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ABSTRACT

Parental perceptions of hypothermia treatment for neonatal hypoxic-ischaemic encephalopathy

Aims: Hypothermia Treatment (HT) is now the standard of care for neonatal hypoxic-ischemic encephalopathy (HIE). We conducted a survey to explore parental perceptions of HT as there is little information about this in the current literature.

Methods: Postal questionnaire survey including families (n=51) whose babies received HT at Princess Anne Hospital, Southampton, UK, with 23 questions covering communication, clinical management, follow-up, and care in general. Statistical analysis of descriptive and analytical tests were done using Minitab 16.

Results: The response rate was 60.8%. All parents had concerns amongst which perceptions of pain and distress were described by 41%. Temporary concerns about bonding were common (83.8%), more so in babies transferred from other hospitals ($p=0.04$). Only 61.3% felt they had a good understanding of HT. The need for improvements in the quality (71%) and frequency of communication (48.3%) were also highlighted.

Conclusion: Parents were worried about pain and distress, bonding and about outcomes after HT. Consistency in communication, regular updates, involvement of parents in decision making, strong support mechanisms and balanced discussions about long term outcomes at an early stage are of high importance to families whose babies undergo HT.

Key Words:

Hypothermia treatment, hypoxic-ischaemic encephalopathy, parental perceptions, pain, bonding.

Main paper:

Parents whose babies need neonatal intensive care develop feelings of stress, strain, separation, depression, despair, disappointment, ambivalence, and often waver between hope and hopelessness. [1, 2, 3, 4, 5, 6] Communication is key although it may be suboptimal in the neonatal intensive care unit.[7, 8] Hypothermia treatment (HT) has become the standard of care for babies who suffer moderate or severe perinatal hypoxic-ischaemic encephalopathy (HIE)[9] There is very little literature on whether parents are sufficiently informed and how parents experience and perceive this particular treatment. The few available studies suggest that bonding and attachment between parents and baby may be particularly affected by the nature of the intervention.[10, 11] The effectiveness of communication between families faced with this condition and the medical teams and their coping mechanisms are also unknown. We set out to explore parental perceptions of HT in order to better inform caregivers on further optimising care and support to families of newborns undergoing this treatment.

Setting

The neonatal unit at Princess Anne Hospital (PAH), Southampton, UK, is a 36 bedded tertiary referral service covering a 3 million population in the south of England. Whole body HT is provided with a servo controlled system (*CritiCool™*) along with continuous amplitude integrated EEG monitoring. The baby is nursed in an open incubator for this treatment.

Prior to initiating HT, a senior neonatologist discusses HT, potential side effects and benefits with the family, provides an information leaflet and obtains verbal assent to treatment. The information leaflet describes what cooling therapy means, the potential benefits and side-effects and provides neurodevelopmental followup information. This leaflet is provided for all parents as soon as the babies have been identified for HT. For

out-born babies, initial discussions are conducted by the local hospital and often supplemented by the transport team before the baby is transferred to PAH for HT. Following transfer, the initial information is provided by the most senior clinician assessing the baby. This could be a consultant neonatologist or a senior neonatal trainee. On-going clinical review, family support, and information is provided by a multidisciplinary team, which includes the neonatologist, nurses, a neonatal neurologist, physiotherapist, speech and language therapist, and the family liaison team. Following 72 hours of HT at 33.5 C, babies are rewarmed to 36.5 C (normothermia). Parents can stay within the neonatal intensive care unit (NICU) in a family room, if available and have access to their baby at all times. Daily updates regarding clinical status and supportive treatments are provided. Other family members and friends are encouraged to visit during visiting hours and encouraged to support the family. Following HT and prior to discharge neuroimaging (Magnetic Resonance Imaging, MRI), electroencephalography (EEG), and a neurological assessment are performed to delineate extent and severity of brain injury and aid in prediction of outcome. These findings are shared with the parents at the earliest opportunity. Religious and spiritual support is provided on request.

Methods

Participants:

All parents whose babies received HT at PAH between 01/01/2009 – 01/09/2012 were sent a postal questionnaire along with a covering letter, consent form, and a return postage-paid envelope. For babies who received HT between 01/01/2009 – 31/12/2011 the questionnaire was sent on 05/01/2012 (n=39), and for those born between 01/01/2012 – 31/09/2012 the questionnaire was sent on the day of discharge (n=12). A reminder was sent after four weeks if no reply was received.

Assessment:

A questionnaire was developed by the authors in consultation with the clinical and family liaison support team as there was no validated questionnaire available. This comprises of 23 questions covering communication, treatment, investigations, follow-up, and overall care (see supplementary material). Each question has tick box options and space for free text and it takes about 10 minutes to complete the questionnaire. Responses were anonymised before analysis. Data such as age, sex, mode of delivery, birth weight, and HIE severity based on Levene's modification[12] of the Sarnat and Sarnat Classification were extracted from clinical notes.

Statistical analysis

Statistics were performed within Minitab-16 statistical software[13]. Student's t-test or Fisher's Exact test, or Mann-Whitney U test was used depending on the nature of the variables, with significance level set at $p < 0.05$. No correction was made for missing data. Free text responses were clustered into six priori domains covering "communication", "pain", "feelings", "bonding", "coping" and "support", and analysed descriptively. Two members of the research team (BT and RG) coded the data independently and then discussed similarities and differences, in order to agree revisions to themes. Synthesis and interpretation of data including development of inferences and links to empirical data were done by all authors. The study team was advised by the local Research & Development department that ethics approval was not needed as the survey was a service evaluation exercise.

Results

Fifty-one newborns underwent HT during the study period. Of those, 31 (60.8%) families completed and returned the questionnaires, of which 18 (58%) were inborn and 13 (42%) out-born. A total of 256 free text comments were recorded. There were no

significant differences in gestational age at birth, birth weight, sex, place of delivery, mode of delivery, or mean age at recruitment between responders and non-responders. However, a high proportion of bereaved families did not respond to the questionnaire (Table 1).

Communication and parents' understanding of HT

The respondents indicated that the baby's clinical condition (31/31), the practicalities of HT treatment (30/31), and its potential benefits (30/31) had been explained to them in sufficient detail. 19/31 (61.3 %) respondents indicated they had a good understanding of what HT actually involved. Despite all parents having had a formal meeting with a neonatologist before commencing treatment, a large proportion of parents perceived that there had not been sufficient opportunities to discuss HT (16/30 or 53%) and its potential side effects and complications (15/29 or 51.7%). This perception was particularly prevalent in parents whose babies were out-born and referred for HT (62%; 33% for inborn babies; $p=0.027$).

‘It would have been nice to be told by a doctor how serious things were before we had seen her. We had no information given to us before we walked in to the ICU.’

‘... The doctors were always too busy to talk.’

‘...the doctors were not always available to answer the questions the nursing staff could not answer’.

Of the 31 respondents, 61.3 % felt they had been given sufficient information on potential long term outcome of their child. However, 21% felt that findings from the brain MRI had not been explained clearly with regards to what it might mean for the baby in the future.

‘We were just told that she was stable most of the time. I asked so many times if she was going to be ok and the reply was ...we just can't say.’

‘Yes we were worried.... Because we didn't know what the outcome would be at the end of the treatment’

‘I wasn’t worried about the treatment. It was more what the outcome would be after the treatment. The not knowing is the hardest part.’

‘They couldn’t tell us more than they did’

‘We should have been warned about long term effects! And appropriate therapies e.g. hydrotherapy’

A high proportion of respondents suggested improvements in quality (71%) and frequency of communication (48.3%). Comments included permitting parents to be present during NICU rounds, privacy when receiving updates from the attending neonatologist, the need for timely discussion with parents soon after initiation of HT, discussing both the positive and negative aspects of their baby’s clinical condition, and avoid “congratulating” parents on the birth of their baby.

Pain, positive and negative feelings

All 31 respondents were satisfied with the care their infant received, with a common theme that they believed HT may have helped their infant achieve the best possible outcome long term. However, 41 % highlighted perceptions of pain and distress from HT to the baby:

‘He felt cold...’, ‘It was very scary and upsetting to see him in the HT jacket and all wired up to machines at first, but we understood that this was to help him...’.

Five respondents (16.1%) expressed distress at the inability to hold the baby and provide skin to skin contact.

‘...we could only hold her fingers. But long term I don’t feel there's any difference - the antenatal classes up on so much about the skin-skin to contact + how important it is that this was another pressure added to us.’

Of the 30 respondents 41.9% perceived HT to be an uncomfortable experience for their babies.

‘ I was told her pain relief was upped as she was uncomfortable..... I have no experience of the cooling treatment. I would not know how to see if she was comfortable or not.’

‘...It did not look a comfortable process. But I understood that everything was being done to help him’

‘..... I did ask for him to be more sedated as he was severely swollen due to failing kidneys and his eyes couldn’t open, but he was clearly crying and in discomfort.’

Bonding

Twenty-six of 31 respondents (83.8%) commented that bonding with their baby was compromised by the inability to physically touch and hold the baby during HT. Four respondents (12.9%) commented that this was exacerbated by the inability to breast feed. Worries about impaired bonding were likely to be more affected if the baby was outborn ($p=0.04$, OR 9.6 (1.02-90.34), and if the parents did not have a good understanding of HT prior to start of treatment ($p=0.005$) OR 22.6 (1.17- 436.4) (Table 2). However, 24 of 26 (92.3%) respondents who had stated that they felt that bonding was affected also commented that this did not affect long term bonding with the baby. In the free text section, comments included:

‘As he was taken away from us at birth we missed out on initial bonding. This could not be helped due to the need of the professionals. After the warm up we are very much happy with our bonding’.

‘It delayed bonding because we could not hold her until the next day, but I do not think it changed things in the long term. But during much of her life time in her last hours and after her death we felt very bonded.’

Coping

Twelve of 31 respondents (38.7%) felt they coped reasonably well with the trauma and upheaval from the unexpected admission, with only one family reporting inability to cope with the situation. Free text comments included:

‘...was in the neonatal unit for just over 3 weeks. This was a devastating time for us as we never expected this and seeing our baby the way he was, was the hardest and most upsetting time that we have ever experienced.’

Four families reported that they had powerful inner sense and control which helped in their ability to cope.

‘I think we even more bond with...’ (baby’s name) ‘... with the treatment wrapping around hers we had "will power" on top for her to get through it. I am sure that she could sense that we were around.’

Support

The majority of the respondents (96.8%) felt well supported by medical and nursing teams, with most parents particularly acknowledging the support and help received from the latter. Parents were also supported by friends and family members and took solace in their spiritual/ religious beliefs in particular.

Free text comments included:

‘We praise God too...because he gave us a hope and a beautiful daughter’.

‘We were just so happy that it went ok for her. Praise God!’

Discussion

The key messages that emerged from the survey were the need for consistency in communication and regular updates of the baby’s wellbeing, particularly from the

medical staff. The parents' also indicated the wish to be actively involved in decision making and a need for strong support mechanisms.

The variable parental understanding of HT and about treatment outcomes may in part reflects the variability in the type and amount of information given to parents, for example when staff changes occurred. Although the survey fails to capture the reasons for individual variations in parental understanding, the findings reinforce the importance of consistency in communication, parental involvement in decision making and the need for strong support mechanisms during HT.

Newborns with HIE undergoing HT usually are born unexpectedly unwell often needing significant resuscitation and multi-organ involvement. Parents face an unexpected, rapidly changing scenario involving separation, anxiety and the need to have unexpected complex discussions about mortality and long term morbidity. In the UK, parents with preterm and other term babies with a preexisting condition, for example, such as congenital diaphragmatic hernia usually have opportunities for antenatal counselling and are likely to be better prepared than parents of babies with HIE. Preterm babies and term babies who are admitted unwell from any medical or surgical conditions needing neonatal intensive care are not cooled.

Despite the different set of challenges, many aspects that emerged in our study of perception of HT are consistent with parental perceptions of having a baby admitted in the NICU for other indications [2, 3, 6, 11, 14]. Heringhaus et al[10] and Nassef et al[11] identified "emotional landscapes", which included vulnerability, sadness, guilt, feeling that the treatment was not natural, hope, despair, powerlessness, and gratefulness. In both studies, anxieties about the results from the brain MRI and the uncertainties about long term outcomes following neonatal encephalopathy and HT treatment were highlighted as areas contributing to parental stress and anxieties.

Anxieties and uncertainties arising from poor understanding were brought to the fore in our study raising the crucial importance of parental understanding during discussions

before and while administering HT might be one of the stressful occasions on NICU where repeated communication whilst in the NICU and post- discharge is key, and frequent checking of parental understanding might be necessary.

It has been suggested in the literature that greater emphasis on continuity of communication might improve parents' ability to cope.[15, 16] Despite satisfaction with overall care, many parents were anxious and felt helpless and unable to protect their baby from pain, and this underlying perception about pain is consistent with other pain literature.[17, 18] All families who said they were able to cope attached great importance to a timely meeting with the clinical team at the start of treatment. It has been suggested that greater emphasis on continuity with communication might improve parents' ability to cope.[15, 16]

Breast feeding and skin to skin care are both perceived by parents as important to co-regulate with their infant and development of bonding.[19, 20]. The nature of HT treatment and the inability to breast feed as a consequence was perceived by parents as a barrier to successful bonding. Parents' reluctance to touch their baby due to the cooling jacket and monitoring equipment can negatively influence the parent-infant relationship[4, 21, 22] especially in the context of HT. Parents who expressed better understanding of HT experienced less anxiety about HT and less worries about impaired bonding. These findings open up possibilities for the attending clinician to focus on improving parental understanding to allay parental anxieties surrounding HT.

Interestingly, there was a significant difference in parental perceptions depending on whether delivery occurred in the treating hospital or whether the baby was transferred from a local hospital to the treating centre. This likely reflects the fact that the communication protocol and the quality of communication could differ between hospitals. However, it is reassuring that none of the parents felt HT had any long term

permanent effect on bonding, although there is evidence that short term early life disruption of bonding can have likely long term consequences.[23] We postulate that changes in management such as enteral feeding during HT[24] and greater skin to skin contact during HT such as holding the infant without removing the cooling jacket may have a potentially positive impact on the parent-baby relationship during and following HT. This could be explored in future studies.

Parents see HT as potentially causing pain and distress for their infants. During HT, many parents were worried, felt helpless and unable to protect their baby from pain. Parental concerns of infant pain on NICU independently contributes to parental stress.[18] Recognizing distressed parents during HT by the healthcare team is vital to organise support and achieve an optimum outcome. Our survey highlighted different preferences for support and individual coping strategies adopted by families including support from family, friends, neonatal staff and religious support. Several parents in our cohort have explored and expressed religious and spiritual sentiments in their replies. These could be related to natural tendency to reduce or avoid inner conflict.[25] Related sentiments (in form of ‘rebirth’ following rewarming with baby appearing more ‘life like’) have been described by Nassef[11] and religion and spirituality have been strongly associated with a host of positive outcomes, including enhanced quality of life.[25] These variabilities highlight the need to consider tailoring support services for each individual family requirements while maintaining quality communication and develop families understanding of HT.

This was a single centre study predominantly involving self-reported data of 31 families living in the South of England where the majority of the population are white, relatively well educated, affluent, and English literate. Some of the parents were interviewed upto 3 years after discharge of their baby from hospital. This might have affected some of the

captured responses since perception may have changed over time and/or may have been difficult to recall. The survey failed to capture responses from all except one of the bereaved families. Nevertheless, this exploratory study brings forward the crucial importance of communication, and also highlights some key issues that should be examined in more detail in larger, prospective studies.

Summary and Conclusions

There is a need for consistency in communication and regular updates of the baby's wellbeing, particularly from the medical staff. The parents' also indicated the wish to be actively involved in decision making and a need for strong support mechanisms. Regular multidisciplinary discussions with parents before, during and after HT is paramount. It is also important to ensure that families are involved promptly in discussion about potential long term outcomes, post-discharge planning and follow-up.

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Declaration of interests

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Abbreviations

HT Hypothermia treatment
HIE Hypoxic ischaemic encephalopathy
UK United Kingdom of Great Britain
EEG Electro encephalogram
NICU Neonatal intensive care unit

MRI Magnetic resonance imaging
PAH Princess Anne Hospital, Southampton
OR Odds ratio

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Table 1: Characteristics of babies admitted for hypothermia treatment

	Respondents n=31	Non respondents n=20	P value
Male sex	14 (45.2%)	9 (45%)	1.00*
Baby died	1 (3.2%)	6 (30%)	0.01^
Outborn	12 (38.7%)	12 (60%)	0.16*
Normal vaginal delivery	12 (38.7%)	8 (40%)	1.00*
Instrumental delivery	3 (9.7%)	2 (10%)	1.00^
Caesarean section	10 (32.2%)	9 (45%)	0.38*
Birth weight in grams, mean (SD)	3203.4 (546.2)	3499.8 (352.7)	0.11*
Gestation in weeks, mean (SD)	39.79 (1.47)	39.54 (1.47)	0.57*
Age in days at recruitment, median (range)	266 (6-919)	323 (6-982)	0.31 [‡]

SD = Standard Deviation * Student's t-test ^ Fisher's Exact test [‡] Mann-Whitney U test

Table 2: Factors affecting worries about impaired bonding during hypothermia treatment

	Bonding affected		Odds ratio* (95% Confidence interval)	P value^
	Yes n (%)	No n (%)		

Transferred from another hospital	Yes	12 (92.3%)	1 (7.7%)	9.6 (1.02-90.34)	0.04 [^]
	No	10 (55.5%)	8 (44.5%)		
Not have good understanding of HT prior to start of treatment	Yes	12 (100%)	0	22.6 (1.17- 436.4)	0.005 [^]
	No	10 (52.6%)	9 (47.4%)		
Chance to speak to staff prior to start of HT	Yes	9 (56.2%)	7 (43.8%)	0.21 (0.04-1.29)	0.12 [^]
	No	12 (85.7%)	2 (14.3%)		
Worried about HT	Yes	10 (77%)	3 (23%)	1.66 (0.33-8.4)	0.69 [^]
	No	12 (66.7%)	6 (33.3%)		
Knowledge of side effects of HT	Yes	10 (66.6%)	5 (33.33%)	0.54 (0.1-2.9)	0.68 [^]
	No	11 (78.5%)	3 (21.5%)		

*Odds ratio and 95% confidence interval calculated as per Altman, 1991. [^] Fisher Exact test.