

Introduction

- Neonates with moderate to severe encephalopathy qualify for therapeutic hypothermia (TH) treatment for a presumed diagnosis of hypoxic ischemic encephalopathy (HIE).
- The treatment is done over three days to protect the brain from further injury. Typically, this is a very stressful time for parents and one of the biggest sources of hope during this time is the potential for neurorehabilitation.
- Currently, there is no standard of care or curriculum for the involvement of neonatal therapists during or immediately after therapeutic hypothermia treatment.
- The parental preference on when and how to introduce neonatal therapies has not been evaluated.

Methods

- The aim of this anonymous descriptive survey study was to determine current practices and parental attitudes of the role of neonatal therapies during and after TH.
- Occupational therapists (OT), physical therapists (PT) and speech and language pathologists (ST) employed at neonatal intensive care units (NICU) in the United States were invited to participate. Recruitment was done via email list serve and social media platforms of the Neonatal Association of Neonatal Therapists (NANT).
- Parents of children, who were 6 months to 24 months at the time of the survey with a history of HIE treated with hypothermia, were also surveyed. Parents were recruited via social media for parent support group Hope for HIE.
- Descriptive statistics (counts and proportions) were calculated for all survey responses.

Results

- A total of 68 parents accessed the survey. Of these, 63 respondents indicated that they had received therapy during the NICU stay. 79% reported they would have wanted more time with therapists. 89% reported NICU assisted with establishing outpatient therapies.
- A total of 115 neonatal therapists accessed the survey. STs was 37.5%, PT 29.5% and OT 33% of respondents. Certified neonatal therapists were 50.9% and had varied years of experience. The majority worked exclusively in NICU (52.6%). Only 7% worked in Neuro NICU designated unit.

Results

Caregiver Responses to key survey items regarding practices and parental attitudes of the role of neonatal therapies during therapeutic hypothermia for HIE

Survey Questions	N (%)
When in the process of cooling did therapy start?	
While baby was cooled	4 (6.8)
While baby was rewarmed	14 (23.7)
After baby had brain picture (MRI)	41 (69.5)
How many days was baby in the NICU?	
3 to 7 days	2 (3.2)
7 to 14 days	9 (14.3)
More than 14 days	52 (82.5)
Did therapist(s) attend meeting to discuss the case?	
No	48 (76.2)
Yes	15 (23.8)
Did therapist discuss MRI and used for therapy plan?	
Yes	9 (14.3)
No	46 (73.0)
Not sure	8 (12.7)

Therapist responses to key survey items on the role of neonatal therapies during therapeutic hypothermia for HIE.

How are the orders in the NICU received for HIE?	
Automatic orders on admission for 100%	75 (66.4)
Selective/problem-based orders	19 (16.8)
Sporadic orders, not a consistent pattern	10 (8.8)
Neonatologist-specific ordering process	9 (8.0)
Does neonatal therapy attend HIE rounds?	
Yes, always	29 (26.1)
Yes, sometimes	38 (34.2)
No, never	44 (39.6)
Does your institution have a therapy protocol for HIE?	
Yes	27 (23.7)
No	76 (66.7)
Standardized neonatal therapy protocol measures used	
None	89 (77.4)
Other/combination	26 (22.6)
Do you feel educational materials for parents could help?	
Yes	107 (93.0)
No	2 (1.7)
Unsure	6 (5.2)
What materials may be most helpful for teaching?	
Written only	8 (7.4)
Videos only	1 (0.9)
Written and videos	99 (91.7%)



Baby during TH.

Do you feel like therapists had time to educate?	
No	31 (49.2)
Yes	32 (50.8)
Did your therapist share materials?	
Yes- shared written materials	28 (44.4)
Yes- shared written materials AND videos	3 (4.8)
No- did not share	32 (50.8)
What kind of material would be the most useful?	
Written only	10 (32.3)
Written AND videos	21 (67.7)
Do you feel like your therapy team understood the details of your baby's case?	
Yes	30 (47.6)
No	16 (25.4)
Not sure	17 (27.0)

Do you start therapy during the cooling process?	
Yes- as soon as the cooling has started	15 (13.4)
Yes- on day 2 of the cooling process	1 (0.9)
Sometimes during the cooling process	30 (26.8)
Never during the cooling process	66 (58.9)
Do you start therapy during the rewarming?	
Yes, always	17 (15.5)
Yes, sometimes	34 (30.9)
Never during rewarming	59 (53.6)
Is there a wait before you can work with infant?	
Yes, 24 hours after rewarming	40 (37.4)
Yes, 48 hours after rewarming	4 (3.7)
Yes, 72 hours after rewarming	5 (4.7)
Other	58 (54.2)
When do you interact with parents/ caregivers?	
During therapeutic hypothermia	41 (37.6)
During the rewarming process	4 (3.7)
Immediately after the rewarming process	38 (34.9)
A few days after the rewarming process	26 (23.9)
Do you automatically complete swallow study?	
Sometimes	34 (30.6)
Rarely	24 (21.6)
Never	38 (34.2)
Other	15 (13.5)
Do you feel like MRI information helps plan?	
Yes	70 (62.5)
No	34 (30.4)
Unsure	8 (7.1)
Do you attend meeting to discuss MRI results?	
Yes	17 (15.0)
No	67 (59.3)
Sometimes	29 (25.7)

Describe experience with I therapists while in the NICU?	
Very dissatisfied	1 (1.6)
Dissatisfied	15 (23.8)
Not sure	18 (28.6)
Satisfied	21 (33.3)
Very Satisfied	8 (12.7)
Looking back, ideal time to have the first meeting with therapy team?	
While baby was cooled	23 (38.3)
While baby was rewarmed	15 (25.0)
After baby had brain picture (MRI)	22 (36.7)
Compared to the NICU therapists, outpatient therapists:	
Knew less about HIE	24 (38.7)
Knew about the same about HIE	19 (30.6)
Knew more about HIE	17 (27.4)
Did not know anything about HIE	2 (3.2)

Satisfied with frequency of therapy involvement?	
Very dissatisfied	3 (2.6)
Dissatisfied	25 (21.7)
Unsure	13 (11.3)
Satisfied	51 (44.3)
Very satisfied	23 (20.0)
Are you satisfied with utilization of therapy?	
Very dissatisfied	3 (2.6)
Dissatisfied	27 (23.5)
Unsure	11 (9.6)
Satisfied	48 (41.7)
Very satisfied	26 (22.6)
Are you satisfied with physician collaboration?	
Very dissatisfied	3 (2.6)
Dissatisfied	31 (27.0)
Unsure	19 (16.5)
Satisfied	49 (42.6)
Very satisfied	13 (11.3)
Do you feel standardized guide could help ordering?	
Yes	85 (73.9)
No	11 (9.6)
Unsure	14 (12.2)
Other	5 (4.3)
Do you feel a standardized guide could help with therapy practices?	
Yes	96 (84.2)
No	5 (4.4)
Unsure	12 (10.5)
Other	1 (0.9)



Same baby receiving outpatient therapies.

Discussion

- The purpose of this two-prong survey was to explore the current practices of care and involvement of neonatal therapists during or immediately after therapeutic hypothermia treatment, as well as synthesize parental preference on when and how to introduce neonatal therapy during TH.
- Neonatal therapy survey revealed variability in practice on when therapies are initiated and no clear standardized protocol. This includes timing of first assessment of the neonate and introduction of therapy services to parents and/or caregivers, outcome measures used and swallow studies.
- Most of the therapists report finding information from MRI results valuable to design a therapy plan, yet they do not consistently attend rounds with the team or attend meeting to discuss MRI results with family. Further collaboration within treatment team is an area of improvement of care.
- Neonatal therapists strongly concluded that national guidelines regarding neonatal therapy for HIE would help with physician ordering practice, delivery of effective therapies and parent/caregiver education. Written and video materials were felt to be the most helpful.
- Parents reported wanting more time with neonatal therapists and they would have preferred to meet during cooling and rewarming most often as opposed to after MRI completion. Parents coincided also expressed interest in educational materials in written and video format. Standardized materials of written and video format could be used during a first session and in subsequent encounters with therapies. These materials could also help during the gap time when patients are able to start outpatient therapies. Parents and/or caregivers endorsed that it took more than a month to start outpatient therapy services.

Conclusion

National guidelines, neonatal therapy education on HIE patterns of injury on MRI for therapy plan design, multi-disciplinary team collaboration as well as earlier parental education with a standardized curriculum are identified areas of improvement in care for infants with HIE undergoing therapeutic hypothermia in the NICU.

References

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