THE UNIVERSITY *of* NORTH CAROLINA *at* CHAPEL HILL

Maternal Resilience: The Navigation and Negotiation of the Postpartum Experience by Mothers of Medically Fragile Infants

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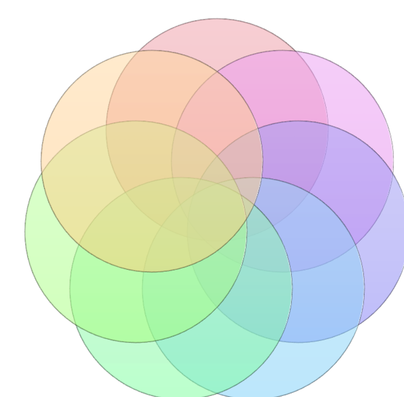
Background & Purpose

- The health and wellbeing of mothers of medically fragile infants is often neglected as attention is prioritized towards infant care in the Neonatal Intensive Care Unit (NICU). [1]
- Compared to mothers of well-babies, Mothers of Medically Fragile Infants (MMFIs) have more chronic and perinatal morbidity, acute care utilization, and unmet health care needs (physical and mental) postpartum [2-4]
- Compatible with a patient-centered asset-based approach, we use a resilience framework to understand the negotiation and navigation process for health-sustaining resources[5, 6] per the lived experiences of MMFIs in the NICU and their transition home.
- Particular attention is given to the seven "tensions" hypothesized to be aspects of the resilience process: *access to material resources, relationships, identity, power and control, cultural adherence, social justice and cohesion* [5, 7]



RESILIENCE =
individual capacity to navigate towards and negotiate for health-sustaining resources [5]
+
the capacity of her environment to provide these resources in meaningful ways [5]

The purpose of this analysis was to explore how seven aspects of resilience map onto the postpartum experience of MMFIs, and ways this framework could inform interventions to successfully link MMFIs to services addressing unmet needs.

Methods

- As part of a larger mixed-methods study, 44 English-speaking and 6 Spanish-speaking MMFIs participated in individual semi-structured interviews either at the baby bedside, in a hospital room near the NICU or by phone
- The seven "tensions" of resilience are mapped onto the qualitative data to capture how interactions between MMFIs and their environment (i.e. families, communities, healthcare settings) facilitate and/or hinder access to health-enhancing resources
- All interviews were recorded and transcribed verbatim. NVivo12 was used to organize and manage the data by a single coder to conduct preliminary analysis. Pseudonyms, indicated by an asterisk, were used to protect the identify of the participants.

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.

The Seven Tensions of Resilience

Tension	Definition	Participant quote
ACCESS TO MATERIAL RESOURCES	"Availability of financial, emotional, medical and employment assistance and/or opportunities, as well as access to food, clothing and shelter" [5]	"**Now I do not have medicine for diabetes. Because since the girl was born, Medicaid ended.**" (Amanda*, infant 43 days in NICU)
RELATIONSHIPS	"Relationships with significant others, peers and adults within one's family and community" [5]	"[My] husband, who is an amazing husband, amazing father, so supportive – **I felt like his place in it all was being diminished…not every husband watches his – watches his wife flatline while giving birth.** But even just in general, care for the dads, emotional care, support, information for how they can better support their wives or partners or whatever. It really did – it really did seem like his place there was less important. And I think that's major." (Claire*, infant 35 days in NICU)
IDENTITY	"Personal and collective sense of purpose, self-appraisal of strengths and weaknesses, aspirations, beliefs and values, including spiritual and religious identification" [5]	"Like I said, I thought it was a little odd that they didn't now she was in the NICU. So there were some questions that they asked that I kind of thought were weird for them asking me. I said you do know my baby's in the NICU, right? No, we didn't know that. And then **they tried to say that I was depressed, which I didn't really think I was.** But it was because they gave me that questionnaire to fill out with a whole bunch of questions like oh, do you cry sometimes? Are you sad sometimes? I said of course I am. She's in the NICU. So they mentioned possibly putting me on medication and I told them I didn't really think that I needed that. It was really more the situation than necessarily being clinically depressed." (Mary*, infant 91 days in NICU)
POWER & CONTROL	"Experiences of caring for one's self and others; ability to affect change in one's social and physical environment in order to access health resources" [5]	"…the midwife would come in and be like, 'Oh, you need to take time to rest and you know, eat, and take care of yourself.' The lactation would come in and be like, 'You need to pump, you need to pump.' …. And then the NICU was like, well, here's what you need to do to take care of the baby. I just felt like there were a lot of different methods. Everybody had a different like agenda and they weren't all melding into one. **I was having trouble figuring out how to take care of the baby, how to take care of myself, how to make sure my milk was coming in because all the messages were kind of going against each other and so that was a little frustrating.** And that's life. There's not that one, clear way to make it all meld together … I just knew I was stressed out and my husband was the one that pointed it out. He was like, 'Well everyone is giving you different messages and you don't know what to do with those.' I was like – yeah, that is exactly what's going on. (Susan*, infant 12 days in NICU)
CULTURAL ADHERENCE	"Adherence to one's local and/or global cultural practices, values and beliefs" [5]	**I was doing what was expected of me, but I wasn't able to concentrate on myself and how I was feeling which was really depressed.** I was overwhelmed. I was literally just falling apart because I couldn't get a grip on things for myself, but I had it all together for everybody else… I think I just put it to the back of my mind. I didn't deal with it until the baby was released. Then again [my husband], running himself ragged, and at that moment I'm looking at my family and thinking I have to be the anchor here. I didn't really deal with it. I knew it and I could feel it, but I had to keep just pushing it aside which is what I think helped me survive at that moment." (April*, infant 42 days in NICU)
SOCIAL JUSTICE	"Experiences related to finding a meaningful role in community and social equality" [5] within the sociopolitical context	"I really don't count on anyone here but my husband…but there's the issue that people are being deported and everything. …He tells me, "When you go out, be careful," because it's scary, because the baby has a condition that is not easy; **…Imagine, I get stopped by the police and ask for my papers and I don't have, and I'm depressed for my country and on the [baby's] condition … because there's a lot of special care he needs.** In my country I don't think this type of help you give us here is available there." (Jennifer*, infant 49 days in NICU)
COHESION	"Balancing one's personal interests with a sense of responsibility to the greater good; feeling a part of something larger than one's self socially and spiritually" [5]	We had lots of responsibilities, and so back to being back at home, we had the whole house to take care of, and the kids to take care of, and things like that. So it was harder to see her as much as we wanted to. …They kept saying, "You guys need to be here for at least _____." And so eventually we started writing it down on the board for them so they could see that we are here sporadically, but we are here. And there were some days, like Sundays are extremely busy. **Church is extremely important to us. And so we would go to church, and that's pretty much an all-day thing. We have a little bit of time between morning service and night service…. So we felt really bad because we couldn't do more….But, anyway, so yes, they did keep bringing it up. And it was almost adding stress and making us – at least myself – very emotional.** Because I felt like I couldn't do anything else. (Laura*, infant 84 days in NICU)

Preliminary Findings

- **Utility of Resilience Mapping:** A contextualized resilience framework provides a nuanced understanding of the lived postpartum experiences of MMFIs at the intrapersonal level and institutional level
- **Diverse Patterns of Resilience**: Tensions emerge in MMFI postpartum experiences in diverse patterns, sometimes concurrently, demonstrating a degree of heterogeneity among participants. (The 'Heterogeneity' Principle [6]).
- **Negotiation + Navigation = Power & Control + Access to Material Resources:** 'Power & Control' and 'Access to Material Resources' emerge more frequently compared to other tensions, which may indicate their influential impact on the negotiation and navigation process is a common dynamic among MMFIs.
- **Disruption of the Dyadic Unit:** The separation of the mother-infant dyad hinders institutional capacity to provide health-sustaining resources that is compatible with MMFI's postpartum experiences.

Implications for Practice

A maternal resilience framework contextualizes unmet postpartum needs in the lived experiences of MMFI, highlighting strategic points of intervention. Examples include:

The truncation of Medicated insurance	→	**Expansion of Pregnancy/Postpartum Medicaid to 1 year**
Compromised Postpartum Visits	→	**Linking maternal and infant medical records to inform postpartum assessment**
Lack of support for Fathers/Partners	→	**Provide family-centered postpartum support services**
Conflicting Postpartum Communication	→	**Adoption a mother-infant dyadic model of postpartum service delivery**

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