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ARTICLE

"All these people saved her life, but she needs me too": Understanding and responding to parental mental health in the NICU

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OBJECTIVE: To explore the mental health needs of parents of infants in a neonatal intensive care unit (NICU), as well as barriers and solutions to meeting these needs.
DESIGN: Qualitative interviews conducted with parents and staff ($n = 15$) from a level IV NICU in the Northwestern United States. Thematic analysis completed using an inductive approach, at a semantic level.
RESULTS: (1) Information and mental health needs change over time, (2) Staff-parent relationships buffer trauma and distress, (3) Lack of continuity of care impacts response to mental health concerns, (4) NICU has a critical role in addressing parental mental health.
CONCLUSION: Mental health support should be embedded and tailored to the NICU trajectory, with special attention to the discharge transition, parents living in rural areas, and non-English-speaking parents. Research should address structural factors that may impact mental health such as integration of wholistic services, language barriers, and staff capacity.

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INTRODUCTION

Parents of infants hospitalized in the neonatal intensive care unit (NICU) are at increased risk of poor mental health outcomes. For example, the rate of postpartum depression is 39–45% for mothers with infants in the NICU [1, 2] as compared to 10–15% in the general United States maternal population [3, 4]. Research also reports high prevalence rates (43%) of severe anxiety among NICU mothers [3], and about one-third to one-half of NICU parents report acute stress. The effects of traumatic stress linger, with approximately 20% of parents displaying symptoms of posttraumatic stress disorder (PTSD) at least a year after NICU discharge [5].

Parental mental health conditions have potentially devastating consequences. Mental health conditions are one of the leading causes of pregnancy-associated mortality (i.e., maternal death during pregnancy through the first year following birth) [6, 7]. Adverse parental mental health also threatens parent-child attachment, which serves as a critical building block for human development across the lifespan. Mental health conditions such as depression, anxiety, and PTSD diminish parents' capacity to demonstrate responsiveness, affection, and play behavior with their children [3–5, 8, 9] and are associated with decreased parenting self-efficacy and unfavorable child emotional, behavioral, and cognitive developmental outcomes [3, 5, 9–12]. These conditions are also associated with decreased use of infant preventive health care, increased use of urgent care/emergency department care, and increased rates of child hospitalization [11, 13].

Emerging research demonstrates efforts to address NICU parent mental health through a variety of approaches [12, 14–17]. Promising interventions include those rooted in cognitive behavioral, infant mental health, and/or trauma-informed care frameworks [12, 14, 16]. This research also calls for stepped-care and layered approaches that allow mental health services to be individualized based on unique parent needs [12, 15, 17]. Despite the known mental health risks and associated consequences of mental illness for both NICU parents and children, as well as the building evidence in support of targeted mental health support for NICU parents, many NICUs do not address parent mental health needs as a universal standard of care [15, 18]. Though NICUs generally share key elements, units are diverse and vary in size, level of acuity, environment design, and service delivery structure. The presence of disparities and geographically diverse catchment areas further complicate the delivery of parent mental health support [19, 20]. Black, American Indian and Alaska Native, and Hispanic families and families with low socioeconomic position are over-represented in the NICU, due in part to preterm birth and low birth weight disparities [19–23]. Additionally, most NICUs are located in cities but provide care for infants whose families may live in suburban and more distant rural areas.

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In light of mental health needs among NICU parents and the associated consequences for parents and children, more information is needed to inform the development of systematic approaches to address this acute need. Mendelson and colleagues (2017) point to the specific need for more qualitative study with NICU parents in order to inform mental health services and program development. This paper presents findings from a qualitative study of NICU parent mental health needs, as well as barriers and potential solutions to meeting those needs, from the perspectives of NICU parents and staff.

METHODS
Setting and sample
This study was led by a social work researcher with a background in clinical social work who is also a graduate NICU parent. Our interdisciplinary research team included social work, neonatology, psychology, general internal medicine, and health services research. The study was conducted in a level IV NICU with a 5-state catchment area in the Northwestern United States in 2019–2020, prior to the COVID-19 pandemic. We used purposive sampling methods to recruit NICU parents and NICU staff. Participants were recruited through the NICU's Family Advisory Council, emails to staff, and in-person invitations to eligible parents. Using maximum variation sampling [24], we sought to diversify the sample by parent gender, spoken language (i.e., English or Spanish), residential distance from the NICU and population density, reason for NICU hospitalization, singleton or multiple birth, and staff role in the NICU. Parent participants were English- or Spanish-speaking mothers or fathers of infants currently or formerly hospitalized in the study site NICU. Infants needed to have been hospitalized in the NICU for at least 2 weeks in order to optimize parents' abilities to reflect on the NICU environment. Staff participants needed to be employed by the study site NICU in clinical or patient-facing roles. The study was approved by the first author's and study site's institutional review boards. All participants completed written informed consent and received a $50 gift card in appreciation of the time participation required.

Data collection
We used a semi-structured interview guide (see Appendix) to explore what was upsetting or confusing for parents, how parents managed the NICU experience, and what they thought could improve parent experiences. The interview guide had two versions, with questions worded to target parents vs. staff. For example, we asked parents, "What have you figured so far about how to manage the NICU experience?" while we asked staff, "How do you see parents manage their NICU experience? How do they seem to get through it?" We conducted interviews on-site or in a quiet public location (e.g., coffee shop in the participant's community) per parents or staff preference. A native Spanish-speaker conducted interviews with Spanish-speaking parents. We conducted interviews until saturation was reached. Interviews were audio recorded and lasted between 22–92 min (median = 50 min). In addition to qualitative interviews, the first author completed approximately 40 h of on-site observation, shadowing NICU staff during rounds, maternal-fetal medicine consultations, discharge planning meetings, and medical team consultations to better understand the study site context. The first author kept detailed reflective notes of observations and qualitative interviews, which aided in analysis and interpretation of findings.

Data analysis
Paid research assistants transcribed interviews and assisted in data analysis. A native Spanish-speaker transcribed interviews conducted in Spanish and then translated those transcripts to English. We used ATLAS.ti to aid in qualitative data management.

We conducted a reflexive thematic analysis using an inductive approach, at a semantic level, and an interpretivist paradigm [25]. Initially, a research assistant and the first author independently read a set of parent transcripts, and met with the senior author to develop a coding scheme. Using a parallel process, we then independently coded the remaining parent transcripts, meeting regularly to discuss the data and reconcile codes. Next, we independently read and coded a set of staff transcripts. As we felt that our existing coding scheme applied to both parent and staff transcripts, we subsequently completed coding the remaining staff transcripts, meeting again to discuss and reconcile codes between all transcripts. We then collapsed codes into preliminary themes, prioritizing those related to NICU

parent mental health, that came up repeatedly from multiple participants, that contributed novel or salient concepts, and that resonated with both parent and staff participant groups. We shared preliminary themes with NICU parents and staff, some of whom were study participants and some of whom were not, as a form of member checking. The full research team discussed findings to determine final themes.

RESULTS
The total sample ($n = 15$) included ten NICU parents and five NICU staff. See Table 1 for further information about sample characteristics. We identified the following themes: (1) Information and mental health needs change over time, (2) Staff-parent relationships buffer trauma and distress, (3) Lack of continuity of care impacts response to mental health concerns, (4) The NICU has a critical role in addressing parental mental health.

Information and mental health needs change over time
As parents navigated power differentials in the NICU, their information and mental health needs were intertwined with each other and evolved over their NICU stay. Parents and staff explained that parents' lack of familiarity and understanding about the NICU environment and their infant's care was upsetting. Conversely, parents and staff believed efforts to orient parents to the NICU and provide direct, transparent information were comforting.

Beginning phase. In the beginning of an infant(s) admission, parents and staff described parents entering an unfamiliar environment under distressing and often traumatic circumstances.

Table 1. Sample characteristics.

		Parents (n = 10)	Staff (n = 5)
Race/ethnicity	Hispanic white	4	0
	Non-Hispanic White	6	3
	Non-Hispanic Asian American	0	1
	Non-hispanic multiracial	0	1
Primary language	English	8	5
	Spanish	2	0
Gender	Female	8	5
	Male	2	0
Singleton or twin birth	Twin	1	
	Singleton	9	
Timing of NICU experience	NICU-graduate parent	2	
	Current NICU parent	8	
Rurality	Rural	2	
	Urban/suburban	8	
Residential distance from NICU	Residence from NICU > 40 miles	3	
	Residence from NICU < 40 miles	7	
Health unit coordinator			1
Social work staff			1
Nurse practitioner			1
Nurse case manager			1
Pediatric hospitalist			1

Parents often felt overwhelmed by the pace of the NICU and influx of information, which made it difficult to orient themselves to the environment and retain details. One parent explained:

> "I don't think in the beginning I even had the mental capacity to identify or acknowledge what I needed. I think at that point you're just kind of in fight or flight. You're in the battle and you don't even have time to think."

While some parents were able to prepare for their NICU stay by touring it prior to delivery, others experienced unexpected stays. In either case, for the first days and weeks parents needed concrete information such as names and roles of healthcare providers, written copies or summary notes of verbal reports, written reminders, and an orientation to the physical NICU environment. A health unit coordinator shared this observation of parents' experiences:

> "Everyone is in scrubs and they are running around. They change all the time from day-to-day, hour-to-hour. So just [parents] identifying, 'Who is my doctor? Who is my nurse?'"

Middle phase. Parents and staff often described a shift in parents' information and emotional needs as time passed. Parents acclimated to the norms and vocabulary of the NICU environment and learned how and to whom to ask questions. Parents grew more knowledgeable about infant caregiving and medical team processes during this time. Asking questions and establishing routines helped provide comfort even as their infant(s) required NICU care. A parent offered this reflection:

> "I was struggling a lot going home. I started getting panic attacks. I realized asking questions and making sure I'm okay has helped. We have gotten into a routine where every morning for peace of mind, when I wake up in the morning, I call to see how he did. Then we come see him in the afternoon. Then at night before bed, I call and check up on him as well. So that at least three times a day I have information on how he is doing."

As the pace and activities of the NICU became more familiar, opportunities emerged for parents to reflect on their experiences. Some parents experienced this time as a liminal space between the initial crisis of hospitalization and inevitable discharge home. This phase was characterized by anxiety and uncertainty about one's role as a parent. Opportunities to provide care for and comfort their infant(s) helped parents gain confidence in their parental role identity. A graduate NICU parent remembered a moment while her infant was hospitalized in the NICU that facilitated attachment and created a sense of parental role identity:

> "That was the first time when the nurses couldn't [comfort] her. She needed her mommy. That was really empowering. I feel like it would be cool if nurses would say that more. For me, it was amazing to understand that she needed me. All these people saved her life but she needs me, too. It was really cool. It made me feel like a mom."

Discharge-to-home transition phase. As infants neared discharge to home, parents often simultaneously experienced intense emotions and fatigue. They felt relief and gratitude that their infant(s) had survived, and they welcomed the chance to bring their infant(s) home and start a new life together. However, by this point in their NICU journey, parents also felt exhausted and emotionally overwhelmed. Previously effective strategies to manage the intensity of the NICU such as compartmentalizing feelings stopped working as well, and parents felt less control over their emotions.

Parents were sometimes surprised by feelings of grief, depression, and anxiety. Parents and staff shared experiences of intense parental anxiety as they prepared to work with new medical teams or developmental specialists. This was especially true for parents with logistical and access barriers (e.g., those who lived in rural areas). These emotions were accompanied by the loss of supportive people they had interacted with in the NICU, some of whom they had developed meaningful relationships with, and the potential social isolation awaiting parents when caring for a medically fragile infant at home. A graduate parent shared her experience of when her infant discharged home from the NICU:

> "About four months [after delivery], I started exhibiting symptoms of PTSD. [Infant] had been home for like two weeks, and suddenly I started to fall apart…I was isolated from the hospital and I wasn't going to bring my baby back to the hospital to go and see my provider. There was no one checking in on me…I found myself just consumed by the PTSD, having flashbacks…I was all alone…and I was afraid."

Persistent language barriers. Because of the relationship between information and emotional needs, parents and staff described how parents who did not speak English as their primary language experienced significant barriers during each of the three time periods—beginning, middle, and discharge-to-home transition. Spanish-speaking parents shared examples of trying to understand the NICU environment, navigate power differentials, and cope with their infant's hospitalization with limited abilities to communicate with staff who predominantly spoke English. Some of their stories were accompanied by frustration, confusion, guilt, and shame. One parent shared:

> "Sometimes I try to say things to them in English and they tell me they don't understand me. They won't let me in until I say the words well to them in English…I blame myself, but then I start to think that I don't have to blame myself for something like that."

Staff-parent relationships buffer trauma and distress

Parents and staff acknowledged that parental distress was inevitable with much of the NICU experience and gave specific causes such as uncertainty around infant prognosis, observing infant resuscitation, witnessing other infants' and their families' distress, and not being able to be physically present in the NICU due to transportation, work, and childcare demands. However, relationships with staff sometimes served a supportive function for parents' emotional experiences.

Attuning to the parent. The ability of staff to be emotionally present and attuned to parents affected parental mental health, regardless of infant health outcomes. A graduate NICU parent who developed severe postpartum depression shared how an empathetic and well-timed interaction with a healthcare provider made an enduring positive impact.

> "Which also brings me back to one neonatologist who made one of the biggest impressions on me and all he did was look at me and say, 'I'm sorry.' He literally looked at me and said, 'I am so

sorry this is happening to you and it's not your fault.' As crazy as that sounds, the fact that he said that will resonate with me for the rest of my life. It was…it got to me. When I'm building up my wall, when I am being strong and tough, when someone says to you, 'It's okay, it's not your fault,' that really gets down past all that stuff that you are trying to build up."

Trustworthy care for the infant. Parents noted how being able to trust staff gave them a great deal of comfort. Parents identified that knowing specifically who would soothe their infant(s) if they were not there, knowing who to ask questions, and believing staff knew and genuinely cared for their infant(s) mitigated the impact of trauma and distress. A parent explained the connection between trusting staff and parental distress:

"I think that's really my main thing that's kept me stressed. Just because he can't be at home with me and I can't be here all the time and take care of him, so I want someone that I feel comfortable with around…I have a group of nurses that I already feel comfortable with, and the way I see them talk to him and watch him is how I would watch and talk to him if I was at home."

Staff schedules and consistency. Parents and staff shared valuable insight into how these relationships were formed. They highlighted the importance of staff consistency in an environment where healthcare provider shifts rotate. Interestingly, staff who worked consistent, routine days of the week provided comfort to parents even if they did not provide medical care. A health unit coordinator explained how routine weekly shifts (e.g., every Monday, Wednesday, and Thursday rather than the rotating shifts of healthcare providers) at the NICU's entrance made her often the first physical point of contact for families and also a dependable presence. A nurse empathized with parents:

"We work this elaborate system of eight- to twelve-hour shifts… Our schedule is kind of a mosaic and parents are there along a straight line. I think a lot of times [parents] worry that people don't know their baby because they see so many new faces during the week. I get why that is necessary for staffing. No one can be there all the time. But I also understand how that would be worrisome."

Informal exchanges and interactions. In addition to predictable schedules and formal encounters such as rounds and care meetings, relationships between staff and parents formed through numerous, informal exchanges throughout the infant's NICU stay. The ability to share anecdotes, receive short updates, and ask questions eased power differentials and facilitated relationship building. Parents' interpersonal resources and the ability to engage and interact with staff also facilitated relationship development. Parents with anxiety or other expressions of distress and trauma were at a disadvantage in developing these buffering relationships with staff. Parents who did not speak English could not access these casual and unplanned interactions, especially with the nurses who provided daily care to their infant(s). A nurse shared:

"People that lack the ability to sort of organize themselves and are frustrated, and it could be from nothing that happened here, but just their inability to manage their life outside of here or sadness or frustration or depression…or not able to speak English. [They] don't end up with that bonded group of primary nurses."

Lack of continuity of care impacts response to mental health concerns

Parents and staff shared observations and experiences related to structural barriers that may have hindered efforts to attend to NICU parent mental health needs. Parents and staff noted that despite good intentions, the absence of structural supports made it difficult to recognize and respond to parent mental health concerns, especially in a systematic and integrated way.

Structure organized around infant care. Parents and staff accepted and appreciated that the NICU staff focused on providing infant care. Staff knew that parents and families were integral to optimal infant health outcomes, but they operated from within a system that was not organized around or accountable for parent outcomes. Documentation and services followed the infant, not the parent, dyad, or family. This incongruence resulted in structural barriers that inhibited staff from identifying and responding to parent mental health concerns.

For example, the study site did not have a standardized protocol for how and where to note concerns about parents' mental health. Parents and staff observed that staff noticed concerns about a parent's mental health, but because the infant was the identified patient and not the parent, they may or may not have documented or communicated it to someone responsible for addressing it. The lack of a standardized practice for recognizing and addressing parent mental health resulted in interruptions to care and potentially left parents unsupported. A graduate parent wondered why no one noticed her mental health history:

"No one stopped to look at my chart. Why don't mothers have charts? Why don't you know my emotional history? My mental health history? I feel like if that would have been in my notes or my chart, that everyone would have treated me differently or maybe approached me from a different angle…I feel like there were just a lot of opportunities where they could have looked at my history and treated me differently…I left with no mental health referral even though I was the most depressed I have ever been in my life."

Structural barriers for non-English speakers. Parents and staff identified institutional barriers to comforting Spanish speaking parents and addressing their mental health. Like many other NICUs, the study site had limited Spanish-speaking staff. The hospital provided interpreters upon request, but they were not available full-time on the unit during day-to-day interactions. A nurse explained how the inability to provide information to parents in their preferred language may contribute to parental stress and anxiety:

"[Spanish-speaking parents] can only be updated really at certain times of the day. We have translators that we can call, but the connections are often not good. There is often times a deference to healthcare providers that people are sometimes afraid to ask for us and to ask us questions. There is sometimes a lack of understanding among all of our patients about the seriousness of what is going on. I think that looking at a fragile baby through the glass, I think…fear is the prevailing emotion initially. It is harder for us to help someone overcome that fear when there is a language barrier."

Staff capacity. Staff capacity also affected continuity of care around parent mental health. When staff were overwhelmed or stressed due to traumatic events in the NICU (e.g., multiple infant

losses in a short period) or unusually high census numbers, parents and staff felt that parent mental health needs were less likely to be noticed and communicated to the appropriate person. A nurse shared her perspective on how staff being overwhelmed sometimes limited their ability to attune to parent mental health needs:

"We do really well in interpersonal, individual moments. I think it is very sweet and touching how that happens…When I think about the nursing staff and their frustrations around parents, at times I think it is because there are so many things competing for their time…It gets harder in a practical sense. It is harder to be empathetic. It is harder to see what people need. It is harder to take action on it when you are feeling pulled in multiple directions or have competing responsibilities that pull on your time and energy."

Perinatal system of care lacks integration.   Parents and staff also noted that beyond the NICU, the perinatal system of care responsible for serving NICU parents contained inadequate mechanisms to connect obstetricians, pediatricians, and other healthcare providers who interact with parents. Parents whose infants were discharging home and parents who lived in rural areas had especially acute gaps in continuity of care. A nurse shared:

"So many of our families come from rural areas. The supports for them aren't there when they leave…We are sending home medically complicated babies. The most complicated have supplies and equipment and that kind of thing. Even though there are programs in [the state] to fund nursing care and to pay for it, there are no nurses to do the care. So, we ask families to learn all these skills and provide all this care…we don't let them go until they can do it successfully. But then they are alone…And who supports them? I would be terrified, and I have been a nurse for a long time."

The NICU has a critical role in addressing parent mental health
Parents and staff agreed that the NICU is uniquely positioned to address parent mental health. In the NICU, staff had frequent contact with parents as they visited and cared for infants, during rounds, care team meetings, and in preparation for infant discharge home.

Depression is ubiquitous.   Parents and staff were well-aware that a NICU stay was perhaps one of the most distressing and potentially traumatic medical moments and that these experiences likely impacted parental mental health. Along with anxiety and traumatic stress, parents and staff named depression as a pressing mental health concern commonly associated with the NICU experience. A hospitalist explained that depression was so common among parents that it almost seemed hard to distinguish between parents who did and did not exhibit symptoms and to differentiate between levels of symptom severity.

"It's a little hard for me to know when the families have significant depression because they hide it pretty well. There's a lot of stress going on, so we expect everyone to be at some level of anxious, stressed, depressed. I don't feel surprised that I don't always know. When there is something significant going on, we hear sometimes from…the OB group because they do follow-ups with the moms…Sometimes they'll say, 'Hey, this mom is really having a hard time. They scored really high on their postpartum depression screen.' And we'd had no idea. They seem like every other mom."

Discharge-to-home transition is critical risk period.   An infant's discharge transition from NICU to home was identified as a critical time period for parental mental health. Parents experienced a great deal of stress as they anticipated caring for their infants at home without the support of trusted healthcare providers and without societal and structural support for ongoing infant caregiving and parental mental health needs. One participant described this experience as akin to "dropping off a cliff." A graduate parent shared:

"I went home and I sunk into the worst depression of my life. I never went anywhere. I think what ended up happening was that I almost lost my mind in the grocery store and realized, 'Something is wrong me.'…I remember my heart was beating so fast and I felt like I had electricity in my arms. I felt like I was going to explode…I remember thinking, 'I can't. I can't do this.' And I found my therapist, who saved my life."

An easy path for services.   Parents and staff agreed that an array of services should be offered to meet different levels of need. They identified these as opportunities to provide mental health screening, support groups, individual, couples, and family counseling, referrals for intensive mental health services, and other forms of mental health support. Most parents and staff believed it was vital to offer mental health services that were located onsite and that parents should have a "really easy path for services." Parents' recommendations included paid peer parent support, weekly check-ins from an onsite mental health provider, "office hours" for an onsite mental health provider, and targeted mental health support for parents whose infants who had or were about to have a medical procedure. One parent noted that because parents often juggle working and numerous other caregiving responsibilities, the NICU might be one of the only entities that can offer accessible mental health services that also allow parents to maximize time with their infant(s).

"I'm finding myself trying to choose between, do I take care of myself and my mental health and go see my counselor? And if I do that, it means that I have to leave two and a half to three hours early and I don't get time with [my baby]. So, it's this balancing act of I have to take time away from him to take care of myself. Where if you had services here in the NICU…where parents could sign up with a counselor… Something where you know that you are not physically leaving for the day or having to choose between time with your baby and taking care of yourself. Because I think obviously every parent will put themselves on the back burner and will not take care of themselves. Having something like that I think would be amazing for the parents."

DISCUSSION

This study's results reflect NICU parents' and staff's shared concern for parental mental health and emotional well-being. All participants communicated first-hand observation or experience of NICU parent distress, and all participants welcomed the notion of offering mental health services to parents within a NICU setting. Parents and staff recognized the central parental tasks of gaining knowledge and gaining a parental role identity in the midst of a distressing environment with complicated power dynamics.

Participants also recognized the critical importance of positive, empowering relationships between staff and parents. Finally, parents and staff identified the need for structural support to enable the NICU and perinatal systems of care to leverage their unique position to identify and respond to parent mental health needs.

Our findings are in line with growing efforts to help NICUs think of parent mental health as part their practice domain [18, 26]. For example, a small pilot-intervention study by Segre and colleagues suggested that training nurses to provide empathic listening and collaborative problem-solving on-site with parents while their infants were hospitalized in the NICU held promise for potentially improving parental mental health and satisfaction with healthcare services [26]. Our study compliments this work by offering additional depth and nuance. For example, our findings offer a developmental trajectory (i.e., timeline) for understanding what to offer parents and when. At the earliest point possible, staff should normalize and work to destigmatize the experience of NICU parent distress. Parents and their social support networks should know that depression, anxiety, and traumatic stress are relatively common among NICU parents. They should be able to recognize symptoms of these conditions, the importance of informal supports, and how to secure formal supports as needed. Parental mental health should be topics of discussion throughout a NICU admission, and efforts to normalize and educate parents about mental health should extend all the way through the discharge-to-home transition.

Results align with research that promotes stepped-care approaches to addressing parental mental health, which include screening followed by incremental offerings of mental health support according to level of need [12, 15, 17]. Stepped-care models engage patients in the least intensive levels of care possible and prioritize using existing infrastructure and resources [27, 28]. This approach has been used to address parent distress and postpartum depression in pediatric settings and among mothers with low socioeconomic position [27–30]. Research suggests that stepped-care models may effectively reduce postpartum depression [30] and may be more cost effective than traditional models that apply a one-size-fits-all approach [31]. A stepped-care model may be especially relevant for support NICU parents given the heterogeneity of mental health symptoms.

A critical developmental step as time progresses in the NICU is the adoption of parental role identity. Research shows that the development of parental role identity is often delayed and complicated in the NICU environment [15]. Opportunities to care for and comfort one's infant may facilitate parental role identity formation and parenting self-efficacy, which are associated with better parental mental health, bonding/attachment, and infant health [32–34]. Our study adds to our understanding of how power differentials may complicate these critical developmental processes. Power differentials exist in the NICU across multiple dimensions, including social class, language, race, ethnicity, gender, and role. Nearly all of our parent participants expressed some form of discomfort as they navigated power differentials while simultaneously trying to bond with their infant, assume their role as a parent, and ensure their infant received the best care possible. This was especially evident for non-English speaking parents.

Parents benefit from establishing routines and learning how to advocate for themselves and their infants. Our study highlighted the importance of NICU staff in helping parents recognize their own intuition—or instinctive knowing—of their baby, as well as their ability to comfort and soothe their baby. As parents acclimate to the NICU, staff should consider practical steps to engage parents in infant care, partner with them in decision-making, and reinforce parental intuition. These efforts are in line with current research on the benefits of implementing family-centered care practices in the NICU [16]. For those unable to be physically present in the NICU, research continues to support the use of telehealth strategies to help parents feel more connected to the unit and their infant, to increase parenting self-efficacy, and decrease parental stress [32, 33, 35].

Building on research related to family readiness for infant discharge from the NICU [12, 15, 36], a key finding in our study was the gap in knowledge and services to support parental mental health through the discharge-to-home transition. Parents experience conflicting and intense emotions right at the time their responsibility for more independent care for their infant increases and formal supports decrease. Distress related to the discharge-to-home transition was especially acute for parents who lived in rural communities. Our participants believed that parents need significantly more attention to their mental health as they prepare to leave the NICU with their infant and in the weeks and months after they are home. This support should include preparation around forming relationships with new medical teams, acknowledgment of conflicting emotions, and identification of informal and formal mental health supports.

Extant research has established the importance of supportive relationships between patients and staff, and the critical role of primary nursing teams is explored extensively elsewhere [37]. However, our study contributes deeper understanding of why positive relationships in the NICU matter and how they form. NICU parents need to trust that staff will give compassionate, personal, and dependable care to their infant(s). Believing that staff know and genuinely care for their infant reduces the distress of leaving their infant in someone else's care and in an unfamiliar environment.

Our study also illuminated the dynamic process through which these relationships are formed. A recent study found that while NICU staff report numerous opportunities for parents to interact with neonatologists and nurses, 20% of parents did not share this perception [38]. Our findings point to the multiple ways staff-parent relationships develop, including informal discussions and exchanges. Parents able to engage staff in positive interactions—especially bedside nurses—benefitted from deeper relationships with staff. Barriers to relationship building with staff were present for parents who did not speak the language of staff, parents unable to be physically present in the NICU, and parents whose interpersonal styles reflected trauma histories through expressions of fear, distrust, reactivity, disengagement, and/or sadness. These findings align with research showing that parents who speak the same language as staff, and parents who exhibit certain behaviors such as kindness, friendliness, flexibility, and appreciation are better able to facilitate positive relationships with NICU staff [39]. From an equity perspective, this dynamic necessitates exploring how staff may cultivate relationships with all parents, but especially those who encounter these barriers.

The consistency of staff schedules also influenced relationship building. Parents were comforted by knowing who they would encounter in the NICU and who would care for their infant(s). Participants noted how even though rotating shifts work administratively, they result in parent perceptions of inconsistency, concern about how well their infant is known and cared for, and challenges to relationship-building. Interestingly, staff positions that are patient-facing such as health unit coordinators may be important points of parent contact and serve as a comforting presence, even though they do not provide direct infant care. These findings align with trauma-informed care approaches to NICU care for infants and their families [40].

Our study demonstrates the positive impact that NICU staff can have on parental mental health when they are able to tune in emotionally and be present with parents, especially in distressing or traumatic moments. This aligns with extensive trauma literature that examines motivation and malleability among parents during the perinatal period [41, 42]. Demonstrating empathy at just the right moment necessitates being present or "awake" to the

moment. Realistically, these moments will sometimes occur in the presence of medical staff and not trained mental health staff. In addition, our study extends understanding of how limits to staff capacity constrains one's ability to attune to parents. Results show that staff's own NICU-related distress (e.g., multiple sequential infant losses, high unit census) may hinder their ability to pause, notice, and empathize with parents.

Finally, this study highlights how structural factors may hinder a NICU's ability to provide wholistic and integrated care. NICUs are designed to provide life-saving care for critically ill infants, but very few are designed to address parent mental health or other needs in an infant's broader social ecology that directly influence short- and long-term health outcomes [15, 18, 19]. Our study illuminated how logistical challenges, privacy concerns, staff capacity limitations, staffing patterns, and language barriers may hinder communication between staff in the NICU and perinatal systems of care. As a result, these systems of care may not have effective protocols to note parents' mental health history, ensure they receive necessary mental health services, and coordinate care across the perinatal spectrum of care and especially in the weeks following infant discharge home from the NICU.

Limitations

This study was designed to explore the qualitative experiences of NICU parents and staff in a single level IV NICU site to more thoroughly understand parental mental health and efforts to address it. Our study sample contained a relatively small number of staff and Spanish-speaking parents. Each staff role was only represented by one participant. However, a strength of this study was the consistency between parent and staff participant perspectives. Qualitative research is not intended to create generalizable findings; thus, our results are not intended to generalize across all NICUs or for all NICU parents. Rather, qualitative research such as ours, produces rich and nuanced understandings of participant experiences that provides potentially transferrable lessons or insights. While our sample represented diversity across a number of dimensions, all of the parents we interviewed reported regular visitation and engagement with their infant while they were hospitalized in the NICU. NICU staff shared their perspectives about parent experiences broadly, but we missed hearing and learning directly from parents unable to regularly visit the NICU.

CONCLUSION

This study demonstrates readiness and enthusiasm on the part of parents and staff for the NICU to address parent mental health more equitably, directly, and wholistically. Results suggest tailoring support for parents along the beginning, middle, and discharge portions of their NICU trajectory. Special attention should be given to parents' information and emotional needs during the discharge-to-home transition, as well as to parents who live in rural areas and who do not speak English. Stepped-care approaches that can be provided depending on parents' mental health needs should be embedded within the NICU system of care so that parents have an easy path to services. Results also point to the need for further examination at how structural factors related to NICU care impact parental mental health. Specifically, better integration of wholistic services across the perinatal system of care, more Spanish-speaking staff, and attention to staff capacity may improve efforts to address parental mental health.

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AUTHOR CONTRIBUTIONS

SK, CM, and CN conceptualized and designed the study. CN and CM provided mentorship and oversight throughout the project. CM and DD provided access to the data. SK and MR conducted data collection. SK, NC, and CN conducted data analysis. All authors contributed to data interpretation. SK and PI wrote the initial manuscript draft. All authors contributed manuscript revisions, approved the final manuscript, and agree to be accountable for the work.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

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