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Parent experience of HIE and hypothermia: A call for trauma informed care

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BACKGROUND

- Therapeutic hypothermia (TH) is the standard of care treatment for infants with hypoxic ischemic encephalopathy (HIE).
- Parent trauma during HIE treatment can be related to separation from the infant, inability to hold or touch their infant, omission of complete medical information, not being able to play the role of the parent, or lack of emotional support.
- Few studies have examined how communication and parent involvement in the Neonatal Intensive Care Unit (NICU) can either repair or exacerbate the parents' trauma experience.

OBJECTIVE

To assess parents' experience of communication with the medical team and involvement with their infant during HIE treatment.

METHODS

A 29-question anonymous survey was posted on a parent support website (<https://www.hopeforhie.org>) and sent to members via e-mail.

Responses from open-ended questions were analyzed using thematic analysis, in which themes were identified inductively from the text.

RESULTS

Responses to Survey Questions	n=165
Parent role: Mother	158 (96%)
Year of child's birth (n=164)	
<=2010	17 (10%)
2011-2015	34 (21%)
2016 to present	113 (69%)
Race/Ethnicity	
White or Caucasian	141 (85%)
Treated with hypothermia (n=164)	108 (66%)
MRI brain done in NICU (n=164)	157 (96%)
Brain injury on MRI (n=157)	123 (78%)
Death from HIE	16 (10%)
Dissatisfied or neutral regarding the quality of <u>communication</u> in the NICU	79 (48%)
Satisfied/greatly satisfied with the quality of <u>parental involvement</u> in the NICU	127 (77%)



Infant being held while undergoing TH for HIE

THEMATIC ANALYSIS RESULTS

Six themes identified:

1. **Setting for communication**
 - Parents preferred in person, face to face communication
 - Desired updates by phone when in person communication not possible
2. **Content and clarity of language**
 - Parents valued having the name of the medical diagnosis, but explained in layman's terms
 - Valued verbal and written communication
3. **Immediate and longitudinal emotional support**
 - Parents wanted providers to show empathy
 - Peer support
4. **Time**
 - Parents valued amount of time spent with providers
 - Wanted to know timing logistics (schedule for rounds, care times, etc.)
5. **Valuing the parent role**
 - Parents strongly desired being involved in cares (diaper changes, baths, temperature checks)
 - Communication with medical team necessary for parents to feel informed and make decisions
6. **Physical presence and touch**
 - Parents valued time spent physically near infant, having alone time with infant, spending night in same room and holding when able



QUOTES

Theme 2: Language

"I never learned the term HIE until my son was 9 weeks old and I got his discharge papers. (He was discharged at 12 days old) so I spent a lot of time not knowing what exactly to search for to understand and learn more about what had happened to him."

Theme 4: Time

"Knowing what time ward rounds was going to be" would have been helpful; "sometimes I waited half the day especially at weekends, missing meals, etc in order to try to be present for rounds"

Theme 5: Valuing the parent role

"I was kind of ignored by doctors when they were on their rounds, it was a teaching hospital and I feel like they should have been showing the new ones [trainee physicians] that communication with the family is important."

"My biggest complaint is that our son was transferred to a hospital with a NICU, but I was recovering in the hospital he was delivered in. Nobody explained to me the risks we were facing and if I had known, I would have been with him as much as possible, not sitting in a hospital bed. As it was, he died before I was discharged, and I never got to have those moments of parenting with him, which to this day 8.5 years later still breaks my heart."

STUDY THEMES RELATE TO TIC PRINCIPLES

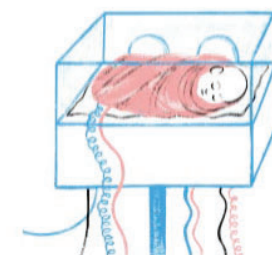
Safety: physical presence; emotional support; in person, private communication; recognition of parent role

Trustworthiness and transparency: honest, clear language

Peer support: emotional support

Collaboration and mutuality: shared decision making; parents are part of care team

Empowerment, voice and choice: valuing the parent role; physical presence (this fostered parents' ability to be involved in decision making); emotional support



Top image from The New Yorker; bottom image from NotMyKid



TRAUMA INFORMED CARE (TIC)



SIX KEY PRINCIPLES OF A TRAUMA-INFORMED APPROACH

1. Safety
2. Trustworthiness and Transparency
3. Peer Support
4. Collaboration and Mutuality
5. Empowerment, Voice and Choice
6. Cultural, Historical, and Gender Issues

SAMHSA's
Concept of Trauma
and Guidance for a
Trauma-Informed Approach

Prepared by
SAMHSA's Trauma and Justice Strategic Initiative
July 2014

CONCLUSIONS

- The themes identified relate to the six principles of Trauma Informed Care (TIC).
- Understanding and implementing TIC principles may allow the medical team to collaborate more effectively with families in the care of infants with HIE.
- Goal is to lessen instead of exacerbate the negative effects of trauma.

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