The Experience of Mothers’ Post NICU Discharge in Caring for Infants Dependent on Medical Technology

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Background

- There is an increased survival of premature and critically ill infants to discharge, and therefore a growing population of infants discharged dependent on medical technology from the NICU.¹⁻⁶
- Feeding tubes, oxygen, tracheostomies, mechanical ventilation
- NICU graduates have been documented to have high rehospitalization rates.²⁻⁹
- 2 weeks to 3 months post-discharge has been noted the most likely time for rehospitalizations or ER visitations.²⁻¹⁰,⁶
- There is a gap in knowledge related to the immediate post discharge period during the transition to home for technology dependent infants and their families.


Methodology

- **Design:** Fundamental Qualitative Description
- **Research Question:** What is the experience of mothers post NICU discharge in caring for infants dependent on medical technology?
  - Focus on the first 2 weeks at home
- **Method:**
  - Recruitment posts via Facebook & Snowball emailing
  - Inclusion/Exclusion assessment
  - Demographic & Infant information forms
  - 45-60 minute semi-structured audio recorded interview

Current Sample

<table>
<thead>
<tr>
<th>INFANT #</th>
<th>Sex</th>
<th>BW</th>
<th>GA</th>
<th>NICU LOS</th>
<th>Time Since Discharge</th>
<th>Technology at discharge</th>
<th>Rehospitalizations since discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Male</td>
<td>3lbs 5oz</td>
<td>34 weeks</td>
<td>6 days</td>
<td>60 days</td>
<td>4 months</td>
<td>Nasal Cannula, Oxygen</td>
</tr>
<tr>
<td>12</td>
<td>Female</td>
<td>1lb 6oz</td>
<td>23 weeks</td>
<td>2 days</td>
<td>124 days</td>
<td>5 months</td>
<td>Nasal Cannula, Oxygen</td>
</tr>
<tr>
<td>13</td>
<td>Male</td>
<td>1lb, 12 oz</td>
<td>25 weeks</td>
<td>1 day</td>
<td>106 days</td>
<td>14 months</td>
<td>Nasal Cannula, Oxygen</td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>6lbs 8 oz</td>
<td>36 weeks</td>
<td>5 days</td>
<td>75 days</td>
<td>3 months</td>
<td>Gastric tube</td>
</tr>
<tr>
<td>15</td>
<td>Male</td>
<td>2lbs, 6 oz</td>
<td>26 weeks</td>
<td>6 days</td>
<td>80 days</td>
<td>1 month</td>
<td>Nasal Cannula, Oxygen</td>
</tr>
</tbody>
</table>

Key: BW is birthweight, GA is gestational age at birth, and LOS is length of stay in the NICU. Time since discharge is approximated by nearest month from the discharge day to the date of the interview. Rehospitalizations are from date of discharge to interview date.
Current Sample

**MATERNAL CHARACTERISTICS**

<table>
<thead>
<tr>
<th>PARTICIPANT #</th>
<th>Age</th>
<th>Race</th>
<th>Household Income</th>
<th>Education</th>
<th>Marital status</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>30</td>
<td>White</td>
<td>$100,000 or more</td>
<td>Masters Degree</td>
<td>Married</td>
<td>Not working in order to care for child</td>
</tr>
<tr>
<td>P2</td>
<td>40</td>
<td>White</td>
<td>$100,000 or more</td>
<td>Associates Degree</td>
<td>Married</td>
<td>Not working in order to care for child</td>
</tr>
<tr>
<td>P3</td>
<td>35</td>
<td>White</td>
<td>$60,000-99,999</td>
<td>Bachelors Degree</td>
<td>Married</td>
<td>Working</td>
</tr>
<tr>
<td>P4</td>
<td>40</td>
<td>African American</td>
<td>$100,000 or more</td>
<td>Masters Degree</td>
<td>Married</td>
<td>Working</td>
</tr>
<tr>
<td>P5</td>
<td>24</td>
<td>White</td>
<td>$60,000-89,999</td>
<td>Some college, but no degree (Diploma Program)</td>
<td>Married</td>
<td>Working, on 8-week maternity leave</td>
</tr>
</tbody>
</table>

Analysis

- Inductive qualitative content analysis
- Transcriptions, field notes, and audio material were revisited in depth by study PI
- in-vivo coding process performed utilizing recommended coding procedures from Creswell
- Main themes were agreed upon by the co-investigator
Results

Within the context of an extremely overwhelming, yet rewarding experience, four main themes emerged.

- Transition to Home: Overwhelming yet rewarding experience
- A need for coordinated discharge care and teaching
- Fighting for In home nursing
- Finding Normalcy
- Adapting to the challenges of technology

A Need for Coordinated Discharge Care and Discharge Teaching

"Like a respiratory therapist would come through the door and say why isn’t there a water collector on that? We didn’t know there was supposed to be a water collector on it."

"...so I didn’t really get how to do CPR or anything. They told you were going to, but when we got the monitors, they really just gave you a little handout that said this is how you would do CPR on a baby ...So I started, I called 911 and I said I don’t know what to do, and she was turning blue at this point."
Fighting for in home Nursing

“By that time my insurance company was like you’ve been doing it this long, and they denied me. They denied me three times, so I feel like that is something that should have been implemented right away when we got home.”

“It was very, very difficult. So, because I only came home on oxygen, my primary insurance denied us outright and said no, forget it.”

“That was frustrating because we do have insurance. It does say we have homecare nursing but in the state of New Jersey, for whatever reason, they felt that whatever services the baby needed did not meet that criteria and they would only give an hour.”

Adapting to technology challenges

“Once we were home for a couple of weeks, we kind of figured out okay, if we put the concentrator in the hallway, we can go ten feet this way, ten feet that way. So, it was kind of a little bit easier once we kind of got the hang of it but the first couple of weeks, it was really crazy.”
Finding normalcy

“Being able to hold him whenever I wanted to, and give him a bath.”

“Yes, with no monitor, no beeping or anything like that”

“I think there was a lot, I mean seeing him improve and grow was amazing. I love rocking him to sleep and bonding with him and having him here all the time. It sounds silly but you don’t get to do that when they’re at the NICU.”

Implications

★ The need for care coordination in the community
★ More discharge preparation and planning
★ More studies needed to address the gap in knowledge
★ **NICU PTSD**
Selected References


