

The New Mother Friendly NICU:

Understanding and Improving the Postpartum Experience for Mothers of Medically-Fragile Infants



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Background & Purpose

- Mothers with babies in neonatal intensive care (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, despite thousands of mothers living this experience every day.

The purpose of this study was to explore the postpartum needs of mothers with babies in the NICU and propose actionable system improvements to address identified needs.

Methods

- We interviewed 44 English-speaking 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 lasted about an hour, were recorded and transcribed verbatim, and were conducted either at the baby bedside, in a hospital room near the NICU, or by phone, depending on mother's preference. Mothers were between 3 and 4 months postpartum.
- Transcripts were coded and analyzed inductively based on a priori interview topics and emergent themes; 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 care, access to care, management of postpartum recovery, supportive health care systems, and suggestions for improving care.

Results: Desire to be by baby bedside impacts mothers' health

Minimize

own

health

needs

By baby bedside

[I didn't attend any classes offered to NICU moms because] I felt like I'm traveling back and forth and I'm wasting time going back and forth. I didn't want to take time out of the time I had to be away from my son. (ID12)

> Don't address existing needs

Even if I'm not doing any good just sitting in the room with her, that's where I needed to be...I felt like that's where my brain was, so that's where I needed to be physically. (ID38)

mothers are like me, they want to me as near as they can be...You've given birth to this baby and you cannot take them home. It was hard for me, very, very hard. (ID39)

I think if any other

Unmet health care needs

Access to mental health care

- Desire for care close to baby
- seek time-consuming care -Home provider far from hospital

- Support groups desired on evening/weekends -Support groups take time from baby

Unmet practical

needs

Comfortable chair A place to rest/nap

-Don't want to drive all the way home -Driving while tired; pulling over to sleep

Parking

-Parking far away to save money is time away from baby Balancing caregiver roles

-Caring for other children is time away from baby;

Judged by nurses for not being bedside enough Easy access to healthy foods

-Limited food options outside of baby care time -Desire for bedside food

I have an autoimmune disease so there were times where I felt like some of my symptoms were flaring up, but I didn't want to take the time away from going to see him to go see my rheumatologist so I just didn't go...at night I got a lot of swelling and I just, for lack of a better word, I just kind of sucked it up. (ID12)

I got a urinary tract infection and I didn't take care of it for myself because I wanted to be [in the NICU]...I didn't really feel like there would be...anybody [I could] see. You'll have to go down to the ER which of course would've taken me away for quite a bit of time...After she passed that Saturday...I finally went to urgent care...I didn't want to be away from her and she was more important than my UTI. (ID37)

- Long wait to see someone
- Access to physical health care
- Don't want to leave bedside to

Social support from other moms

I felt like I was finding places to sleep like an airport. You know, sort of sleeping in a corner somewhere. [I would have liked somewhere to] close my eyes for 30 minutes; that made a big difference to then have the energy to sit at her bedside for a few more hours through the day. I never felt like there was an okay, designated place to do that. I felt like I was sort of sneakily doing it. (ID43)

I don't really focus on myself. Like I'm fine, and I'm the only

one here, so I have to just bear through it if I was going

through something. (ID1)

...a lot of the classes were done during

care time, so not a lot of moms went,

because it's one of the only times you

get to touch your child and be proactive

with your child. We had to choose

whether we wanted to change a diaper,

take a temperature, or sit in the

classroom and do a class. (ID13)

..everything just happens so quickly and

it's like when I really need to talk to [the

therapist] I need to wait three weeks

from now to talk to her. (ID1)

...for moms [with cesarean sections] that means that they're still in recovery themselves...That was the hardest thing for me, at times, was just [not having] a chair, and I'm standing, and the weight of the incision, and my legs are swelling, my feet are swelling. It was just - and, again, for our children, we'll do pretty much anything. If we had to stand on our heads, we would stand on our heads, but [a chair] would have been ideal. (ID53)

I mean [the baby's NICU] nurses would tell me, "You need to make sure you get sleep because you have to take care of yourself," but other than that no. Nobody really came." (ID14)

officially checking on Mom

No one

Results: Demographics

Average Weeks' Postpartum at Interview (range)	17 weeks (12-20)
Average Age (range)	31 years (20-45)
Race	
White	29 (66%)
African American	14 (32%)
Other	1 (2%)
Married/Partnered	38 (86%)
Insured	43 (98%)
Other Children in Home	24 (55%)
Residence while Baby in NICU*	
Home	32 (73%)
Ronald McDonald House	16 (36%)
Local Hotel	1 (2%)
Other	4 (9%)

^{*}Respondents able to select more than one response

Conclusions

- Postpartum mothers of medically fragile infants are driven by an overriding desire to be at the baby bedside and will minimize their own health needs so as to attend to baby.
- These mothers experience significant social-emotional-mental health needs which, in this population, were coupled with difficulty accessing mental health services and support.
- Unmet practical needs, such as lack of childcare for other children, parking difficulties, and lack of a place to sleep while visiting the NICU, caused significant burden.
- No medical professionals were "officially" checking in on mothers, in spite of their unique postpartum health care needs.

Implications for Practice

- Interventions targeted at this population should consider mothers' overwhelming desire to be near the baby bedside and design services
- NICU design/setup might consider devoting attention to mothers' postpartum comfort and health needs, such as providing a place to nap and comfortable chairs at the baby bedside.
- Mothers might benefit from a health professional assigned to round on them while baby is in the NICU.

