The Role of Social Support in Mothers' Experiences with Periviable Births

by
Christina Bui

A THESIS

submitted to

Oregon State University

Honors College

in partial fulfillment of
the requirements for the
degree of

Honors Baccalaureate of Science in Biology
(Honors Scholar)

Presented June 5, 2017
Commencement June 2017

AN ABSTRACT OF THE THESIS OF

Christina Bui for the degree of Honors Baccalaureate of Science in Biology presented on June 5, 2017. Title: The Role of Social Support in Mothers' Experiences with Periviable Births.

Abstract approved:_____

Melissa Cheyney

The periviable period is defined as birth between 20 and 26 weeks gestation—the limit of viability or the earliest age at which a premature neonate may be expected to live—during which clinical outcomes vary widely. The medical uncertainty with this pregnancy complication can cause a significant amount of physical and emotional distress for a mother and her family. The purpose of this study was to identify sources of social support and the roles they play in coping in order to help inform best practices for supporting parents of periviable neonates. Thematic analysis of de-identified interviews (n=9) using an open-ended, semi-structured, and consensus coding methodology enabled the identification of four salient themes that related to mothers' experiences with navigating a periviable birth and the immediate postpartum experience: 1) misdiagnosis and miscommunication, 2) family support, 3) the tertiary care team, and 4) connections with others who have had periviable births. Of the four themes, misdiagnosis and miscommunication added significantly to patients' fear and suffering, whereas the tertiary care team provided critical forms of social support that enabled families to better cope with the anxiety and unknowns of an extremely premature infant.

Key Words: social support, mothers, periviable births, premature births

Corresponding e-mail address: buich@oregonstate.edu

The Role of Social Support in Mothers' Experiences with Periviable Births

by
Christina Bui

A THESIS

submitted to

Oregon State University

Honors College

in partial fulfillment of
the requirements for the
degree of

Honors Baccalaureate of Science in Biology
(Honors Scholar)

Presented June 5, 2017
Commencement June 2017

Honors Baccalaureate of Science in Biology project of Christina Bui presented on June 5, 2017.

APPROVED:

Melissa Cheyney, Mentor, representing Anthropology

Indira Rajagopal, Committee Member, representing Biochemistry

Norman Eki, Committee Member, representing Pediatrics

Toni Doolen, Dean, Oregon State University Honors College

I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

Christina Bui, Author

Acknowledgements

I would like to thank Dr. Melissa Cheyney for being my mentor for my undergraduate thesis. Her patience, understanding, and support were truly monumental in my completion of this project and my knowledge of the subject. I appreciate all of the time in between all of your well-deserved award ceremonies, other thesis projects, and your own work to call me and clarify what I need to do to have a thesis I am proud of. Thank you for the late nights editing my writing and for giving me direction on this project. More importantly, thank you for your unwavering support in all aspects of my life. You are truly an example of a strong female role model who can do everything and then some.

Secondly, I would like to thank Dr. Indira Rajagopal for agreeing to be on my committee. I met Indira my freshman year in honors biology and I could not be happier that I get to end my undergraduate career. I would not love Oregon State University as much as I do had I not met you. Thank you for being my second mother in Corvallis, giving me advice, reassuring me when I have doubts, and for supporting me in all of my decisions.

Thirdly, I'd like to thank Dr. Norman Eki for being the first physician I have shadowed back in high school. While it was difficult to secure a job shadow as a student in high school, he welcomed me into his clinic and let me familiarize myself with the environment. Nearly four years later, he again gave me the opportunity to shadow him but as a more educated student and individual. Dr. Eki has been incredibly helpful and understanding and did not hesitate to agree to drive down to Corvallis from Gresham to attend my thesis defense. I thank him for opening new doors for me and for enthusiastically supporting my endeavors as a pre-med student.

Lastly, I would like to thank my parents and siblings. Their support for me throughout my entire undergraduate career has helped me to adventure new opportunities and realize what I enjoy doing. Although I didn't have much time to see them in the duration I was writing my thesis, they understood my obligations and supported me the whole way through. Thank you for being my biggest fans.

Table of Contents

CHAPTER 1: INTRODUCTION

Extremely premature births occurring between 20 and 26 weeks gestation are referred to as periviable births because infants are born at the limit of viability—or at the earliest gestational age at which a neonate might be expected to survive. Currently, births occurring at gestational ages before 23 weeks generally have about a 5-6% survival rate and commonly result in death of the neonate regardless of whether life-saving measures are attempted at delivery (Stoll et al). Periviable births make up about 0.5% of all births in the United States, yet this complication accounts for more than 40% of all infant deaths (Ecker et al.). Survival rates for infants between 23 and 24 weeks gestation are around 30%, although data indicate that this rate may be improving (Younge et al.). In addition, the health status of periviable babies can fluctuate rapidly with respiratory, cardiac, and brain function declining or becoming unstable with little warning. Approximately, 93% of premature infants will experience acute life-threatening respiratory distress (Stoll et al.) while in the Neonatal Intensive Care Unite (NICU), and all of these complications are more prevalent the earlier the gestational age at birth. Many of these problems also have long-term effects that can lead to impaired cognitive skills, vision problems, and hearing impairment (Patel) when the infant does survive.

Medical complications, such as periviable births, are devastating for parents because of the degree of medical uncertainty and fear of loss or lifetime disability they carry (Srinivas). In addition, the time, energy, and financial costs spent caring for an extremely premature infant can cause severe distress, anxiety, and feelings of vulnerability (Kantrowitz-Gordon et al.). Because periviable newborns are at high-

risk for such extreme complications, intensive psychosocial support is believed to be especially critical for these families. Research suggests that a mother's social support system can significantly impact her experience of a periviable birth and the aftermath (Mirabzadeh et al.). Having a strong support system can ease distress by enabling a mother to feel like she is not alone and that she has resources for coping with whatever the outcome may be (McCubbin et al.). When parents perceive that they have multiple people who genuinely care for them and their child, they describe feeling better able to manage or cope with severe distress (Mirabzadeh et al.; Lynch et al.).

Following a periviable birth, parents commonly meet with multiple health care team members who include bioethicists, social workers, spiritual care providers, nurses, and palliative care pediatricians (Ecker et al.). All of the care providers who assist mothers with navigating the postpartum period following a periviable birth can have a positive influence on how a mother sees or feels about the overall experience (Ecker et al.). However, the intended "support" provided during this time does not always have a positive effect and some forms of intended support can further strain the parents of a very preterm infant; these may also have lasting effects on the mother's perception of the experience. For example, confusing or conflicting information, prognoses and recommendations coming from different providers on the team can significantly increase familial distress (Lynch et al.).

Perceived social support has been argued to be a good predictor of positive health outcomes (Miller) via its mitigating impact on acute and/or chronic stress reduction (Mirabzadeh et al.). However, in the case of periviable births, mothers have

been shown to have high levels of stress, anxiety, and depression associated with their birth experiences, even many years later, and these negative psychosocial sequelae increase with the perception of the seriousness of their child's condition (Sophie et al.). Social support can help reduce short- and long-term negative feelings however, when there are low levels of support perceived around the time of delivery, mothers appear to be more vulnerable to long-term anxiety and depression (Kantrowitz-Gordon et al.). Studies have shown that mothers of premature infants have increased susceptibility to mental health conditions relative to mothers who babies are born at term. Overall, this body of work suggests that social support plays a critical role in both short- and long-term mental outcomes for mothers of periviable babies and that not all forms of social support are experienced as equally supportive. Less is known about the specific forms of support and methods of support delivery that are most essential to periviable families. Thus, the purpose of this study was to examine women's social support narratives following periviable births in order to identify the sources of comfort deemed most helpful by study participants. Ultimately, our goal was to use an analysis of women's periviable birth experiences to help inform best practices for supporting parents of severely premature infants.

CHAPTER 2: BACKGROUND: SOURCES OF SUPPORT AND STRESS IN PERIVIABLE BIRTHS

Periviable births, like many other medical complications, are associated with multiple adverse effects on a baby, the mother, and her family; social support has been found to ameliorate these. One qualitative study by Olsen and his colleagues used semi-structured interviews from patients in intensive care units and identified that support comes in two prominent forms: emotional and informational support (Olsen et al.). Emotional support is defined as helping a person feel that he or she is a valuable person and is cared about. Informational support helps patients to understand an event better and to determine what resources are available to them throughout their clinical encounter and following (Olsen et al.). However, Olsen and colleagues also found that the inability to identify which form of support a mother needs may actually increase her stress experience. For example, if a mother needs to be reassured and comforted and her family members offer advice regarding decision-making that does not align with her values, the mother might feel even more burdened.

The emotional effects of delivery to an extremely premature infant can be severe for both mother and baby. In a study conducted with 100 mother-infant pairs, psychological assessments were administered one year after the delivery of a very preterm neonate in an attempt to determine how emotions during the experience correlated with stress-induced conditions such as depression following the birth (Petit et al.). Results of this study indicated that mothers are likely to experience a higher degree of emotional and posttraumatic response after preterm birth relative to normal, term births. Another study suggested similar results wherein mothers of periviable

infants were also been shown to be at a higher risk for depression and anxiety disorders (Eutrope et al.). In this study, mothers completed a questionnaire that screened for traumatic elements relative to their premature birth. Results showed that mothers were more susceptible to posttraumatic stress disorder due to prolonged uncertainty rather than in response to physical characteristics of a neonate such as weight. However, a different study with 53 parents of premature children who filled out a stress survey and questionnaire reported that the greatest source of stress was the appearance of a fragile and sick infant, which leads to an altered parent-child relationship (Miles). Regardless of the precise primary source of stress (which appears to differ by study), collectively this body of work indicates that periviable births are extremely distressing for all involved. This is likely tied to the high degree of medical uncertainty involved in these cases; decision-making is complex and ethically challenging. Making one decision over another requires critical thinking about benefits and consequences in regards to the health and well being of the child, often in the absence of complete information.

However, research also shows that social support can also improve women's psychosocial health by serving as a buffer against stress and its consequences. One qualitative study found that certain types of social support safeguarded mothers against specific stress-related conditions including depression and post-traumatic stress disorder (Longfellow et al.). Data from interviews with mothers whose children had survived a periviable birth and were now older found that social support in the form of child care significantly increased maternal perception of life satisfaction. Life satisfaction was defined as how mothers currently rated the quality of their lives and

whether there were ways they felt their lives could be improved. Social support was also found to reduce the effects of stress on the maternal lifestyle. Agreeing with the results found by Longfellow and his colleagues, stress and support differentially affect maternal attitudes with developmentally at-risk infants; an adequate amount of emotional social support mitigates the impact of stress from having a premature infant (Crnic et al.). In this study conducted by Crnic, 104 mother-infant pairs were examined with 50% of the sample having had premature births and the other 50% full-term births. Each mother-baby dyad was assigned to another in a matched-pairs method where demographic features such as ethnicity and education of the mothers were used for matching. The results from home interviews and surveys indicated that mothers with perceived low support and high stress gave their general life satisfaction a low rating, indicating that stress negatively impacts maternal attitudes toward life. However, mothers with a perceived high support and high stress had higher general life satisfaction ratings, suggesting again that social support acts as a buffer for the consequences of stress. Furthermore, closer and more intimate relationships with supporters appeared to amplify this effect.

The quantity and quality of social support has also been shown to affect a mother's chronic and acute stress after a traumatic experience (Mirabzadeh et al.). The sheer number of people who offer emotional social support can reduce stress and its concomitant effects, but the quality has been shown to perhaps have a deeper impact on a mother. The "quality" of social support is described as the level of intimacy experienced within the relationship. A prospective longitudinal cohort study that identified women who had given birth to infants at gestational ages of between

24 and 32 weeks collected data using three questionnaires about: perceived social support, depression, anxiety, and stressful life events. Although there was no correlation between stress and social support with increasing gestational age, the study did find that the more intimate the relationship (like those exhibited between spouses or parents) the more likely that the effects of stress were reduced regardless of how traumatic the situation was (Mirabzadeh et al.). These findings suggest that the quality, and not just the quantity, of support influences mental health outcomes.

It has also been suggested that mothers who do not receive appropriate social support have more difficulty in coping with their premature births in the aftermath. One study sought to understand and measure mothers' memory of hospitalization. The researchers conducted phone interviews with 63 mothers who had given birth to premature infants sometime within the previous years (Sophie et. al). They found that mothers had a higher emotional connection to the experience if they perceived a deeper gravity in the state of the newborn. That is, women whose babies were thought likely to die could remember and describe more minute details than women who did not think their infant was at high-risk for mortality. Dissatisfaction of mothers' hospitalization also was lessened if the mothers perceived that the quality of medical information given to them was appropriate. Lack of support was associated with a negative maternal perception of her experience and her ability to cope with the situation (Sophie et al.). Mothers' present emotional condition and attitudes about the experience were used as proxies to estimate maternal coping ability.

Mothers who experience a periviable birth may delay development of maternal competence and attachment in response to medical uncertainty and fear of

loss. In a meta-synthesis of multiple qualitative studies explaining mothers' experiences of having a preterm infant in the Neonatal Care Unit, (Aagard and Hall) researchers found that giving birth to an extremely premature child often leaves mothers feeling separated from their infant until conditions have stabilized as the infant is being monitored. This sense of separation contributes to developmental delays in forming a maternal identity. Furthermore, the mothers can become hyper-vigilant around changes in or and threats to the child's health. This vigilance may make mothers even more susceptible to having a negative experience while hospitalized because they are continually distressed over things they ordinarily would not have to deal with in a term infant (Aagard and Hall).

In a study by Widding, interview narratives from parents of periviable infants were collected and analyzed with a focus on the experience of becoming a mother to an extremely premature child. Widding hoped to identify how parents managed and made sense of their negative feelings after delivery. Interviews in retrospective and took place months after the experience; 80 parents were included in the study. Both mothers and fathers described feeling distinguished from other parents because of the concomitant difficulty with prematurity. When an outcome or response to an intervention had a negative effect on the child, mothers described an extreme amount of guilt, making them especially vulnerable to both short-term and long-term health effects. Mothers in this study who knew about the medical uncertainty of the prognosis for their infant felt a shift in their maternal attitude and sometimes expressed an urge to reject their child in a way that is similar to what has been described for other animals that give birth to visibly impaired offspring. Widding

reports that some women tied feelings of rejection to thinking their child was “ugly”. This attitude led the mothers feeling conflicted and guilty relative to societal norms that require unconditional love. In this way, mothers’ mental health is compromised not only because of the stress of having a periviable birth and its uncertain prognosis, but also because of guilt over reduced attachment. Conversely, a comparative study involving both mothers of premature and full term infants sought to identify and explain any differences in emotional reactions between groups using questionnaires (Ionio et al.). Results from this study found that mothers with premature infants experienced more stress and negative feelings like anger, anxiety, and depression than mothers who delivered at term. The authors argue that the more negative a mother perceives her situation to be, the more risk she has for developing severe and long lasting poor mental health conditions.

The literature on periviability and social support has also examined the role family and friends can play in helping parents of an extremely premature infant. The primary support that a mother relies on for both emotional and informational aspects is family and close friends. This form may consist of emotional support, advice, information, involvement in decision making, prayer, and playing calming music for the mother (Kavanaugh et al.). Some mothers identified common people such as family and friends who can be present for the mother when she feels the need to express her thoughts and emotions during a difficult time. They may also offer advice and insight on decision-making. Having input from a variety of people with different backgrounds can impact a mother’s way of thinking and feeling about her birth and the choices she makes afterwards regarding care. Investigators have reported that

mothers feel more supported when they are able to ask family and friends with medical backgrounds for clarification on information provided by hospital staff (Kavanaugh et al.). If a mother has existing children, knowing they are well cared for by loving friends or family can allow her to focus on the preterm infant that is hospitalized, thus minimizing other responsibilities that mothers feel they still need to juggle. This is one critical way in which the grandparents of the infant can support the mother. Prayers from family and friends have also been shown to increase a mother's perception of support when religion is a significant aspect of the mother's life. Knowing she is being prayed for can increase her sense of hope for the situation. Investigators also found that playing soothing music to calm the mother could be helpful (Kavanaugh et al.).

If a patient is religious, then he or she may find comfort in confiding in religious leaders or counselors. As such, many hospitals now offer religious services like baptisms for patients. Because there are many factors like upbringing, culture, and religion that influence decision-making, offering such services to reinforce the mother's beliefs and emotional stability may lead to a more positive experience, especially in an event where the infant's health is uncertain (Kavanaugh et al.).

In addition to family, friends, and religious counselors, secular therapists and counselors have also been shown to be important sources of support for patients who have had a difficult birth and are struggling to cope with the outcome. These professional services may be offered by hospitals or found by the mother or someone in her social network, as women report a common need to talk to someone after having had a traumatic experience like a periviable birth (Gottlieb). By discussing

unresolved emotions, therapists and counselors can help improve a mother's emotional and mental health and by mitigating the negative effects of internalizing those feelings.

The goals of counseling are to support decisions, assist with confidence, and to provide general and ongoing support throughout the birth, the death or NICU stay, and the transition to life at home for those babies who survive.. One qualitative study involving patients of extremely premature infants, aimed to identify the main factors that influence decision making for extremely premature neonates (Srinivas). Researchers found that counseling and communication with all providers involved in the care of the baby were the most important factors (Srinivas). Counseling, in general, can involve the patient, their partner, and other family allowed by the patient. In these sessions, outcomes are explained and decisions are supported so that the mothers and their families are as best medically informed as possible. Other people involved in these sessions include healthcare personnel so that everyone has a common understanding of what is going on. Participants in the Srinivas study recognized the urgency of the situation but did not believe that they were sufficiently informed to make rational and confident decisions for care of their child.

Similar, in another study by Gaucher and Payot, seven women hospitalized for preterm labor were interviewed; researchers found that patients especially appreciated clear and consistent information when it came to outcomes of the neonate and their health management (Gaucher and Payot). Patients also indicated that they preferred counseling verbally and repeatedly so that they could better comprehend all of the information correctly. Patients felt the most positive about their experience in regards

to counseling and communication when they had verbal counseling along with supplemental written material that reiterated what had been said.

Therapy for mothers who have had a periviable birth is focused on the mother and how best to help her before and after the traumatic experience. Therapy can include healthy coping mechanisms, active listening, and positive regard for the mother (Kavanaugh et al.). This process may be utilized more by mothers who have lost a child due to the complications of being born at the limit of viability than those currently in the situation. Studies of therapy show that mothers who were able to share feelings of helplessness and not being able to ease their infant's pain benefited and reported lower levels of maternal stress (Miles).

While support can come from multiple places, the health care team is a significant factor in a mother's perceptions of feeling supported. The mother interacts with healthcare professionals throughout her experience including primary care physicians, the NICU nurses, and the tertiary care staff. In this way, the health care team is a central factor that determines how a mother feels about her periviability experiences. Communication and understanding on a healthcare provider's end plays a substantial role in whether a mother perceives her overall situation as negative or positive (Miles).

Oftentimes, mothers and their neonates are separated right after delivery because of the neonate's high-risk of health complications. Mothers often do not even have the chance to hold or see their newborn until they are stable. One prospective case study of women (n=75) who were interviewed before and after having a child in the periviable period collected information on how involved families and other

support systems were in the parents' decision making (Kavanaugh et al.) Parental stress was found to have stemmed from separation from the infant, altered parental role, and lack of communication with the healthcare team. Miles has argued that this stress can be alleviated by reducing such factors like parent-child separation and by enhancing the maternal role whenever possible (Miles).

Physicians and other healthcare providers have traditionally focused more on death and morbidity when providing information to parents, which contributes to a more negative experience because parents rely significantly on hope to get through an experience (Boss et al.). A qualitative, multicenter study involving three hospitals and parents that had an infant who died from issues stemming from extreme prematurity found that of the 26 mothers interviewed, all agreed that physicians were a significant factor in how they felt about the situation. Few of the women recalled that physicians talked to them about delivery room resuscitation and comfort care, even when documented in medical charts. Findings from this study also suggest that the coping mechanisms of religion and hope overshadowed the urgency and grimness of the situation for some women. Without optimism and compassion coming from others, parents felt abandoned and restless. Because mothers are trusting a large number of health care providers who they do not know well, feeling like they are misunderstood or not heard at all adds to more stress and leads to a negative experience while hospitalized (Miles).

Healthcare providers at all levels can offer a positive role of social support by personalizing each case. Patients experience a stronger connection when they feel supported and cared for (Janvier et al.). Showing compassion on behalf of health care

providers includes being understanding of the situation and recognizing how severe the stress is that patients are experiencing. Extreme stress from experiences as traumatic as a periviable birth can also complicate the learning process of parents in terms of decision-making, making it especially important to clarify any and all questions. Taking into account 48 other studies surrounding decision making for periviable infants, it is suggested that the most effective way to enhance the physician-patient relationship in these situations is to learn how to personalize, sympathize, and empathize with parents (Janvier). Additionally, identification of the needs of the parents, whether it is informational or emotional, also affects how they will feel about their hospitalization. A descriptive study using 19 interviews and 64 questionnaires further supports Janvier's assertion that patients heavily rely on their health care providers for support and guidance in an urgent situation (Bazy et al.).

In the Bazy et al. study, the decision making process for mothers and their spouses carried different needs during different times during the experience. For example, there may be decisions before delivery that emphasizes infant survival while the focus shifts to infant care after the delivery. Parents in this study also had a tendency to be more passive recipients before a delivery, while they actively sought information in the latter parts of the experience. The authors argue that this means that nurses and physicians in the NICU must learn to recognize when this shift in values and goals happen and how to best accommodate patients for the most effective communication. Because mothers must make decisions under constant and severe stress, health care providers can play a significant role by providing comfort and information.

Overall, this body of literature reveals that having a periviable birth is extremely distressful for a mother (Aagard and Hall) and that mothers could describe more minute details the more negative they perceived an experience (Sophie et al.). Social support can constitute either emotional or informational support (Olsen et al.) and forms of support that is more intimate, like those between spouses or parents, are more influential in emotionally helping mothers after a traumatic experience (Mirabzadeh et al.). Lack of such support may have an increased risk for stress-related conditions such as depression, anxiety, and posttraumatic responses (Eutrope et al.). Higher levels of perceived of social support can mitigate the effects of such conditions by increasing ratings for life satisfaction for mothers (Longfellow et al.; Crnic et al.).

However, the majority of research on social support and periviability to date comes from surveys and questionnaires, which can limit the range of answers women can provide about their experiences. Thus, the purpose of my project was to use open-ended, semi-structured interviews to identify sources of social support and the roles they play in coping in order to help inform best practices for supporting parents of periviable neonates.

CHAPTER 3: METHODS

The purpose of this project conducted at Oregon State University was to examine the role of social support in mothers' experiences with early prematurity through the analysis of data collected from open-ended, semi-structured interviews (n=9). This project utilized existing data intended for a separate study conducted by researchers at Albany Medical Center and Oregon State University (Lynch et al.). Approval for the analyses reported here was received from Oregon State University's Institutional Review Board.

Researchers at Albany Medical Center, a tertiary care hospital in New York, collected the interview data from women who gave birth to very premature infants between 20 and 25 weeks gestation at their facility. Women were invited to participate in interviews prior to delivery; those who agreed met with a study team member for an interview as soon as possible following the birth. All participants were prompted to describe the events prior to and following their periviable delivery (Figure 1). Questions were both structured and open-ended and designed to elicit women's perspectives on their experiences in their own words. Audio-recorded interviews were transcribed verbatim and de-identified.

Figure 1: Interview Prompts

- Please describe the events leading up to your labor. (follow-up with any clarifying questions)
- Please describe the events of your actual delivery. (follow-up with any clarifying questions)
- Why do you think you delivered early?
- How helpful was the information presented to you by your health care providers?
- What was your biggest fear throughout the whole experience?
- What kinds of social support did you receive during the experience? How helpful were these?
- Please describe your experiences in the Neonatal Intensive Care Unit (NICU).
  (follow up with any clarifying questions
- Do you have any advice to give to others going through a similar experience?

For this project, Cheyney and Bui independently analyzed the transcripts from a subsample of interviews with a focus on sources and roles of social support using a modified grounded theory approach (Charmaz). The goal of using grounded theory in this project was to facilitate the examination of periviable birth experiences from the perspective of the people who are directly experiencing them (Shreiber and Stern). This approach involves a methodology in which the phenomena being investigated (in this case, periviability and social support) are allowed to emerge from women's narratives. Key themes are therefore said to be "grounded" in participants' stories and not the result of questioning around *a priori* concepts or categories which may

function to limit responses (Strauss and Corbin). Analyses should lead to theory or hypothesis generation (Strauss and Corbin); as such, the goal is to explore some component of social life instead of confirming existing theories (Wagner). Both researchers completed codings of the interview transcript and then met to compare the codes or emic themes that emerged from independent analyses; any differences in coding were discussed until consensus around key themes was achieved (Bradley et al.). Emerging themes related to social support and periviability are discussed in detail below.

CHAPTER 4: RESULTS

Mothers' interview narratives revealed a wide array of feelings, attitudes and experiences around their periviable births interspersed with several common themes and sentiments. Different factors pertaining to social support evoked a multitude of feelings that contributed to both negative and positive experiences overall. Thematic analysis of the nine interviews exposed four salient themes that were grounded in women's experiences of birthing and grieving or caring for a severely premature infant: 1) misdiagnosis and feeling unsupported by primary care physicians; 2) the important of family support; 3) the excellence of the tertiary care team; and 4) the value of talking to others who have undergone similar experiences.

Theme One: Misdiagnosis and Miscommunication

Misdiagnosis during the early stages of a threatened early birth was a common factor that negatively contributed to a mother's experience of a later periviable delivery. Misdiagnosis encompasses any and all of the times that a health care provider did not understand that a mother's signs and symptoms were pointing towards a premature delivery. Miscommunication also relates to misdiagnosis because participants commonly described feeling like they were not being understood or "taken seriously" in terms of their initial symptoms and concerns over something "not being right with the pregnancy." In many instances, providers assumed contractions or pressure in the low pelvis were caused by a urinary tract infection, despite participants' assertions that they felt like they might be going into labor prematurely. This theme also refers to times where participants felt providers did not clearly present information to the patient or their family, leading to a more negative

experience during the birth itself or in the time that followed as participants navigated the Neonatal Intensive Care Unit (NICU).

Women's periviable narratives indicate that the beginning of the experience (i.e. the initial onset of symptoms and start of fears that something was wrong) for a mother was the most memorable. Because periviable births are so uncommon (less than 0.5% of births in the United States), many of these mothers' symptoms were dismissed and consequently received a misdiagnosis.

One mother expressed that her primary care provider "kind of just dismissed it" and told her that her symptoms looked like a urinary tract infection. The same mother was crying and "felt like [she] was being paranoid or overreacting because they did not seem like it was a big deal". Receiving a misdiagnosis or dismissal of symptoms like the aforementioned mother led to feelings of being ignored and unimportant which heightened negative feelings in retrospect. As study participants all went on to have periviable births, some with losses, all were able to reflect back on how they felt about the early stages of diagnoses and misdiagnoses. This time was described as traumatic, as was the experience of actually delivering a child in the periviable period. In these cases, being told that their pain was a urinary tract infection when the symptoms were, in retrospect, a precursor to an early delivery was upsetting for families; all wondered if their periviable birth could have been prevented had her physician quickly and accurately identified the warning signs. Mothers described not feeling valued or supported by their physicians and this contributed to negative feelings and regret upon reflection back to the stage prior to a clear diagnoses. Participants often felt as though their primary providers had failed

them through misdiagnoses and poor communication. Experiences like these hindered the mothers' ability to cope in the aftermath of the birth because they often blamed their primary care physician for not catching the condition earlier, thereby increasing the stress they experienced. This aspect of misdiagnosis was experienced as a lack of social support, which exacerbated or worsened the already negative experience of the periviable birth itself.

Women also felt like did not have effective communication with medical staff because they were reporting symptoms that would eventually lead to a periviable birth, yet there was little response from their primary providers. Women often cried when discussing these experiences during the interview—some to the point where they could not speak and a break in the interview was needed. Participants believed that effective communication with the medical staff at first onset of symptoms would have improved their experiences by at least allowing them to feel heard; feeling like there were being taken seriously initially also would have removed helped to reduce fears and regrets associated with wondering if "catching things earlier' would have made a difference in the outcome. A participant who felt like she did not receive adequate support from her primary care providers said: "I have no faith in it [prenatal care] at all anymore". Trust, in these cases was lacking on the patient's end. The uncertainty this added to the physician-patient relationship prevented women from trusting their physician's judgment and ability to provide care—a significant hindrance to having a positive experience as a patient.

Perviviability comes with a higher level of medical uncertainty, making mothers more vulnerable to stressors. Outcomes range from high survivability to

death with a wide spectrum in between these two extremes. For this reason, doctors do not have a lot of concrete information about how well an infant will do. Several mothers mentioned that they had wished they had more information about their condition or that the information should have been conveyed in a better way. One mother who delivered twins wished that her "doctors had more information about the mono-di twins". She described feeling like she "wasn't educated fully enough". This mother believed more information would have allowed her to notice symptoms earlier and to perhaps get a timely and accurate diagnosis. Participants believed that their health care providers at all levels of care could have improved these experiences by more accurately identifying the informational and emotional needs of their patients. Because a newborn's health conditions can change rapidly, parents must make difficult decisions regarding the infant's life quickly. The combination of misdiagnosis and miscommunication can produce strong, negative attitudes about the experience as a whole because mothers feel like they are denied the time and information that might make a difference for their newborns.

Theme Two: Family Support

Familial support provided by spouses, grandparents and even close friends who were described as "like family" was commonly experienced as a positive form of social support for study participants. Forms of familial support given to the mothers varied among participants. When asked about familial support, none of the participants perceived it as contributing negatively to their experience. Mothers identified their primary source of support as their husbands in the decision making process, as well as in the larger experience overall. Many felt it was important that

they and their husband "were able to come to the decision together". Women who did not have a spouse described the pressing burden of feeling like the outcome (whether good or bad) could only be "blamed" on them as the sole decision makers. These women relied more on family and medical staff to help guide their decisions.

Second to a spouse, grandparents to the infant were mentioned frequently as providers of social support. One mother shared that her mother, "was there with [her] initially…and stayed the first week" while she "had other family come in and stay with [her]" during the following weeks. This participant described being "close with [her] family so that that was wonderful". The presence of people that care for the mother and her child alleviated stress and helped mothers keep their minds off worries about the future or other unknowns. Another participant had her husband with her the entire time, but when she needed advice, she would call her mom and "always kind of checked with her" before going to medical personnel. Another participant talked about how helpful it was that her "mom and husband were there the whole time…they were just so supportive". In this way, mothers turned to an older generation for support whether it was just for someone to talk to or for advice and direction. Trust is an important component of social support and when women felt they could trust their support system, they perceived the experience in a better light. One woman described relying on her mother throughout the process: "My mother was there with me initially…she said she was very impressed with the way that there was a nurse that kept coming in. We felt well cared for." This participant also described feeling appreciative of the ways the tertiary care team interacted with the entire

family, including her mother and husband. It was important to her that her providers cared for the entire family and not just her and the baby.

Familial support was also described as vital for "lessening other burdens". If the mother had other children prior to her periviable birth, the social support that she had from grandparents and close friends who would take care of the other children during hospitalization "made a huge difference". Participants also appreciated support people who alleviated stress by visiting with flowers, food, and company. Input about decision-making and sympathy for the mother and her infant were also generally appreciated as they made women feel cared for. All of these actions from others allowed mothers to focus on their current health and their infant's health.

Theme Three: Tertiary Care Team

The tertiary care team includes all of the medical staff that a mother may interact and communicate with once she is admitted to the hospital with a diagnosis of imminent premature labor. Study participants expressed far more positive experience with their care providers once they were referred to a higher level of care. This was largely because due to the kindness and empathy they felt they received from the NICU nurses and physicians. Mothers described their care staff at the tertiary facility as helpful and understanding; they trusted the medical personnel they encountered and felt as though the ways information was shared conveyed compassion and understanding.

Mothers were, overall, extremely satisfied with their tertiary care team especially as compared to their primary care providers. One mother said: "They do a great job at what they do". Another woman praised the tertiary care team: "There was

such an urgent emergency situation…everything was handled amazingly fast". One mother who was frustrated with her misdiagnosis at her primary care provider stated: "It was nice to actually feel like people knew what was going on and that [she] wasn't crazy and [she] wasn't overreacting". In this way, the tertiary care team provided a positive form of social support by conveying compassion, competency and understanding. Another mother said: "To have people on top of everything and to say, 'this is what we can do, this is what we can't do, these are your options' that was so helpful for us." This participant was very impressed with the clarity of the information she was receiving and described feeling like the tertiary care team, did an "exceptional job in communication"; this eased her suffering. Participants expressed deep gratitude for these providers and explicitly discussed how being treated so well at the tertiary care facility deepened their dissatisfaction with their primary physicians. One woman described her experience this way: "The providers at the tertiary care facility actually sat down and took time with us and really seemed like they cared". She contrasted that with her primary care provider: " I didn't feel like they cared at all". This participant was especially impressed with the "way the NICU nurses cared for us. They really conveyed that they genuinely cared about what was going to happen with us". Feeling understood by the tertiary care team in this way increased mothers' trust, and this trust contributed to a more positive experience despite the urgency of the situation. Even when mothers lost their child, they still perceived a positive emotional connection with their healthcare providers. One woman said: "The memory boxes they did for us and all the encouragement to hold

the babies and have photos of them really helped me." These memories of what felt like true compassionate and support were very powerful for participants.

All but one of the mothers interviewed trusted that the medical staff was competent and understanding. For the one who did not, the tertiary care team contributed to a negative periviable experience. This participant described wishing that "more things were laid out… everything was just a mess". She felt that the tertiary care team was not as organized or as professional as they should have been and that the care team neglected to tell her "every step that [she] had to do" and that she "just wasn't prepared". Careful, compassionate explanations offered by medical personnel regarding treatment options and the infant's condition was deeply appreciated by participants and contributed to a more positive experience for mothers. Perceiving that health care providers were available to answer questions or clarify information was also appreciated as was being compassionate and understanding. However, the team also had the potential to impact a mother negatively especially if she did not feel like she was being listened to, understood or taken care of.

Theme Four: Others with Similar Experience

Mothers who had access to other people who had gone through a similar situation described being able to hear other mothers' stories as comforting and as contributors to a more positive experience. Hearing about success stories, getting advice from other parents who also had premature deliveries, and being able to share their own advice with others who were facing a periviable birth were also described as important forms of social support that helped to mitigate suffering and fear following the birth. After listening to medical jargon and statistics about health

outcomes for their child, mothers described feeling overwhelmed, exhausted, and in some cases, hopeless. Mothers shared that they appreciated hearing success stories as they enabled them to stay hopeful. One participant said: “I met a lot of people that I never knew that had premature children and it was nice to hear their success stories”. Participants described wanting to share their experience because they felt like, “people who will go, or who are going, through this situation want information on how things can turn out, you know on what to expect.” They wanted other mothers to, “see that there’s a bright light at the end of the tunnel sometimes”. Because the statistics on outcomes for periviable infants are not optimistic, knowing from other people’s experiences that a newborn has the possibility to grow up healthy felt helpful to some mothers in the midst of the experience as these stories gave them hope

Knowledge of other successful cases also reinforced the idea that they were not alone; others know what they were going through. Mothers who went to support groups felt that they were helpful, “because they make you feel like you’re not the only person in the world that something bad has happened to”. This also reinforced the idea that being understood was a big component of having a good experience, whether it was from medical personnel or from other mothers. Other mothers with severely premature infants offered more companionship than medical advice, which aided participants’ abilities to cope.

Mothers in our study also commonly expressed a desire to help others with similar experiences because they understood how traumatic and frightening a periviable birth could be. When asked about advice mothers would give to other mothers, one participant answered: “I would tell them to keep as much hope as they

can while having a realistic outlook on what could happen". The desire to offer positive words of encouragement emerged from an obligation some felt "to let others know what we've been through", what they were feeling at the time, and what they would do differently. When asked about why they volunteered to participate in this study, a majority of participants described "wanting to help someone else who will go through a similar situation" often citing how someone else's success story had helped them through their own traumatic experience. Mothers who felt that they were not alone wanted other mothers to also feel that. One participant said: "There's a lot of people, like me, who came into this without knowing anything that was going to happen". In reflecting back on their births and deaths or extended NICU stays, many felt that one of the most beneficial things that had gotten them through their "nightmare" was getting to meet and talk with other mothers with similar experiences.

CHAPTER 5: CLINICAL IMPLICATIONS AND CONCLUSIONS

Findings suggest that misdiagnosis and miscommunication played important roles in shaping participants' interpretations of their experiences as many expressed regret and frustration in the time leading up to their referral to the tertiary care facility. Participants' narratives also indicated that mothers rely on familial support to cope and that in general, families were grateful for the informational and emotional support provided by their tertiary care teams. NICU nurses were especially important sources of support for mothers whose babies survived delivery. In addition, this study found that mothers drew comfort from meeting other families with similar experiences; it was important for them to know that they were not alone in their suffering.

Based on our interpretation of maternal periviability narratives in this study, a series of clinical recommendations can be proposed. First, in order to help reduce the effects of the numerous stressors associated with a periviable birth, primary care teams could explore ways to implement more effective communication. Effective communication from a physician's perspective includes helping patients understand what they are telling them about a condition or diagnosis. However, it is important for health care providers to realize that communication is a two way street between a mother and her provider. Women in this study did not feel listened to during the early stages of a threatened periviable birth. We can understand this as a function of how rare such premature births are. Yet, we also see that misdiagnosis is a major source of distress, especially as families reflect back and try to make sense of their experiences. Taking this time to truly listen to women's concerns, especially regarding any

symptoms that could be related to prematurity, may help avoid later conflicts between a physician and mother that arise from a lack of communication or misinterpretation of information. Improved communication may also help to alleviate the "what if?" thinking that plague the postpartum period, especially for mothers whose babies died or who were significantly compromised. Women also need the opportunity to have questions answered about how effective attempts to stop preterm birth can be even when caught early or diagnosed immediately.

Tertiary care providers can also practice improving communication by allowing the opportunity for mothers to debrief their prior experience with their new medical team. Additionally, offering more insight and clarity about why some pregnancies result in prematurity can be essential for families who are struggling to understand what has happened to them. For example, providers can offer information about how rare periviability is and how difficult it is to predict so that they can work through any feeling of guilt or blame they may be grappling with. They can also help women to understand that once labor starts, it is extremely difficult to stop. Implementing these communication and debriefing practices might help reduce suffering associated with wondering about hypothetical "what ifs?" as they will have had sufficient opportunity to talk through their questions and concerns.

Secondly, because all participants expressed how appreciative they were of the various kinds of support they received from their spouses, family members, and close friends, we recommend that hospitals actively facilitate patients' access to support people. For mothers who do not have an extensive network of people around them, hospitals could appoint a support person, similar to a doula, to provide

continuous care for the mother from delivery into the NICU period. The person in this position could have duties that would resemble familial support but also include duties like talking through options, ensuring she is comfortable, helping to troubleshoot other concerns like childcare for other children or concern over how to explain the situation to siblings etc., and playing calming music. Such a "prematurity doula" could also have responsibilities to coordinate other forms of support for the mother, like a support group that consists of other mothers delivering prematurely.

Thirdly, results from the interviews showed that mothers were very satisfied with their experience with the tertiary care team. Women especially appreciated how much the team cared for them because of how frequently they would be visit to ensure that women were doing okay. The consistent influx of providers who made the women's emotional and physical health a priority contributed to a more positive experience. Physicians at this particular medical center are already implementing practices that aid with coping and help to mitigate suffering. Other facilities should aim to emulate these practices for mothers going through similarly traumatic situations.

Finally, women described the importance of hearing about and talking to other women who were going through (or had gone through) similar experiences even when there was not a happy ending to that woman's story. When asked why women participated in the study, many of them described the desire to help someone else who is going through or will go through this difficult situation. Because it was so essential for women to feel like they are not alone, medical centers should aim to create and facilitate support groups that include mothers who have delivered extremely

prematurely. Having access to other mothers may greatly improve the psychosocial health of mothers throughout their hospital stays by reducing the perception that they are alone in their experience. These recommendations are summarized in Figure 2.

Figure 2: Recommendations of Best Practices for Periviable Birth Care Situations

- Primary care teams should explore ways to implement more effective communication in the time leading up to a diagnosis of impending periviable birth; communication is a two way street;
- Debrief the experiences extensively, making sure parents have the opportunity to have all of their questions answered, especially those related to the time leading up to a dignosis;
- Implement a periviability doula program in hospitals to provide continuity of care from birth into the NICU period, especially for women who are under-supported;
- Evaluate and share interventions that improve families' perceptions of their experiences of care at tertiary facilities; and
- Facilitate support groups with other periviability families.

Implementing a periviability doula program could help hospitals meet many of the social support needs of mothers and their families that this and other studies have indicated are essential. Because doulas would get to know each family individually, they would be well positioned to identify need and coordinate services.. For example, if a mother is struggling to make sense of the time leading up to the birth, the doula could convey this to the medical team and facilitate additional debriefing/counseling. Periviability doulas could also provide continuity of care in a way that facilitates the meeting of individualized needs and prevents critical aspects of support from being missed by healthcare providers.

Overall, analyses of women's periviability narratives indicate that the best practices to help support women with periviable births include reducing negative experiences of misdiagnosis and miscommunication, supporting access to familial support, continuing the excellent work described for the tertiary care teams in this study and improving access to other families who have navigated a periviable birth..

REFERENCES CITED

Aagaard, Hanne, and Elisabeth O. C. Hall. "Mothers' Experiences of Having a Preterm Infant in the Neonatal Care Unit: A Meta-Synthesis." *Journal of Pediatric Nursing: Nursing Care of Children and Families* 23.3 (2008): e26–e36. *www.pediatricnursing.org*. Web.

Boss, Renee D. et al. "Values Parents Apply to Decision-Making Regarding Delivery Room Resuscitation for High-Risk Newborns." *Pediatrics* 122.3 (2008): 583–9. *search.library.oregonstate.edu*. Web.

Bradley, Elizabeth H, Leslie A Curry, and Kelly J Devers. "Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes, and Theory." *Health Services Research* 42.4 (2007): 1758–1772. *PubMed Central*. Web.

Brazy, J. E. et al. "How Parents of Premature Infants Gather Information and Obtain Support." *Neonatal network: NN* 20.2 (2001): 41–48. *PubMed*. Web.

Charmaz, Kathy. "Grounded Theory." 2014: 2023–2027. Print.

Burcher, Paul et al. "Cesarean Birth Regret and Dissatisfaction: A Qualitative Approach." *Birth* 43.4 (2016): 346–352. *search.library.oregonstate.edu*. Web.

Crnic, Keith A. et al. "Effects of Stress and Social Support on Mothers and Premature and Full-Term Infants." *Child Development* 54.1 (1983): 209–217. *search.library.oregonstate.edu*. Web.

Ecker, Jeffrey L. et al. "#3: Periviable Birth." *American Journal of Obstetrics and Gynecology* 213.5 (2015): 604–614. *ScienceDirect*. Web.

Eutrope, Julien et al. "Emotional Reactions of Mothers Facing Premature Births: Study of 100 Mother-Infant Dyads 32 Gestational Weeks." *PLOS ONE* 9.8 (2014): e104093. *PLoS Journals*. Web.

Gaucher N, Payot A. From powerlessness to empowerment: mothers expect more than information from the prenatal con- sultation for preterm labour. Paediatr Child Health. 2011;16(10):638– 642.

Gottlieb, Benjamin H. *Social Networks and Social Support*. Beverly Hills, Calif.: Sage Publications, 1981. Print. Sage Studies in Community Mental Health ; v. 4.

Hamilton I. McCubbin, A. Elizabeth Cauble, and Joan M. Patterson. *Family Stress, Coping, and Social Support*. Springfield, Ill.: Thomas, 1982. Print.

Ionio, Chiara et al. "Mothers and Fathers in NICU: The Impact of Preterm Birth on Parental Distress." *Europe's Journal of Psychology* 12.4 (2016): 604–621. *PubMed Central*. Web.

Janvier, Annie, Keith Barrington, and Barbara Farlow. "Communication with Parents Concerning Withholding or Withdrawing of Life-Sustaining Interventions in Neonatology." *Seminars in Perinatology* 38.1 (2014): 38–46. *ScienceDirect*. Web. Periviable Birth: Management and Counseling Issues Part 2.

Julianne S. Oktay. *Grounded Theory*. Oxford ; New York: Oxford University Press, 2012. *search.library.oregonstate.edu*. Web. 22 Apr. 2017. Pocket Guides to Social Work Research Methods.

Kantrowitz-Gordon, Ira, Molly R. Altman, and Roxanne Vandermause. "Prolonged Distress of Parents After Early Preterm Birth." *Journal of obstetric, gynecologic, and neonatal nursing: JOGNN* 45.2 (2016): 196–209. *PubMed*. Web.

Kavanaugh, Karen et al. "Extended Family Support for Parents Faced with Life-Support Decisions for Extremely Premature Infants." *Neonatal Network: The Journal of Neonatal Nursing* 33.5 (2014): 255–262. *CrossRef*. Web.

Longfellow, X et al. "The Role of Support in Moderating the Effects of Stress and Depression". *Society for Research in Child Development*. 1979. Web.

Miller, Luana Marques. "The Interrelationship between Social Support and Post-Trauma Symptoms in the Aftermath of a Severe Motor Vehicle Accident [dissertation]." N.p., 2007. Print.

Mirabzadeh, Arash et al. "Path Analysis Associations between Perceived Social Support, Stressful Life Events and Other Psychosocial Risk Factors during Pregnancy and Preterm Delivery." *Iranian Red Crescent medical journal* 15.6 (2013): 507–14. *search.library.oregonstate.edu*. Web.

Miles, M. S. "Parents of Critically Ill Premature Infants: Sources of Stress." *Critical care nursing quarterly* 12.3 (1989): 69–74. *search.library.oregonstate.edu*. Web.

Olsen, Kristin Dahle, Elin Dysvik, and Britt Sætre Hansen. "The Meaning of Family Members' Presence during Intensive Care Stay: A Qualitative Study." *Intensive and Critical Care Nursing* 25.4 (2009): 190–198. *ScienceDirect*. Web.

Patel, Ravi. "Short- and Long-Term Outcomes for Extremely Premature Infants." *American Journal of Perinatology* 33.03 (2016): 318-329. *search.library.oregonstate.edu*. Web.

Petit, Anne-Cécile et al. "Mother's Emotional and Posttraumatic Reactions after a Preterm Birth: The Mother-Infant Interaction Is at Stake 12 Months after Birth." *PLOS ONE* 11.3 (2016): e0151091. *PLoS Journals*. Web.

Schreiber, Rita Sara, and Stern, Phyllis Noerager. Using Grounded Theory in Nursing, edited by Rita Sara Schreiber, and Stern, Phyllis Noerager, Springer Publishing Company, 2001. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/osu/detail.action?docID=423411.

Sophie, Denizot et al. "Maternal Psychological Impact of Medical Information in the Neonatal Period after Premature Birth." *Early Human Development* 85.12 (2009): 791–793. *ScienceDirect*. Web.

Srinivas, Sindhu K. "Periviable Births: Communication and Counseling before Delivery." *Seminars in Perinatology* 37.6 (2013): 426–430. *ScienceDirect*. Web. Periviable Birth: Obstetric and Neonatal Management and Counseling Issues Part 1.

Stoll, Barbara J. et al. "Neonatal Outcomes of Extremely Preterm Infants From the NICHD Neonatal Research Network." *Pediatrics* 126.3 (2010): 443. Web.

Strauss, Anselm, and Juliet Corbin. "Grounded Theory Methodology: An Overview." 0: n. pag. Print.

Tucker Edmonds, Brownsyne et al. "'Doctor, What Would You Do?': Physicians' Responses to Patient Inquiries about Periviable Delivery." *Patient Education and Counseling* 98.1 (2015): 49–54. *ScienceDirect*. Web.

Wagner, Helmut R. "Review of The Discovery of Grounded Theory: Strategies for Qualitative Research." *Social Forces* 46.4 (1968): 555–555. *JSTOR*. Web.

Widding, Ulrika, and Aijaz Farooqi. "'I Thought He Was Ugly': Mothers of Extremely Premature Children Narrate Their Experiences as Troubled Subjects." *Feminism & Psychology* 26.2 (2016): 153–169. *SAGE Journals*. Web.

Younge, Noelle et al. "Survival and Neurodevelopmental Outcomes among Periviable Infants." *New England Journal of Medicine* 376.7 (2017): 617–628. *CrossRef*. Web.