Life around NICU discharge from the perspective of low socioeconomic status mothers

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Disclosures

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Background

- 380,000 premature infants (< 37 weeks) born in 2014
- Substantial investments have improved survival
- Transitioning these infants from NICU to home deserves more attention
Problems with transition

- Fragmented communication
- High resource utilization
  - 20-25 primary care visits 1\textsuperscript{st} year
  - Increased readmissions and ER visits
Background

- **Parental stress:**
  - Perceived fragility
  - Transition to unmonitored environment

- **Apnea and bradycardia:**
  - Common problem
  - Resolves around 36 weeks corrected GA
  - Often delays discharge
Interventions

- Billions invested in home visiting
  - Limited effect on outcomes of premature infants
- Top down approach to design: missing parent perspective
  - Participatory action techniques can improve effectiveness of interventions
- Perceptions of parents and providers differ
Low SES Families

- Disparities in perinatal outcomes → Infants of low socioeconomic status (SES) families over-represented in the NICU
  - Perspectives are underrepresented
- Higher risk for adverse outcomes after discharge:
  - Higher readmission rates, ER use, infant mortality
Specific Aims

To explore, in a low SES population, the experiences of families of infants less than 35 weeks in the peri-discharge period using a participatory action framework

Secondary aim: What are parents attitudes towards home visitors?
Methods

Setting: Level III NICU serving a mostly Medicaid, inner-city population

Design: Semi-structured, open-ended telephone interviews 30 days after discharge

Inclusion criteria:

✓ Infant born less than 35 weeks
✓ Discharged from study site
✓ Low SES: Medicaid/Uninsured OR low income zip code
Interview domains

1. Life after discharge
   - Stress, coping, support network

2. Experience with NICU discharge process

3. Attitudes towards home visitors
Statistical Analyses

NVivo qualitative analysis software

Team of 3 coders

- Coder 1 and 2 split primary coding responsibilities
- Coder 3 double codes every 3rd interview
- Met at multiple time points

Modified grounded theory and constant comparison approach
Results

• 32 of 35 families consented
• 27 of 32 interviews completed
  • 84% response rate
• 48% were first-time mothers
<table>
<thead>
<tr>
<th>Table 1: Infant and maternal demographics</th>
<th>n=27</th>
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<tbody>
<tr>
<td><strong>Infant demographics</strong></td>
<td></td>
</tr>
<tr>
<td>Gestational age, wks, mean (SD)</td>
<td>31.2 (3.0)</td>
</tr>
<tr>
<td>Birth weight, g, mean (SD)</td>
<td>1501 (572)</td>
</tr>
<tr>
<td>Length of stay, d, mean (SD)</td>
<td>48.1 (33.5)</td>
</tr>
<tr>
<td><strong>Maternal demographics</strong></td>
<td></td>
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<tr>
<td>Maternal age, yrs, mean (SD)</td>
<td>29.1 (5.3)</td>
</tr>
<tr>
<td>Black race, %</td>
<td>85</td>
</tr>
<tr>
<td>Medicaid insurance, %</td>
<td>81</td>
</tr>
<tr>
<td>High school diploma or less, %</td>
<td>30</td>
</tr>
<tr>
<td>US-born, %</td>
<td>78</td>
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<tr>
<td>Limited health literacy, %</td>
<td>52</td>
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Themes

1. Concern over infant health
2. Trust and informational consistency
3. Social support and coping
Theme 1: Infant health is #1 concern

- Substantial stress and anxiety

"...if it [apnea and bradycardia] was a concern then, why isn’t it a concern now?"

"I would cry the whole way [home from the hospital], because I didn’t really understand the whole brady situation at first."

"The first couple of days I didn’t have a [apnea] monitor. And I really wish I had one because being a new mom, you’re so nervous."
Theme #2: Trust

- Strongly trusted nurses
- Mistrusted social workers
- Concerns over informational consistency

“I’d still ask [the NICU staff] the same questions just to make sure that the answer was the same.”

“I don’t want them to think that I'm a danger to me and the baby. Because that's what mainly what social workers think, especially DHS.”
Theme #3: Support and Coping

- Resilience
- Extended support network vs. social isolation

"I’m a mom. It’s my responsibility. I have no choice really but to deal with it."

“But with the area I’m at, there’s no community centers.”

“If [the NICU] could recommend some type of support group, because I didn’t realize how hard it would be."
Secondary aim: Home visitors

- Families appreciative of visitors in their capacity to provide reassurance about infant health
- Nurses preferred over community health workers

“Medically, so to speak, [the nurse] knows what’s going on... I can ask her any questions that has to do with health.”

“Because the nurse would not be the one to call DHS on me.”
Discussion

- Infant health is families’ number one concern
  - Families value interventions that provide reassurance
- Trust and informational consistency strongly relate to satisfaction and engagement
- Social support is essential to a successful transition
Next steps: Infant health concerns

1. Leverage technology to provide flexible education (Telehealth, Facetime, educational apps)

2. Anticipate family concerns during home visits and outpatient visits
Next steps: Trust

1. Unit wide policies to provide consistent communication
2. Home visiting programs to meet families prior to discharge, emphasize the training of the visitors
3. Reduce stigma of social work, conduct assessment of all families
Next steps: Support and Coping

1. NICU to assess support network well before discharge

2. Connect families to community resources in the NICU, during home visits, and in primary care
Limitations

Narrow demographic

Telephone interviews

One time point
Conclusions

- Participatory action research can yield important information for the design and implementation of interventions
- Several targets to improve the discharge transition of premature infants
- Stakeholders should coordinate efforts
Acknowledgements

Study Team
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<table>
<thead>
<tr>
<th>Theme</th>
<th>Area</th>
<th>Interpretation</th>
<th>Next Steps</th>
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<tbody>
<tr>
<td>Stress and Emotions</td>
<td><strong>NICU</strong>: Excitement and anxiety over discharge. <strong>Home</strong>: Anxiety over bradycardia, infant health.</td>
<td><strong>Families’ number top concern is infant health.</strong></td>
<td>Improve communication with families around discharge.</td>
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<td><strong>Trust</strong>: High trust in providers. Easily broken with informational inconsistency. <strong>Home</strong>: Trust in credentialed home visitors, distrust of SW.</td>
<td><strong>Trust is essential</strong> to family centered care. Informational consistency is key</td>
<td>Unit wide policies to ensure consistent communication. Feedback for home visiting programs.</td>
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<td><strong>Coping</strong>: Nursing provided support. <strong>Home</strong>: Resilience, acceptance of challenges. Social support vs. isolation.</td>
<td><strong>Families’ with low resources compensate with family support, high level of resilience.</strong></td>
<td>Identify potential social isolation.</td>
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<td>Unmet Needs</td>
<td><strong>NICU</strong>: Getting to hospital. Communication around discharge and infant safety. <strong>Home</strong>: Emotional support, reassurance that infant is ok.</td>
<td><strong>Informational needs and visiting hospital are top barriers.</strong> <strong>Families top concern is infant health.</strong></td>
<td>Assistance with visiting hospital. Telehealth/Facetime. Anticipatory guidance. Feedback for home visiting programs</td>
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Interview guide

Content generation:

Literature review, interviews with key stakeholders (nursing, physicians, follow-up, outpatient pediatricians).

Script refined and piloted with 5 families with infants in the ICN who met study criteria.

Using the constant comparative method, script further refined during data collection.

No changes in overall content themes
Experiences in the NICU

“A lot of parents say they don’t feel comfortable leaving their child or whatever. But I actually – they made me feel comfortable. And when I came, they made me feel welcome.”

“It would’ve been nice if I had a – and it might be too much, but I think, it would’ve been nice if there was like some type of counselor there.”
“...and this was the one time that my brother came to see her, and I had nothing. I didn’t have a Pamper, a crib. I had nothing. So, that Saturday, we went to BabiesRUs and he spent maybe $500 and just got her everything she needed.”

“I haven’t been involved in anything. It’s just stay home with baby, that’s all.”
“It probably would be... nice for somebody to be there to make you understand something that you don’t understand at the time, instead of you just signing it.”

“I think the nurse would be okay – just for the fact that at least – let me think, what was I gonna say? Medically, so to speak, she knows what’s going on and stuff like that. I can ask her any questions that has to do with health wise.”
Thematic Analysis

Coding team individually wrote down major themes

- Overall
- Domain

Themes discussed, refined

Narrowed down to 4 major themes

- NICU
- After discharge