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### The Lasting Impacts of the NICU Experience and How a Community Supports the Premature Infant and Their Family

Susan Koester

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**The Lasting Impacts of the NICU Experience and How a Community Supports the  
Premature Infant and Their Family**

By

Susan Koester

A Thesis

Submitted to the Graduate Faculty

Of

Saint Cloud State University

In Partial Fulfillment of the Requirements

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Master of Science in

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Thesis Committee  
JoAnn Johnson, Chairperson  
Brittany Sullivan  
Sara DeVos

## **Abstract**

Every year, approximately 500,000 babies in the United States are born before 37 weeks gestation. Often premature birth results in a stay in the Neonatal Intensive Care Unit (NICU) for some length of time. A literature review shows that there are lasting impacts on both the parents and the premature infant due to a stay in the NICU. These impacts can affect the parents' mental health, the attachment between parents and infant, and the infant's overall development for years to come. Findings from two qualitative questionnaires completed by previous parents of infants who stayed in the St. Cloud Hospital Neonatal Intensive Care Unit, and St. Cloud area agencies show how the St. Cloud community supports the parents and the premature infant after discharge from the NICU. The parents shared that the biggest support while in the NICU was the March of Dimes, but after discharge, there was limited support from previous supports or local agencies. With limited responses to the questionnaire from local agencies, it became apparent that it may be difficult to get into contact with the agencies. These findings showed the disconnect between supports while in the NICU and supports once discharged from the NICU. The connection between the St. Cloud Hospital NICU and local agencies needs to be an item of focus to increase support for parents and infants born prematurely.

### **Dedication and Acknowledgement**

I would like to dedicate this paper to my daughter Madelyn, who made me the proud parent of a premature infant. Together we navigated the NICU, discharge, and the life that followed. Thank you for always being my inspiration to never give up and keep fighting as you did so early on in your life! Premie strong!

I would also like to take the opportunity to thank a few very important people who have helped me get this far in my education.

First, I would like to thank my mom, Rita. She has always believed that I could do anything I put my mind to! Next, I would like to thank my husband, Bryan, for always supporting and encouraging me to try my hardest in school. I want to thank my sister Mary Jo for being my chief editor and advisor. This paper would not flow smoothly without her positive input! Of course, I would not have been able to do any of this without the willingness of my in-laws, Scot and Lillian, to watch Madelyn during my endless hours of working on my Master's.

I want to give a shout-out to my cheerleader, my sidekick, and my adventure buddy Elise for helping me and supporting me along the way. She has been a crucial part of my completing this project! Also, to JJ for supporting us through this journey by answering endless questions, meeting with us multiple times and always believing in us!

Thank you to each and every one of you for your dedication to helping me reach my goals!!!

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## Chapter 1: Introduction

### Overview

Despite the increases in medical advancements, each year in the United States about 500,000 babies are born before 37 weeks gestational age or weighing less than 2500 grams (Tomlin, et al., 2016). As many as 10 to 15 % of babies born in the United States require some type of treatment in the Neonatal Intensive Care Unit (Tomlin, et al., 2016). The emotional impact on families that have a baby born prematurely and are admitted to the Neonatal Intensive Care Unit (NICU) affects them for months and possibly years to come. The NICU experience also has a dramatic impact on the infants themselves. Often children who are born prematurely continue to be followed by medical and developmental specialists for months or years after their NICU graduation due to a wide variety of reasons.

### Importance and Purpose of the Study

A significant number of premature babies spends a period of time in the NICU prior to getting to come home from the hospital. The traumatic event of having an infant admitted to the NICU can have lasting effects on parents. Upon discharge from the NICU, infants are regularly referred to an early intervention program to receive support under the Individuals with Disabilities Education Act, Part C. Parents are a crucial part of the early intervention team and programming for the preemie. As professionals, early intervention teachers need to be aware of the impacts of the NICU experience and the effects that the experience has on parents. Professionals also need to have knowledge of the local resources available to help support parents of babies born prematurely. No current research is available that highlights the support systems that exist for infants



and their families during the discharge process and after transitioning home from the St. Cloud Hospital Neonatal Intensive Care Unit.

### **Research Questions**

1. What lasting impacts does the NICU experience have on parents of babies born prematurely during the discharge process and after transitioning home?
2. What impacts does this NICU experience have on the premature infant?
3. How does the St. Cloud community continue to support the parents and infant after NICU discharge?

### **Literature Search Description**

During my literature search, I used Academic Search Premier, Educational Resources Information Center (ERIC) and Ebsco Host search databases. I began by using the key terms “post-traumatic stress disorder and neonatal intensive care unit,” “mental health and neonatal intensive care unit,” “infant mental health,” and “post-traumatic stress disorder and prematurity.” I learned rapidly that I needed to expand the list of search terms, so I used terms and combination of terms such as “depression,” “anxiety,” “psychology,” “parental mental health,” “acute stress disorder,” “stress,” “post-traumatic stress disorder symptoms,” “parental stress,” “premature infants,” “preterm birth,” “extremely low birth weight,” “preemie,” “neonates,” and “postpartum.” I then needed to expand my research to include information about the discharge and home transition process, so I added search term such as “NICU discharge,” “NICU transition,” “care coordination,” “family centered care,” and “medical coordination.” The articles range from 2003 to 2018 and are peer-reviewed articles.

## **Definition of Terms**

*Premature Infant:* An infant born before 37 weeks gestation (Gondwe & Holditch-Davis, 2015).

*Individuals with Disabilities Act, Part C:* A federally funded program implemented at the state level for infants and toddlers with disabilities (ages birth through 2 years) and their families that provides early intervention services (Early Childhood Technical Assistance Center, n.d.).

*Acute Stress Disorder (ASD):* A traumatic or stress-related disorder due to exposure to a traumatic event, witnessing a traumatic event, learning that a traumatic event happened to a family member, or experiencing repeated or extreme exposure to details of traumatic event. Symptoms may include intrusion symptoms, negative mood, dissociative symptoms, avoidance symptoms, and arousal symptoms. Symptoms appear approximately 3 days to 1 month after traumatic event or stressor (Substance Abuse and Mental Health Services Administration, 2016).

*Neonatal Intensive Care Unit (NICU):* An intensive care unit designed with special equipment to care for premature or seriously ill newborns.

*Post-Traumatic Stress Disorder (PTSD):* exposure to actual or threatened death, serious injury, or sexual violence via one or more of the following ways: direct experience, witness the event, learning that a traumatic event happened to a family member, or experiencing repeated or extreme exposure to details of traumatic event. Symptoms include intrusive thoughts, avoidance of stimuli associated with the event, increased arousal (not present before that event), and negative alterations in cognition

and mood associated with the event. The duration for symptoms is more than 1 month (Center for Substance Abuse Treatment, 2014).

### **Closing**

In the next chapter I will discuss, through a literature review, how the Neonatal Intensive Care Unit experience has lasting impacts on the premature infant and his or her parents. The literature describes the lasting impacts that the NICU has on parents' mental health, the parent-child relationship, and the infant's mental health. Also described are some recommendations for NICU staff and community resources on how to successfully support the family as they transition home from the NICU.

## Chapter 2: Literature Review

The literature review includes three areas: (a) lasting impacts on parents, (b) lasting impacts on premature infants, (c) supports for premature infants and their parents.

### **Lasting Impacts on Parents**

When an infant is born prematurely, the parents' entire world shifts abruptly from pregnancy to survival mode. A birth is considered preterm if the infant is born before 37 weeks gestation (Gondwe & Holditch-Davis, 2015). "Preterm birth, whether planned or unplanned, is an unexpected experience that may result in maternal guilt over failure to deliver a healthy term baby" (Gondwe & Holditch-Davis, 2015, p. 8). This guilt is often just the beginning of the emotional rollercoaster parents travel during their time spent in the Neonatal Intensive Care Unit (NICU) with their premature infant.

Many factors impact a parent's mental health during their child's time spent in the NICU. Parents may have feelings of uncertainty about their neonate's outcomes, the appearance of their child, their own medical health, financial burdens and hardships, feelings of loss of their role in their infant's care, understanding complex medical language, and communication issues with the medical team (Gondwe & Holditch-Davis, 2015; Lefkowitz, et al., 2010; Lotterman, et al., 2019). Another large factor is parents' prenatal mental health and prior mental health supports (Chang, et al., 2016). All of these factors vary on an individual basis; however, research supports that these factors impact a parents' mental health after the birth of a preterm infant (Holditch-Davis, et al., 2015).

Parents' mental health in relation to the NICU experience continues to impact them for years to come. One study found that mothers of preterm infants can have high levels of anxiety and/or depressive symptoms for months after the infant's hospital discharge (Holditch-Davis, et al., 2015). As noted by Chang, et al. (2016), distressing memories from the birth and NICU experience can persist for 3 years after the birth of a premature infant. More than 25% of preterm infants' mothers had significant distress 6-48 months after delivery. "Studies have shown that premature infants' mothers are at higher risk for significant psychological distress compared with mothers of term infants" (Zerach, et al., 2015. p. 204). Long term distress can lead to the diagnosis of psychological disorders.

The majority of psychological disorders parents of preterm infants may be diagnosed with include Acute Stress Disorder, anxiety, depression, Post-Traumatic Stress Disorder (PTSD), and a combination of the previously listed diagnoses (Lotterman, et al., 2019). Acute Stress Disorder (ASD) is defined as intense fear, horror, or helplessness in relation to a traumatic event and the symptoms of re-experiences, avoidance, physiological arousal, and dissociative symptoms. ASD describes the presence of symptoms with onset and duration between 2 days and 4 weeks after the traumatic event (Lefkowitz, et al., 2010). Post-traumatic Stress Disorder is a psychological disorder defined by symptoms of re-experiencing, avoidance, and hyper-arousal after a traumatic event involving the threat of death or serious injury to the individual or another that is accompanied by feelings of horror, helplessness, or intense fear. Symptoms typically occur within 3 months of the traumatic event (Holditch-Davis, et al., 2003).

Parents of preterm infants can experience some or all of the symptoms, which can impact the parent, the child, and the parent-child relationship. “Avoidance of trauma can result in mothers trying to forget the experience, avoid thinking about the experience, suppress reminders, or deny potential problems in the baby” (Gondwe & Holditch-Davis, 2015. p. 12). Over-protectiveness of the infant, persistent fear that the child might become sick or die, sleep difficulties, and generalized anxiety are ways that increased arousal is displayed in parents of neonates (Holditch-Davis, et al., 2003). Parents have reported to be anxious, stressed, and helpless as well as having difficulties with sleeping and eating, self-esteem, resuming tobacco use, marital or co-parenting conflict, and violence towards others (Gondwe & Holditch-Davis, 2015). Parents sometimes avoid taking their child to health care providers due to the reminders of the NICU experience (Holditch-Davis, et al., 2003). According to Lotterman, et al. (2019), maternal depression during infancy and childhood is linked to higher levels of internalizing problems (e.g., social withdrawal, anxiety), externalizing problems (e.g., bullying, acting out in school), and general childhood psychopathology.

### **Lasting Impacts on Premature Infants**

The Neonatal Intensive Care Unit has a lasting impact not only on parents, but also on the relationship between parent and child. “When a parent experiences stress from the intensive care experience or other sources, depression and trauma symptoms may develop or be exacerbated, interfering with parents’ ability to respond to their babies in ways that form healthy and nurturing relationships. This is concerning, as a positive relationship between the parents and infant supports healthy social and emotional functioning and is understood to form the foundations for gains in all other

areas of development” (Tomlin, et al., 2016. p. 310). Children who are born prematurely are at a higher risk for the development of behavioral issues and developmental delays (Holditch-Davis, et al., 2003).

When NICU parents are faced with the difficulties of their own personal circumstances such as their own mental health, financial burdens, and the feelings of loss in their role as a parent, it may keep the parents from being able to provide their vulnerable baby what they need at that time. The relationship between the parent and child may be compromised or impacted by these stressors on the parent. This increases “the chances that the baby will suffer negative outcomes, reducing the effectiveness of the parent-child relationship as a source of regulation and buffer for stress, and resulting in further insults to the growing parent-child relationship” (Tomlin, et al., 2016. p. 310). In time, the stressors and compromised parent-child relationship can contribute to ongoing behavioral and relationship issues that can carry on into childhood and beyond.

“The impact of adverse experiences related to hospitalization in intensive care, intrusive sensory environments, and restricted ability of parents to serve as buffers make for a ‘perfect storm’ that potentially compounds stressful responses in both babies and their parents” (Browne & Talmi, 2017. p. 20). During the infant’s NICU stay, there are often necessary but painful and stressful procedures that are done to provide the infant with the needed medical care. Ongoing treatment and caregiver procedures also add to the number of stressors the infant is faced with. As quoted by Browne and Talmi, Peters stated that infants in intensive care units typically have up to 60 caregiver procedures done to them per hospitalized day and it is even higher for smaller, younger infants (Browne & Talmi, 2017. p. 19). It is noted that after being handled, a procedure,

or caregiving was done that an infant's sleep was disruptive compared to prior to these events (Browne & Talmi, 2017). Browne and Talmi cited Smith and colleagues by saying that "in a typical hospitalization of babies in a neonatal intensive care unit, the number of invasive procedures is related to brain development" (Browne & Talmi, 2017, p. 19).

There is an emerging understanding that the early stressful events on an infant can impact their socio-emotional and physiological regulation and developmental outcomes. Children who are born prematurely are at a higher risk for the development of behavioral issues and developmental delays (Browne & Talmi, 2017). The infants experience long-term impacts of toxic stress, which refers to stressful or neglectful events early in life that occur on a continuing basis in the absence of buffering protection from a primary caregiver (Browne & Talmi, 2017). Early regulatory dysfunction and later cognitive and social-emotional delays lead to necessary referrals to a variety of support services as the infant grows and ages.

### **Supports for Premature Infants and Their Parents**

To help ease the strange and hectic world families suddenly find themselves in upon the birth of a premature infant is the Neonatal Intensive Care Unit staff. Parental involvement in the NICU is necessary. This allows for parents to provide their own parenting approaches that are regulatory, culturally significant and experiences-based as soon as possible (Browne & Talmi, 2017). "Parents who are encouraged to be present as often as possible without restriction for any reason, who are included in medical "rounds" where the attending physician discusses the infant's care and progress, and who are given opportunities to engage in all caregiving experiences offer



optimal opportunities for early relationship development and a more regulated infant and mother” (Browne & Talmi, 2017. p. 22). Having a nurturing, supportive and safe relationship with the NICU staff is crucial for the family to guarantee that the values of a solid relationship are transferred directly to the babies through the nurturing and supportive interactions they experience (Browne & Talmi, 2017).

Many NICUs today begin preparing for discharge by teaching and guiding the family soon after admission to the NICU. However, families continue to report that they feel underprepared to take their premature infant home. Parents have expressed that “discharge from the NICU is like being placed on a raft in the middle of the ocean without oars” (Tomlin, et al., 2016. p. 310). Upon discharge, parents want to normalize their family life; however, despite desiring normalcy, there remains this constant worry and anxiety about illness, physical complication, and developmental delays (Browne & Talmi, 2017).

A comprehensive approach to discharge and transition home planning can allow for the crucial supports that families need during this time such as psychological support, social support, and an emphasis on parent-child relationship (Murch & Smith, 2016). Two components of the transition home are the discharge readiness of the family and the integration and coordination of transition back into the community (Murch & Smith, 2016). Discharge readiness of the family consists of the discharge readiness of the infant and the preparation of the parents to provide care once at home (Murch & Smith, 2016). A transition home should involve an active discharge preparation program for parents to learn the care of their infant as well as arrangements for ongoing medical

interventions from their primary care physician or other related health care providers who are experienced in providing care for high-risk infants (Murch & Smith, 2016).

As part of the preparations for the infant to transition home, the parents need to acquire food, clothes, and other supplies, as well as explore available social supports. A social worker who is familiar with intensive care can be included in this process to help facilitate coordination of community resources and services for the family. The social worker can also discuss the range of emotions that accompany the transition of a premature infant home from the NICU. If therapeutic interventions are warranted, then the social worker can make such referrals.

It is crucial during this transition period that the NICU staff and the community providers come together on the behalf of these families to help support the family and infant in the process. The service providers need to “create and maintain a safety net of relationships and well-integrated services” (Murch & Smith, 2016. p. 300). A family’s experience and resources when transitioning home vary from community to community and state to state (Murch & Smith, 2016). Therefore, I want to learn what resources and supports are available here in Minnesota, but more specifically in the St. Cloud area.

## Chapter 3: Method

### Overview

The two main purposes of this Thesis Paper are first, to understand the long-term influence of the Neonatal Intensive Care Unit experience on infants born prematurely and their parents, and second, to provide parents and colleagues with the most current research-based information regarding supports after NICU discharge available in the St. Cloud area.

### Research Question

1. What lasting impacts does the NICU experience have on parents of babies born prematurely during hospitalization and after being discharged?
2. How does the St. Cloud Hospital Neonatal Intensive Care Unit support parents of preemies during their stay?
3. How does the St. Cloud community continue to support the parents after the infant's discharge?

### Research Design

The research design used in this study is qualitative research. Two questionnaires were developed to gather information about resources available during a NICU stay and after discharge from the NICU in the St. Cloud area.

For the first questionnaire, parents with an infant who was discharged from the St. Cloud Hospital Neonatal Intensive Care Unit in the last five years were asked to voluntarily participate. The questionnaire included basic questions to collect demographic data. Also included in the questionnaire were information-seeking questions that relates to their child(ren) and time spent in the NICU. Open-ended questions about resources available

during NICU stay and post discharge were included, as well as how helpful the individual believed these resources were. The final questions asked about reflecting back on the time spent in the NICU and post discharge and what supports they wish were available for them at the time.

The second questionnaire was given to a variety of agencies located in the St. Cloud area community who provide services to infants and their families. The first questions inquired about the agency and the role of the individual who is answering the questionnaires. The next few questions gathered information about services available, the requirements to receive the services, if the services have costs associated with them, and how long these services are available to an infant and/or family. There were questions about interagency collaboration and the process of how a family is referred to the agency. The last question inquired about other agencies or services that may be available to a premature infant and/or their family in the St. Cloud area.

### **Participants**

The sample for the first questionnaire included parents with infants hospitalized in the St. Cloud Hospital Neonatal Intensive Care Unit for at least ten days within the last five years (2016 - 2021). All participants had the ability to read and write English and reside within 30 miles of St. Cloud. These individuals were selected from member volunteers on the MN Premie and NICU Parent Facebook support group. Once agreeing to participate in the research, a private message was sent directly to them along with a link to the Google Forms fillable NICU Supports and Resources questionnaire for parents.

The sample for the second questionnaire included agencies located within the St. Cloud area that provide services to infants and their families. The link to the Google Forms

questionnaire was sent to an agency individual currently in a leadership position and is knowledgeable of the services the agency provides. The agencies were asked to participate in this research were identified and selected from my previous experience as a parent of a preemie and as an early intervention teacher in the St. Cloud area for 8 years.

### **Data Collection Method**

Data was collected in the form of questionnaires sent to individuals whose child either spent time in the St. Cloud NICU or who represent an agency in the St. Cloud area that provides services and supports to infants and their families. The participants were sent an email with a link to the Google Forms fillable questionnaire. The participants were asked to complete the questionnaire as soon as possible. If no response was received from them after seven days, a follow-up email was sent. The parent completed questionnaires were sent directly to my Google Forms account. No contact information was included in the report of findings. The participants representing agencies were asked to include their agency information to be able to understand specific services and supports each agency is able to provide. The agency participants were also asked to include their role in representing the agency to ensure a position of leadership.

### **Data Analysis**

Numerical data items were electronically tabulate and analyzed with descriptive statistics. A qualitative approach was used to analyze the remaining data by looking for patterns and themes of findings. Data gained from the parents was analyzed to see if there are additional agencies that should be contacted. An attempt to gain data from those agencies was made. The data collected from all agencies was compiled into a

grid. This analysis helped highlight resources still needed in the St. Cloud area and lack of information about support agencies in the area shared with parents at discharge.

## Chapter 4: Results

### Overview

The purpose of the questionnaire sent to parents of premature infants was to gather further understanding of the supports they had during their NICU stay and identify what supports were available once they were at home. Also, I was hoping to gain further information about the helpfulness of these supports. The purpose of the questionnaire sent to agencies was to gain specific information about the services they provide, qualifications to receive services, the cost of the services, length of services, how to make a referral and other agency related information.

I posted on two different dates for parents on the MN Premie and NICU Parent Facebook support group asking for volunteers that meet the criteria. I received a total of seven responses after the two postings. Unfortunately, I could only use the data from six of the responses due to one response not meeting criteria of length of stay in the NICU.

For the agency questionnaires, I contacted a total of thirteen agencies located within the St. Cloud area. I received three responses from my first email attempt. After a week, I emailed a follow-up email to the remaining ten agencies that had not sent responses. The follow-up email did not generate any additional input from agencies. I received a total of three agency responses.

### Demographic Results

All responses from my parent survey were completed by females ranging in age from 30 to 36 years with the primary language of English. The majority of the participants had a college degree (n=5), made \$50,000 a year or more (n=5), and were

married (n=5). See Table 1 for the demographic breakdown of the participants. The length of NICU stay varied from as short as 12 days to as long as 109 days. The premature infants gestational age ranged from 25 weeks 4 days to 34 weeks and weights from 1 pound 14 ounces to 4 pounds 11 ounces. There were no common causes of premature labor among the responses received. See Table 2 for the demographic breakdown of the premature infants.

**Table 4.1**

*Parental Participant Demographics*

	Number (n=)
<b>Age</b>	
younger than 20 years	0
20 - 24 years	0
25 - 29 years	0
30 - 34 years	5
35 - 39 years	1
40 years or older	0
<b>Gender</b>	
Female	6
Male	0
<b>Primary Language</b>	
English	6
Other	0
<b>Marital Status</b>	
Single, never married	1
Married or domestic partnership	5
Widowed	0
Separated or divorced	0
<b>Level of Education</b>	
Less than a high school diploma	0
High School/GED	0
Some college	1
Associate's/Bachelor's Degree	4
Master's Degree or above	1



**Table 4.1 (continued)**

<b>Socio-Economic Status</b>	
less than \$20,000	1
\$20,000 - \$34,999	0
\$35,000 - \$49,999	0
\$50,000 - \$74,999	1
\$75,000 - \$99,999	2
over \$100,000	2

**Table 4.2***Premature Infant Demographics*

	<b>Number (n=)</b>
<b>Length of NICU Stay</b>	
10 - 29 days	1
30 - 59 days	3
60 - 89 days	0
90 - 119 days	2
120 or more days	0
<b>Gestational Age</b>	
younger than 24 weeks	0
24 weeks - 26 weeks 6 days	2
27 weeks - 29 weeks 6 days	1
30 weeks - 32 weeks 6 days	2
33 weeks - 35 weeks 6 days	1
36 weeks or older	0
<b>Birth Weight</b>	
less than 15 ounces	0
1 pound - 1 pound 15 ounces	1
2 pounds - 2 pounds 15 ounces	1
3 pounds – 3 pounds 15 ounces	2 (twins)
4 pounds – 4 pounds 15 ounces	3
5 pounds or more	0
<b>Reason for Prematurity</b>	
Cervical insufficiency	1
Placenta Previa	1
Pre-eclampsia	1
Preterm premature rupture of the membranes (PPROM)	1
Other or Unknown	2

### **Supports Available While in the NICU**

The main response for supports that were available while in the NICU was the March of Dimes (n=6). Additional responses of supports were the NICU nurses (n=2), the hospital social worker (n=1) and Spare Key Foundation (n=1). Four individuals found these supports somewhat helpful in meeting their needs during their NICU stay, while only two individuals found these supports helpful.

Participants reported they wished there were more individualized supports during their stay as everyone's experience is different. Some specific examples that participants mentioned were mental health and emotional support for the parents, a list of non-profit organizations that provide support or resources, and support groups to connect to other parents and families in the NICU. One specific participant would have like more information about what life down the road might look like as their premature infant aged. They were not aware of some of the potential long-term medical and developmental challenges.

### **Supports Available After the NICU**

Upon discharge from the NICU, several of the participants' premature infants were referred to additional medical specialist such as ophthalmologists, retina specialists, and nutritionists or dieticians. One participant mentioned a referral to the Human Services department of the county they resided in. Another participant shared they received a referral for home care nursing to monitor the infant's medical needs on a weekly basis without the exposure to the clinic office's potential germs. Some participants were referred to follow along programs such as Help Me Grow (n=3) or the NICU follow-up clinic (n=2).

Once at home, participants reported they received support from the Help Me Grow program (n=3), NICU follow-up clinic (n=2), county human services (n=2), primary care doctor (n=1), lactation consultant (n=1), and March of Dimes (n=1). Two participants reported these supports as helpful, three as somewhat helpful, and one as not helpful.

Parents reported they wished there was more support after discharge from the NICU specifically for their own mental health (n=3), connections to individuals that supported the parents during the NICU stay (social worker, March of Dimes representative, etc.) (n=2), connections to other parents of premature infants (n=1), and increased availability for working parents of in-home resources or supports (n=1). One participant shared they felt like the support stopped once the premature infant was discharged from the NICU. An overarching area of need expressed by several of the participants (n=4) was the need for the continued support they felt they received while in the NICU from the nurses and March of Dimes about a variety of different areas of concerns or issues. Some of the areas of concern or issues topics were retinopathy of prematurity, feeding complications, failure to thrive, gastroesophageal reflux disease, warning signs or red flags.

### **Agency Results**

The information gathered from the three agencies that participated is compiled in Table 3. In this table, the questionnaire content is as follows:

- Name of agency
- Services the agency provides to premature infants and their families
- Requirements to qualify to receive services

- Costs associated with services
- Length of time services are available
- Referral process to receive services

**Table 4.3***Agency Questionnaire Results*

<b>Name</b>	<b>Services</b>	<b>Requirements</b>	<b>Costs</b>	<b>Length of Availability</b>	<b>Referral Process</b>
<b>Benton Stearns Education District</b>	Early Childhood Special Education (PART C)	qualify based off criteria set by the state for Part C (Low birth weight, identified medical conditions that have a high probability of causing developmental delays, hearing loss, or scoring - 1.5 standard) deviations or more in one domain of development)	no-provided under Free Appropriate Public Education	up to 3 years of age, then evaluated for services under Part B.	Help Me Grow website portal or directly to the agency
<b>Ellison Center</b>	individual therapy (grief, loss, trauma), caregiver-child therapy, Circle of Security class	therapy: caregiver must have a mental health diagnosis and have insurance or a way to pay for services  class: no requirements	therapy: yes (can be partially or fully covered by insurance)  class: cost is covered by grants secured by Ellison Center	therapy: as long as necessary  class: 16 weekly hour-long class sessions	Referral from outside source or directly on Ellison Center website

Table 4.3 (continued)

Name	Services	Requirements	Costs	Length of Availability	Referral Process
<b>St. Cloud Area Schools: Early Childhood</b>	Early Childhood Special Education (ECSE),	ECSE: qualify based off criteria set by the state for Part C (Low birth weight, identified medical conditions that have a high probability of causing developmental delays, hearing loss, or scoring - 1.5 standard) deviations or more in one domain of development	ECSE: no-provided under Free Appropriate Public Education	ECSE: up to 3 years of age, then evaluated for services under Part B.	ECSE: Help Me Grow website portal or directly to the agency
	Early Childhood Family Education (ECFE)	ECFE: no requirements	ECFE: sliding fee scale for families based off annual income	ECFE: variety of classes with different age ranges (Birth to 5 years)	ECFE: St. Cloud Area School District website to enroll in classes

## Chapter 5: Discussion

### Importance of Findings

As a result of my research, I hoped to answer the following questions: 1. What lasting impacts does the NICU experience have on parents of babies born prematurely during the discharge process and after transitioning home? 2. What impacts does this NICU experience have on the premature infant? 3. How does the St. Cloud community continue to support the parents and infant after NICU discharge?

With the support of my literature review, I was able to answer the first two questions. The literature review showed unequivocally that the current research shows a lasting impact of the NICU experience on both the premature infant and their family. This is valuable information because about 500,000 babies each year in the United States are born prematurely (Tomlin, et al., 2016). Their birth impacts an even larger number of individuals in the United States each year.

For the third question, I used my qualitative research to gather information to answer how the St. Cloud community supports parents and premature infants. Unfortunately, there seems to be a lack of support for these families once they are discharged from the NICU. The parents reported they felt supported to some degree while their infant was admitted to the St. Cloud Hospital NICU. However, once at home, they felt supports were unhelpful or limited.

These results lead me to believe that there needs to be a better preparation for discharge from the NICU as well as a plan of available resources and supports in place once the premature infant goes home. There seems to be a gap between the carry-over

of support and collaboration with the St. Cloud Hospital NICU and the St. Cloud community supports and resources after discharge.

### **Comparison to Literature**

The qualitative data gathered from parents of premature infants confirms the literature reviewed for this study. Local parents reported similar struggles found in the literature review of international parents. Overall, the parents struggled with the process of returning home with a premature infant just discharged from the NICU. They struggled with their own mental and physical health. They believed they lacked support and resources once available to them from the NICU. They had some supports available, but did not believe it was enough or specific enough to their individual families' needs.

My research about specific agencies and the supports available in the St. Cloud community has deepened the concern that there are too few resources and services available in the immediate area that work with premature infants and their parents. These agencies are also difficult to connect with due to the possibilities of limited staff, limited funds, or other issues.

Additional research areas could investigate how to help connect parents and premature infants to resources provided outside of the NICU setting. Determining what strategies work well for building the bridge between the two so that the families do not feel adrift "in the middle of the ocean without paddles" when they get home from the NICU (Tomlin, et al., 2016. p. 310). The St. Cloud Hospital NICU and the St. Cloud community agencies, including the early intervention service providers under IDEA Part C, need to develop a plan on how to implement these strategies to increase

collaboration for the purpose of successful transitions home for premature infants and their parents.

### **Constraints of Study**

There are several constraints to this study that were unforeseen when beginning the process of gathering data. One such constraint is the lack of responses overall from the questionnaires, but specifically from the agencies contacted. There is no direct contact information for many of these agencies. The contact email listed was often a general email address for an entire agency. My emails requesting participation in the questionnaires could have been sent to an email folder receiving several hundreds of emails a day.

Another constraint of the lack of responses was related to the postings on Facebook to gather parental participants. The post on Facebook would not necessarily show up on the feeds of the members of the support group, but was viewable if an individual was looking at the posts on the support group's direct page. Therefore, for a person to specifically see the post about participation, they would have to go to the support groups page and look for the specific post. This was an unforeseen factor in recruiting participants.

### **Final Thoughts**

Overall, the results of my research were surprising. I had expected to learn about other unknown or undiscovered agencies from the parent participants. No new information was found about unfamiliar agencies. The limited overall participant response was disappointing, specifically in regard to the agencies. The findings have identified an area of need in the St. Cloud community to increase the collaboration of



schools and agencies with the St. Cloud Hospital NICU for the long-term care of premature infants and their families. The information gathered should be shared with the local schools, agencies, and the St. Cloud Hospital NICU to help begin the process of building that bridge of support and collaboration. It was reaffirming to learn that the parents found the NICU staff and supports available in the NICU to be helpful and supportive. However, as with everything, there is large room for improvement as well. This information will be useful to help myself and my colleagues understand the difficult transition home after the NICU stay and the need for additional supports once at home. The impacts of and extended stay in the Neonatal Intensive Care Unit will stay with a family for their entire lifetime.

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**Appendix A: Draft Email to Parents**

To whom it may concern,

You are receiving this email because you have agreed to participate in a qualitative research study, as partial fulfillment of my master's Thesis (The Lasting Impacts of the NICU Experience and How a Community Supports the Premature Infant and Their Family) I am enrolled in through St. Cloud State University. Please take the time to answer the following questions and return to me as soon as possible. I understand that these questions may bring up difficult emotions, please feel free to skip a question or change your mind about participating. To respect your privacy, names will not be used when I use the information to report on the findings. Also included in this email is an informed consent form. If I have not received a response within seven days, I will follow up with an additional email to you.

Thank you, and I look forward to receiving your responses.

Sincerely,

Susan Koester

js9538tm@go.minnstate.edu

## Appendix B: Consent for Parents

### The Lasting Impacts of the NICU Experience and How a Community Supports the Premature Infant and Their Family

#### Consent to Participate

You are invited to participate in a research study about Neonatal Intensive Care Unit and St. Cloud area community supports and resources.

If you agree to be part of the research study, you will be asked to complete a one-time email questionnaire that takes approximately 5 minutes to complete.

Benefits of the research is to understand the lasting impacts of the NICU experience for premature infants and their families and what supports the St. Cloud area community has available to support them after transitioning home.

Risks and discomforts may include recalling a potentially traumatic period of time when transitioning home with a premature infant from the NICU. Please feel free to skip any questions or change your mind about participating.

Data collected will remain confidential. Your responses will be kept strictly confidential, your name will not be disclosed nor will identified direct quotes be used. You may refuse to answer any questions.

Participating in this study is completely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University, or the researcher. If you decide to participate, you are free to withdraw at any time without penalty.

If you have questions about this research study, you may contact Susan Koester (Principal Investigator): [js9538tm@go.minnstate.edu](mailto:js9538tm@go.minnstate.edu) or JoAnn Johnson (Faculty Mentor): [jojohanson@stcloudstate.edu](mailto:jojohanson@stcloudstate.edu). Results of the study can be requested from the researcher.

Your completion of the survey indicates that you are at least 18 years of age and your consent to participation in the study.

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Signature

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Date

## Appendix C: Questionnaire for Parents

### NICU SUPPORTS AND RESOURCES

Please answer each question to best of your ability. If you choose not to answer a question, please leave it blank. If the question does not pertain to you, please mark N/A.

Age: \_\_\_\_\_ Gender: \_\_\_\_\_

Primary Language: \_\_\_\_\_ Marital Status: \_\_\_\_\_

#### Level of Education

- Less than a high school diploma  
 High School/GED  
 Some college  
 Associate's/Bachelor's Degree  
 Master's Degree or above

#### Socio-Economic Status

- less than \$20,000  
 \$20,000 - \$34,999  
 \$35,000 - \$49,999  
 \$50,000 - \$74,999  
 \$75,000 - \$99,999  
 over \$100,000

What year was your admittance to the NICU: \_\_\_\_\_

NICU Stay: \_\_\_\_\_ days

Gestational Age: \_\_\_\_\_ weeks \_\_\_\_\_ days

Birth Weight: \_\_\_\_\_ lbs. \_\_\_\_\_ oz.

Reason for Prematurity:

\_\_\_\_\_

What supports were available for you while your preemie was in the NICU?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

How helpful were those supports in meeting your needs during the stay? (Circle one)

not helpful

somewhat helpful

helpful

What referrals were you provided when your preemie was discharged from the NICU?

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What supports and resources were available when you transitioned to home?

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How helpful were those supports in meeting your needs once at home? (Circle one)

not helpful

somewhat helpful

helpful

How long were those supports and resources available once at home?

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Looking back, what supports do you wish you had during your NICU stay?

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Looking back, what supports do you wish you had once at home?

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Is there anything else you feel is important to share with me in relation to my research?

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### **Appendix D: Draft Email to Agencies**

To whom it may concern,

You are receiving this email in hopes that you or someone within your agency with knowledge of the pertinent information is willing to participate in a qualitative research study, as partial fulfillment of my master's Thesis (The Lasting Impacts of the NICU Experience and How a Community Supports the Premature Infant and Their Family) I am enrolled in through St. Cloud State University. Please take the time to answer the following questions and return to me as soon as possible. To respect your privacy, names will not be used when I use the information to report on the findings. However, agency name and agency contact information will be included in my final report. Also included in this email is an informed consent form. If I have not received a response within seven days, I will follow up with an additional email to you.

Thank you, and I look forward to receiving your responses.

Sincerely,

Susan Koester

js9538tm@go.minnstate.edu



## Appendix E: Consent for Agencies

### The Lasting Impacts of the NICU Experience and How a Community Supports the Premature Infant and Their Family

#### Consent to Participate

You are invited to participate in a research study about Neonatal Intensive Care Unit and St. Cloud area community supports and resources.

If you agree to be part of the research study, you will be asked to complete a one-time email questionnaire that takes approximately 5 minutes to complete.

Benefits of the research is to understand the lasting impacts of the NICU experience for premature infants and their families and what supports the St. Cloud area community has available to support them after transitioning home.

There are no foreseen risks or discomforts with completing the questionnaire.

Data collected will remain confidential. Your responses will be kept strictly confidential, your name will not be disclosed nor will identified direct quotes be used. You may refuse to answer any questions. Agency name and agency contact information will be included in the final report.

Participating in this study is completely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University, or the researcher. If you decide to participate, you are free to withdraw at any time without penalty.

If you have questions about this research study, you may contact Susan Koester (Principal Investigator): [js9538tm@go.minnstate.edu](mailto:js9538tm@go.minnstate.edu) or JoAnn Johnson (Faculty Mentor): [jojohanson@stcloudstate.edu](mailto:jojohanson@stcloudstate.edu). Results of the study can be requested from the researcher.

Your completion of the survey indicates that you are at least 18 years of age and your consent to participation in the study.

---

Signature

---

Date

**Appendix F: Questionnaire for Agencies**

## Supports for Premature Infants and Their Families

Please answer each question to the best of your ability. If you do not feel like you are the proper person to be answering these questions for your agency, please pass along to an individual that is able to answer them for your agency.

Name of Agency:

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Title of Individual Representing the Agency:

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What supports does your agency have available for infants born prematurely and their families after Neonatal Intensive Care Unit (NICU) discharge?

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What are the requirements to receive these services?

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Is there a cost associated with these services?

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How long are these supports available to the premature infant and their family?

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In what ways does your agency collaborate care and coordination with other agencies the premature infant and family may be accessing?

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How is an infant and/or family referred to your agency?

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Are there any other services or agencies available in the St. Cloud area that may be of support to premature infants and their families after NICU discharge?

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