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“Me Against the World”: Parental Uncertainty Management at Home Following Neonatal Intensive Care Unit Discharge

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ABSTRACT

This study explored the uncertainty management processes experienced by parents at home following their child’s discharge from the neonatal intensive care unit (NICU). In-depth, semistructured interviews were conducted with 18 mothers and fathers whose children were cared for and “graduated” from NICU units in seven different hospitals from 6 to 183 days ($M = 63.58$ days). Interviews revealed three types of parental uncertainties: parental role shift, caring through equipment, and adherence to provider advice. Parents relied on three strategies to manage these uncertainties: reorientation, calibrating appropriate responses, and limiting exposure. Findings highlight how parental experiences, communication interactions, and expectations in the NICU complicate parental uncertainties postdischarge and negatively affect parental perceptions of self-efficacy, readiness, and competency. Our findings suggest that family-centered care can be enhanced by redefining discharge as an ongoing process that necessitates distinct uncertainty management practices to negotiate tensions between protecting preterm children and supporting parents.

According to the Centers for Disease Control and Prevention (2015), 1 out of 10 babies are born prematurely each year in the United States. A premature birth occurs when a baby is “born alive before 37 weeks of pregnancy are completed” (World Health Organization, 2015, para. 2). Neonates born before 37 weeks are more likely to encounter a variety of health issues, including “[an] increased risk of life-long disabilit[ies] and early death compared with infants born later in pregnancy” (Martin, Osterman, & Sutton, 2010, p. 1). To date, research has concluded a preterm birth is more stressful for neonatal parents, compared to full-term parents, because parental expectations are disrupted and complicated by the acute care situation of their newborn (Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Hughes & McCollum, 1994; Nottage, 2005; Shaw et al., 2009; Shin & White-Traut, 2007).

Premature babies often require an extended stay in a neonatal intensive care unit (NICU) where the neonate is cared for by a team of highly trained neonatologists, nurses, specialists, and therapists (Jones, Woodhouse, & Rowe, 2007). Communication in the NICU has been highlighted as a significant feature and focus of family-centered care (FCC) and transition programming (see Lopez, Anderson, & Feutchinger, 2012). The family-centered approach has transformed critical care for neonates by shifting the focus of care from “saving infants’ lives to minimizing survivors’ long-term complications, and thus extending clinicians’ responsibilities beyond the baby to the broader family” (Meyer et al., 2011, p. 212). Despite the quality of care provided in the NICU, parental experiences are often characterized by anxiety, uncertainty, and perceived lack of agency (Lasiuk, Comeau, & Newburn-Cook, 2013; Watson, 2011). Although the communication discipline has begun to examine communication challenges experienced by parents of preterm infants in the NICU during the hospital stay (Charchuk & Simpson, 2005; Golish & Powell, 2003), this study extends existing research by examining an often overlooked, but vital, aspect of family-centered care

that addresses “the role(s) family members play” beyond the discharge process (Dokken & Ahmann, 2006, p. 563).

The transition home from the NICU is a challenge for all parties involved (Bruder & Cole, 1991), including families and professional providers, because the process is characterized by stress and anxiety, which can negatively affect parental-child interactions (Dellenmark-Blom & Wigert, 2014), parental well-being, and quality of neonatal care (Smith, Hwang, Dukhovny, Young, & Pursley, 2013). Although the American Academy of Pediatrics’ (2008) discharge policy indicates the “demands of home care can be physically and emotionally draining” (p. 1122), it does not identify the interpretative and communication uncertainties parents may experience at home following discharge from the NICU. Moreover, though the policy statement highlights that “the availability of social support is essential for the success of every parent’s adaptation to the home care of a high-risk infant” (p. 1123), it does not account for how, and in what ways, parental uncertainties may affect their conceptualization and utilization of social support. Consequently, established benchmarks for discharge developed by healthcare providers may not address parental uncertainties because “patient perspectives about care transition interventions have been conspicuously absent” (Cawthon et al., 2012, p. 313).

Discharge from the NICU initiates a variety of uncertainties and concerns not necessarily addressed in the discharge policy process. According to Smith et al. (2013), “families often report that they feel their infant’s discharge date abruptly appeared” (p. 419), whereas nurses believe parents are prepared for discharge (Sheikh, O’Brien, & McCluskey-Fawcett, 1993). Thus, the transition from the NICU to home has been characterized as challenging and stressful for parents who must suddenly assume responsibility for continuing care and monitoring the special health needs of their child beyond the confines of NICU expert staff and round-the-clock services (Bruder & Cole, 1991; Lopez et al., 2012). Because the perspectives and feelings of parents during the transition process may inhibit quality of care at home and decrease the quality of life for parents (Hutchinson, Spillett, & Cronin, 2012), this study seeks to better understand the recurring uncertainties and management strategies experienced particular to the home context in light of parents’ previous care experiences in the NICU.

Uncertainty management theory

Individuals experience uncertainty when faced with complex, ambiguous, and inconsistent information and situations (Brashers, 2001). The interpretation and assessment of uncertainty (e.g., relevance, dangerousness, problematic nature, positive/negative associations) shapes emotional responses and prompts particular types of communication responses and behaviors (Babrow, Kasch, & Ford, 1998; Dillard & Carson, 2005).

Although initially focused on communication designed to reduce uncertainty and increase predictability (Berger & Calebrese, 1975), uncertainty management has since evolved and expanded to include a variety of theoretical iterations and applications in interpersonal, health, and organizational relationships and contexts. Consequently, examinations of uncertainty must now account for a range of motives, types, sources, contexts, evaluative appraisals, and management responses that may reduce, maintain, and/or increase the perception of uncertainty associated with the triggering event(s) and associated meanings (see Affi & Matsunaga, 2008; Babrow et al., 1998; Brashers, 2007; Goldsmith, 2001; Kramer, 2004; Mishel, 2014). Specifically, amidst the appraisal(s) of uncertainty, people seek to manage uncertainty through a variety of cognitive (e.g., denial, tolerance for uncertainty, acceptance of uncertainty) and behavioral (e.g., solicitation of social support, information-seeking) strategies (Brashers, 2007; Brashers, Hsieh, Neidig, & Reynolds, 2006; Kramer, 2004).

Uncertainty management has been used to examine responses to a variety of health challenges whereby providers, family members, and supporters co-manage uncertainty (Dillard & Carson, 2005; Scott, Martin, Stone, & Brashers, 2011; Vevea & Miller, 2010). To date, research has also identified the communicative nature of parental uncertainties and management strategies during their child’s stay in the NICU, including the importance of the NICU context in exacerbating the uncertainty management processes for parents who are neither organizational insiders nor

outsiders (White, Hull, & Gilstrap, 2014). Caring for a child at home, following discharge from the NICU, may alter parental uncertainties because parents may experience a “change in their personal and social identities as they leave their organizational roles” (Davis & Myers, 2012, p. 195).

Consequently, parental uncertainties, postdischarge, must account for the “contextual features” of the home setting negotiated against the backdrop of their NICU experiences (Brashers, Goldsmith, & Hsieh, 2002, p. 266). For example, parents may experience uncertainties unaccounted for in the NICU as the transition from the formal NICU context to the informal home setting may present “entirely new cues, contains too many different cues, or contains contradictory cues” (Kramer, 2004, p. 70). Because “individuals in transition must restructure a new reality” (Hutchinson et al., 2012, p. 3), neonatal parental scripts at home, post-NICU discharge, may engender new uncertainties and management strategies that call forth unanticipated parental performances, meaning making, and social support dilemmas.

Although research has examined uncertainties related to planned, organizational member disengagement processes (Davis & Myers, 2012), it has not explored how discharge from the NICU to the home context may “evoke multiple and potentially conflicting goals” for parents as care providers (Goldsmith, 2001, p. 517). To better understand the uncertainty management processes of parents after leaving the NICU for the private home setting, the following research questions were examined:

RQ1: What uncertainties do parents of premature babies experience at home following their child’s discharge from the NICU?

RQ2: How do parents manage these uncertainties?

Method

Participants

Eighteen parents (13 mothers, 5 fathers), four of which were couples, were interviewed as part of a larger study investigating parental NICU experiences. Each parent had a baby born before the 37-week gestation period, thereby necessitating a stay in the NICU from 6 to 183 days ($M = 63.58$ days). Fifty-five percent of participants were first-time parents while 45% of participants were already parents prior to their NICU experiences.

Participants were recruited using criterion and network sampling. First, parents’ premies (a) must have “graduated” from the NICU and (b) had to be home at least 12 weeks in order to allow for immersion in the home setting. All mothers and fathers interviewed were officially discharged from neonatal intensive care units in seven different hospitals in the southeast. Second, participants were found by (a) drawing upon the third author’s contacts as a parent member of a NICU education committee at a large southeastern children’s hospital, (b) emailing personal networks, and (c) creating a Facebook post soliciting participation. Although 31 individuals initially answered the participation request, six individuals never confirmed an interview, six did not qualify based on one of the two inclusion criteria, and one accepted the invitation to participate but declined after his/her spouse requested he/she not participate.

Procedure

Face-to-face, in-depth semistructured interviews were conducted with parents over a three-month period in their homes. All participants signed an IRB-approved informed consent and completed demographic forms. Given the interview protocol was designed for a larger study, participants were

asked a variety of questions about their experiences before, during, and after their child's stay in the NICU. Guided by UMT, parents were asked about the types of uncertainties they experienced postdischarge (e.g., "After you brought your child home from the NICU, what was your biggest uncertainty?") and how they sought to manage those uncertainties in the home setting (e.g., "When at home, how did you attempt to manage that uncertainty?"). All interviews were audio-taped and transcribed verbatim. Interviews lasted 40 minutes to 2 hours ($M = 64$ minutes), resulting in 259-pages of single-spaced transcripts. Transcripts were verified by two of the study's authors who reviewed the verbatim transcripts while (re)listening to the audio recordings. If needed, final corrections for inaccuracies or errors were made during this process. Pseudonyms were used in the transcripts in place of interviewees' names for anonymity and confidentiality.

Data analysis

Employing the constant comparative analysis (Glaser & Strauss, 1967), researchers began by individually reading transcripts multiple times to familiarize themselves with the data. Next, analytic memos individually were developed to create conceptual categories by "delineating concepts" through similarities and differences in the data (Corbin & Strauss, 2008, p. 195). After discussing each author's analytic memos and collaboratively eliminating overlapping and/or irrelevant categories, axial coding was performed to ascertain relationships between categories identified in open coding (Strauss & Corbin, 1990). Axial coding continued until full consensus was met regarding the characteristics and naming of final themes.

Findings and interpretation

After a preterm child is released from the NICU, parents have achieved a major milestone. Despite this accomplishment, participants revealed three recurring and interrelated uncertainties particular to the home context: parental role shift, caring through equipment, and adherence to provider advice. Additionally, parents highlighted specific strategies they used to manage each of these uncertainties.

Parental role shift

Following the team-based, expert care their child received in the NICU, parents felt unprepared as to the suddenness of their new role and its corresponding responsibilities. The shift from the NICU to the home setting initiated a new recognition that what was expected of them was drastically different than the collaborative, team-based approach to parenting they had experienced in the NICU. Parents also highlighted that they were "scared because care was entirely their responsibility." For example, Lori, whose child spent 118 days in the NICU, described how this home-based uncertainty was inexorably associated with the transition from a care team member to the primary decision maker and provider.

When [my child] was in the NICU and his specialist[s] came to see him, they are making the decisions. There were some doctors, if you spoke up, they would let you have input, but for the most part, they are making those decisions. You get him [home] and you take him to the pediatrician who, all of a sudden, is looking to you to tell him what your child's norm is and gives you obviously, a lot more control. All of a sudden, it's like, you're the mom. I didn't feel like I was prepared for that sudden shift. All of a sudden I am making the decisions and some of them that I didn't want to make. Some of them I didn't feel qualified to make. There was just so much more on you.

Parents' role-based uncertainties were exacerbated at home because their scripts for care were deemed inadequate and incomplete when evaluated against the backdrop of the team-based care they had come to rely upon in the NICU. Consequently, the solace of communal care was replaced by the stark recognition of sole responsibility.

When their child was cared for in the NICU, parents often felt the medical staff's job was to "worry" about their child's progress. When contrasted with the home context, the knowledge that "there wasn't a nurse looking over my shoulder making sure I was doing everything right" reinforced the belief their child's ongoing well-being and development might only proceed as far as their individual efforts. Thus, uncertainty was accentuated not only by the perception of added responsibility, but also by the perceived increase in ambiguity concerning what necessitated worry. For example, parents described feeling inadequate and unprepared for their new role because they had become accustomed to a shared model of care that allowed them to outsource responsibility and worry to specialists and nurses who would help them discern what was worthy of concern. At home, however, there was no such filter. Ashley, whose child spent 6 days in the NICU, highlighted her perceived anxiousness stemming from the contrast in role expectations post-NICU:

You are responsible for them. You have to worry ... You are staring at them making sure they are breathing. It is so different. You are so used to other people worrying about that stuff for you. You are worried [in the NICU], but they are worried more because that's their job.

Unlike the team-based expert care provided in the NICU, which allowed parents to filter their uncertainties through the authority and wisdom of provider expertise, parents felt they not only had to worry about "everything" at home, but they also had to make sense of these concerns on their own. As a result, parents' tolerance for uncertainty was lower at home because they felt they were unprepared for the interpretive burden of individual judgment and responsibility devoid of the assurance and understanding they had grown accustomed to expecting from team-based sensemaking in the NICU.

Reorientation

Parents used reorientation to manage uncertainties associated with parental role shift. As a cognitive management strategy, reorientation allowed parents to accentuate their parental control, which was absent while in the NICU. By reminding themselves that the home setting provided more parental decision-making control than deemed possible amidst the organizational constraints of the NICU, Georgia, whose child spent 100 days in the NICU, reoriented herself to the benefits of her renewed sense of agency. At home, she said,

I was able to do everything. Instead of being able to leave [the hospital] at 10 or 11 at night, and calling in the middle of the night while pumping to see how she was doing, I got to do it all and I loved it. I felt like she was finally ours. She's 100% ours. No one could tell me to put her down. No one could tell me how she did. She's mine.

Rather than trying to replicate the rigorous schedule of the NICU, parents situated their post-discharge parenting responsibilities as a type of empowerment by emphasizing the capacity and benefits of autonomously co-constructing their own schedule, rules, and routine with their preterm infants. For instance, David, whose child spent 108 days in the NICU, managed his new parental role uncertainties by reminding himself of the empowerment-based benefits associated with co-parenting at home.

We can do this now, so it is in all of our control. I was helpless [in the NICU] and at home [I] was back in control. We could make the decisions. We decide what to do or what is going on right now.

In the midst of their newfound uncertainties, parents repeatedly used self-reminders to feature their "new freedom" concomitant with their discharge from the hospital and arrival home.

Although the strategy of reorientation was designed to highlight the advantages of parental independence, it also created communication challenges between parents as a result of perceived care disparities. Upon bringing her child home from the NICU, Mary, whose child spent 56 days in the NICU, said she was "scared. Really scared. Scared because I guess I knew it was on me. I knew my husband was very intimidated." Similarly, for Karen, whose child spent 108 days in the NICU,

the feeling that she was the best care provider for her child also intensified upon arrival home from the NICU. She emphasized,

It's all me. I felt like it was all me because I knew more than [my husband]. I was there more. I couldn't leave the house because I couldn't trust that someone else knew how to feed [the preemie twins]. It was a lot of stress.

As such, mothers, in particular, recognized the empowerment possibilities associated with this strategy, but also felt the stress of an increasing burden of sole responsibility resulting from a perceived care capacity gap with their spouses.

Caring through equipment

Throughout their child's stay in the NICU, parents became accustomed to an assortment of equipment and machines used by experts to monitor their child's health. Repeatedly, they recounted the "major peace of mind" they received in the NICU knowing their child was carefully and constantly monitored by experts whose competency in using and reading machines was an ongoing source of reassurance. Although many of the same machines and equipment (e.g., apnea monitor, oxygen, feeding tubes) used in the NICU were also used at home, parents expressed feelings of inadequacy regarding their ability to effectively use and interpret the equipment.

Equipment usage in the home environment created multiple uncertainties for parents. First, parents highlighted the newfound ambiguities associated with simply adapting necessary equipment into the home context. For instance, Natalie, whose child spent 183 days in the NICU, addressed the logistical challenges associated with equipment following the transition home. She said,

Doing it for 8 hours [in the NICU]—no big deal, because you are at the hospital and you are in one room. It is not the same as coming home, and hooked up with the oxygen and a 25-foot hose with a concentrator in one room.

Beyond mere functionality of the equipment in the home, parents also were uncertain about their ability to accurately interpret the equipment in their new setting. Parents' worries over misreading the machines designed to (re)assure them of their child's well-being seemingly contradicted the goal of the equipment itself, which included preempting problems, enhancing quality of care, and alleviating parental concern. For example, Lynn, whose child stayed in the NICU for 35 days, recalled the anxiety she experienced when interacting with her child's monitoring devices.

Do you know the scene from the movie where it's like they hate working, *Office Space*? Do you know where they demolish the printer in the field? I literally had fantasies of taking that monitor into the driveway and destroying it. It was the most stressful thing ever because it was always going off. Anything would cause it to go off. When she was eating it was so loud ... it's like you can hear it across the house. God forbid you were not in the room next to her. I have a beep disorder now. It makes anyone mentally insane after a five-week period. It triggers your heart to jump, the anxiety that it's associated with. It is very unsettling.

Because parents relied on the equipment to care for their child, their self-perceived (in)ability to properly assess, monitor, and discern between false alarms and real emergencies was used as a criterion to evaluate their capacity to provide quality care for their child. For example, Steve, whose twins spent 6 days in the NICU, recalled how his interactions with even something as simple as a faulty thermometer "made me mad. Damn it. You know, I really screwed up. I'm screwing up as a father." Compared to the around-the-clock care-based efficiency of the NICU, parents felt uncertain about their ability to effectively monitor their child through machines without respite, especially at night when uncertainties were most pronounced due to perceived gaps in care.

Calibrating appropriate responses

Parents did not seek to prevent misreadings and mistakes associated with caring through equipment; rather, they cognitively and behaviorally sought to manage uncertainty by learning to respond

appropriately through experience and couple-based sensemaking. For instance, Natalie highlighted the importance of experience as a necessary step in managing her uncertainties regarding the equipment:

When [the machine] first started going on, we would worry. Now we have done this long enough to know the difference if she is stretching or in contact with her arms or if she is just sleeping really deeply ... I promise you it can go wrong. It really has. And the thing is, everything that went wrong, it's scary and it kind of built our confidence. We thought, 'Well, shoot, we got this.'

Thus, parents' tolerance for uncertainty increased as a result of their home-based care experiences that helped them better calibrate their expectations and responses to the machines deemed vital to the care process.

Similarly, participants emphasized the important role communicating with their spouse played in helping to quickly discern false from real alarms, especially at night. For example, Mary recalled an emotion-filled scenario echoed by many parents, whereby a parent relied on his/her spouse to accurately assess and differentiate the child's well-being from the quirks of the monitoring devices themselves.

It only has an 8-hour life on the battery, so it's two or three o'clock in the morning and the machine goes off and I am like, 'Oh my gosh, she is not breathing!' Her heart stopped possibly. I am half asleep and I cut through this little tiny thing and I am like OMG, I am picking her up and I don't know what is going on. She is so little. She is only four pounds. And then [my husband] finally gets in there and it's only the battery he said. I just freaked out. My heart has stopped. I am trembling and I am thinking we are losing her. But he knew that light [on the machine] and I didn't know, so I was so nervous about the kid, and wasn't thinking the machine was off. I will never forget that night.

Although these "traumatic" experiences were frustrating and overwhelming, firsthand experience with the machines and couple-based sensemaking was believed essential to managing uncertainties while also building caregiver confidence.

At the same time, however, this management strategy complicated parental interactions with other family members because the emotional turmoil endured when calibrating their responses to care-based equipment often affected the entire family despite parents' best efforts to quarantine the impact of their responses. According to Lynn,

I have been trying so damn hard. I mean, I have tried. There is so much. You are short with your husband. You don't think it is affecting [my older daughter] because she is not seeing what you are going through, but they picked up on it. It was horrible.

When such spillover occurred, parents expressed feeling guilty because they believed they had "failed" their other children. Despite attempts to manage their responses through firsthand experiences and shared scripts of interpretation, parents recounted feeling incapable of preventing the anxiety associated with this learning process from upsetting the entire family system and "trigger-[ing] a landslide."

Adherence to provider advice

Amidst the overwhelming desire to have their child meet necessary requirements to be discharged from the NICU, salient exit messages from NICU providers became ongoing sources of parental uncertainty. Once home, parents experienced anxiety regarding their perceived (in)ability to faithfully follow healthcare providers' exit messages regarding home-based threats believed perilous to the well-being of their child. Though parents recalled memorable exit messages addressing a range of topics from their child's sleep to nutrition, the most frequently mentioned uncertainty involved parental doubts concerning their ability to adhere to provider warnings regarding germ-based threats (e.g., colds, Respiratory Syncytial Virus). The constant fear that their child might get sick from germ-based threats accentuated uncertainties, once home, because parents questioned their

ability to personally mitigate their child's exposure to threats compared to the controlled and highly regulated environment of the NICU.

Upon discharge, parental uncertainties were aggravated when NICU staff's "scary" admonitions pinpointed germs as a pernicious threat requiring significant and ongoing changes to behavior and expectations that impacted the entire family system. For example, prior to discharge, Reese, whose child spent 32 days in the NICU, recalled the farewell advice she and her husband received from doctors: "We can't tell you not to put her in daycare; but if there's anything you can do to not put her in daycare, don't put her in daycare." Thus, providers' protection-based exit messages (e.g., limit the amount of time people are in your house, only let grandparents into your house) exacerbated parental uncertainties because they were believed to defy their postdischarge experiences, desires, and everyday realities.

Overall, provider exit messages were believed to require strict control regarding who entered the house and interacted with parents and their children. Thus, communication interactions with healthcare providers were sources of uncertainty because attempts to loyally adhere to these memorable messages created a hyper-awareness of anything, or anyone, whom might jeopardize parents' capacity to protect their child. Consequently, parents interpreted providers' messages as "creat[ing] more worries" because they seemingly required them to be more "judgmental of other people" in the hopes of mitigating risks. For example, Ashley acknowledged how this uncertainty inhibited her ability to reach out to others for help and support:

Everybody wants to be supportive but the reality is there are so many people that can't do anything. [My husband] and I are the only ones. Anybody else is new germs. I think people have been understanding that they can't hold or play with her like another newborn, but as far as being supportive, it feels like me against the world.

The fear of germs and the corresponding parental belief that their own efforts could control this ominous threat was justified in the name of following provider advice, even though this approach knowingly disrupted avenues for parental social support.

Limiting exposure

To manage uncertainties related to the home-based threats of germs associated with outsiders, parents sought to alleviate their concerns by limiting exposure. This behavioral strategy encompassed multiple approaches to enhance parents' perceived control in an attempt to remain faithful to provider forewarnings. First, this strategy involved assiduous attention to sanitization, such as constantly cleaning the house and wiping the door knobs after they were touched. Ryan, whose child spent 6 days in the NICU, spoke about his family's concern for creating a safe home environment: "We sanitized galore. We wanted to make sure we were always clean since she was still susceptible." Second, house rules regarding access were initiated to maintain control over who, and under what conditions, entered and exited the home. When discussing this control-based strategy, Carol, whose child spent 14 days in the NICU, said "We didn't want anybody over! We didn't want people to come over. If family came over, they had to scrub and we didn't want people to hold him for a long time. We were really adamant about it." Parents' overriding desire to control access was conceived of as a worthy "sacrifice" though it oftentimes contradicted parental desires for freedom of movement beyond the confines of the house.

Parental desires to adhere to provider advice also created a communication paradox particular to the change of location from the NICU to the home setting. When their child was being cared for in the NICU, parents talked about the possibility of maintaining social networks. For instance, Reese said, "You have to go on with life when they're in the NICU with all the uncertainty." Thus, schedules were created based on the "regularity" of parental and team-based NICU patterns (e.g., visiting the NICU on a routine, nursing the child at a certain time). These expected patterns also made it possible for parents and friends to maintain ongoing face-to-face contact.

Once home, however, social support systems were significantly altered as the desire to adhere to provider advice took precedence over the benefits of social support. According to Lori, the transition from the NICU to the home setting initiated a corresponding change in how, and in what ways, friends and family were engaged.

When [our preemie] was in the NICU, before he came home, I had a set of friends, my friends. They were so good when [he] was there. Getting us meals ... things like that when [he] was in the NICU. They came to clean my house a few times. So when he came home, you can't really do it because of germs and it wasn't that they stopped, it just transitioned to texting and stuff that way.

Though social support did not cease entirely, the perceived benefits of in-person support were reconceived in light of parental concerns over the dangers (e.g., germs) of regular in-person interactions.

Although this behavioral management strategy was justified based on the advice received from healthcare providers, parents described having to reconcile family members' expectations and desires amidst their own attempts to protect their child through limiting exposure. For example, upon learning her mother-in-law flew across the country to visit without disclosing she had a cold until she arrived, Jill, whose child spent 13 days in the NICU, explicitly told her mother-in-law she could not hold the baby. In addition to this house rule, Jill said:

I follow[ed] [my mother-in-law] around everywhere with Clorox for a week. Every night, before I would go to bed, I would wipe down every handle. I sprayed the couches with Lysol, and I covered [my child's] things with sheets so germs wouldn't fall on them. I didn't let her touch [my child] the whole time she was there.

As such, this strategy created "more worries" for parents, limited social support possibilities, and complicated family interactions.

Discussion

Analysis of the data reveals parents experience three major uncertainties following their child's discharge from the NICU: parental role shift, caring through equipment, and adherence to provider advice. In response to these recurring, home-based uncertainties, parents employed cognitive and behavioral management strategies, including reorientation, calibrating appropriate responses to machines through experience and couple-based sensemaking, and limiting exposure to germ-based threats. Three major conclusions can be rendered from these findings.

First, the types of uncertainties parents experienced were significantly impacted by the caregiving experiences, communication interactions, and expectations cultivated during their child's stay in the NICU. Although three categories of patient-specific uncertainties (e.g., medical, personal, and social) have been identified in health communication literature (see Vevea & Miller, 2010), findings from this study highlight how prior, care-based organizational experiences both inform and complicate parents' postdischarge, home-based roles. Though providers can help patients "reappraise uncertainty" in helping discern what constitutes a threat (Brashers et al., 2006, p. 236), our findings pinpoint how parental care-based experiences with NICU providers may also exacerbate home-based uncertainties in ways that negatively affect parental perceptions of self-efficacy, readiness, and competency. Specifically, preterm parents' uncertainties at home cannot be understood apart from their care experiences in the NICU because parents don't necessarily reconstitute a "new reality" (Hutchinson et al., 2012, p. 3) in the home setting as much as they seek to reconcile their home-based experiences to care expectations and roles shaped in the NICU.

Second, although the management strategies utilized by parents can be characterized as functional because they sought to accommodate perceived risks through the prism of control, these same strategies also draw attention to the contradictory, relation-based challenges parents experience throughout the transition process. Specifically, strategies used to manage one uncertainty sometimes contradicted other uncertainty management strategies, thereby creating dilemmas of social support

“when achieving one goal comes at the expense of achieving another” (Scott et al., 2011, p. 395). For example, parents simultaneously negotiated couple-based alienation resulting from perceived care (in)capacities (i.e., reorientation) while also emphasizing the need to collaborate (i.e., calibrating appropriate responses) to manage the uncertainties associated with care-based equipment.

Additionally, parents endured communication challenges when attempting to manage uncertainty across care contexts as the home setting presented parents with “contradictory cues” (Kramer, 2004, p. 70) that transformed well-intentioned, face-to-face interactions and support into potential threats. In the process, this context-specific discrepancy regarding conflicting interpretations of family and friends (e.g., potential threats, sources of support) may enhance parental isolation by reinforcing the belief that their in-home experiences, challenges, and care constraints cannot be adequately understood by outsiders (e.g., providers, family, friends). Our findings, therefore, provide further insight regarding how, and in what ways, the “family system must respond and adjust” to a premature birth as a result of a change of care context from the NICU to the home setting (Golish & Powell, 2003, p. 310).

Third, our findings underscore how the static view of NICU discharge as a definitive organizational marker, rather than an ongoing, co-collaborative process negotiated amongst providers, family, and changing contexts of care, may further complicate parental uncertainties. As such, our research confirms that parental adjustment to the home setting requires additional support (see Rehm & Bisgaard, 2008). Rather than focusing on home readiness as evidenced by the “availability of social support” and the “identification of at least 2 family caregivers and assessment of their ability, availability, and commitment” (American Academy of Pediatrics, 2008, pp. 1123, 1124), we propose enhancing family-centered care by reconceiving the NICU transition as an ongoing process that accounts for the (a) continual (re)negotiation of parental roles, (b) appreciation that provider-based exit messages must account for child, parental, and familial uncertainties, (c) identification of “knowledge structures” that helps providers and parents distinguish NICU scripts from home-based scripts of care (Brashers, 2007, p. 207), and (d) recognition that changing contexts of care necessitates distinct uncertainty management practices to negotiate the tensions between protecting children and supporting parents.

Our findings underscore the important role UMT plays in the interpretation, enactment, and communication of uncertainties throughout the transition process from the NICU to the home setting. Hospitals can use the findings from our study to improve FCC throughout this vital transition by helping providers, parents, and family members identify and communicate salient uncertainties and management strategies that compose this dynamic, and sometimes contradictory, process. Specifically, FCC may be enhanced through the expansion of provider communication training focused on organizational exit messages (Cawthon et al., 2012; Meyer et al., 2011) that better account for the communicative and relational interconnectedness between NICU experiences and home-based, parental uncertainties. Additionally, ensuring that FCC communication resources be made accessible and relevant to parents beyond their NICU experiences might allow parents to more effectively “bridge the gap between hospital and home and to support the family’s adaptation to life at home” (Dellenmark-Blom & Wigert, 2014, p. 584).

With this broader goal of discharge preparation in mind, we suggest the incorporation of multiple stakeholder voices (e.g., provider, parent, family) into hospital-based resources to highlight and reflect the multi-dimensional nature of transitional-based uncertainties. In particular, hospitals might better prepare and sustain parents throughout the process by highlighting the role of communication in helping participants negotiate inevitable tensions of protecting their preterm children while also maintaining important social support connections. For example, hospital-sponsored online resources (e.g., YouTube videos, FAQ websites, advice from former NICU parents and family) focused on identifying common care and communication-based challenges may aid in the parental and family transition process by addressing interpersonal and familial communication dilemmas that occur when well-intentioned expectations from family and friends are viewed as incompatible with parental and practitioner concerns.

Although this exploratory study provides an important lens to understand the uncertainty management processes of parents after transitioning home from the NICU, it has three major limitations. First, our analysis did not account for children's length of stay in the NICU. Therefore, future research should examine how differences in parental uncertainties and management strategies may be affected by the preterm child's health spectrum and amount of time spent navigating the NICU context. Second, although our findings highlight the important role spouses and spousal support play in the uncertainty management process after transitioning home, this study did not formally assess the impact of uncertainties on spousal relationships. Communication researchers need to examine this phenomenon since it plays an important role in the quality of familial relationships, peer relationships, and patient care. Third, since all participants in our study were married, our findings may not reflect the experiences of single preterm parents who often face unique social, economic, and environmental challenges. As a result, researchers should continue to investigate how the uncertainty management process may differ for uncoupled caregivers who take on the primary caregiving responsibilities for their preemies. As family-centered care continues to evolve as a dynamic and ongoing construct, communication researchers are ideally equipped to examine the implications of uncertainty management that both constrain and empower provider, patient, and familial perceptions and relationships within and beyond institutional contexts.

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