS

Two main categories were inductively identified during the analysis of the five FGs: hardships and reliefs during TH treatment and struggles of everyday life. The first experience of TH among parents was that it had felt unrealistic and harsh. During the treatment of the asphyxiated infant, the expectations changed and became merely hope of survival. At home, as the years went by, the struggles of everyday life were constantly present for the parents.

The parentheses below the quotes of the participant show the number of the FG in chronological order, the parent in alphanumeric order and age at the time of the FG.

3.1 | Hardships and reliefs during TH treatment

The birth of the infant was surrounded by chaos and uproar, which was not expected by the parents. They thought they knew what the first meeting with their newborn infant would be like, but instead, they saw their baby fighting for his or her life. After resuscitation, the infant was transferred to a NICU providing TH. Infants born in hospitals not providing TH, were transported within first hours, given passive cooling, to one hospital in the region that provided TH. The fact that their infant was affected by perinatal asphyxia and treated with TH, had a great impact on parent's emotions and their reflections about the future prognosis.

The category hardships and reliefs during TH treatment includes three subcategories: (1) concern and gratitude for the unrecognized treatment, (2) insufficiency of information and proposed participation and (3) NICU nurses instilled security and hope.

3.1.1 | Concern and gratitude for the unrecognized treatment

Many parents described their gratitude for the treatment their child received after birth, but, several years later, they also expressed strong, and mixed feelings from that time. One father said that he still relived the resuscitation of his newborn minute by minute but acknowledged that his experiences probably differed from that of the staff's. Another father said that he was forced into a situation where he felt torn between the mother and the infant. On the one hand, he did not want to miss anything about the resuscitation of his newborn and the decisions made. On the other hand, he wanted to be an emotional support to his partner, whose childbirth did not turn out as expected and who was worried about her infant's outcome.

For one of the mothers, it had been a terrible feeling seeing the cold infant lying there during TH with all the technical equipment and leads the infant was connected to:

You just want to tuck them in when they're small and new.

(FG 1, mother A, 44 years)

Parents were convinced that the treatment saved the life of their infant, and they trusted the staff who assured them 'we're going to fix this'. Parents felt gratitude even though it was hard not being able to hold their newborn during TH treatment. Although the mothers had birth-related injuries and pain, they were not concerned about them since they were so anxious about the prognosis of their newborn. They tried to grasp the situation:

It was like a little bubble, here am I and here is my baby, even if it was difficult to understand that it really was my baby and not an alien.

(FG 4, mother P, 41 years)

Many parents thought that even if the infant was going to survive it might have permanent disabilities, for example, not being able to walk and being dependent on a wheelchair. Some parents adopted the approach that everything was going to be all right, even if the prognosis was uncertain. One father realized the seriousness of his infant's status when he was in the NICU which he described as 'the most intensive care unit of the intensive care units'. One mother sat beside her infant as long as she was able to during the treatment, held him in her leg and constantly prayed to God that he would survive.

During TH, parents had yearned for their baby to wake up and start screaming. It was only after the warming that parents fully realized they had a newborn that could breathe and move, and it was a wonderful feeling to finally be able to hold their baby:

First it was not normal, and it was, kind of, wrong. Then it was like 'yeah, she's going to survive!' Well, then you were happy with it. And it was then you...
3.1.2  Insufficiency of information and proposed participation

Parents emphasized that there was insufficiency of the information they received in general, that the information was sporadic and not adapted to their situation. Parents observed the staff’s facial expressions prior to any communication or information about their child’s status in order to interpret if it would be negative or positive information. Also, parents did not understand all the given information, it was difficult to understand what various stages of the treatment meant and what the subsequent expectations were:

We got some information about how bad it was. Or how bad it could go. No one said outright that she could kind of die.

(FG 2, mother F 42 years)

One parent described that information about interventions was given, but not what consequences to be expected:

My experience was that the doctors and nurses talked about what was happening and what they planned to do, not about the consequences. I can't remember that they ever talked about positive or negative consequences but more like “this is the plan,” it was always the plan and where we were in the plan.

(FG 2, father E, 45 years)

Some parents felt that clinicians withheld information and only told half the truth, or even lied to them as not to create unnecessary anxiety, although their wish was to get straight and honest information. Other parents wanted to get information about the prognosis but did not dare to ask if their infant was going to survive or not. However, there were also parents reporting that the information was adequate and understandable but tough.

Parents complained that they were not asked about participation in caring for their infant during TH treatment. One mother said she wanted to do something but did not dare to ask because she was afraid that she should receive news that her infant would not survive. Mothers were also not asked whether expressing the breast milk went well, especially not those mothers staying at the maternity ward. There was a lack of information about how often and for how long the mother should express the breast milk. As they recalled, ‘you just followed along’.

I absolutely did not feel involved nor looked at.

(FG 3, mother O, 48 years)

Most parents stayed at the maternity ward during their infant’s TH treatment in NICU and visited their infant on a regular basis. They were asked to be present at their infant’s bedside because ‘the baby could feel the presence of the parents’ as one father had been told. Although being present at their infant’s bedside, parents still felt left out and not involved in the care. Some parents were told not to overstimulate their infant, that they ‘should not touch their infant too much because it could affect their brain’. Even though they initially were not involved in the care of their infant, they felt it was expected of them to become independent and know everything about parental care at discharge, which was challenging.

3.1.3  NICU nurses instilled security and hope

Many parents reported that the nurses instilled security and hope and that they made their stay in NICU bearable. Parents needed the positive position and attitude shown by the nurses. The nurses provided emotional support and made the parents never feel alone:

The staff at NICU was always there but when you were at the maternity ward it was deserted, and you could go out or call on them and try to find someone.

(FG 2, father I, 53 years)

The physicians were objective and professional in the medical care, but it was the nurses in the NICU who made the parents feel calm and peaceful with their competence and commitment:

The doctors are good at their thing so to say, but it was the nurses who created the calmness.

(FG 2, father G, 42 years)

One mother said that there was a special nurse that she dared to talk about her worries if her infant will be able to walk. From the first day this nurse gave the mother hope. The mother said that it had been nice with a nurse that said that everything could be fine in the long run. Another mother said that she got so interested in nursing science that she herself became a nurse:

Seeing the nurses taking care of her (i.e. the infant) so professionally, sparked my interest in studying to become a nurse.

(FG 5, mother T, 33 years)

3.2  Struggles of everyday life

Although there were manifested challenges at home and parents struggled to manage their everyday life, they were positive about the survival of their child. Despite their child’s yearly follow-ups at the hospital, parents had concerns about whether the HIE had affected their child or not. Over the years, parents kept a close eye on
their child's development and skills, and the TH-treated child was often compared to healthy siblings.

The second category *Struggles of everyday life* includes three subcategories: (1) unprocessed experiences of the TH treatment, (2) later challenges at school and (3) existential and psychological challenges in everyday life.

### 3.2.1 Unprocessed experiences of the TH treatment

During the stay in NICU, support from family and friends was essential. Some of the parents had counselling with the social counsellor, but for others the counselling had not been at the appropriate time or they were not receptive to it. Parents reported that the social counsellor came to visit them when they were busy doing something else or wanted to rest. Certain parents told they were not in the mood or had too much of a crisis to be able to receive the support from the social counsellor.

After discharge, it had been a transition to come home. The parents considered that support from a psychologist or a social counsellor after discharge would have been much needed:

You never had this possibility to process; you never had this professional support.

(FG 3, mother N, 42 years)

Parents expressed fear for respiratory arrests or seizures in their infant during the following weeks and months after discharge. The parents did not sleep well since they could not relax, and they felt the need to go and control their infant's breathing during the night. A few parents also expressed that they had nightmares after coming home:

I dreamed, I was really scared to sleep because I kind of dreamed horrible nightmares about her, that she died.

(FG 5, mother R, 39 years)

One parent said it was so scary to come home that she used an apnoea alarm for her son for several years. One mother described feeling traumatized by the chaotic childbirth and the TH, and another mother said she never had a possibility to process the event. A third mother described having had an untreated postpartum depression and that it had been difficult for her to bond with her baby. A fourth mother said that she waited for a miracle after discharge and she had difficulties in bonding with her infant for a long time, something she had never told anyone. She was happy to participate in this study because she felt that she could describe 'how difficult it had been to bond and discussing it with strangers maybe would help her to start talking about it with family members'. Nor had she and her partner ever talked about what happened as she hoped they might.

### 3.2.2 Later challenges at school

Afterwards, at home, when it was time to go to the Children's Health Center for regular follow-ups of the child's development and for vaccinations according to the Swedish vaccination programme, some of the nurses working there had no knowledge about TH. That made the nurses less aware of the challenges the families had gone through. As their children were getting older, most parents had told their child about their birth and the TH treatment, and one mother said that she had raised her daughter not to be ashamed of herself. One father added that he did not want to 'overdramatize but let him live his boyhood life'. Most parents said that they had been worried about their child's schooling. Yet, for many of the children, school was unproblematic. However, for some of them, the older they got, the more challenging it became:

She got CP (cerebral palsy) and other things afterwards which make her life a little troublesome sometimes with school and so on. We ask how it goes and they say, "it's going so well." We experience exactly the opposite when she comes home and tells us how it has been.

(FG 1, father C, 48 years)

In the present, the challenges or diagnoses of the children described by the parents were allergies, tics, fainting, attention deficit disorder (ADD), Asperger syndrome, autism, developmental coordination disorder (DCD), cerebral palsy (CP), dyslexia, problems with short-term memory, self-endangering behaviour, and suicidal thoughts. It was described as an uphill struggle of cooperation difficulties with the school, where one mother said that she had to fight like a 'berserk', to get the school management and the principal to recognize the challenges her child faced at school. Parents emphasized that the management was far too late to act when problems appeared in school. When an issue occurred, it took months or even years before there was an arrangement, for example, an assistant teacher or a referral for a neuro psychiatric examination.

At this age in school, it is there where the pressure increases, absolutely. That's when it turns out how they have endured. They don't show anything in school, instead they come home and release all emotions. No, we hear "it goes so well in school," instead it goes to hell at home.

(FG 1, mother A, 46 years)

Despite the challenges some of the children have, parents described that their child had shifted into a positive approach about TH and what had happened to them in the neonatal period. One parent said that his son had made a school project about TH and had shown pictures of himself to his teacher and classmates as a newborn on TH in the NICU. Furthermore, he had explained that this was something that he had gone through and would live with. Another parent said...
her daughter had talked in school about TH as an identity authentication for her: ‘this is who I am, this is me’.

3.2.3 | Existential and psychological challenges in everyday life

It was often difficult for parents to explain to people what their child had gone through as a newborn. It was not easy because they really wanted to explain ‘but it is too big a deal, and you get emotional because you want them to understand exactly how it was’.

For some parents, it was the first time at the FGs that they met other parents who had the same experience as themselves. For other parents, it was the first time they talked about their experiences of TH openly during the FG. The TH had affected the parents over the years, and some parents expressed having feelings of guilt:

> It is my fault, I had hypertension but didn’t take it easy … and from that feeling … of course I should have taken it easy, especially when I, weeks before, had preeclampsia. But the doctor said there are no answers about what happened during the childbirth.

(FG 2, mother F, 42 years)

The experience was strongly fortified in their memories: ‘this whole thing is stuck firmly in you’, and parents wanted tools to deal with this. Parents asked themselves if the asphyxia could have been avoided if the staff at the maternity ward had followed the guidelines of instrumental ventouse extraction, or if they would have planned a caesarean section. They also reflected upon the parent-infant separation during TH and if it had affected the infant in a negative way. Parents often thought that their infant’s behaviour or impairment was caused by the asphyxia event in the perinatal period and if it had not been for TH, their child’s condition would have been worse. One mother said that sometimes when new things happen to her child, in behaviour or regarding something else, she considered whether it was due to the asphyxia or if it was the child’s personality. One mother had twins and one of the twins was treated with TH. She said that she was continuously comparing the twin’s development. One father thought his son may have existential reflections and questions later in puberty and teenage years as he starts to notice his own body:

> And such questions may pop up in our children’s lives later and especially during the existential teenage years. We never know, but we might need tools for such things. These are things that I’ve reflected upon.

(FG 2, father M, 53 years)

Although parents were continuously concerned about the future, they were grateful and concluded that if it had not been for TH, things would not have ended this well.

4 | DISCUSSION

The results of this study show that parents went through multidimensional transitions simultaneously after having an infant that was treated with TH following perinatal asphyxia. Becoming a parent is a universal experience and transitioning into whileness is under normal circumstances a life-changing event (Meleis, 2011). To have an infant suffering perinatal asphyxia, necessitating TH treatment, makes the situational transition as described by Meleis (2011), even more challenging for these parents. Parents in this study described insecurity and feelings of anxiousness when moving from a safe hospital context to their home after discharge. During the developmental transition, parents were concerned about the future and the hardships of their children. Nurses’ awareness of the various stages in the transition theory and parental transitioning during childbirth, parenthood and discharge from NICU can be crucial for improving the support for the parents.

Four children in this study were born in 2007, eight children were born in 2008 and three children were born in 2009 which were during the first years of TH becoming standard of care for infants with HIE. There is a significant difference between what the situation looked like for the parents in this study, compared to how it is today. Recently, in one of the NICUs in this study, some infants in TH have been cared for in height-adjustable adult hospital beds after respiratory and circulatory stabilization with intubation and catheterization. This increases parental accessibility and closeness to their infants as they can lie down beside them. Furthermore, the same NICU has, in some cases and if the infant’s medical status allows it, a short moment of skin-to-skin contact between the infant and the parent before starting the TH treatment.

This study showed that when TH treatment was new, the parents were not much involved in the nursing care of their own infant. However, there were grand expectations on the parents having transitioning into independent parents at discharge. This misalignment could have been avoided by preparing parents the transitioning into parenthood if FCC had been implemented. Today, FCC has been implemented to support parental transition. In our previous study, it was evident that parents transitioning into parenthood was facilitated by the context of FCC (Nassef et al., 2020). Although there are still challenges in fully implementing FCC in NICUs where parents are working in co-care and partnership with the staff (Serlachius et al., 2018; Sigurdson et al., 2020), there are many benefits for both infants and parents when the NICU has succeeded in the task. In addition, the Mother-Newborn Couplet Care has developed with specially designed NICUs to guarantee patient safety and minimization of separation between the mother, her partner and the asphyxiated infant (Klemming et al., 2021; Nassef et al., 2020). The FCC promotes the possibility of an individualized understanding of the parental situation enabling nurses to identify and plan the preparations and interventions into a healthy transition for the discharge.

Despite the commitment and emotional support from nurses to parents during TH in this study, we identified a lack of communication...
and information to the parents during the whole NICU stay. This is an inhibitor for the transition into the emotional and physical well-being and feelings of safety and security after discharge. Parents sometimes did not know the function of the technical equipment and why it alerted. If they had been given relevant knowledge about the alarms and the technical equipment, they could have mastered the situation according to their capacity. Many of the deficiencies concerning information, communication and participation that appeared in this study would be minor or non-existing with a successful implementation of FCC promoting participation, transparent information and mutual dialogue. FCC also prepares the parents for a more successful transition to the home setting (Schumacher & Meleis, 1994).

Some parents in the present study believed the clinicians were witholding the truth or even lying to them. Parents wished that clinicians had informed them about the prognosis of their child as soon as possible. The intention should be to optimize communication with parents about their infants’ status and prognosis consistently and frequently, even when uncertain. Connecting parents with their individual needs of trauma-adapted psychosocial support is a major task for the multi-disciplinary teams in the NICU. It has been shown that the whole family needs to get integrated during the hospital stay in NICU during TH to be able to continue and be prepared for the care and the rehabilitation after discharge (Pilon et al., 2021). This was also expressed by parents in this study. During a transition, there is a level of stress involving depression, anxiety, frustration, insecurity and loneliness emphasizing parents’ need for healthy responses and outcome of their transitions.

There is an association between parental mental health, socio-economic factors and child developmental outcomes up to 6.5 years (Danguecan et al., 2021). Parents in this study emphasized the need for professional psychological support or therapeutic follow-up after discharge. Helping and supporting parents, with professional care may also facilitate and improve their child’s development. Having Meleis’ definition of the ‘biopsychosocial-cultural’ perspective of nursing in mind (Meleis, 2011), the results from this study suggest that person-and family-centred nursing support and interventions after discharge can be facilitating factors for the parents when their newborn infant was treated with TH following perinatal asphyxia, and when the parents’ transitioning into parenthood was not yet successfully achieved before discharge.

4.1 | Limitations

One limitation in this study was that the FGs took place during the pandemic outbreak of SARS-CoV-2 infection COVID-19. Many parents would have accepted an individual interview or an on-line interview but did not want to take part in a face-to-face FG. Some parents first accepted to participate but did not show up because of their fear of being exposed to the infection. This limited the number of parents in some of the FGs. However, despite this, 21 parents to 15 children, which is 29% of the total population of 51 children treated with TH from 2007 to 2009, participated in the study which strengthens the possibility of transferring the results to a similar context.

4.2 | Recommendations for further research

Even though routines and nursing care of infants and families in NICU continuously are improving, further research of interventional studies of psychological and nursing support to parents of infants treated with TH before and after discharge may be needed. In addition, follow-up interviews with parents and their children reaching teenage about their daily lives and thoughts could be valuable studies. Furthermore, nurses and other multi-disciplinary NICU staff are also valuable informants for feedback in the field of both qualitative, quantitative and triangulation research of this field. One research question is how nurses in NICU with FCC support parents to be better prepared for discharge.

5 | CONCLUSION

The findings of this study highlight the hardships that parents are going through during their newborn infant’s treatment with TH following perinatal asphyxia. Despite being grateful, the parents’ fears and concerns after discharge, that is, transitioning from having health care staff taking care of the child to having sole responsibility as a parent, could have been eased with support from NICU nurses before and after discharge, or in some cases, referrals to a psychologist. Further, information and communication were deficient at the time, maybe due to staff’s inexperience of TH and that FCC was not yet fully implemented in the NICU. When the child reached 10–13 years, communication and dialogue with teachers and principals in school were lacking. Parents felt that the problems their child had were lessened and not understood. A better understanding of the problems these children have in this actual age in health care and school context will help both the children and their parents to respond to future challenges.

AUTHOR CONTRIBUTIONS

S.K.N., M.B.B. and M.J planned and designed the study. S.K.N. and M.J, performed the focus group interviews and analysed the data. S.K.N wrote the first draft of the manuscript. S.K.N., M.B.B. and M.J reviewed and edited the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.
DATA AVAILABILITY STATEMENT

Author elects to not share data due to privacy/ethical restrictions.

ETHICS STATEMENT

This study is approved by The Swedish Ethical Review Authority (reference number 2014/1175-31/1 and 2019-01447).

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