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Parental participation during therapeutic hypothermia for neonatal hypoxic-ischemic encephalopathy

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ABSTRACT

Objectives: To examine parental participation in the care of newborn infants receiving therapeutic hypothermia, and to explore the possible impact of in-born vs out-born status, and location of hospital accommodation.
Study design: Retrospective, quantitative and descriptive design.
Main outcome measures: Infants medical charts were reviewed for defined aspects of parental participation (infant holding, tube feeding, and diaper change), and related to their in-born vs out-born status, and whether the parents were accommodated in the NICU or elsewhere. All infants have been cared for at the University Hospital Neonatal Intensive Care Unit, serving as a regional referral center for hypothermia treatment. This study is a part of a population-based regional cohort of asphyxiated newborn infants (n = 112) that received therapeutic hypothermia in 2007–2015.
Results: Parents engaged in holding (60/112, 54%) or tube feeding (59/112, 53%) their infant. Parents of in-born infants (24/112, 21%) were more likely to check the placement of the feeding tube (11/24, 46% vs 15/88, 17%; $p < 0.01$) and change diapers (9/24, 38% vs 14/88, 16%; $p < 0.05$) than parents of out-born infants (88/112, 79%). A similar pattern of more extensive involvement was observed for both mothers and fathers who stayed at the neonatal intensive care compared to those accommodated elsewhere ($p < 0.05$).
Conclusions: Active parental participation is feasible at the NICU even during therapeutic hypothermia. Timely postnatal transfer of parents of out-born/transported infants, and the provision of on-site accommodation may influence the quality of parental involvement.

Introduction

Several randomized trials have demonstrated that therapeutic hypothermia (TH) can reduce mortality and the risk of later neurological disability in infants suffering from moderate to severe hypoxic-ischemic encephalopathy (HIE) after asphyxia [1–4]. In Sweden, the incidence of moderate to severe HIE is approximately 0.8/1000 live-born infants [5] and TH for neonatal HIE was introduced in 2007 [6].

The sequence of events leading up to TH often represent a pathway of acute life-threatening medical complications and actions, which have significant emotional impact on the parents. Many report feelings of helplessness [7], distress [8] and separation [9], particularly when mother and infant cannot be cared for together [7]. Witnessing the infant's discomfort during TH and being unable to hold the infant skin-to-skin is stressful to both parents and staffcc [8,10]. Parents describe the neonatal intensive care unit (NICU) environment as unnatural, scary and unfriendly [9], and to constitute an obstacle to infant attachment [7,9]. In mothers, being unable to take care of the infant and protect it from pain and distress, invokes feelings of inadequacy that also persist after discharge [7,11].

During the NICU stay, parents to an infant with HT make use of several coping strategies. Important ways to gain control include attaining a basic understanding of the medical care given, such as monitoring of vital signs and/or indications for drugs that are being administered [9]. Support from family, friends and NICU staff is important, and to be able to engage in care procedures such as feeding and changing diapers are strengthening [7,9,12].

Being part of the infant's care builds the relationship between parents and their infant [13], increases parental self-esteem, reduces anxiety and strengthens their parenting role [13–16]. Presence and participation are inter-related and positively feedbacks one another [14]. The staff plays an important role in promoting a welcoming

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Table 1
Descriptive statistics of the included hypothermia-treated infants (n = 112).

Characteristic	Median (range) or n (%)
Gestational age, wks	40.4 (36–42.6)
Birth weight, g	3782 (1801–5220)
Caesarean section, n (%)	53 (47)
Inborn, n (%)	24 (21)
Female, n (%)	54 (48)
Days at the referral NICU	4 (1–56)
Ventilator therapy, n (%)	75 (67)
Discharged home, n (%)	14 (13)
Discharged to other hospital, n (%)	72 (64)
Mortality, n (%)	26 (23)

Values are given as medians (ranges) or n (%). NICU = neonatal intensive care unit.

environment and atmosphere, and inviting parents to participate in their infant's care [15,17,18], while lack of routines and high staff work-load may be barriers [14].

In view of the positive effects of parental presence and participation in the NICU, it is obvious that parent-infant separation should be minimized but to our knowledge no such data has been presented in infants receiving TH. The aim of the present study was to evaluate aspects of parental participation during TH by retrieving data that could serve as a marker for parental involvement, in relation to factors (in-born and out-born status, and the location of parent's accommodation) assumed to influence the separation between the infant and its parents.

Methods

Subjects

The cohort consists of all infants (n = 121) admitted to the NICU of Uppsala University Children's Hospital for TH during the period 2007–2015. Nine infants were excluded because of non-initiation or early (< 12 h) withdrawal of treatment. In the remaining (n = 112; Table 1) a detailed chart review and data analysis were performed. Treatment decision was based on the Swedish Neonatal Society guidelines on TH [6], defining criteria for patient selection regarding both the hypoxic event (severe birth acidosis, low Apgar score, and need for resuscitation) and the presence of subsequent encephalopathy (altered wakefulness, tone and reflexes, or seizures). The guidelines specify the target start time (prior to 6 h of age), temperature (core body temperature 33–34 °C) and duration (72 h) of TH. In addition, the recommendations clearly state that TH should only be provided at centers with 24-hour access to full neonatal intensive care resources including cerebral monitoring (amplitude integrated electroencephalography/electroencephalography (aEEG/EEG)) and diagnostics (ultrasonography/magnetic resonance imaging (US/MRI)). Most infants included were out-born (n = 88) and transported for TH.

Setting

Uppsala University Children's Hospital is a regional referral NICU (level IIIB) serving a population of approximately 23,000 births/year from seven county hospitals at distances ranging from 70 to 300 km. To ensure adherence to the < 6-hour mandatory treatment start, infants referred for HT are most often retrieved by a dedicated neonatal helicopter transport team based at the referral center. While in-born infants most often are accompanied by a parent or relative at admission it may take hours to days before transport of "out-born parents", particularly the mother, can be arranged. The NICU has mid-sized open-bay intensive care rooms with four care spaces, each with an adult bed and privacy screens to promote the parents' presence with their infant 24 h/day. The NICU has long experience of family centered care [19] by promoting parental presence [14,20] and participation in the infant's care [17,18]. At least one parent can always stay in the NICU at the infant's bedside. Nevertheless, many parents choose not to stay cot-side around the clock. A limited number of family rooms are available but otherwise parental accommodation is offered in a nearby (5-min walk) facility. Visits from siblings and relatives are unrestricted. Out-born patients/families are transported back after the completion of TH and re-warming.

Data collection

This retrospective, descriptive medical chart review was conducted during 2017 by the first two authors (EM; TP), 39 (35%) of the medical carts were also reviewed by the last author (YTB) to ensure data quality. The (all-electronic) patient data management system was reviewed for the duration of TH and rewarming (96 h), using a specifically designed standardized manual. The infant's charts hold no information on parental presence *per se* and thus the authors identified pre-defined indicators of parental presence and participation that was: (1) uniformly reported and thus reliably identified, and (2) could serve as a proxy for parental involvement. These indicators were defined based on the authors' clinical experience and review of the literature. The data collected included whether (but not the extent of) the parents had been involved in: Holding their infant; tube feeding; checking the placement of the feeding tube; diaper change, and "other actions" (defined as any of the following: upper airway suctioning, weighing/measuring, cleaning the infant, checking body temperature, and bottle/cup feeding). At the time of the study; to weigh an infant with HT; two individuals (two nurses, one nurse and one parent, or both parents) helped each other. The infant is routinely weighed in the radiant warmer bed using its integrated scale.

Detailed information on the extent and timing of parental participation was extracted from two sources where this information is routinely recorded: the "parental participation guide" that is kept bedside with each infant, or in the infant's medical chart.

Data about in-born/out-born status and where the parents stayed during night time (in the NICU or outside) were also collected. Data on the time point when information was given about infant holding, expression of breast milk, as well as when the first consultation with the attending neonatologist and the social worker took place.

Ethical considerations

The study was approved by the Regional Ethical Review Board (File No: 2015/511) and by the Medical director.

Statistical analysis

The data were analyzed using the Statistical Package for Social Sciences version 23 (IBM SPSS, Inc., Chicago, IL, USA). Descriptive analysis of all variables involved the calculation of medians, ranges and/or percentages. Comparisons were performed using the chi-square test and a p of less than 0.05 was considered statistically significant.

Results

Among the markers of participation studied, holding and tube feeding were most commonly observed (Table 2). These aspects of participation were not significantly different in in-born vs out-born status nor were they impacted by the location of NICU accommodation. More advanced involvement in the infants care such as checking the placement of the feeding tube or changing diapers were more commonly observed in parents to in-born infants (11/24, 46% vs 15/88, 17%, and 9/24, 38% vs 14/88, 16%, respectively; Table 3). Parental participation was independent of mode of delivery.

Most infant's charts contained information about where the mothers (105/112, 94%) and fathers (103/112, 92%) were accommodated

Table 2
Documented parental participation in the infants' care (n = 112).

	n (%)
Holding the infant	60 (54)
Tube feeding	59 (53)
Checking the placement of the tube	26 (23)
Changing diapers	23 (20)
Other[a]	17 (15)

[a] Defined as upper airway suctioning, weighing/measuring, cleaning the infant, checking body temperature, and bottle/cup feeding.

Table 3
Documented parental participation in infant care in relation to whether the infant was in-born or out-born (n = 112).

	In-born (n = 24)	Out-born (n = 88)	p-value
Holding the infant, n (%)	16 (67)	44 (50)	0.111
Tube feeding, n (%)	15 (63)	44 (50)	0.196
Checking the placement of the tube, n (%)	11 (46)	15 (17)	0.005
Changing diapers, n (%)	9 (38)	14 (16)	0.025
Other[a], n (%)	4 (17)	13 (15)	0.519

[a] Defined as upper airway suctioning, weighing/measuring, cleaning the infant, checking body temperature, and bottle/cup feeding. NS = non-significant.

during their infants' NICU stay (Table 4). In parallel with the findings above, infant holding and tube feeding did not differ significantly in relation to NICU accommodation. However, parents who stayed in the NICU around the clock were more actively involved in checking the placement of the feeding tube and changing diapers as compared to those accommodated outside the hospital (All $p < 0.05$; Table 4).

In 32/112 (29%) infant's charts, it was documented that parents had received information about expression of breast milk, and this occurred at a mean postnatal age of 1.2 days. In 86/112 (77%) of the parent couples, it was documented that they met with a social worker, and in 100/112 (88%) with a physician, at a mean postnatal age of 2.1 and 0.7 days, respectively. The provision of parent information and support not differ significantly in relation to in/out-born status or the where the parents stayed.

Discussion

The present study demonstrates that it is feasible to involve parents in several aspects of care also in critically ill infants during TH for neonatal HIE. Further, our data show that whereas participation in some aspects of care (holding and feeding) were equally common in in-born and out-born infants, taking part in more advanced care procedures such as the checking of feeding tube placement were more frequently observed in in-born infants. In parallel, parents accommodated in the NICU were more commonly observed to participate in such procedures than those who stayed outside the hospital. These findings indicate that early parental presence and the time spent interacting with the infant (and staff) promotes active involvement.

It is known that practical arrangements are essential to enable parents to be present and participate in their infant's care. A recent investigation found that NICUs who offered parents to stay with their infant overnight demonstrated more parent-infant closeness [21]. Indeed our findings are in accordance with previous studies in preterm infants showing that routines supporting early parent-infant interaction [18], as well as spending more time in the NICU [22], both promotes parental participation.

Noteworthy, almost half of all parents did not hold their infant during HT, clearly an area for improvement. Being unable to hold the infant skin-to-skin during HT has been shown to be stressful [10], and although skin-to-skin contact has to be limited due to thermoregulatory constraints, infant holding is indeed feasible [23]. Adequate staff training, and written guidelines could be ways to further promote this aspect of parent-infant interaction.

We found that parents of in-born infants and those accommodated in the NICU participated to a greater extent than those to out-born infants and those who stayed outside the hospital. The reasons for this can only be speculated upon. It is conceivable that parents of out-born infants are further away from home and their social network who would otherwise have provided both practical and emotional support. In addition, with few exceptions' parents of out-born infants arrived later to the referral center. A recently published study found that parents to out-born infants were more concerned about how the HT would affect the bonding to their infant than parents to in-born infants [8]. In this respect parents to out-born infants, seems to be particularly vulnerable to the initial separation from their infant and/or family support, and it is reasonable to argue that they should be given priority to in-NICU accommodation.

Since active participation offers a sense of control, helps parents cope, strengthens their motivation to spend time with their infant [14], and enables the formation of a strong bond [15] it would seem reasonable to involve parents in their infant's care as much and as soon as possible. Each family should be carefully guided to gradually taking increasing part in their infant's care [17,18]. Given the potential positive impact of family centered care [17,24], the advancement and routine implementation of this practice also in such a critical and stressful condition as HIE could be expected to benefit the wellbeing of both parents and infants.

In our study, only a limited proportion of mothers received information about expression of breast milk, and at a mean age of 1.2 days. Since mothers often have insufficient knowledge about how to initiate and maintain breast milk production when they cannot breastfeed [25], these results clearly identify this as an area for improvement.

Full and timely disclosure of all relevant medical information to parents [13], and provision of social/financial support [14] has been

Table 4
Documented parental participation in infant care during hypothermia-treatment in relation to where the parents were accommodated during their infants' neonatal intensive care unit (NICU) stay.

	Mothers (n = 105[a])			Fathers (n = 103[a])		
	In NICU (n = 44)	Outside NICU (n = 61)	p-value	In NICU (n = 46)	Outside NICU (n = 57)	p-value
Holding the infant, n (%)	25 (57)	30 (49)	0.283	25 (54)	29 (51)	0.440
Tube feeding, n (%)	27 (61)	28 (46)	0.086	28 (61)	26 (46)	0.089
Checking tube placement, n (%)	16 (36)	10 (16)	0.018	16 (35)	10 (18)	0.038
Changing diapers, n (%)	14 (32)	7 (12)	0.010	14 (30)	7 (12)	0.021
Other[b], n (%)	11 (25)	5 (8)	0.019	11 (24)	5 (9)	0.033

[a] Where the mothers and fathers were accommodated during their infants' NICU stay was only recorded in 94% and 92%, respectively, of cases.
[b] Defined as upper airway suctioning, weighing/measuring, cleaning the infant, checking body temperature, and bottle/cup feeding. NS = non-significant.

demonstrated to reduce parental distress and impact on the parents' willingness to spend time in the NICU. In the present investigation a documented consultation with a neonatologist (either at the infants' bed-side or a booked sit-down talk) and a social worker was found in most charts and took place at a mean age of 16 h and 2 days, respectively. Assuming that parents were also provided additional bedside information, this seems reasonably timely.

Limitations

The study's limitations are mainly linked to its retrospective nature and the review of the documentation performed in the infant's medical chart that to a variable extent limits data completeness and accuracy. Accordingly, the data does not provide a complete delineation of parental participation. Nevertheless, the chosen markers of parental involvement were all reported in a high proportion of the study population and reflect common care procedures that parents engage in. While the population base and single center approach could be expected to yield more uniform documentation and data collection [26], it might also limit the generalizability of the findings. On the other hand, the clinical features and management of neonatal HIE/TH is well standardized [27]. Thus, we believe that our conclusions can be applied to other critically ill infants and their families in the NICU.

Further prospective research should preferably look beyond crude measures of participation and analyze also longitudinal information on parent wellbeing.

To conclude, active parental participation is feasible during therapeutic hypothermia for neonatal HIE. Timely postnatal transfer of parents of out-born/transported infants, and the provision of on-site accommodation may influence the quality of parental involvement.

Authors 'contributions

All authors responsible to the study design. EB, TP and YTB performed the medical chart review and made the initial data analysis and the first drafting of the manuscript. All authors made critical revisions to the paper. All authors have given a final approval of the version submitted.

Ethical approval

The study was approved by the Regional Ethical Review Board at Uppsala University, Uppsala, Sweden (File No: 2015/511).

Declarations of interest

None.

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References

[1] Gluckman PD, Wyatt JS, Azzopardi D, Ballard R, Edwards AD, Ferriero DM, et al. Selective head cooling with mild systemic hypothermia after neonatal encephalopathy: multicentre randomised trial. Lancet 2005;365(9460):663–70.
[2] Shankaran S, Laptook AR, Ehrenkranz RA, Tyson JE, McDonald SA, Donovan EF, et al. Whole-body hypothermia for neonates with hypoxic-ischemic encephalopathy. N Engl J Med 2005;353(15):1574–84.
[3] Shankaran S, Pappas A, McDonald SA, Vohr BR, Hintz SR, Yolton K, et al. Childhood outcomes after hypothermia for neonatal encephalopathy. N Engl J Med 2012;366(22):2085–92.
[4] Azzopardi D, Strohm B, Marlow N, Brocklehurst P, Deierl A, Eddama O, et al. Effects of hypothermia for perinatal asphyxia on childhood outcomes. N Engl J Med 2014;371(2):140–9.
[5] Swedish Neonatal Quality Register; SNQ. Annual Report 2016. available at http://wwwmedscinetcom/pnq/Uploads/Årsrapport%20SNQ%202016_2pdf.
[6] Swedish Paediatric Society; the Neonatology section. Recommendations for hypothermia treatment of newborn infants with birth asphyxia aviable at http://neobarnlakarforeningense/wp-content/uploads/sites/14/2014/03/hypotermi_20xxpdf.
[7] Heringhaus A, Blom MD, Wigert H. Becoming a parent to a child with birth asphyxia-From a traumatic delivery to living with the experience at home. Int J Qual Stud Health Well-being. 2013;8:1–13.
[8] Thyagarajan B, Baral V, Gunda R, Hart D, Leppard L, Vollmer B. Parental perceptions of hypothermia treatment for neonatal hypoxic-ischaemic encephalopathy. J Matern Fetal Neonatal Med 2018;31(19):2527–33.
[9] Nassef SK, Blennow M, Jirwe M. Experiences of parents whose newborns undergo hypothermia treatment following perinatal asphyxia. J Obstet Gynecol Neonatal Nurs 2013;42(1):38–47.
[10] Craig A, James C, Bainter J, Lucas FL, Evans S, Glazer J. Survey of neonatal intensive care unit nurse attitudes toward therapeutic hypothermia treatment. Adv Neonatal Care 2017;17(2):123–30.
[11] Sikorova L, Kucova J. The needs of mothers to newborns hospitalised in intensive care units. Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub 2012;156(4):330–6.
[12] Lemmon ME, Donohue PK, Parkinson C, Northington FJ, Boss RD. Communication challenges in neonatal encephalopathy. Pediatrics 2016;138:3.
[13] Wigert H, Dellenmark Blom M, Bry K. Parents' experiences of communication with neonatal intensive-care unit staff: an interview study. BMC Pediatr 2014;14:304.
[14] Heinemann AB, Hellstrom-Westas L, Hedberg Nyqvist K. Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room. Acta Paediatr 2013;102(7):695–702.
[15] Smith VC, Steelfisher GK, Salhi C, Shen LY. Coping with the neonatal intensive care unit experience: parents' strategies and views of staff support. J Perinat Neonatal Nurs 2012;26(4):343–52.
[16] Wigert H, Johansson R, Berg M, Hellstrom AL. Mothers' experiences of having their newborn child in a neonatal intensive care unit. Scand J Caring Sci 2006;20(1):35–41.
[17] Nyqvist KH, Engvall G. Parents as their infant's primary caregivers in a neonatal intensive care unit. J Pediatr Nurs 2009;24(2):153–63.
[18] Baylis R, Ewald U, Gradin M, Hedberg Nyqvist K, Rubertsson C, Thernstrom Blomqvist Y. First-time events between parents and preterm infants are affected by the designs and routines of neonatal intensive care units. Acta Paediatr 2014;103(10):1045–52.
[19] Griffin T. Family-centered care in the NICU. J Perinat Neonatal Nurs 2006;20(1):98–102.
[20] Blomqvist YT, Nyqvist KH. Swedish mothers' experience of continuous Kangaroo Mother Care. J Clin Nurs 2011;20(9–10):1472–80.
[21] Raiskila S, Axelin A, Toome L, Caballero S, Tandberg BS, Montirosso R, et al. Parents' presence and parent-infant closeness in 11 neonatal intensive care units in six European countries vary between and within the countries. Acta Paediatr 2017;106(6):878–88.
[22] Wigert H, Berg M, Hellstrom AL. Parental presence when their child is in neonatal intensive care. Scand J Caring Sci 2010;24(1):139–46.
[23] Craig A, Deerwester K, Fox L, Jacobs J, Evans S. Maternal holding during therapeutic hypothermia for infants with neonatal encephalopathy is feasible. Acta Paediatr 2019.
[24] Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. Semin Perinatol. 2011;35(1):20–8.
[25] Lucas R, Paquette R, Briere CE, McGrath JG. Furthering our understanding of the needs of mothers who are pumping breast milk for infants in the NICU: an integrative review. Adv Neonatal Care 2014;14(4):241–52.
[26] Vassar M, Holzmann M. The retrospective chart review: important methodological considerations. J Educ Eval Health Prof 2013;10:12.
[27] Wigert H, Hellstrom AL, Berg M. Conditions for parents' participation in the care of their child in neonatal intensive care – a field study. BMC Pediatr 2008;8:3.