BACKGROUND

- Despite the improvement in outcomes of high risk neonates born preterm or with serious medical or surgical conditions, parents of neonatal intensive care unit (NICU) graduates experience high levels of stress and anxiety.
- Stress often comes from facing tremendous challenges during transition from the highly structured environment of the NICU to home.
- Our outpatient primary care clinic and the complex care program employ parents of children with special healthcare needs (CSCN) as Parent Navigators to assist families navigating the healthcare system.
- These services have not previously been made available in the NICU but may prove to be a valuable resource to address the stress experienced by NICU families around transition home.

OBJECTIVE

To describe the unique needs of NICU families transitioning home to inform the development of a post discharge peer to peer Parent Navigation intervention.

METHODS

- Semi-structured focus groups and interviews
- Participants:
  - Parents of infants who had a NICU stay (3 focus groups, 2 interviews, n=18)
  - Current Parent Navigators (1 focus group, n=3)
  - NICU nursing staff (1 focus group, 1 interview, n=9)
  - NICU social workers and case managers (1 focus group, n=10)
  - Attending NICU physicians (1 focus group, n=6)
  - Community pediatricians (1 focus group, n=2)
- Interviews and focus groups were audiotaped and transcribed.
- Qualitative analysis was done in aggregate by the study team.
- Themes were identified to inform the Parent Navigator intervention.

RESULTS

The findings were organized around four domains:

1) Parents Emotions Around Discharge: Parents have complex emotions around discharge and may face steep learning curve as they transition to caring for their infant independently, without the support of the NICU.

   “I think one of the more challenging things [about going home] was learning how to react to him when he needed fairly immediate help in a way that didn’t upset him. (Mhm) cuz we’d be playing with him and all of a sudden alarms would be going off, so we’d need to...” —parent of recently discharged NICU baby

   “I’ve been in the hospital, been with the doctors and the nurses they’ve been helping to take care of the baby and I—even if I was in the room I knew he was good to go. And so, there’s that excitement but there’s also that, “Oh wow okay this is the real deal”. “We’re really about to be parents for real.” Waking up early... in the middle of the night... so there was a little bit of apprehension”—parent of recently discharged NICU baby

2) Ideal role of a Parent Navigator: Parent Navigators would be part of a support system for parents by providing emotional support, serving as liaison between parents and the medical system, providing access to resources, normalizing the post discharge experience, and helping families adjust to post discharge life.

   “I think it would be important just for the role of the Parent Navigator to be more of an empowerer and an educator on the system more than a problem solver for the family because that’s not really gonna leave them with a sustained skill set that they can use when they’re still trying to navigate.” —NICU social worker

   “I think one of the main things that gets thrown to the side is the parents’ emotional health. Everything is focused on this medically fragile child, which is understandable. But, there’s that parent who looks like they’re holding it together and they’re not. And, yeah, we go to appointments and we do this but I’m sleeping 2 hours at a time and I’m not eating and I cry in the bathroom and lock the door and nobody knows. And that’s a huge issue.” —current Parent Navigator and parent of a NICU graduate

3) Timing of Parent Engagement and Interactions: Stakeholders support the introduction of the Parent Navigator to the parent in the NICU during discharge planning. Parent Navigators should check in regularly with parents, offer home visitation, and attend medical appointments to provide supportive guidance.

   “I think continuity would be the thing...I think that would be a lot of touches so by discharge they feel really semi-bonded with this person, and that is the person that’s going to help offer you a continuity of care once you’re discharged, so someone that you’re still gonna have contact with.” —NICU social worker

4) Training of Parent Navigators: Stakeholders agree the training curriculum should focus on effective communication/listening and establishing and maintaining professional boundaries. Parent Navigators should acquire a baseline knowledge of medical terminology and procedures.

   “You can teach tricks and tools and tips on how to be a good listener... but at the same time set up boundaries because we don’t want compassion fatigue...every family may have needs for—you may hear that they need food but we don’t want you to buy groceries. So, listening, but not internalizing. Have empathy but find resources without feeling that you have to be the person to solve it. Because you can’t always solve it.” —current Parent Navigator

CONCLUSION

- Initial analysis of aggregate focus group and interview data reveals the complex emotions parents have around discharge and ways in which peer to peer support may be helpful.
- Next steps include:
  - Further qualitative analysis of the focus groups/interviews by stakeholder group
  - Development of NICU specific Parent Navigator training curriculum
  - Implementation and assessment of a randomized Parent Navigator intervention in the NICU

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