



Insight into the experiences of Spanish-speaking Latina mothers with babies in the NICU

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Background & Purpose

- Mothers with babies in neonatal intensive care units (NICU) face a host of challenges following childbirth.
- Compared with mothers of well babies, they have a greater burden of chronic disease, poor perinatal health outcomes, and are at increased risk for mental health problems, while at the same time are faced with navigating the health care system on behalf of their medically complex infant and managing their own postpartum recovery.
- Limited research is available on the postpartum health needs of these women.
- Such challenges are likely magnified for non-English speaking mothers but existing literature is scant.

The purpose of this analysis was to explore the postpartum needs of Spanish-speaking Latina mothers with babies in the NICU and identify opportunities for systems-level changes to meet those needs.

Methods

- We interviewed 6 Spanish-speaking Latina mothers aged 18 and older whose babies were in neonatal intensive care for at least 3 days as part of a larger mixed-methods study from June 2017 – May 2018.
- Interviews in Spanish lasted about an hour, were recorded and transcribed verbatim, and were conducted either at mothers' homes, in a clinical observation room, or by phone. Mothers were between 3 and 4 months postpartum.
- Transcripts were coded and analyzed inductively based on a priori interview topics and emergent themes in Spanish; NVivo12 was used to organize and manage the data.
- A NICU Family Advisory Board, comprising mothers who had previously had babies in the NICU, served in an advisory capacity providing input on instrument design and results interpretation.

Interview topics focused on the *mother's* needs and experiences and included: background and events leading to NICU admission, health needs including recommended and desired services, access to care, management of postpartum recovery, supportive health care systems, and suggestions for improving care.

Results

This analysis focuses on the results from in-depth interviews with 6 Latina mothers whose preferred language was Spanish.

Table 1. Demographic, health, delivery and postpartum characteristics of Spanish-speaking Latina mothers, Care4Moms study (n=6)

Bilingual	1
Married or partnered	4
Average age (range)	34 (21 - 40)
Employed outside the home prior to delivery	5
Plans to return to work or returned already	2
Other children at home <18	3
Lived at home while baby in NICU	4
Medicaid-insured at delivery	6
Has regular source of medical care	4
Diabetes	3
Cesarean section	4
Tubal ligation	3
Postpartum visit	4

The experiences and needs that emerged from Spanish-speaking Latina mothers while baby was in the NICU were similar to those voiced by participants in the larger study and fell within two main themes.

What was unique to the Spanish-speaking Latina mothers was that these challenges and needs were compounded by immigration-related factors.

Immigration-related stressors



1. Emotional and physical health needs

- Deep sadness that their pregnancy and birth did not go as expected and that their baby did not come home from the hospital with them.
- Linguistic isolation in the NICU → less informal support from NICU staff and other NICU mothers.
- Family separation → less emotional support in-person from family.
- Fear of deportation → added stress.

"And it saddened me because I do not have anybody, I do not have anybody here, I do not have brothers, uncles, cousins, And seeing that everyone came to visit them [others in the NICU] and I felt more sad, I said: "My God, give me strength that my son does well, that immigration does not take him, or police don't stop him". (ID 29)

- Loss of Medicaid after delivery → no follow-up postpartum for diabetes

"Now I do not have medicine for diabetes. Because since the girl was born, Medicaid ended." (ID 10)

- Putting their own needs aside to be with baby

"Then I did not want to take it [muscle relaxant] because I wanted to spend time with my baby, my priority was to see - I wanted to be with my baby 24 hours a day." (ID 29)

2. Logistical challenges

- Visiting the NICU daily
 - Driving 15 to 70 miles (25 - 90 minutes) each way from home
 - While recovering from a cesarean section
 - Without a drivers license
 - Paying for gas and parking on top of already strained finances

"I used to drive almost every day this way for the hospital and sometimes the operation [cesarean] hurt me. Sometimes it was hard to drive because I didn't have anyone who could take me . . . I took Tylenol so that the pain would calm down and I tried to drive slowly because of the pain." (ID 10)

- Family separation → less logistical support from family or friends particularly with childcare for siblings of the baby in the NICU.
- Variation in NICU services → less practical support for some mothers.

Conclusions

Limitations

We aimed to recruit 20 Spanish-speaking mothers but encountered difficulties due to:

- Fear in the current social and political environment
- Administrative delay in gift card reimbursement
- Limited hours of when recruitment staff were available
- Although the number recruited fell below our target, it was in keeping with the proportion of Spanish-speaking Latina mothers in the NICU census (12.0% of our interviews vs. 10.1% in NICU census).

Implications for Practice

- Spanish-speaking Latina mothers experienced significant social-emotional and physical health needs which were coupled with difficulty accessing services and support due to lack of insurance postpartum, language barriers, social isolation, financial strain, and fear.
- Unmet practical needs caused significant burden that were compounded by immigration-related stressors.
- **Spanish-speaking mothers' suggestions for improvements include:**



Hiring more Latinx and Spanish-speaking nursing staff who are sensitive to the needs and experiences of Latina mothers and take an interest in her well-being



Offering private lactation areas, food and water



Offering financial assistance with parking



Assistance with child care for siblings



Coordinating support groups

- More attention to the orientation and care of Spanish-speaking Latina mothers in the NICU is needed to address the additional burden that these mothers faced due to immigration-related stressors.
- Interventions should consider mothers' desire to be near baby's bedside, and preference for in-person services provided by bilingual/bicultural nurses rather than via written materials.
- Relying on interpreters to communicate key information about the baby did not mitigate the social isolation these moms encounter.
- Spanish-speaking Latina moms were eager to help other NICU moms, and this could be harnessed to reduce social isolation and help one another to meet their practical needs while their baby is in the NICU.

