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, postpartum 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 mothers, 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 to 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.

Background & Purpose

- Mothers with babies in NICU 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.

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

By baby bedside

- I think if any other mothers are like me, they want to be 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, very hard. (ID38)

Unmet health care needs

- Access to mental health care - Long wait to see someone - Desires for care close to baby - Access to physical care - Don’t want to leave bedside to seek time-consuming care

Social support from other moms

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

Minimize own health needs

- 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 it 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 eat a class. (ID11)

...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)

Don’t want to drive all the way home. It was...you need to make sure you get sleep because you have to take care of the baby...but other than that no. (ID43)

I didn’t want to leave bedside to seek time-consuming care...You’ve given birth to this baby and you cannot take them home. It was hard for me, very, very, very hard. (ID38)

Unmet practical needs

- Comfortable chair - A place to rest/nap
- Parking far away to save money is time away from baby

Balancing caregiving 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 got a urinary tract infection and 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)

I feel like I was finding places to sleep like an airport. You know, sort of sleeping in a corner somewhere...I would’ve liked somewhere to close my eyes for 30 minutes; that made a big difference to the thing 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. (ID33)

...for moms [with cesarean sections] that means that they...are 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. (ID33)

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)

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)

...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 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)

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: Demographics

- Average Weeks’ Postpartum at Interview (range): 17 (12–20)
- Average Age (range): 31 years (20–45)
- White: 29 (66%)
- African American: 14 (32%)
- Married/Partnered: 38 (86%)
- Insured: 43 (88%)
- Other: 3 (7%)

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 either 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 accordingly.
- NICU design/setup might consider devoting attention to mothers’ postpartum comfort and health needs, such as providing a place to sleep 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.