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Supporting the Paternal Role and Transition Home From the NICU: A Mixed Method Study

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Supporting the Paternal Role and Transition Home From the NICU: A Mixed Method Study

Abstract

Background: Limited research has focused solely on fathers' experiences following a Neonatal Intensive Care Unit (NICU) stay. The study aimed to identify occupational therapy's role in supporting paternal wellness and mental health through routines and occupations following discharge.

Methods: Online surveys (n = 32) and virtual interviews (n = 11) were collected to complete a mixed method design study. Interviews were manually transcribed and coded to perform thematic analysis.

Results: Five themes were identified: *adjusting expectations, changes in priorities, the unexpected toll of the NICU, coping and healing,* and *fathers and health care providers.* This study emphasized how the continued difficulties and emotional toll following a NICU stay affects fathers' engagement in self-care because of feelings of guilt. Narrative writing became an important occupation for fathers by creating a therapeutic and community space for them to cope. Furthermore, this study indicates areas in which to improve communication between fathers and health care providers.

Conclusions: These findings indicate that fathers would benefit from continued support post NICU discharge because of the continued challenges following a NICU stay. Occupational therapists can help support NICU fathers' occupational balance to promote positive engagement in self-care activities, and these needs can be addressed during interactions in early intervention.

Comments

The author declares that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

NICUdad, NICU, paternal role, OT, occupational therapy in the NICU, early intervention

Cover Page Footnote

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Credentials Display

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The fourth edition of the *Occupational Therapy Practice Framework* (*OTPF*-4) defines occupational therapy as a profession that enhances participation in valuable occupations through the therapeutic use of everyday life occupations (American Occupational Therapy Association [AOTA], 2020). Occupational therapists work with a wide variety of people and play an important role in the neonatal intensive care unit (NICU). The NICU is a specialized area of the hospital equipped to handle medically fragile infants, including premature infants (Vandermeer, 2018). In 2019, the Centers for Disease Control and Prevention (CDC) reported that 1 in 10 births were affected by prematurity in the United States. The United States is one of the top 10 countries with the greatest annual number of preterm births at 517,400 (World Health Organization [WHO], 2018). Prematurity rates are major determinants of health and these statistics emphasize that there is a need for improvement in the United States.

Families also face the financial burden that an extended hospital stay accrues. These extended hospital stays can average $21,500; in comparison, a hospital stay for a full-term infant can average $3,200 depending on how long the child needs care (Kim, 2018). There are only eight states that have paid family-leave programs (National Partnership for Women and Families, 2019). Despite the U.S. Family and Medical Leave Act (1993), a federal law that gives family members the right to take up to 12 weeks of leave during hospitalization, the law does not provide paid leave, nor does it protect the individual's job position (Family and Medical Leave Act of 1993, 2009).

It is important to recognize the difficulties encountered when a family transitions from having 24/7 care in the hospital to the responsibility of caring for their child independently. A qualitative study, with a title that indicated it solely focused on fathers, included eight fathers and 10 mothers (Kim, 2018). This study provided insight into the transition home, but also supports the disproportionate representation of fathers. Fathers in the study indicated that further support from health care providers would have eased the transition home and promoted peer support, emotional support, and paternal confidence (Kim, 2018). Although there are a number of resources available to parents online and from providers, many described feeling overwhelmed. Parents are left unsure about what they should be advocating for or what behavior is considered normal for their child (Boykova, 2016). One mother described how any small cough or alarm would send her and her husband into a panic (Boykova, 2016). These stressors on a day-to-day basis can greatly impact emotional and physical well-being over time. In a longitudinal study, researchers examined the stress and depression of 146 fathers at admission, 3 weeks later, at discharge, and 2 months post discharge. The study indicated that fathers experienced more stress at admission and post discharge, which echoes a need to explore post discharge care (Alves et al., 2018).

The AOTA (2018) has stated that occupational therapists have a strong understanding of infant development and can be vital resources in assisting families through a child's life stages from infant, toddler, preschooler, and beyond. While anticipating the child's needs, occupational therapists take a holistic approach to evaluation and intervention by enhancing the infant-caregiver dyad through confidence and competence in parenting skills all while considering family circumstances, cultural beliefs, and family goals (AOTA, 2018). Occupational therapists have an understanding of how an occupational imbalance from unanticipated caregiver roles can affect physical and mental health (Reitz & Scaffa, 2020). Podvey (2018), who focused on maternal mental health, stated that while other disciplines can address medical and mental disruptions separately, occupational therapy has the unique perspective to address the occupational performance challenges motherhood brings. The *OTPF*-4 (AOTA, 2020) can be used to support the scope of this study as it describes how child-rearing is an instrumental activity of daily living (IADL) that falls within the self-identified role of being a father. The IADLs are defined by the *OTPF*-4

as more complex activities in comparison to ADLs and support life in the home and community. Parenting is also considered a co-occupation as it involves interaction with the child and sometimes a significant other (2020). The *OTPF*-4 (AOTA, 2020) also specifies how occupational therapists can play a distinct role in life transitions or transitions through the continuum of care; in this instance, from the NICU to home and early intervention.

Early intervention therapists specialize in providing therapy from birth to 3 or 5 years of age depending on the state and can include occupational therapists as a service provider (AOTA, 2014). Families are usually referred to early intervention providers by the pediatrician after a NICU stay, and they are important for the transition home because of the emphasis on the natural environment that helps families adjust to their routines and rituals in their homes. These services can also be provided in an outpatient or hospital setting (AOTA, 2014).

Many studies have considered the implications of having a child admitted to the NICU and have explored the psychological effects that mothers and fathers experience during admission. However, there is limited research that focuses on the disruptions of paternal routines and occupations after discharge. It is important to explore the difficulties of transitioning home in-depth from the father's perspective as occupational therapy can play an integral role in providing support. The purpose of this study is to identify occupational therapy's role in supporting paternal wellness and mental health through routines and occupations following the transition from the NICU back home. This study is important because of the need to identify the impact that transitioning home has on occupations and roles.

Definition of Terms

- ***NICU***: An area of the hospital equipped to handle the most medically fragile infants, including premature infants (Vandermeer, 2018).
- ***Prematurity***: An infant delivered before 37 weeks of gestation and further categorized by gestational age (WHO, 2018).
- ***Occupational Imbalance***: A lack of balance or disproportion of occupation resulting in decreased well-being (Wilcock, 2006).

Literature Review

Fathers' Perspectives During NICU Admission

NICU fathers have described their child's delivery as a stressful experience where they are put in a situation where they have to choose between following the infant into the NICU or staying with their partners following delivery (Lasiuk et al., 2013). Balancing work life and visits to the NICU are taxing on a person, especially when adding on the care of other children. Fathers expressed feeling as if they were the backbone of the family and needed to be strong for everyone (Logan & Dormire, 2018).

Best Practices to Support the Transition

Fathers play a critical role in caring for a preterm infant. Qualitative studies have shown they want to be more involved and included in the care of their infant (Kim, 2018). Purdy (2015) found that "involving parents in their baby's care is a crucial step toward empowering and enabling their competence and confidence as caregivers. This empowerment must begin in the NICU and should be continued into the home" (p. 25). Parents were more likely to attend follow-up visits and therapies solely based on staff and how well supported they felt (Phillips-Pula & McGrath, 2012).

In a cohort study of 40 low-income families conducted by Enlow (2014), language and literacy were highlighted as impacting follow-up with only 33% of families calling a provider for advice. Spanish

speakers indicated that finding providers was difficult for them post discharge. Another study conducted by Lakshmanan et al. (2019) discussed the disparities among Hispanic and Black families by referencing how they are less likely to be referred to high-risk infant follow-up programs. Black families are also 5 to 8 times less likely to follow up at early intervention programs. The researchers went on to state that these disparities should be addressed by "engaging families in the process of re-designing transition of care from NICU-to-home" (p. 2). The families indicated that at discharge they were overwhelmed with all of the information given and suggested a virtual platform to access information and communication with their providers as all the participants had a device with Internet access.

Internet Platforms as a Means of Support

Online support may be a better domain for fathers (Kim, 2018). A study looking at 278 families of premature infants found that the Internet was a primary source for parents of very low birth weight infants to find information. According to Gabbert (2013), "after discharge, the most frequently researched topics were 'specific medical problems associated with prematurity' (61.5 %), 'general information on prematurity' (51.6 %), and 'outcome of preterm infants' (49.1 %)" (p. 1673). Furthermore, the study found that mothers were more likely to use discussion posts. However, 64% of parents felt that social networking sites and parenting sites were not meeting their needs of caring for a very low birth weight infant. Lastly, Gabbert's (2013) study found that 79.1% of parents would be interested in joining a native-language networking site for parents of preterm infants.

Difficulties with Transition Home and Impact on Mental Health

Families of preterm infants have reported significantly higher levels of stress in comparison to parents of full-term infants (Treyvaud, 2014). A study conducted by Cheng (2016) focusing on depressive symptoms found that fathers of preterm infants may experience depressive symptoms related to the challenges of the transition to fatherhood and identifying with the new role. If not addressed, these stressors can cause a great impact on the father's role and participation in occupations. Many parents' social lives were greatly impacted as they became hypervigilant about the fragility of their child and avoided taking them out (Adama et al., 2016). Some fathers faced the stress of working and the desire of being at home to help ease some of the stress of their partners (Adama et al., 2016). Sleep has also been highlighted as an area of concern but is little studied. It was seen that fathers have difficulty catching up with the appropriate amount of sleep, which in turn affects relationships at home and work (Marthinsen et al., 2018). Peer support has also been shown to be beneficial in increasing confidence, well-being, problem-solving, coping, and acceptance among parents of NICU infants (Hall, 2015). However, fathers that participated in Kim's (2018) study focusing on social support expressed that they were too busy to participate in-person at a support group.

The literature indicates that the transition home is difficult for families and underscores the importance of understanding fathers' experiences. Furthermore, the literature touches on the occupational impact of the transition in areas of wellness, sleep, and socialization, but it does not encompass all areas of occupational impact, indicating a need to explore roles, routines, and occupations in greater depth.

Method

This mixed methods study received approval from an institutional review board. This study was conducted from July 2020 to December 2020 to identify themes and occupational disparity among fathers transitioning home from the NICU. To gather detailed information on fathers' roles, routines, and environments using the Model of Human Occupation (1980), surveys and virtual interviews were conducted. It was intended that the survey questions (see Appendix A) gather broader information about

fathers' experiences in the first 18 months of bringing their child home. Adama's (2016) study indicated that feelings of stress and anxiety can persist for parents up to 18 months. The final question of the survey gave the participants the option to consent to contact for an hour-long semi-structured interview (see Appendix B) by providing their email.

Inclusion criterion for the study was fathers of a child that had been admitted and discharged from the NICU. There were no definitive requirements that defined "being a father" to be sensitive to different family dynamics. If an individual felt that they fit the father role in their family, they could participate in the study. Anticipating that this population may be hard to reach during the COVID-19 pandemic, there were no exclusion criteria to participate in the study. One participant was from Canada and the rest were from the United States. The fathers who participated in the semi-structured interviews were diverse: first-time fathers, a father of twins, a father of multiple NICU babies, a father of an adopted NICU baby, fathers of NICU babies with unique diagnoses, fathers of infants born during the COVID-19 pandemic, and fathers of premature infants. All of the fathers who participated in interviews referred to their significant other as "wife." Questions about sexual orientation and gender were not asked in the current study.

The participants were recruited through purposive sampling via virtual platforms and the researcher's mentor connections. Service provider groups throughout the United States, such as follow-up clinics, were emailed a script. A social media script with the survey link was used to create greater outreach to fathers on social media platforms. Facebook was used by joining support group pages dedicated to NICU service providers, fathers, and families and sharing the social media script and direct survey link on their pages. Instagram was used by direct messaging the social media script to families and providers with public accounts that had posts hashtagged #NICUgrad and #NICUDAD. These methods of recruitment were selected because the literature suggests that fathers prefer online platforms, and they enabled more outreach to this population (Kim, 2018).

Thirty-two surveys were collected. Fathers that consented to participate in an interview on the last question of the survey were contacted by email with the consent form to schedule an interview time. Of the 16 fathers that provided their emails, 11 responded and completed an interview with the primary researcher via Zoom. Only audio recordings were collected to preserve anonymity. Once the interviews were transcribed, identifiers were removed by labeling interviews with the given pseudonym of Father A, B, C, etc., in the order of when the interviews were conducted. The interviews were manually transcribed by the primary researcher. After the interviews were transcribed, they were uploaded into Dedoose, a website application designed to analyze qualitative and mixed-method research. The interviews were coded and recoded by the primary researcher. Overarching codes, themes, and subthemes were discussed with the primary researcher's mentor and other doctoral students to account for biases. Data from the surveys and interviews were analyzed separately, as the surveys provided quantitative data as shown in the Results section.

Results

Survey Results

Demographic Overview of Participants

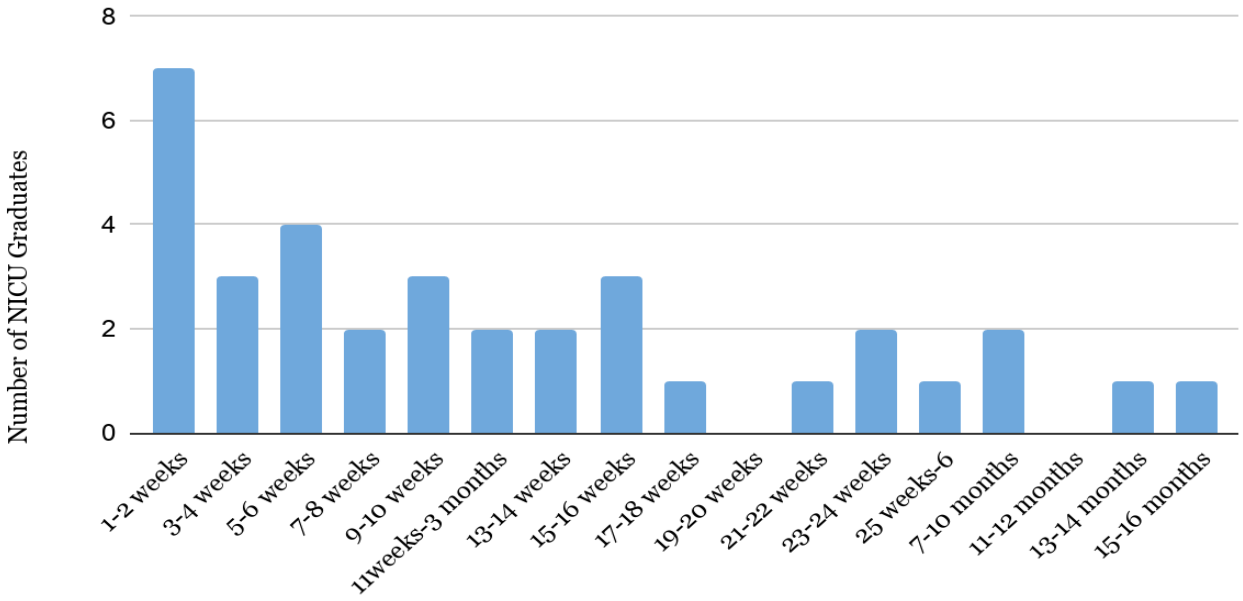
Table 1 shows the demographic overview of the survey participants. Although there were 32 participants, one father had three NICU graduates and another father had twins. Thus, the ages were out of 35 children. Figure 1 shows the range of length of NICU stays for infants that were included in this study.

Table 1

Demographic Overview of Participants n = (32)

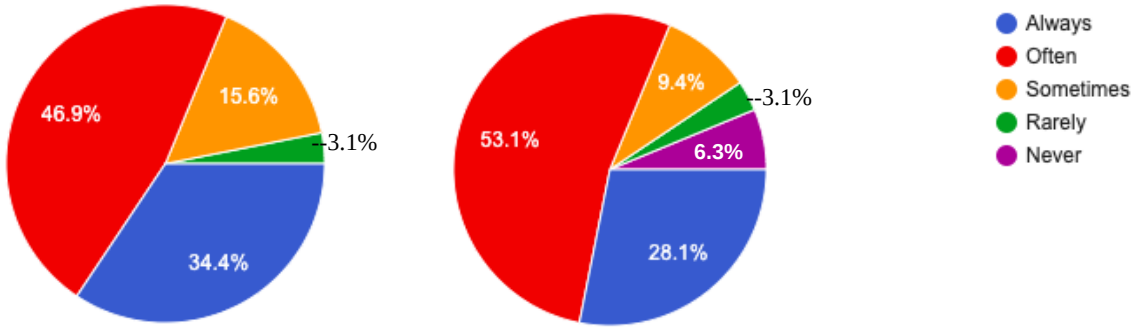
Characteristics	N	%
State		
California	4	12.5%
Colorado	6	18.8%
Georgia	1	3.1%
Illinois	1	3.1%
Massachusetts	2	6.3%
Michigan	1	3.1%
Minnesota	2	6.3%
Missouri	2	6.3%
New York	1	3.1%
New Mexico	1	3.1%
Tennessee	1	3.1%
Texas	4	12.5%
Utah	1	3.1%
Virginia	4	12.5%
Canada	1	3.1%
Self-Identified Race/Ethnicity		
African American	3	9.4%
Hispanic	3	9.4%
Japanese White	1	3.1%
Pacific Islander	1	3.1%
White/Caucasian	23	71.9%
Household Size		
2–3	22	68.7%
4–5	8	25%
6–7	2	6.25%
Employment Status		
Full Time (40–80 hr)	31	96.9%
Part-Time (8–32 hr)	1	3.1%
Utilization of Family Leave		
9–12 weeks	5	15.6%
5–8 weeks	9	28.1%
2–4 weeks	7	21.9%
< a week	4	12.5%
None	7	21.9%
Age of NICU Grad at time of Survey	N = 35	
0–6 months	13	37.1%
7–12 months	4	11.4%
13 months–2 years	7	20%
3–5 years	8	22.9%
6–13 years	3	8.6%
Premature		
Yes	26	81.3%
No	6	18.8%
Infant in the NICU during the COVID-19 pandemic		
Yes	10	31.3%
No	22	68.8%

Figure 1
Length of NICU Admission



The fathers were asked how often they felt health care providers included them in the care of their child during admission versus post discharge (see Figure 2). A higher percentage of the fathers reported rarely or never feeling involvement post discharge (9.4%) in comparison to during NICU admission (3.1%). There were no fathers who reported never feeling involved, and 3.1% of the fathers reported rarely feeling involved.

Figure 2
How Often Fathers Felt Involved in the Care of Their Child by Health Care Providers



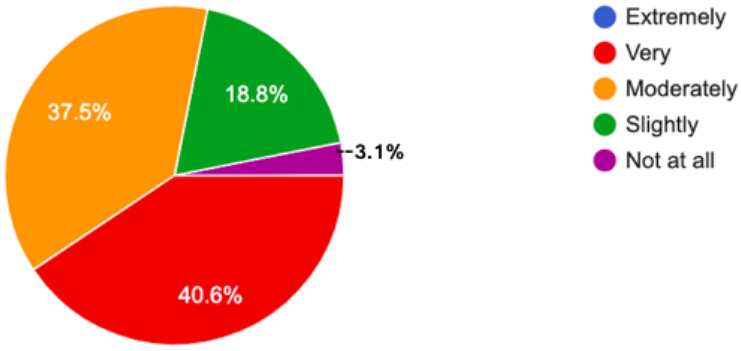
During NICU Admission Post-NICU Discharge

The participants were asked how prepared they felt when bringing their child home at discharge. Of the fathers who participated, 40.6% reported feeling very prepared, 37.5% reported feeling moderately prepared, and 21.9% reporting feeling slightly prepared or not at all prepared (see Figure 3). There were no fathers that indicated that they felt extremely prepared for discharge. When asked if they wanted any extra support during the transition home, 56.3% of the NICU fathers agreed and 43.8% responded that they did not need extra support. The next question asked the participants to choose the top three things

they wish they had more information about at discharge. The options included the child's medical needs, feeding, mental health, work-life balance, financial, and a blank fill-in box. More of the fathers scored the child's medical needs (71.9%) highest with mental health (65.6%) and work-life balance (65.6%) being scored as equally important.

Figure 3

Preparedness to Bring Child Home at Discharge



In an open-ended fill-in question the fathers self-reported feeling adjusted to having their child home at various stages ranging from immediately following discharge to not adjusted yet (see Figure 4). Six of the fathers stated they were ready immediately after discharge with another three fathers feeling prepared within the first week home. Seven of the fathers stated they adjusted within a month, and one specified a month after each major change. There were various responses ranging from 2 weeks (n = 1), 6 weeks (n = 1), and a couple of weeks (n = 1) to 2 months (n = 2) and 3 months (n = 2). Three of the fathers reported adjusting by 6 months. One father added:

> Around six months after our son returned home, we established a stable routine. Up to that point, day-to-day activities were a struggle. Our son came home on supplemental oxygen, a g-tube, and five medications. All of that in addition to the normal "new parent" experiences was quite overwhelming many days.

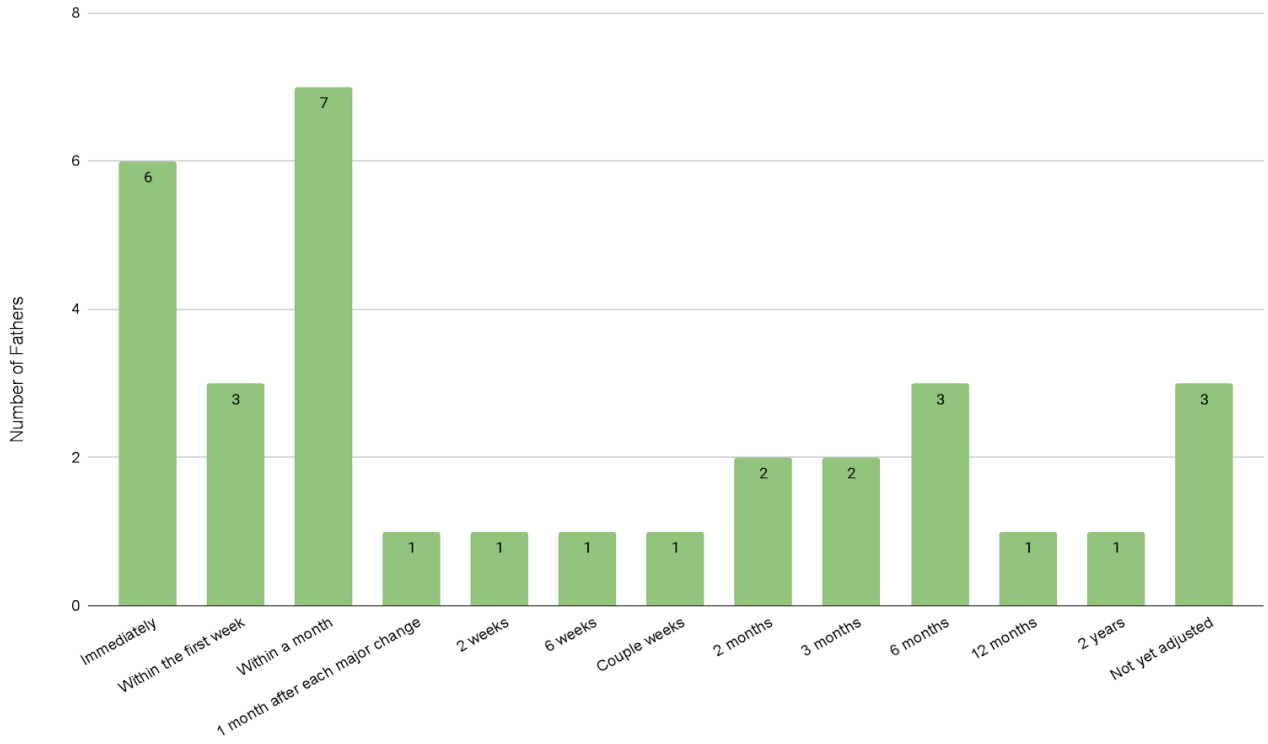
Additional responses beyond 6 months were at 12 months (n = 1) and 2 years (n = 1). It is important to note that three of the fathers indicated they were not adjusted at the time the survey was taken. Further, 37.5% of the participants indicated requiring 2 months or more to adjust or not yet adjusted. In the survey, 13 of the fathers indicated that fathers should ask questions and advocate for their child. Many of the fathers felt confident in advocating for their children but the survey responses indicated that they needed encouragement to do so.

Three questions in the survey focused on the fathers' participation in IADLs, leisure, and social activities. In regard to the prioritization of stress-reducing activities since bringing their child home, 21.9% reported they were prioritizing, 31.3% reported sometimes, and 46.9% reported rarely or never. When asked to consider hobbies, sports, and recreation, 62.5% of the fathers reported a change when engaging in these activities since bringing their child home, 21.9% reported there was sometimes a change, and 15.6% reported they rarely or never noticed a change in participation. When asked about participation in social activities since bringing their child home, 62.5% of the fathers reported rarely or never engaging in social activities, 34.4% of the fathers reported sometimes engaging, and 3.1% of the fathers indicated

often engaging in social activities. Seven of the survey responses asking the fathers to give advice to other fathers emphasized the importance of prioritizing their spouse and child. Another 15 survey responses about giving advice to other fathers indicated that fathers should prioritize themselves and their health.

Figure 4

Perceived Feeling of Adjustment Post Discharge



Interview Results

Audio recordings were saved on a personal password-protected computer and were manually transcribed onto a word document. The transcriptions were uploaded to Dedoose and coded using Braun and Clarke's (2006) 6-step framework for thematic analysis. There were 100 initial codes. These were grouped on Dedoose and then regrouped on written paper to produce preliminary themes. After numerous reviews, the final themes were solidified into five final overarching themes: adjusting expectations, changes in priorities, the unexpected toll of the NICU, self-care, and fathers and health care providers. The theme of the unexpected toll of the NICU had two subthemes: (a) mental health and emotions and (b) strong dads and validation. The main theme describing self-care had two subthemes associated with it: (a) outlets for emotions and (b) social media.

Adjusting Expectations. The NICU stay is a monumental event in a father's life, and this experience does not end when the baby is discharged. Discharge is an anticipated event for families, but for some, it came abruptly. The transition home is an adjustment to having the child home and accepting the future challenges that can be associated with a NICU graduate. Families are required to coordinate multiple doctors' and therapy visits while still adjusting to being a new parent without the 24-hour care families grow accustomed to having:

> One thing I would say it's not like it's over when they come home, you have this traumatic experience and you have to be so careful with everything and, like, I even, when you go home it's,

> like, don't have visitors over you have this immunocompromised baby so things are so different, you have to hold her a certain way when you feed her, so I guess like there is not, like, you almost expect like this relief, like it's over, but it's not. She had OT twice a week, PT twice a week, feeding therapy . . . (Father E)

Many of the fathers described the fears revolving around the care of their child and the pressure of caring for their infant without medical staff:

> In the moment of discharge, I was like, oh I don't know, I really don't, we had so much time in the NICU where they watched him 24/7, going home was terrifying, like, we left the parking lot and I was, like, is this really happening? Am I really driving him home, is this…they're releasing him to us . . . we're not nurses . . . we're not clinical . . . we're barely parents. (Father G)

While conducting thematic analysis of the interviews, six of the fathers specifically described the fear that their child may stop breathing, which put them in a constant state of alertness. Father B described:

> You're used to having all these bells and whistles and you don't have any machine when you come home, and it's like, okay, is he breathing? Every hour on the hour you would take shifts where you would sleep for a couple hours and then, okay, it's your turn to go to sleep now, I'll stay up and make sure he's breathing. (Father B)

Changes in Priorities. When delving into a typical day for a NICU father post-discharge, it was evident that fathers demonstrated concern for their partner at home and empathized with the amount of time spent caring for their child or children. Thus, a major focus was on being home to provide relief. This routine became a cycle of wake up, help significant other, work, relieve partner, downtime, sleep, repeat. This routine indicated a shift in occupational priorities and what fathers find meaningful:

> As far as normal routines go, I wanted to make sure that my wife's routines were as disrupted as little as possible . . . I made sure that she was still able to go to the gym. She hates going to the grocery store, so I would always go to the grocery store . . . sometimes I just felt like this with postpartum concerns, which she didn't have, or with just general mental health. I just thought it would be better if sometimes she would have some quiet time. So that's more, so what I was focused on more so than anything else. I should probably go to the gym more often. (Father F)

The Unexpected Toll of the NICU. The fathers described how no one understood what they were going through and some tried to disguise their emotions to be the strong dad they felt their family needed. Furthermore, the fathers described how their mental health and engagement in self-care were impacted.

Mental Health and Emotions. Six of the fathers stated that no one understood what they were going through: "I don't really have a ton of friends that really would understand . . . you also feel like you don't want to, like, be like the Debbie Downer and make people . . . feel sad while you're feeling sad," said Father K. Emotions became buried so they could be strong for the family or not burden others with the emotions they were feeling:

> I feel like you almost have to be machine-like in those situations and just take one day at a time . . . . You don't think about yourself, you know what I mean? You can't think about yourself in that situation. So, you don't think, oh do I need help? Am I going to be okay? Just 100% not about me. (Father E)

With no one to understand what they were going through and emotions being hidden, many of the fathers faced difficulties with mental health. These struggles were described by seven of the fathers interviewed. Father I explained how these difficulties increased post-discharge.

> For the past year I've been preaching that after NICU care is almost more important than anything we get in the NICU, you know, your baby's in the NICU, it's taken care of, and you're dealing with everything that's there, but I think the aftercare . . . once you leave the NICU, that's it, you know, as far as the hospital and everything and you're on your own, but you're still carrying all this baggage from, you know, the NICU experience, so it's crazy, especially on the dad perspective because the dad care in the NICU is barely getting talked about, so it seems like nothing's going to get done on the aftercare because we're barely here. (Father I)

Father C mentioned that the only reason he recognized psychological symptoms was because a social worker had talked about her own experience:

> I think just knowing about her experience with that made me realize that I will probably have some of these strong feelings persist for more than just a few weeks or months afterward, and she was correct, so 6 months after I was still pretty high strung and then I realized it's part of the process. That was one of the supports of being just honest with what to expect, not just in the near-term but also long-term as a NICU parent. Which is good, because since it was farther out, I would have associated the stress with something else, not the NICU experience. (Father C)

Strong Dads and Validation. The fathers who had a positive engagement in self-care mentioned validation to participate in self-care as described by Father C:

> I think just having permission to go do these things was huge. Once my wife was like, it's okay to go on a run while she's in the NICU, she's not going to die while you're running, was huge. I think just getting that permission whether through your spouse or support systems at the hospital that you're not being selfish if you want to go do that. (Father C)

Without this validation, feelings of guilt were associated with prioritizing oneself as seen with Father J:

> That's been a challenging area to get out and do things both because it's hard to find the time and also because it's also not been a strong suit of mine to begin with, and I think I've gotten much worse at it feeling like I'm never supposed to leave when that's not really . . . like right now my wife's here and the nurse is here, like, I could go anytime I wanted to, but it's hard to feel like it's okay to get out of the house and go somewhere else and not be right there. (Father J)

Coping and Healing

With much of a father's focus on family and facing strong emotions, the question arises about how fathers are caring for themselves. Two subthemes emerged, including outlets for emotions and social media. The fathers described how the act of writing and the act of connecting was therapeutic.

Outlets for Emotions. The fathers described how the occupation of writing about their experiences became a therapeutic outlet for emotions. Father F stated:

> The conversations I was having were tough, that I didn't want my wife to hear, so I was surprised at how therapeutic writing that (referring to a Facebook page usd to give updates about his child) was and again, I'm not a reader, I'm not a writer, but as I was sharing that stuff they kept it from being locked up inside of my head and lock[ed] up inside of myself. (Father F)

Four of the fathers used narrative writing as a therapeutic tool. Two of the fathers solely used blogs, one father found writing a letter was therapeutic, and another father journaled and blogged. Living out the experience on a blog or paper made it so the fathers were not keeping it to themselves. Writing also gave the fathers a sense of relief that they could write out their thoughts and feelings for their family or friends to see and not have to worry about verbally reliving that experience again when asked questions.

Social Media. Whether it be through a blog or virtual peer support group, social media helped the fathers connect with others. The fathers described connecting to family members through their blogs to keep them updated, connecting to fathers that had similar experiences, or creating a following that helped the fathers feel a sense of community or sense of understanding: "There's something going on right now where dads or NICU dads are really wanting to share their experiences and I don't think anybody realizes how big the void really is," said Father I. Father K described not only that social media can form connections, but that there is a desire for more connection to better cope:

> It would be nice if there was, like, hey once a month, if people want to jump on to a zoom call or if people want to do a phone conference call or something like that it probably wouldn't be the worst thing, or once a quarter or whatever. I don't know, I'm sure there's, you know, a portion of dads that would be like, oh that's not for me, I don't . . . I don't like to talk about my feelings or, you know, my experience, and then there's the other piece that, you know, people would, you know, probably come and share and, you know, I probably fall into that group but, you know, I certainly think it's, it would be more beneficial to have more open lines of communication around, you know, what you go through cause it's, you know, obviously not something anyone ever plans. It's a pretty emotionally scarring thing. (Father K)

Fathers and Health Care Providers. Many of the fathers talked about the great relationship with the NICU staff and providers following their NICU stay. While there was a lot of praise, many of the fathers expressed feeling as if they were an afterthought. The fathers acknowledged that they did want their significant other to have a priority when it came to care and would preface that they did not think this neglect was on purpose; however, it echoed a calling that as providers there is more the medical profession can do to make fathers feel as if they are valued and contributing. The fathers weighed in on how this neglect made them feel and also highlighted ways in which providers went above and beyond for them. Father F brought insight into how fathers may feel intimidated by providers and how the team aspect helped shape his NICU experience:

> I think hospitals are businesses, there's no doubt, and I think that it takes a special hospital to try to make you feel like you're the only one there when you know that you can see 33 other babies, but we never thought for one moment that we were just a number, we always felt personalized and I think that's what (hospital name) does better than anybody. Actually, humanize that whole entire experience the first couple days, it takes a little bit to get used to . . . I had [sic] that a lot of my friends who have gone to the NICU different places [who] didn't experience . . . they felt intimidated, they felt left out, they felt spoken to versus spoken with. (Father F)

Father A shed light on how acknowledging that a NICU experience is difficult for both parents and simply asking how are you doing can impact the process in a positive way:

> In the hospital, they make note to the dad, but it's just like, oh yea, you're the dad, okay cool, hi. But the mom, which I'm not saying the mom shouldn't have a big role because the moms are obviously an important part of the whole thing, but the mom was on a pedestal type of thing and the dad was in the shadow on the pedestal, you know, like they were an important role and acknowledged, but it was just kind of a basic thing . . . there was a counselor that would come in and they would always ask my wife, oh, are you ok? Is everything okay at home? Which is good, I'm glad they asked her but, then half the time I wouldn't get asked if I'm okay and the other times when I would get asked it was like, oh dad, are you okay? Oh, okay, fine and just brush it off from there. And it's like I'm glad you're asking my wife because you definitely should be, but this definitely mentally affects me, too. I'm not just sitting here twiddling my thumbs like, oh this is great. (Father A)

Father J makes an important comment on what society and culture expect of fathers and goes on to describe how these cultural norms are translated into the health care world:

> It does kind of feel like there's a lot less focus on dads and I think that's because in general dads are less involved in parenting in this culture. I don't think it's a bad thing that the culture recognizes is [sic] the norm, but I think it makes it a little bit harder to be more active when it feels like they're a little bit marginalized in that one area. Not trying to be like men have it so hard in this world cause . . . it's different . . . I will just say if you're trying to be a male, that's different than the gender stereotype, there's a lot pushing against trying to do that. Even now we've had to go back and forth on listing my phone number [with health care providers] as mother's phone number because their system has like mother's phone number, father's phone number and which one is primary and the which one is primary is completely irrelevant; everyone just calls mom's number first . . . and that's still been an interesting process of the default is always assumed it's mom stuff. (Father J)

Early intervention providers specifically play a major role in helping families learn about developmental delays and how adjusted ages impact development. This was an area of praise that families saw as important and reassuring. Because of COVID-19, only one parent was allowed to attend therapy sessions. Father G described an experience where his infant's early intervention provider made a difference in making him feel involved through take home activities that may be beneficial to parents that are not always present for therapy sessions:

> I think it was nice that the therapist told my wife "you and your husband work by doing" . . . kind of, like, gave us homework, if you will, so that was kind of nice and then my wife brought it back to me and said make sure you're doing this when you're feeding him. (Father G)

Lastly, Father D applied an insightful perspective on how to approach families with empathy and an open mind:

> Don't prequalify people on how involved they are going to be based on the way they look or the way they talk . . . . We have financial resources, we have time, we have flexibility, we can be there all the time and that's . . . that's a privilege that a lot of folks just don't have. I would say, you know, just, you know, there's a lot of families that would really like to be there more and they just,

they simply do not have that option and I don't think that they deserve judgement for not being able to be there. It's not really a choice that they get to make. (Father D)

Discussion

This study's findings not only describe the impact a NICU stay has on fathers but sheds light on how this experience impacts fathers even after discharge. Multiple themes were derived in this study starting with the initial adjustment following a NICU stay where fathers may expect some type of relief but continue adjusting to their role as a father of a NICU graduate. For some, the transition home continued to bring about feelings of fear and stress. This is consistent with Adama's (2016) meta-synthesis that describes how parents live in a constant fear that something unprecedented would happen to their child outside the NICU, which in turn can affect sleep and everyday life, indicating that families would benefit from continued reassurance and improved self-efficacy when transitioning home.

When delving into the fathers' routines, it was evident there was a change in their prioritization of occupations once the baby was born. Fathers would shift their focus away from their own needs to the needs of their family. Govindaswamy et al. (2020) found that fathers consistently prioritized their needs as least important, putting the baby and mother's needs above their own. These findings were echoed by the decline in self-care and engagement in IADLs of this study's participants: 46.9% of the fathers reported rarely or never engaging in stress-reducing activities; 62.5% of the participants reported a change in participation in hobbies, sports, and recreation since bringing their child home; and 62.5% of the fathers reported rarely or never engaging in social activities. These figures suggest decreased participation in personal occupations and increased participation in co-occupations. Not all of the fathers indicated dissatisfaction with this change during the interviews; however, it is an area that should be explored for fathers that are dissatisfied, especially when considering that 37.5% of the participants felt that they needed 2 months to 2 years to adjust their routine to having their child home.

The current study's findings revealed that the fathers were experiencing feelings of guilt when working away from home. Guilt was a common experience for NICU fathers and was also revealed as a subtheme in Adama's (2016) meta-synthesis. However, this study indicates that these feelings of guilt may also affect participation in occupations that do not involve a father's partner and child. Although the fathers acknowledged that they needed an outlet for their emotions, not all of the fathers participated in coping strategies.

Many fathers in this study felt as if they were not prioritized, which is consistent with Kim's (2018) study that highlighted the theme of "inclusion" of fathers. This study recommended maintaining eye contact, keeping fathers updated, encouraging fathers emotionally, and engaging in conversation with fathers. Based on the results of the current study, it is recommended that health professionals make a point to ask fathers, specifically, how they are doing by engaging in dialogue through open-ended questions. These dialogues would help fathers feel that they can discuss their emotions candidly. The occupational therapist or early intervention therapist could suggest coping mechanisms, if appropriate.

Many of the fathers felt confident in advocating for their children, but 13 of the survey responses indicated that they needed that encouragement to do so. It is important as health care providers to teach them advocacy so that they are listened to and heard, as Boykova (2016) found that because families do not feel they are truly able to be a parent to their child, they doubt their ability to advocate for their child. Furthermore, the results of this study suggest the importance of fully understanding the dynamics of a household to avoid assumptions of parent involvement.

Recommendations and Implications for Occupational Therapy

The AOTA recognizes that the transition to new parenthood can be difficult for families experiencing a normal birth. Occupational therapists are experts in "helping caregivers establish routines that facilitate the balance of caregiving, self-care, and leisure can promote mental wellness for both the caregiver and the child" (AOTA, 2017, para. 10). Since early intervention is one of the first services provided to infants and their families following a NICU stay, early intervention providers can play an important role in helping families adjust to life after the NICU.

The Model of Human Occupation was used to understand the key aspects of fathers' volition, habituation, and performance capacity (Kielhofner, 1980). Habituation includes a person's roles and routines. This study emphasized a shift in how fathers of NICU graduates prioritized their participation in previous and new occupations. The fathers in this study identified changes in their motivation (volition), which became more focused on their child and partner. This emphasis on the importance of co-occupations modified most of the fathers' typical routines. It is important to note that although there were changes in routines, not all of the fathers in this study expressed dissatisfaction with this change in routines during the interviews.

Occupational therapists providing early intervention services should be aware of the changes in both routines and occupational participation. Occupational therapists can support fathers by helping them find the right balance between self-care, work, and home to promote mental and physical health. Identifying the caregiver satisfaction with routines is critical. The occupation of narrative writing and social media was a therapeutic tool that some fathers found helpful. Occupational therapists can help introduce this occupation as a coping strategy for the stresses of transitioning home.

Occupational therapists in early intervention should strive to ask routine-based questions of all caregivers when developing individualized family service plans. Fathers may not be present for all of the therapy sessions but should feel acknowledged. They can be given specific activities to work on with their child. It is essential that health care providers fully understand each individual family dynamic, as social norms should not dictate which parent should be contacted regarding their child's services. By being sensitive to different family dynamics, providers can ensure parents feel equally involved in their roles. Working with multiple health care providers on a daily basis can be intimidating for families. Therefore, it is important to create an environment that promotes collaboration. Fathers may need help knowing how to advocate for their child and their role. Occupational therapists are in the position to create future programming that will address the needs of fathers to promote a smooth transition home.

Limitations and Future Considerations

It is important to make note that this study was conducted during the COVID-19 pandemic. The added challenges associated with the pandemic may have affected the transition home and the difficulties the fathers may have faced. Many COVID NICU families were only allowed to see their child alone during hospitalization and had to choose one parent to visit at a time. Furthermore, the added stress of contracting the virus and giving it to their immunocompromised baby may also have heightened stress levels. Shortages of diapers and other infant supplies made the transition difficult when the fathers felt they could not purchase essential items for their child. Fathers that had been out of the NICU longer stated that the quarantine was a very similar experience to when they first brought their child home and felt it was not a major difference.

Future studies could focus on more specific demographics, such as single fathers, same-sex couples, fathers of medically complex infants, or adoptive fathers. Some of the participants fell in some of these demographics; however, it would be beneficial to explore each individually. The majority of the participants in this study identified as White/Caucasian and may indicate that resources such as the Facebook groups are not as readily available to a diverse population. The fathers in this study were all in various timeframes after discharge. Therefore, their recollection of events may differ from how they actually felt at the time.

Conclusion

This research study adds to the body of literature focusing on the paternal experience beyond the NICU. The effects of a NICU stay are long-lasting and life-changing. It is important to continue work focusing on the role of fathers and how to better support them. With 56.3% of fathers wanting more support post discharge, there is a need for encouragement and engagement in self-care and occupational balance to positively impact the transition from the NICU back home.

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Appendix A
Survey Questions

If your NICU graduate is over the age of 18 months, please answer questions as if it was the first year and a half of bringing your child home:

1) **What state do you live in?**
    a. Fill in answer
2) **Race/ethnicity?**
    a. Fill in answer
3) **Do you work:**
    a. Full time
    b. Part time
    c. Unemployed

    How many hours do you work on average in a week?
    d. Fill in answer
4) **How old is your NICU graduate now?**
    a. Fill in answer
5) **How many people are in your home?**
    a. Fill in answer
6) **Was your child born prematurely?**
    a. Yes
    b. No
7) **How many weeks did your child spend in the NICU?**
    a. Fill in answer
8) **How prepared did you feel bringing your child home at discharge?**
    1. Extremely
    2. Very
    3. Moderately
    4. Slightly
    5. Not at all
9) **How often did you feel involved in your child's care by health care providers during your child's hospital admission?**
    1. Always
    2. Often
    3. Sometimes
    4. Rarely
    5. Never
10) **How often do you feel involved in your child's care by health care providers after bringing your child home?**
    1. Always
    2. Often
    3. Sometimes
    4. Rarely
    5. Never

11) **Did the COVID-19 pandemic affect how often you got to see your child?**
    a. Yes
    b. No

12) Did you take family leave? Approximately how many weeks?

a. None
b. Less than a week
c. 2–4 weeks
d. 5–8 weeks
e. 8–12 weeks

13) Did you want extra support when transitioning home?

a. Yes
b. No

What type of support?

Fill in answer

14) What do you wish you had more information about once your child was discharged home? Pick your top 3:

- Child's Medical needs
- Feeding
- Mental Health
- Work/Life Balance
- Financial
- Other: (write in)

15) How often are you prioritizing stress-reducing activities into your routine to promote relaxation and wellness? Select the number you most identify with:

1. Always
2. Often
3. Sometimes
4. Rarely
5. Never

16) How frequently did your participation in hobbies, sports, and recreation change since bringing your NICU graduate home? Select the number you most identify with:

1. Always
2. Often
3. Sometimes
4. Rarely
5. Never

17) How often do you participate in social activities since bringing your child home? Select the number you most identify with:

1. Always
2. Often
3. Sometimes
4. Rarely
5. Never

18) At what point in time did you feel adjusted to bringing your child home?

a. Fill in answer

19) What advice would you give a father going through the same experience?

a. Fill in answer

20) We are also conducting virtual interviews that will provide us with greater in-depth understanding of your experience as a NICU father. Participation in this interview will require up to 45–60 minutes of your time. If you wish to schedule an interview please provide your email below to be contacted:

a. Fill in answer

Appendix B
Interview Questions

Roles
1. What are you responsible for in the care of your child? 2. Are you responsible for caring for other children? 3. Did you take Family Leave or keep working? 4. Has your work been impacted by the birth of your NICU graduate? 5. Aside from being a father what other roles do you engage in?
Environment
1. Do you have a close relationship with your child's healthcare providers? Does your child have an occupational therapist? 2. If you answered no to the previous question; Do you want more involvement? How can that relationship be improved? 3. Has the COVID-19 pandemic impacted your home life and the activities you participate in with your child? If so how?
Routine
1. What does a typical day look like? 2. Is there anything you wish you had more time for? 3. How have your sleep routines changed since bringing your child home? Any difference in the amount of sleep you are getting? 4. How often do you participate in leisure activities (e.g., gym, dates, hobbies)? Has that changed since you brought your child home? 5. Has your work/home balance changed since the birth of your child? How? 6. At what point in time did you feel a sense of normalcy in your routine?
Experience
1. What do you want me to know about your child? 2. What keeps you up at night? 3. How long was your child admitted to the NICU? 4. Did the COVID-19 pandemic impact your experience in the NICU? How? 5. Did you feel equally involved with the care of your child as your partner? 6. Did you feel ready to bring your child home from the NICU? Why? 7. Was post discharge what you expected it would be? 8. Did you seek out any peer support from other NICU fathers? Did you find it beneficial? 9. Have you joined any virtual support groups? Would you be interested in joining any?