# The Lived Experience of a NICU Father: A Descriptive Phenomenological Study

Senior Honors Thesis, Florida Southern College

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### I. Abstract

In the United States, one out of every nine babies born is premature, many of which are admitted to the Neonatal Intensive Care Unit (NICU) due to their prematurity. Additionally, admission rates to the NICU for normal-birth-weight infants continue to rise. These infants often require a long-term stay due to their many medical issues and complications. Early separation from the infant due to the NICU stay is associated with high levels of distress in mothers, but there is limited research on the fathers' experiences. The purpose of this descriptive phenomenological study was to explore the paternal experience of having a child admitted to the NICU. Six participants were purposefully recruited based on their unique understanding of the phenomenon of interest. Participants completed an audio-recorded semi-structured interview.

Interviews were transcribed using pseudonyms. Thematic analysis revealed five themes: horrible storm, piece by piece, "I'm the father", the gift of support, and little fighters.

The results of this study will help health care professionals in the development of interventions that promote family-centered and developmentally supportive care.

### II. Introduction and Literature Review

The United States has staggering rates of premature birth, with current estimations that one out of every eight infants born are born premature (Heidari et al 2013). These high rates of prematurity result in high rates of admission to Neonatal Intensive Care Units, which often leads to long stays in the NICU. This long stay can affect the transition to parenthood as there is a prolonged duration from hospital to home. Other factors like abnormal behaviors and appearance showcased by the child, overwhelming introduction to medical technology and jargon, as well as the risk of their child dying heighten stress (Purdy et al 2015). Coupled with all of this, many mothers undergo maternal anxiety, depression, and stress as a result of their birth experience, which many lead to a worsened maternal-child relationship (Turner et al 2014). Even if neonates are not patients of a NICU on a long-term stay, the separation from their parents still plays a negative role in their development. The newborn instinctually attaches to its closest caregiver (mainly the mother) during the first few hours and days after birth. If this attachment is interrupted due to a NICU admission just after birth (i.e. post-Caesarean Section or during the delivery room due to low Apgar scores), attachment is not established (Wigert et al 2006). This interruption can negatively affect the child's emotional development, as well as negatively affect the mother's perception of the birth experience (Wigert et al 2006). Mothers are often left feeling guilty for being unable to give birth to a healthy, normal baby and often feel that they lost the child they once envisioned they would give birth to (Wigert et al 2006).

Understanding these parents' experiences and the impact of the NICU on their relationship with their child is vital when it comes to improving the health of the patient as well as the parent (Hutchinson et al 2012). However, there is very little research focused on the transition from hospital to home factoring in a NICU stay. There is almost no research regarding the parental experience

long-term after the discharge, i.e. several years after the birth of the child. In order to ensure success for the child later in life related to their health and overall wellness, it is imperative that more research involves improving the parents' experience during the NICU stay to lead to better patient outcomes post-discharge.

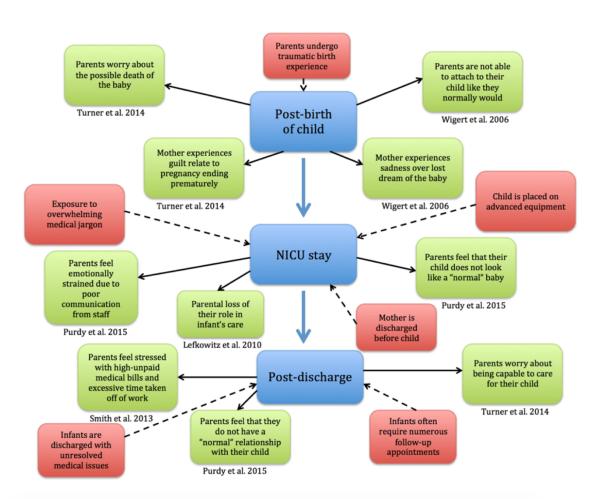


Figure 1. Concept map demonstrating the effect of factors on a parental relationship.

### III. Manuscript for Publication

The Lived Experience of a NICU Father: A Descriptive Phenomenological Study
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#### **Abstract**

In the United States, one out of every nine babies born is premature, many of which are admitted to the Neonatal Intensive Care Unit (NICU) due to their prematurity. Additionally, admission rates to the NICU for normal-birth-weight infants continue to rise. These infants often require a long-term stay due to their many medical issues and complications. Early separation from the infant due to the NICU stay is associated with high levels of distress in mothers, but there is limited research on the fathers' experiences. The purpose of this descriptive phenomenological study was to explore the paternal experience of having a child admitted to the NICU. Six participants were purposefully recruited based on their unique understanding of the phenomenon of interest. Participants completed an audio-recorded semi-structured interview. Interviews were transcribed using pseudonyms. Thematic analysis revealed five themes: horrible storm, piece by piece, "I'm the father", the gift of support, and little fighters. The results of this study will help health care professionals in the development of interventions that promote family-centered and developmentally supportive care.

### Keywords

Fathers, Family centered care, paternal relationship with infant, family support

### Introduction

Many infants that are admitted to a NICU upon birth are admitted for diagnoses that were not know until birth, and these infants often require a long-term stay due to their many medical issues and complications. The long weeks spent in the intensive care unit can begin to be a large barrier to their relationship with their parent (Cinar et al 2017). This long stay can affect the transition to parenthood as there is a prolonged duration from hospital to home. Fathers also experience unique role demands as they juggle their employment, care of their spouse and other children, as well as caring for the newborn (Feeley et al 2012). Many mothers undergo maternal anxiety, depression, and stress as a result of their birth experience, which may lead to a strained maternal-child relationship (Turner et al 2014).

Regardless of the time spent in NICU, separation from the parental unit can play a negative role to the attachment of the infant to their parents. The newborn instinctually attaches to its closest caregiver (mainly the mother) during the first few hours and days after birth. If this attachment is interrupted due to a NICU admission just after birth (i.e. post-Caesarean Section or during the delivery room due to low Apgar scores), attachment is delayed (Wigert et al 2006). This interruption can negatively affect the child's emotional development, as well as negatively affect the mother's perception of the birth experience (Wigert et al 2006). Mothers are often left feeling guilty for being unable to give birth to a healthy, ideal baby and often feel that they lost the child they once envisioned they would give birth to (Wigert et al 2006).

#### Methods

## Research Purpose

The aim of this study was to explore the lived experience of a father whose child was admitted to the Neonatal Intensive Care Unit.

Inclusion and Exclusion Criteria

The inclusion criteria were: 1) Fathers of infants born within the United States, 2) English-speaking fathers, 3) Fathers of infants with diagnoses that were not known until birth, 4) Fathers of infants that were in the NICU for longer than a week.

**Study Population** 

Participants included 6 fathers that were recruited using the snowball sampling technique. The recruitment lasted from September 2018 to April 2019. Fathers aged from 25-55+, 1-4 total children (m= 2.33), and all remain married to their partner.

Ethical Approval

The study obtained IRB approval through Florida Southern College. Participants all signed and received a copy of written consent. No personal identifiable data was reported. Participants were instructed that they could withdraw from the study at any time. All study materials were converted to an electronic file format and kept on an encrypted secured file by the principal investigator. A pseudonym was used for all names mentioned during audio-recorded interviews. Fathers were compensated with a \$25 Visa gift card for their time.

Data Collection

Participants completed a short demographic form that included seven questions about their age, salary, etc. A semi-structured interview, lasting no more than 60 minutes,

was conducted for the purposes of the study (see Table 1). Fathers were asked to talk about their experience as a NICU father, post-discharge, from birth until the present, and how the experience was similar or different than they expected. Audio-recorded interviews were transcribed verbatim. After transcription, original audio recordings were destroyed.

Table 1.

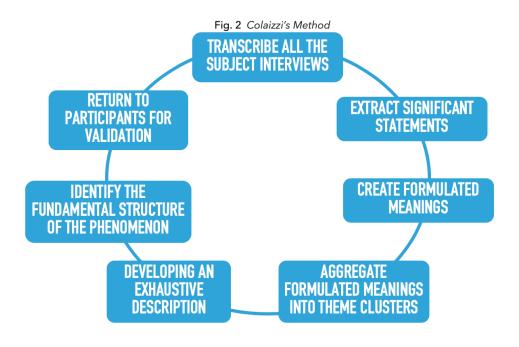
Interview Questions Asked During Data Collection

Question	Prompt
1.	Tell me about your experience being a father of a child that was
	admitted to the NICU.
2.	Tell me about your experience post-discharge.
3.	What has your experience been like, from birth until now?
4.	How has your experience been similar or different than you
	expected?

## Data Analysis

Data was analyzed using Colaizzi's method (Morrow et al 2015). Three members from the research team individually read the verbatim transcripts of the fathers.

Significant statements relating to the phenomenon were extracted from each father's transcript and by hand. Team members met to review significant statements. Meanings were formulated from the statements and themes arranged to create a rich and exhaustive description of the fathers' lived experience. The Final description was shared with fathers who participated in the student to validate the description of the experience and to ensure trustworthiness of the findings. (see Figure 1).



### Results

The following themes overarching themes emerged as a final result of the analysis process: horrible storm, piece by piece, "I'm the father", support, and little fighters.

Horrible Storm

Fathers described the journey they encountered starting with the pregnancy, to the tumultuous birth and NICU experience. Difficult challenges they felt along the way included the systematic frustrations from their perspective. Emotions ranged from fear, denial, sadness, and emptiness. Fathers described their experiences and the unknown as being traumatic and hard throughout.

"You gotta hand in there with your significant other and family and ride the storm out because it's a horrible storm" (Will)

"You know that it's a long road, and you're scared to death, because it's not natural" (Noah)

"I think it's just the unknown. If someone doesn't have experience with it, it can be kinda scary" (David)

Participants also discussed practical matters relating to their role and responsibilities of this new child. Day-t0-day challenges included commuting back and forth to the NICU while maintaining a family at home. Participants also described the visitation hour schedule and insurance as areas that were systematically frustrating.

"You really don't have enough hours in the day to make sure that everybody is fine" (Noah)

"Yeah. Oh it's sleep-deprived. You don't get sleep" (Daniel)

"But the thing that is difficult is when you see someone like Corinne who is 20-some-thousand on Florida's Medicaid list before she will be eligible for services" (James)

Piece by Piece

Participants spoke about the loss that they initially experienced, and the adjustment they had to make to the child that was now theirs. Participants talked about their lives being "dismantled". Fathers discussed the difficulty of being separated on their child for so long through the NICU experience. All six fathers reflected on their child[ren] being separated from them immediately following birth

"It felt like after a while as though we had a life for my daughter and doctors were just dismantling it piece by piece. They would just take away a part" (James)

"You have two pieces of your heart laying on a table. Even if everything wasn't going at one time, to now, everything is going no matter how tired or fatiguing it might be" (Noah)

"It's hard to think of—Corinne is our daughter, she's the baby we get to bring home and look at in the NICU,' because we didn't get to hold her and all that stuff, she kind of disappeared after she was born, she's got her name there, she's got my last name on that, so this is the baby we get to look at, but it took a while for us to really see her as our child" (James) "Watching and not even being able to touch your child right away, that's also—it's hard" (Noah)

As the journey went on, fathers begin to search for signs of hope admist the chaos and ultimately made meaning with all that they encountered. Despite everything that they had faced, the fathers began to appreciate the gift of their situation and phrases like "it could have been worse" emerged.

"And I remember going to the church thing in the hospital, what do they call it—the chapel—and I remember I said to God, 'give me a chance right now, that's all I want'" (Will)

"That's what I mean, it's an opportunity to appreciate life more. Because it was, it was on the cusp of not being there" (Noah)

"I'm the Father"

Fathers touched on the journey of identifying with the title of "father." They began to see themselves in the paternal role and discussed the ways that they were able to

participate in their child's care. Participants reflected on how programs such as Kangaroo Care (skin-to-skin) impacted their bonding with their child. Fathers sought to identify the ways that their child was similar to them. Noah even discussed how his mother thought that his child was the 3.0 version him, "he's me, 3.0."

"I was the first one to hold them...and she had to be okay letting me enjoy that and I had to be okay letting her enjoy that she was the only on that got to nurse them and have that intimacy with them" (John)

"I know that he's always going to see me as Daddy...and I think that had a lot to do with the Kangaroo Care because he could feel my heartbeat"

"He's got these problems because of me" (Will)

"And then just the process of being in the NICU, I personally, I had some issues when I was born, my lungs weren't developed at all...So I am familiar just from what my parents had told me about the NICU" (David)

The importance of the role of advocacy was noted by multiple participants. They discussed advocacy for both the child and their partner. Not only was this a point of the father taking on his paternal role, but also an attempt to gain some control during the "horrible storm".

"I said, 'well I have to know, I'm her father, I'm going to be taking care of her the rest of my life" (James)

"Some of them [HCP], were really annoyed that we would question their decisions. But we were thinking of her life, they were thinking of her at that moment and getting her well enough to leave the NICU...So we very

(Noah)

much had to be fierce advocates for her" (James)

"My mind is in overdrive mode because I need my wife back" (Noah)

"It was important for me to be there and what to know what was going on and to support her" (David)

## The Gift of Support

Support was identified as a critical element in managing the NICU experience—both how positive support enhanced their journey, and how negative support was detrimental to it. Multiple levels of support were identified including between partners, family, health care practitioners (HCPs), external support, and spirituality. They mentioned the role of their partner in this experience and how they supported each other.

"Make sure your wife takes care of herself. That's the biggest thing.

Because the minute she doesn't, she's not taking care of the babies"

(Daniel)

"She, my wife, was a warrior. She didn't let on how tired she was" (Noah)
"I didn't want her to ever feel like she was ever on her own at times. So
that was something we did together and I think that was helpful in getting
through it being a team together" (David)

They discussed the role of health care practitioners and the importance of their support or lack thereof. All participants highlighted the role that nurses specifically played while their child[ren] were in the NICU. Fathers also touched on the difficult situation when there was a disagreement between HCPs regarding the plan of care for their child.

"She had no worries about it and that was good to see every time we went to the doctor and she could just put us at ease" (David)

"So we had some doctors say, 'she must have this very major surgery to put her diaphragm back together.' The doctor that paralyzed her diaphragm was saying, 'it's not a big deal, don't worry about it'" (James)

"It's a special heart those nurses have. They know what they are doing, and they are extremely...for us, she was an angel. The care that she gave, the monitoring, it was" (Noah)

Resources such as Ronald McDonald House and other early intervention programs were noted as well. Family presence and extended family involvement was identified as a key source of external support.

"And it took us a little bit to be willing to accept that help, to figure out that it's okay to take that help...No. Take that free program utilize that, bring them into your house. Like when help is offered, take it" (John)

"It's nice and helpful when you have people surrounding you to help out. So that's a huge gift to have" (David)

Spirituality was a means of support through prayer, spiritual community, reliance on God. Several fathers reflected on spirituality as an important component during their NICU experiences.

"But the Lord made a way that we were able to stay a few nights over there" (Noah)

"I believe in the power of prayer, Garrett had a lot of people praying for him and praying for the mindset of those looking over him" (Noah) "It's just the way things worked out, and God had a hand in that obviously" (David)

"Jesus did far beyond whatever we could have done" (Noah)

## Little Fighters

Regardless of the size of their child, all fathers reflected on their child's ability to overcome obstacles while in the NICU and later on in life. They were amazed by their resiliency and perseverance to preserve through numerous trials that had confronted at them since birth.

"Because when you are in the NICU, they are in there fighting for their life. Even 8lbs, 7lbs, whatever if it's a preemie baby, 2 or 3lbs" (Will) "He was living those two years and he went through stuff that he could never truly explain. He can't tell you how hard he fought, and you know he fought" (Noah)

"Then, after she recovered from that surgery, you start to marvel at the resilience of infants" (James)

"They have already battled life and death already, so it's just nothing that you should really be afraid of" (Noah)

#### Discussion

There continues to be limited research in the area of paternal experiences and needs during and following the Neonatal Intensive Care Experience (NICU). Results from this study indicate that fathers of a NICU child experience a variety of perceptions throughout the experience. Their whole journey is quite extensive, with many unexpected roadblocks and challenges along the way. Our results support previous research findings

that the NICU experience is traumatic and fathers often experience psychological distress, which can be long lasting (Pierrehumbert et al., 2003, Candelori et al 2015). Previous work by Feeley et al. (2012) found that the NICU environment itself can be a barrier to parent infant bonding. Similar results were noted in our study. Fathers also touched on how multi-rooming affected them negatively. Will states, "They had different babies in there so now you are not only seeing your baby but also seeing more. You're not just worried about your child." During this horrible storm, they experienced a loss of control, fear of the unknown, and have traumatic memories. Will noted, "I would not wish it on my worst enemy to have a child that is the NICU."

Fathers mentioned loss in their interviews. Losses included the loss of life, "We had thought we had lost him initially, early on in the pregnancy, the doctor had thought there wasn't anything still in there" (David) as well as a loss of what was anticipated, "it felt like something was missing" (David). All six fathers discussed the means of separation from their child immediately following birth, as all were admitted to the NICU just after birth. David states, "as he had gotten out, immediately put him in a box incubator and took him to the NICU." They also reflected on policies of visitation hours causing separation. John notes, "The hardest part for me in the NICU was not being able to stay there overnight." Noah mentioned visitation hours causing siblings to be separated as well. In the end, they reflected on hope as a key element, "You just hope that they are healthy" (Daniel).

The creation of their identity as a father was instrumental, four of the six fathers were first-time fathers for their child that was admitted to the NICU. Fathers reflected on the uniqueness of their relationship with their child. John states, "I was the first one to

hold them...she had to be okay letting me enjoy that and I had to be okay letting her enjoy that she was the only one that got to nurse them and have that intimacy with them."

Several fathers discussed being the first parent to hold or see their child and the magic of that moment. Fathers become more confident throughout the experience and begin to adapt the "father" identity as well (Lindberg et al 2008). A component of this identity was advocating for their child and partner. This was seen mainly in regards to advocating for the infant towards HCPs, but also nurses. James remarks, "and after all this surgery, we said, 'No! We're going to teach her to breastfeed, we're going to feed her somehow, we are not going to put a feeding tube in her.""

Support was a consistent theme and has seen as both a barrier and facilitator to a father's NICU experience (Feeley et al 2012). This includes the support from nurses, family, programs and interventions, and God. Noah describes the power of their nurse, "but I just felt that she [NICU nurse] was a little different and we were lucky to have her in our corner." There was often a lack of support noted, especially from HCPs. James states, "so he basically told me that my daughter might be blind and just very casually, just like we were talking about the weather or something like that." Programs that were specifically touched on included Ronald McDonald House, Kangaroo Care, and Early Intervention programs. Fathers also remarked about the importance of "being a team" (David) together with their partner through this experience.

Fathers saw their child as a "little fighter" through this journey. Other research has validated this perspective with adjectives like "strong" as well (F. Koliouli et al 2016). Fathers talked about the ability to "marvel at the resilience of infants" (P2) and "he was a fighter, he was strong" (Noah). Remarks were also made towards their size,

"he was just small" (David) and "preemie baby, 2 or 3lbs" (Will). Participants remarked on all that their child overcame during their experience, "he just kept going, kept improving. It was just amazing, to see where he was and to see where he came from" (Noah).

One of the interesting consistencies that emerged across interviews was the fathers' response to the first question: Tell me about your experience being a father of a child that was admitted to the NICU. Consistently, instead of answering by describing their first NICU memory or even the birth of their child, three of the six fathers immediately began by discussing the pregnancy.

### Conclusion

Our study examined the father's experience of having a child in the NICU. The study builds on limited research in the paternal experiences and unique needs during this stressful time period. Fathers in the study consistently discussed the NICU experience as a traumatic experience where they felt they had little control or access to their child. The benefits of kangaroo care in facilitating the bonding experiences were touched on in our study. This finding is supported by previous works (Blomqvist et al., 2012; Helth and Jarden, 2013; Koliouli et al., 2018).

Fathers in this study noted support as a major factor in managing the horrible storm experienced during their infant(s) NICU experience(s). Support was identified through multiple sources including spouse, family, healthcare workers and agencies, as well as spirituality. Previous work by Negron et al (2013) supports the importance of support, noting that the absence of support is associated with parental mental health decline. Fathers in this study highlighted the importance of the health care team in

providing support. The role of the nurse's support was seen as critical in the father's ability to navigate through the NICU experience. This result is consistent with the work of O'Brien and Warren (2014), which found fathers received functional support in the four areas of emotional, information, care-giving and appraisal from nurses.

#### Limitations

The sample recruitment process was difficult as subjects were not recruited from a specific hospital during a given time period. This allowed for a more diverse group of subjects, but also meant for more of a challenge to recruit. All interviews were conducted by a female researcher, which may have limited the fathers' responses.

### Suggestions for Further Research

Further research needs include examining the NICU experiences of non-traditional family units. Additional research is needed in the development of programs and interventions that are specific for fathers during the NICU time period. Fathers that touched on concepts like Kangaroo Care and not being limited in terms of visitation hours spoke positively of their experience, but these could be utilized more consistently across NICUs. Additionally, exploring what the paternal specific needs are during this time period may lead to better implementation of interventions and programs that increase the paternal bond.

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# IV. Acknowledgements

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