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Exploring parent expectations of neonatal therapeutic hypothermia

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Abstract

Objective—We aimed to assess the parent experience of therapeutic hypothermia (TH), specifically focusing on unmet expectations.

Study Design—Open-ended questions were used in a focus group setting. We employed an inductive approach to develop thematic content from the transcribed recordings.

Results—30 parents of infants treated with TH participated. Within the principal theme of managing expectations, four sub-themes emerged. These included parental concerns about morphine use; specifically the association of morphine with end-of-life care and addiction. Parents perceived their role as key in the decision to implement TH and were emotionally burdened by this during and after TH. Parents recall intense fear for the infant's immediate survival and were not sufficiently reassured regarding survival. Parents also experience ongoing uncertainties about the long-term prognosis after TH.

Conclusion—The identification of these four areas in which parents have unmet expectations is important in order to improve the delivery of care.

Introduction

Therapeutic hypothermia (TH) is an intervention used for neuroprotection in newborn infants suspected of having a perinatal brain injury [1]. TH involves decreasing the infant body temperature to 33–34 °C for 72 h. While extensive research has demonstrated the improved clinical outcomes of infants treated with TH [1, 2], relatively fewer investigations have examined the parental experience of TH. Parental emotional themes such as “being thrown into chaos”, “being in a state of unreality/ uncertainty” were described in a study of 26 parents of infants treated with TH in Sweden [3]. Themes developed in another qualitative study of Swedish parents included “emotional landscapes”, a moment of “rebirth” associated with holding the baby for the first time, a change in attitude toward life after TH and adapting to new situations [4]. Within the adapting to new situations theme,

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Compliance with ethical standards

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several sub-themes of strategies parents used to cope with emotional turmoil were identified. These included creating a sense of control, use of external and internal supports, “normalizing the abnormal” and “reconciling oneself to uncertainty” [4]. In the United States, one study investigated specific aspects of communication about TH and described three themes; fragmented communication, inherent challenges of discussing a complex therapy and uncertainty of infant prognosis [5]. In a second publication addressing the longer-term experience of these same parents, three additional themes of longitudinal grief, “entangled infant and family interests” and parents becoming advocates were described [6]. Much of the qualitative research thus far has focused on the emotional disruption parents experience when the unanticipated event of a traumatic delivery occurs or communication challenges, whereas our research focused on parent expectations surrounding TH.

Expectations, in healthcare, refer to strongly held patient beliefs about an anticipated experience within the healthcare system [7]. Pregnancy may heighten parental expectations given the intense planning that often occurs prior to delivery [8, 9]. A sudden shift in events can result in disappointment, anger [7] or in the case of infants treated with TH, intense fear on the part of the parent. Understanding patient expectations has been shown to improve satisfaction [7] and in prematurely born infants, managing parent expectations has led to improved bonding with the infant [10]. Our research aimed to examine parent expectations surrounding TH treatment and in particular develop an improved understanding of unmet expectations parents have during and after TH treatment with the goal to ultimately improve the delivery of care.

Methods

This exploratory, qualitative study was conducted on the parents of infants treated with TH in a 51-bed Level III Neonatal Intensive Care Unit (NICU) at a single tertiary care center in the Northeastern United States. Focus groups were employed rather than individual interviews to study a larger number of parents, to allow parents to support one another during the discussion and to promote shared experiences that might lead to more dynamic conversations and greater depth of data. The researchers wanted to insure that participants did not feel vulnerable in a one on one interview with a medical professional and wanted to encourage parents to freely disclose all positive and negative aspects of the TH experience.

Clinical care

TH is used at our institution for infants who are <6 h old at the time of initiation and who are 35 weeks gestation or greater. Infants must also demonstrate a combination of abnormalities including umbilical cord blood acidemia (pH <7.0), a base deficit of (−16 mmol per liter), a 10 min Apgar score of less than 5, an acute perinatal event such as uterine rupture or umbilical cord prolapse and evidence of moderate to severe encephalopathy per Sarnat criteria [11]. Hypothermia is achieved by placing an infant on a cooling blanket for 72 h during which time the temperature is maintained between 33 and 34°C and continuous EEG is monitored for seizures. The infant is treated with a continuous infusion of morphine (5 µ/kg/h) during TH and this is titrated up or down for comfort. The infant is rewarmed over 12 h and at completion of rewarming, an unsedated MRI of the brain is performed. The same

neurologist (A.C.) is typically involved in the care of all infants treated with TH and performs outpatient follow up visits at 3, 6 and 12 months.

Sample

Parents of infants treated with TH in the time period from 2013 to 2015 were offered the opportunity to participate. Parent contact information was contained within an existing TH database. To maximize diversity, all parents who could be contacted, regardless of socio-economic status or educational background were invited to participate. Once they expressed their desire to participate by phone, focus group participants were matched based on the severity of the presenting neonatal encephalopathy according to Sarnat criteria [11]. Parents were included if they spoke English, if their infant survived TH, if TH had been performed in the 24 months prior to the study initiation and if they lived within a 100-mile radius of the hospital. Informed consent was obtained from all participants and the study was approved by the local institutional review board.

Focus group

The focus groups were led by a Child Psychiatry resident (C.J. or R.G.) and a Social worker (J.B.), none of whom provided direct care to the child or parent during the NICU admission for TH. Parents of 3 children were present at each focus group which typically lasted about 90–120 min. A semi-structured approach was taken by the person leading the group using open-ended questions targeting various aspects of their experiences. Examples of questions include “Please tell us about your experience in the NICU” and “Please tell us about your experience of your baby being transported” (see supplemental information). Parents were provided with dinner during the session and a \$100 gift card/gas voucher to thank them for traveling to participate. Upon conclusion of the focus group, parents were provided with resources for additional emotional support and were contacted by an investigator (C.J. or R.G.) within 48 h to insure there was no need for professional support. The focus groups were recorded and transcribed verbatim; however names were not used during the recording so it was not possible to identify who the speaker was and whether it was a mother or a father unless they made direct statements about their role within the text.

Chart review

Clinical information about mothers, infants, delivery, TH treatment, electroencephalogram (EEG) results and magnetic resonance imaging (MRI) results were abstracted from the electronic medical record by a research coordinator for the institutional TH database and used to create Table 1.

Data analysis

Descriptive statistics of quantitative data for Table 1 were generated using R software [12]. Qualitative analysis was performed using an inductive approach [13]. Four investigators (R.G., S.E., J.B. and A.C.) independently read the transcriptions multiple times and met as a group to develop predominant themes. Using a commercially available software program, MAXQDA, each manuscript was individually coded by the four investigators for the four major themes. The four investigators then met again and developed sub-themes within the

principal themes. The four investigators then independently coded the sub-themes and then met five more times, once for each focus group, to review the entirety of each manuscript and to resolve differences in the coding of both the principal and sub-themes.

Results

Fifty-three infants were treated with TH during the period from June 2013 to July 2015. Five infants who died during the hospitalization were excluded. Six more infants were excluded; two infants from non-English speaking families, two infants who moved to different states due to adoption and two more infants who moved out of state with their parents. Of the 42 remaining infants who met inclusion criteria, parents and grandparents of 15 infants (35.7%) participated in one of five focus groups (relatives of 3 children present at each group). Table 1 highlights maternal and infant clinical characteristics comparing those who opted to participate in the focus groups to those who did not. The mothers of infants who did not participate were overall slightly younger than participating mothers. Nonparticipating infants were born slightly more than a week earlier and their birthweights were accordingly smaller. Apgar scores and cord pHs were similar in both groups. More participating parents had infants with seizures and MRI injury than those who chose not participate.

In total, 30 adults were interviewed including 15 mothers, 12 fathers, 2 grandmothers and 1 grandfather. Grandparents were in attendance when there was no direct involvement of the infant's biological father at the time of TH treatment. Eleven infants (73%) were transferred from outside hospitals. At the time of the focus groups, the infants were between 2 months and 2 years old. Four principal themes were identified and included managing expectations, communication, emotional experiences and supportive or healing experiences. The communication and emotional/supportive experiences principal themes are described in other manuscripts. The managing expectations theme and its four sub-themes including use of morphine during TH, parent decision burden regarding implementation of TH, the immediate survival of the infant and the uncertainty of prognosis after TH are discussed in this manuscript.

Use of morphine

Morphine can be administered by continuous low dose intravenous infusion or by intermittent bolus doses for pain, agitation or shivering during TH (Table 2). Parents expressed an expectation that the discomfort their infant experienced in the NICU during TH would be minimized, however many parents reported significant apprehension with the use of morphine commenting on how much they perceived was given stating "it wasn't easy to find out that he [baby] was being pumped full of morphine". Parents were also uncomfortable with morphine use in the context of prior experiences with this drug surrounding end of life care or cancer care for older relatives, "The only experience I ever had with morphine was when my grandfather was sick just before he died in the hospital so I didn't really have very good feelings about it". One parent also expressed concerns about the possibility of future addiction, "You know my thought is addiction and coming down off of it so that's all I thought about". Given the elevated level of discomfort parents had with morphine being given at all, parents became quite angry when they perceived that morphine

was given unnecessarily. One parent reported that morphine was given to calm her infant when she would have preferred to use non-pharmacological techniques to calm him, “One of the nurses pushed morphine at one point unnecessarily”. Morphine was perceived as preventing the baby from acting normally and the absence of movement and interaction was distressing to parents; “I want him [baby] to react and move and flinch; I don’t want him to lay there and not react; we’re looking for these typical behaviors; I don’t want him all drugged up”.

Parent decision burden regarding implementation of TH

Parents were grateful for the ways in which they perceived members of the medical team acting decisively in the immediate post-delivery period. Parents expected medical personnel to have this capability (Table 3). Parents were then confused by what they in retrospect identified as their greater than expected involvement in the decision-making surrounding whether or not TH was implemented. One parent stated “Do we have a choice? I mean like are there any other choices?” and others questioned who in fact had made the decision “You know we [parents] were talking, like are we making the right decision; is this even a choice that we have?” Parents also highlighted their understanding of how important it was to make this decision quickly, “The sooner the better...say yes, cool, send the kid and then ask all the questions after you’re done panicking.” Other parents lamented the challenges of having made this decision in the days during which TH was ongoing; “still, it was a hard decision to follow through with. It wasn’t a hard decision to make because in that minute, you just say it and that’s what’s going to happen. It was the next day when you still can’t hold your baby; and it’s the next day when you still can’t hold you baby that you’re like, oh man, I don’t know if we made the right decision”. Parents also reflected on their child’s outcome in the context of the decision they made wondering what the outcome would have been had they not made the decision to treat with TH (Table 3). One parent reported feeling reassured in retrospect about his decision in the context of a mildly abnormal MRI (Table 3). Another parent statement embodies the feelings surrounding this important decision that was seemingly made with inadequate information; “Later we [parents] talked about how we just let our daughter get frozen; why did we do that? But ...we’re glad we did...”

Immediate survival

The parents in all focus groups expected to deliver a healthy baby at term and expressed how surreal it was to suddenly find themselves in a situation in which the immediate survival of the infant and/or the mother was uncertain (Table 4). There was a consistent theme of fear for the immediate survival of the infant and several unmet expectations regarding the communication of survival. One parent suggested that the providers say something to a family such as “we can’t give you any estimation on brain damage, we can’t give you any estimate on if this [TH] is going to work, but he’s probably going to live”. Parents highlighted the importance of the provider initiating this reassurance about immediate survival as this fear is not always easily expressed by the parent to the healthcare team, “I didn’t verbalize that I was concerned about [survival]...You feel like you shouldn’t have to verbalize it”. Another parent said “I was scared the whole time I wasn’t going to be able to take him home”. This fear for survival was not necessarily resolved after TH was complete and the MRI results were available. One parent reported having to feel reassured that the

infant was still breathing and would put a hand on the infant's chest to make sure even after they were home (Table 4).

Uncertainty of prognosis

Parents expressed an expectation that modern testing such as EEG and MRI of the brain would tell them whether or not the hypothermia treatment had worked and prognosticate definitively for a normal or an abnormal developmental outcome (Table 5). This expectation was often unmet and parents had lingering uncertainties about the prognosis of their infant in the short and the long term. The older infants in the study had EEG recording during the first 24 h to screen for seizure activity and therefore did not get daily EEG updates after 24 h. Parents of these infants reported a struggle with waiting 3–4 days for the MRI to “get answers” as little was said about prognosis until the MRI was done. Due to a protocol change, the younger infants in the study had 72 h of continuous EEG recording during TH. Parents were updated daily on the presence or absence of seizures and reported that the absence of seizures was something they held onto as a reassuring finding (Table 5). Parents were also updated daily about the presence or absence of sleep wake cycling on EEG and reported relief when infants were found to have sleep wake cycling, an EEG feature known to be associated with better outcomes (Table 5).

While daily updates on EEG seemed to help parents with the shorter term prognosis, parents remained fearful of longer-term prognosis and outcomes such as epilepsy, autism or cerebral palsy. One father stated “it could be a couple of years down the road and then they’ll [seizures] start back up. So we’re just going to keep an eye on that”. Another parent expressed concerns for a future diagnosis of autism, despite having a normal MRI (Table 5). Another parent expressed concern about a future diagnosis of cerebral palsy and said “For me, it’s the CP risk. He has an elevated risk for cerebral palsy; based on the old studies, it’s about 40%, but we won’t know and can’t test for a long time.” Some parents report having persistent fears despite the neurology follow up appointments at 3, 6 and 12 months. A parent reported, “So all we ever had were those 3 follow up appointments. But you know, we still have this nagging fear that like you know, what if he needs early intervention, what if, what if, what if.”

Discussion

Parents of infants treated with TH described several areas in which their expectations of their healthcare team and their infant's care were not met. These include the use of morphine for treating infant discomfort, the perceived parental burden of decision-making regarding initiation of TH, and inadequate provider information/reassurance about immediate survival and about short-term and long-term prognosis.

In a prior survey of NICU nurses at two academic institutions, nurses expressed frustration and at times outrage at the inconsistencies of morphine administration for infants treated with TH [14]. The strength of the nurse assertions that infant pain was not being adequately addressed was instrumental in the design of the parent questions for this study in which we asked specifically about morphine. We anticipated that parents would express a positive response to the use of continuous low dose morphine infusion as it appeared to us to keep

infants visibly more comfortable. Unexpectedly, we discovered the opposite; that parents do not respond favorably to morphine administration. This study raises very strong concerns on the part of parents whose prior experience with morphine involved end of life care for elder relatives and raised parental concerns for future addiction in their infants based on the narcotic exposure. Parental discomfort about morphine use was compounded for several families when they perceived that morphine was given to their baby unnecessarily for the purpose of calming the infant. This research highlights deep concerns that parents have about the use of a powerful narcotic in a newborn and these concerns are justified in the literature which demonstrates elevations in morphine levels and slower clearance in infants undergoing TH [15]. Future research is urgently needed to define the beneficial effects of treating infant discomfort versus the potential for future sensitivity to addiction and adverse neurodevelopmental outcomes that may be associated with use of narcotics.

The second theme of unmet parent expectations was commented on by parents in three out of five focus groups. Parents perceived their role as a decision maker in the determination of whether or not TH was to be implemented. This is striking as TH is considered standard of care at our institution and not a procedure with a specific consent process. The confusion surrounding consent for transfer of an infant for TH and parents giving permission for TH has been described previously [5]. The authors postulated that this confusion was the result of an entanglement between signing paperwork to consent for transfer and the transport team discussing the plan to initiate TH [5]. Regardless of why or how parents assume or are given the impression that the decision was theirs to make, there may be a role for eliminating this confusion and having providers employ language that is more definitive in this regard. This could potentially alleviate some of the guilt parents experience as they observe some level of infant discomfort during TH.

Understandably there was intense parental fear for the immediate survival of the infant. This research however illuminates the unmet expectation that parents want to be told that their infant is likely to survive and that this should be initiated by the medical team as the parent may be unable to verbalize this fear. This research also demonstrates that fear for survival of the infant may persist beyond the completion of TH. This sentiment of intense fear for survival has been echoed in other research on parents of infants treated with TH [16] and on parents of infants in the NICU for other reasons [17, 18]. Preempting the concern for survival with information may be a significant step toward managing parent expectations and improving parent experience.

Parents seem to respond positively to the short-term updates that can be provided daily from the EEG, however some parents expressed enduring uncertainty about the longer-term prognosis regarding seizures, cerebral palsy, autism and other developmental or behavioral diagnoses despite reassuring MRI findings. This persistent parental concern has been previously demonstrated in a qualitative study on the parent experience of communication about brain imaging studies and neurological prognosis in prematurely born infants [19]. As more research is done such as the 6–7 year follow up of infants treated with TH [20, 21], clinicians can be more definitive with parents about the enduring positive effects from the TH. It would be informative to study the impact of parents feeling more positive during the inpatient admission on the longer-term bonding and development of the baby.

A major strength of this research was that the fact that the physicians caring for the infant in the NICU, were not present for the focus group. This was consciously planned to allow families to speak openly and honestly about their experiences. The focus group rather than individual interview, as well as the open-ended style of questions, seemed to allow parents to develop themes that might have otherwise been missed such as the perception that parents had made the decision to treat with TH. While the focus group setting may have contributed to the richness of the data, it was also a weakness given that we were not able to identify in the transcript whether the quotes came from a mother or a father or whether they were from a parent with an infant who had a normal or an abnormal outcome thus limiting our analysis in some ways. An additional weakness of this study is the fact that more parents of infants with complicated clinical courses chose to participate and therefore the possibility exists that some sentiments expressed in this manuscript may not generalize to a wider audience of less severely affected infants. Recall bias was likely present to some degree but hopefully minimized by limiting participation to parents of infants younger than 24 months. Another limitation of this study was that parents of infants who did not survive were not interviewed. It is very likely that they would contribute even more to the conversations surrounding immediate survival and prognosis. Bereaved parents of infants treated with TH could be a subject for a future research study. Because this study was done at a single center, the results may not generalize to other institutions.

Conclusion

Parents of infants treated with TH experience a unique situation in which their expectation of a normal uncomplicated delivery is abruptly shattered. In the face of this sudden change they have significant reservations about the use of morphine in their newborn. They also second guess what they perceive to be their decision to provide TH and experience uncertainty about the survival and long-term prognosis of their infant. Identifying the unmet expectations surrounding these issues may lead to strategies to improve the parental experience of TH and may ultimately benefit the infant.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Maternal and infant characteristics according to status of participation in the focus groups

	Participants (N = 15)	Non-participants (N = 27)
Maternal age (years)	29 (5.7)	23.8 (4.7)
Gestational age (weeks)	40.0 (1.3)	38.7 (2.1)
Birth weight (kg)	3.70 (0.57)	3.2 (0.62)
Female	4 (26.7%)	9 (33.3%)
<i>Apgar Scores</i>		
1 min	1.0 (1.0, 2.0)	2.0 (1.0, 2.0)
5 min	3.0 (2.0, 5.0)	4.0 (3.0, 5.0)
10 min	6.0 (3.0, 6.0)	6.0 (4.3, 7.0)
Umbilical arterial pH	7.01 (6.9, 7.1) ^a	7.07 (7.0, 7.2) ^b
Mean hour of life TH started	2.9 (1.8)	4.4 (1.6)
Transferred from outside hospital	11 (73%)	23 (85%)
Seizures on EEG	7 (46.7%)	7 (25.9%)
Abnormal MRI	6 (40.0%)	6 (28.6%)
NOT orally feeding at discharge	2 (13.3%)	2 (7.4%)
Length of stay, days	12.3 (5.5)	13.2 (5.8)

EEG electroencephalogram, *LOS* length of stay, *MRI* magnetic resonance image, *TH* therapeutic hypothermia^a Available for only 8 subjects (53%)^b Available for 13 subjects (48%). Results are presented as *n* (%), mean (SD) and median (IQR)

Table 2**Quotes describing parental experience of morphine use during TH**

Sub-themes	Quotes
Too much morphine	<p>“child was frozen and then <u>overdosed on morphine</u>”</p> <p>“because he was loaded up on <u>more morphine</u> that an adult human probably”</p>
Associations with the word morphine	<p>“It’s scary to hear the word morphine”</p> <p>“I just think of it [morphine] as more <u>death related</u>”</p> <p>“the morphine was very difficult because my <u>grandmother</u> passed away with cancer and it was...right after they put her on morphine...they just kept upping and upping it and upping it and she was gone. So you know to find out your son’s on morphine, it was like that’s not good news...”</p>
Use of morphine to calm the infant	<p>“the nurse wanted to give him extra morphine and I said he’s not and she wanted to give him more morphine to calm him down and all we needed to do was switch the indicator [oxygen saturation probe] from one foot to the other and then it was fine. And I’m thinking, if she would’ve given him more morphine, it would’ve been totally unnecessary.”</p> <p>“[morphine was] weaned down to almost off and she [nurse] upped it back to what it had been. I want to know what she really thought was fussy in order to give him that. You know what I mean, like what justifies fussy?”</p>

Table 3
Quotes describing parental perceptions of their involvement with the decision to treat with TH

Sub-themes	Quotes
Was there a choice?	“But I mean in the end, there wasn’t any other choice and I’m glad that we did it.” “When they said you know this is what I would do [hypothermia treatment] if it were my child, then you say, I think that’s what we need to do even with limited information as to what it [hypothermia] is.”
Timing of the choice?	“we pretty much need to decide right now if we’re going to do this or not” “We didn’t hesitate. We just said, do it”
Outcome of the decision	“Well you always have that question in your mind of what if you’d said no...we wouldn’t have the same babies that we have.” “...it was really nice to know that...we made that decision and that you know we made the right decision”

Table 4

Quotes describing parental fears for the immediate survival of the infant

Sub-themes	Quotes
Fear statements from parents	<p>“we were kind of sitting there not knowing if he would live”</p> <p>“watching him being pulled out in full cardiac arrest”</p> <p>“and I was pretty scared. I didn’t think he was going to make it”</p> <p>“[the baby] had been taken out [C-section]... I’m laying there in the room...there’s no baby crying so I just said to my husband, I said, I don’t hear him crying. And he was... watching the chest compressions, which is an image he says he cannot get out of his mind”</p> <p>“it was kind of scary and sometimes I would just put my hand like this [on infant’s chest]...just to know he was okay because even after he had warmed up, he didn’t really move”</p>
Provider comments reported by parents	<p>“I finally had to say like, are they alive? And she’s like, oh they’re alive, I’m like, more please? She [stated] well I have bad news, I’m like what are you telling me?”</p> <p>[MD says] “it doesn’t look good; we’re going to have a rough couple of days here. And I’m [parent] like...I didn’t know to the extent of how bad he was at that point so when she [MD] said that to me, that kind of like put me in a whole new frame of mind because it wasn’t just he needed help breathing”</p>

Table 5

Quotes describing parental uncertainty about infant prognosis

24 h EEG group	<p>"[we] had no idea what to expect"</p> <p>"[TH] either worked or it didn't"</p> <p>"We had no answers so I think that's the hardest part and then waiting the 3 days until cooling's over to really get any answers."</p>
72 h EEG group	<p>"it was very reassuring when she [doctor] told us that if he hadn't had any seizure like activity, that within a certain amount of time, that the chances of him having a seizure now were... extremely slim."</p> <p>"if it were some of the problems [on EEG] we're looking for, you'd see different patterns going on. She [doctor] called it the inchworm pattern [sleep wake cycling]... because [it was] good to know that at least there were no alarming problems ... not to feel worried; just wait for that MRI to at least confirm it."</p>
Longer-term concerns	<p>"we were wondering if she was ever going to speak when she was cold"</p> <p>"we have to watch out for things now like he could have a seizure at any moment and we won't know;"</p> <p>"okay, yes, his MRI was pristine, but I mean, is he going to be autistic?"</p>