

Perspectives of Low Socioeconomic Status Mothers of Premature Infants

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abstract

BACKGROUND AND OBJECTIVES: Transitioning premature infants from the NICU to home is a high-risk period with potential for compromised care. Parental stress is high, and families of low socioeconomic status may face additional challenges. Home visiting programs have been used to help this transition, with mixed success. We sought to understand the experiences of at-risk families during this transition to inform interventions.

METHODS: Mothers of infants born at <35 weeks' gestation, meeting low socioeconomic status criteria, were interviewed by telephone 30 days after discharge to assess caregiver experiences of discharge and perceptions of home visitors (HVs). We generated salient themes by using grounded theory and the constant comparative method. Interviews were conducted until thematic saturation was achieved.

RESULTS: Twenty-seven mothers completed interviews. Eighty-five percent were black, and 81% had Medicaid insurance. Concern about infants' health and fragility was the primary theme identified, with mothers reporting substantial stress going from a highly monitored NICU to an unmonitored home. Issues with trust and informational consistency were mentioned frequently and could threaten mothers' willingness to engage with providers. Strong family networks and determination compensated for limited economic resources, although many felt isolated. Mothers appreciated HVs' ability to address infant health but preferred nurses over lay health workers.

CONCLUSIONS: Low-income mothers experience significant anxiety about the transition from the NICU to home. Families value HVs who are trustworthy and have relevant medical knowledge about prematurity. Interventions to improve transition would benefit by incorporating parental input and facilitating trust and consistency in communication.



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WHAT'S KNOWN ON THIS SUBJECT: Discharge from the NICU to home is a time of high parental stress. Interventions to improve the transition have had limited effectiveness. Direct parent input, particularly from those of low socioeconomic status, is often missing when these programs are designed.

WHAT THIS STUDY ADDS: Low socioeconomic status mothers of premature infants worry most about their infant's health and perceived fragility. Trust and informational consistency are highly valued. During the transition from NICU to home, mothers value services that provide reassurance about infant well-being.

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Medical advances have vastly improved survival of preterm infants, increasing the number of infants discharged from the NICU. Less is known about optimally transitioning these infants from the NICU to home. Improving transition is important because these infants have high health care utilization and costs after NICU discharge.¹⁻⁵ Premature infants without significant complications, who make up the majority of NICU patients, have postdischarge costs >3 times those of their term peers.⁵

Additionally, discharge increases parental anxiety, which is linked to increased risks of acute care visits after NICU discharge.⁶ Families of low socioeconomic status (SES) and of minority race or ethnicity may be at even higher risk. First, they are overrepresented in the NICU because of disparities in preterm birth.⁷ Furthermore, their infants have higher rates of readmission and emergency department (ED) use and differential use of prescription medications.⁸⁻¹⁰ These families are also disproportionately burdened by stress over the high out-of-pocket costs of having a premature infant.¹¹⁻¹³ The large disparities in medical home access for low-SES infants make it even more important to optimally prepare parents for discharge.¹⁴ Finally, the perceptions of low-SES NICU parents are underrepresented in the literature, especially the perspectives of low-income African American women, who have the highest rates of preterm birth in the United States.^{7,15-18}

Many interventions aimed at improving discharge transition have incorporated a home visitor (HV).¹⁵ These programs may use HVs with different levels of training, including registered nurses and lay health workers (LHWs). Unfortunately, home visiting has not measurably improved health outcomes or utilization for premature infants, for reasons that are unclear.¹⁹⁻²³ Participatory action research, which engages patients in

multiple stages of research design and implementation, can address any misalignment between patient and organization priorities.²⁴ By using this approach, effective LHW programs have been created to transition adults from hospital to home.²⁵

To better understand the needs and perspectives of at-risk families during the discharge transition, this study used a participatory action framework to explore the peridischARGE experiences of low-SES families of infants born at <35 weeks' gestation. Secondly, given our interest in the role of home visiting in improving the transition to home, we explored parental views of HV acceptability and preferred type of HV.

METHODS

Setting

Participants were recruited from a 36-bed, level III NICU in urban Philadelphia that serves primarily a Medicaid-eligible population.

Participants

Low-SES primary caregivers of infants born at <35 weeks' gestation and discharged from the study site were screened for inclusion. One caregiver, either the mother or father, from each family was recruited; however, no fathers elected to participate. Low SES was defined as mother being Medicaid insured or uninsured at delivery or residing in a zip code where $\geq 25\%$ of inhabitants lived below the poverty line. These criteria were used in previous work.²⁴ Participants were excluded if they did not meet low-SES criteria or if they did not speak English. Recruitment concluded once thematic saturation was reached.^{26,27}

Design

Study participants were approached in the NICU within 2 weeks of the infant's anticipated discharge. After enrollment, participants completed demographics and the Parent

Health Literacy Activities Test, an 8-item validated measure of health literacy and numeracy developed for families of infants.²⁸ Participants were considered to have low health literacy if they scored ≤ 5 correct out of 8 questions.

Within 1 month of NICU discharge, participants were contacted by text, e-mail, or phone to schedule a semistructured telephone interview conducted by a researcher experienced in qualitative interviewing (AEM). A literature review and key stakeholder interviews with NICU physicians and nurses and primary care physicians, nurses, and social workers informed the design of the interview guide. The interview was then piloted with 5 NICU mothers meeting eligibility criteria but not enrolled in the study, and modifications were made based on their feedback. During data collection we used the constant comparative method to refine the guide.²⁹ The interview included 3 domains:

1. Experiences of NICU discharge,
2. Facilitators and barriers after NICU discharge, and
3. Acceptability of HVs and preference for type of HV (nurse versus LHW)

Interviews were recorded on a secure phone line, then transcribed by a third-party transcription service. Participants received a \$20 gift card upon interview completion.

Analysis

Demographic and clinical variables were analyzed via descriptive statistics, and responders and nonresponders were compared via χ^2 analyses, Fisher's exact test, and the Wilcoxon rank-sum test where appropriate, in Stata version 13.0 (Stata Corp, College Station, TX).

Transcripts were imported into NVivo software, a qualitative analysis software package, (QSR International Pty Ltd version 10, 2012, London, UK). A team of 3 people with backgrounds

in neonatology (EE), general pediatrics (LJF), and nursing (SWK) reviewed the transcripts. Two coders (EE and LJF) split primary coding responsibilities of the transcribed interviews, and a third coder (SWK) double-coded every third interview to maximize internal validity and coding consistency. The team analyzed the data in several stages derived from grounded theory³⁰:

1. Open coding to identify themes and concepts,^{30,31}
2. Prolonged engagement and peer debriefing to interpret data and establish validity of the codes,
3. Axial coding using both inductive and deductive techniques, and
4. Group consensus to solidify core concepts.

In step 1, the team members jointly reviewed the first few interview transcripts to identify preliminary codes that were used to develop the codebook. Once each coder completed an initial analysis of the data, the team moved to step 2, which involved secondary and tertiary transcript reviews, while iteratively debriefing as a team to discuss emerging themes and refine our codebook. In step 3, we performed axial coding to assign context and meaning to our key themes by using inductive and deductive reasoning. Finally, in step 4, we solidified key concepts that arose from the interviews.

Planned secondary analyses included comparing those of high and low literacy and those with infants born at <32 weeks and ≥32 weeks to see whether the content or frequency of themes differed. The University of Pennsylvania Institutional Review Board approved this study.

RESULTS

Demographics

Thirty-two of 35 eligible participants provided consent; 27

TABLE 1 Infant, Maternal, and Neighborhood Demographics

	<i>n</i> = 27
Infant demographics	
Gestational age, wk, mean (SD)	31.2 (3.0)
<32 wk, %	52
<28 wk, %	19
Birth wt, g, mean (SD)	1501 (572)
Small for gestational age, %	30
Twin gestation, %	11
Length of stay, d, mean (SD)	48.1 (33.5)
Chronic lung disease, %	15
Apnea monitor at discharge, %	11
Medications at discharge, median no. (IQR)	2 (2–2)
Specialists at discharge, median no. (IQR)	1 (0–2)
Maternal demographics	
Age, y, mean (SD)	29.1 (5.3)
Black race, %	85
First-time parent, %	48
Previous premature infant, %	11
High school diploma or less, %	30
Medicaid insurance, %	81
Met income and zip code inclusion criteria, %	70
Live with partner, %	48
No. in household, median (IQR)	3 (2–5)
Limited health literacy, %	44
US born, %	78
Income <\$25 000/y, %	52
Unemployed, %	44

IQR, interquartile range.

completed interviews (response rate of 84%). Compared with nonresponders (*n* = 5), those with completed interviews had infants born at an earlier gestational age (median gestational age 31.9 weeks vs 34.0 weeks; *P* = .03), had more formal education (70% attended some college vs 60%; *P* = .03), and were less likely to be unemployed (44% vs 100%; *P* = .02).

Of participants who completed interviews, the infant's mean length of stay was 48.1 days (SD 33.5 days), and 52% of infants were born <32 weeks' gestation (Table 1). Mean maternal age was 29.1 years (SD 5.3 years), 85% were black, 48% were first-time parents, and 81% received Medicaid or were uninsured at delivery.

Themes

The main themes are presented below, with additional representative quotations in Table 2 and opportunities for action in Table 3.

Theme 1: Concern About Infant Health

Parental anxiety about their infant's perceived fragility and their readiness for discharge around and after NICU discharge emerged as the predominant theme.

Around Discharge

Many mothers thought the discharge process seemed unexpected and rushed. Many worried about apnea and bradycardia (AB) events, a common complication of prematurity. One mother said, "I would cry the whole way [home from visiting the NICU], because I didn't really understand the whole brady[cardia] situation at first." Much of the stress before discharge concerned the discharge delays from persistent AB events and the uncertainty they created about whether the infant would ever be truly safe for discharge.

After Discharge

Families spent many sleepless hours worrying whether infants were

having undetected AB events. They experienced stress about transitioning from a monitored NICU to an unmonitored home environment: “For 119 days, I have been so comfortable with a monitor telling me what she verbally can’t express.” Their infant’s prematurity significantly heightened their concerns after discharge: “I was so worried that maybe something might happen every time [he fed] because he was so tiny.” Several mothers were visited by a nurse after discharge and said these visits reduced their stress: “I was so nervous with her having those brady[cardia] episodes. . . . A nurse came out almost immediately . . . and made sure she was breathing fine and she was eating good and she had gained a little bit of weight.” Families valued the medical training of nurse HVs and their ability to provide reassurance about infant well-being.

Theme 2: Trust and Information Consistency

Trust and information consistency were important. Many distrusted providers, such as social workers, who were associated with child protective services.

Around Discharge

Mothers trusted providers who seemed genuinely invested in their infant and communicated in an open and honest manner: “I like the way she takes care of him . . . and tries to explain what it is that’s happening to him.” Conflicting information from different providers endangered this trust. Many recommended that other NICU parents ask the same question of different care team members to ensure that they receive consistent information: “And even if I met someone different, I’d still ask them the same questions just to make sure that the answer was the same.”

After Discharge

Some were reluctant to accept community resources when they thought the organization was

TABLE 2 Representative Quotations by Theme

Theme	Representative Quotations
Anxiety about infant’s fragility	<ul style="list-style-type: none"> • “If [apnea] was a concern then, why isn’t it a concern now? Because honestly, because she’s not hooked up to these machines, I don’t even know if she’s still having them or not.” • “I couldn’t sleep at all . . . because I was just too scared she would wake up and start screaming or if she was okay or if she was having a brady.” • “Knowing that he was a preemie . . . I was so afraid for the first week.” • “The [nurse] home visit was nice at least, because . . . I was worried about him not gaining weight. . . . So the home visit really helped, because the nurse took his weight.”
Trust and information consistency	<ul style="list-style-type: none"> • “And even if I met someone different, I’d still ask them [NICU staff] the same questions just to make sure that the answer was the same.” • “I paid attention to not only how they [NICU nurses] interacted with my baby, but with other babies as well, just to see how nurses act when the parents aren’t around.” • “The safest person I would go would be the [home visiting] nurse [versus community health worker]. Because the nurse would not be one to call DHS [Department of Health Services] on me.” • “It [community health worker program] may feel . . . that they [parents] aren’t trusted enough to take care of their child . . . it’s an extension of the hospital keeping eyes and ears on them.”
Support and coping	<ul style="list-style-type: none"> • “I have a huge support from my church. They make sure she has everything she needs.” • “I do feel a little overwhelmed. . . . My mom will watch the baby and my son, and I will just go up to a [drug addiction support] meeting.” • “Even if they [the NICU] could recommend some type of support group, because I really didn’t realize how hard it would be.” • “I haven’t been involved in anything. It’s just stay home with baby, that’s all.”

probing too far into their personal lives. In regard to HVs, they were trusted and accepted as long as they were well trained. Repeatedly, participants mentioned “credentials” as a positive attribute of an HV.

Concern about having strangers in the home was alleviated if the HV appeared professional, with appropriate credentials. Nearly all families preferred a nurse over an LHW. Families were notably more suspicious of LHWs compared with nurses because of the perception that they did not have training and seemed similar to social workers, thus child protective services.

Theme 3: Coping and Support

Despite limited financial resources, many mothers coped by relying on a strong support network, whereas others faced social isolation.

Around Discharge

Many appreciated the role NICU nurses played in providing support. Another was happy to have support

from other NICU parents: “It also put me at ease, because there were other parents there [in the NICU], too, who were very friendly.”

After Discharge

Family members provided clothing, diapers, and other infant supplies. Many women displayed determination and acceptance of the struggles that accompany parenthood, observing, “If you don’t have a choice, then you do it.” Other women thought there was limited support available. Even those with a strong support network requested more community resources and emotional support and thought that HVs could fulfill these need. One mother wanted information on “support groups . . . [and] resources that the state has or the federal government has that families can utilize.”

Secondary Analyses

We conducted a secondary analysis by comparing quotations from those

of high and low literacy, and we found no significant differences in the content or frequency of salient themes. Similarly, we divided participants into those with infants born at <32 weeks and ≥32 weeks. We also found no substantial differences between these groups.

DISCUSSION

We identified a number of issues that low-SES, urban mothers face when taking their premature infants home. There was significant anxiety during this transition because of their infant's perceived medical fragility, particularly in relation to apnea of prematurity. Even mothers of "older" moderate and late premature infants viewed their infants as highly fragile. In contrast to previous studies in infants in the NICU, trust was a prominent theme and greatly influenced satisfaction with care, particularly around information consistency. This trust influenced their level of engagement, which has implications during the NICU stay and afterward. Although most supplemented low economic resources with extended support networks and appreciated the support that NICU nurses and HVs provided, they also thought more community resources would be helpful.

Anxiety about infants' perceived fragility was the predominant theme. In this aspect, our cohort demonstrated remarkable similarity to other groups with different demographics. Stress about apnea of prematurity and transitioning out of a highly monitored NICU environment was a common theme in studies of higher-SES NICU parents and lower-SES Latino families, indicating that these concerns are highly generalizable and should be a high priority for any NICU.^{16,17,32,33} This anxiety about infants' readiness for discharge and feeling unprepared can have consequences

TABLE 3 Major Themes and Potential Solutions

Theme	Care Environment	Interpretation	Next Steps and Potential Solutions
Anxiety about infant's fragility	NICU: Frustration about timing and preparedness for discharge.	• Families' number 1 concern is infant health, specifically apnea and breathing.	NICU • Systematic discharge planning starting at admission. • Anticipate parental concerns about apnea. • Deescalate monitoring near discharge. • Explore impact of anxiety on maternal–infant outcomes.
	Home: Anxiety about AB and being in an unmonitored environment.	• Transitioning from a highly monitored to unmonitored environment is a major challenge.	Home • Partnership between HVs, primary care, and NICU to streamline transition.
Trust and information consistency	NICU: High satisfaction related to trust in staff. Information inconsistency puts trust at risk.	• Trust is essential to family-centered care.	NICU • Unit policies to ensure consistent communication.
	Home: Trust in home visiting nurses, mistrust of providers associated with child protective services.	• Consistent communication is key. • HVs are acceptable if highly trained and credentialed.	Home • Minimize stigma associated with social workers. • Specific training on prematurity for HVs. • HVs to meet families before discharge. • LHWs need to have formal training and credentials.
Support and coping	NICU: Families appreciate support provided by nursing, other parents.	• Families with low resources compensate with social support, high level of determination.	NICU • Routine assessment of parents' support network. • Emphasize parental ability and capacity early. • Connection to resources before discharge.
	Home: Determination, wide social support network. More community resources needed.	• Those without a support network are at risk.	Home • HVs to provide coping support and connect to community resources.

that may go unrecognized by NICU providers. Parental unreadiness for NICU discharge is associated with suboptimal communication with outpatient providers.³⁴ In term infants, unreadiness is associated with increased phone calls to providers and poorer self-rated infant and maternal health status.^{34,35}

To address this stress, discharge planning ideally begins on the day of admission, and clinical pathways should be implemented.^{36–39} A structured discharge planning

process reduced ED visits and costs in a population of very preterm infants.⁴⁰ Although this concept is not novel in the general pediatric setting, there has been a lag between design and implementation in the NICU setting. Leveraging technology such as telemedicine, FaceTime, and other applications might enable NICUs to improve family-centered care and perform discharge teaching in a flexible manner, which is particularly important for low-income families who may face additional barriers to coming to the NICU.

Trust was particularly important in our population, which mirrors the widespread mistrust of the health care system in this demographic.^{41,42} This emphasizes the importance of unit-wide consensus on care practices such as discharge timing after AB events. Ensuring consistency of care may also be facilitated by HVs engaging with families before discharge. Adult patients being discharged from the hospital value meeting the HV before discharge.²⁴ Additionally, the medical home must be contacted before discharge so that pertinent information is relayed and the infant is appropriately scheduled for follow-up.^{39,43} Poor communication between the NICU and the medical home threatens parental trust and may compromise care.^{34,44,45} Finally, mistrust of providers associated with child protective services needs to be addressed to remove barriers to addressing social determinants of health. This will require an active process to reframe the role of social workers and other providers.

It is unclear why many discharge interventions have been unsuccessful in improving outcomes for premature infants, but our results suggest a few possibilities. First, families in our study highly valued trust and preferred to meet HVs while their infant was still in the NICU. A recent randomized controlled trial pairing a mother–infant developmental training intervention with a discharge preparation program, with components before and after discharge, reduced acute care visits at 6 weeks' corrected age.⁶ Another trial that randomly assigned families to discharge preparation with a health coach before discharge but did not provide postdischarge follow-up showed no difference in health care utilization at 1 month after discharge.⁴⁶ Combined with our data, these results suggest that home visiting may be an effective peridischarge intervention, but

interventions may be needed both before and after NICU discharge.

Another issue with home visiting programs may involve the type of HV. Whereas families appreciated HVs with medical training, they were more suspicious of LHWs, whom they viewed as similar to social workers. Rigorous training and credentialing are important when LHWs are used as HVs.⁴⁷ In 1 study, an LHW–nurse HV team compared with a nurse-only approach showed improved uptake and improved access to maternal mental health services but did not improve health outcomes for low-SES infants.^{48–50} Although LHWs as HVs may be a promising, cost-conscious solution based on data in other populations, if families of infants in the NICU do not find these HVs acceptable and helpful, they may not be effective.

This study has several limitations. The intention was to reflect a typical level III NICU that serves a low-SES population, so its generalizability may be limited. Therefore, specific concerns of families of infants at the limits of viability, with surgical issues, congenital anomalies, and technology dependence, may be less represented. However, our interviews reached thematic saturation, suggesting that the population studied reflects the needs of our target population. Also, poverty is not created equal, and in the United States, particularly in the African American community, there are high levels of mistrust in the health care system that influence our results.^{41,42} Furthermore, other settings may have different providers responsible for interacting with child protective services, and thus the role of the social worker may be less stigmatized.

CONCLUSIONS

Parental anxiety about their infant's perceived medical fragility

is a prominent theme in NICU discharge, regardless of SES. In our sample of mostly inner-city black mothers, we found that building trust and communicating in an open and consistent manner are crucial. Negative perceptions of providers associated with child protective services are widespread. Low-SES mothers supplement low economic resources with reliance on extended family, but they would benefit from more connection to social support networks and community resources.

Interventions to improve the transition from NICU to home might be strengthened by incorporating parent input in the design and implementation phase, engaging with parents before and after discharge, and prioritizing ways to improve trust and to remove the stigma from social services. By using principles of participatory action research, NICUs and outpatient providers can adapt interventions to their population while providing family-centered, culturally competent care.

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ABBREVIATIONS

AB: apnea and bradycardia
ED: emergency department
HV: home visitor
LHL: limited health literacy
LHW: lay health worker
SES: socioeconomic status

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