Isolation and social support among mothers of medically fragile infants

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ABSTRACT

Objectives. To increase knowledge about how isolation and social support are experienced by mothers of medically fragile infants and understand how to better provide care and services to this population. Methods. Qualitative analysis of transcribed interviews with 31 women from the Postpartum Plus Prevention Program (P4) Study, a longitudinal, prospective cohort study of mothers recruited from the Neonatal Intensive Care Unit (NICU). Women were interviewed at 3, 6, 9, 12 and 18 months postpartum by a nurse-midwife who provided support and medical advice. Findings. Experiences of social support were diverse and complex. Effective support was tailored and trustworthy. Family was a major source of material and emotional support. Improving interactions with health systems and support services emerged as a need for many of the women. Conclusions. Social support is important for ensuring mothers’ mental and physical wellbeing and providing them with the resources they need to take care of themselves. Public health professionals and health care providers need to be mindful of the unique challenges faced by these mothers when constructing programs and messages to improve interconception health.

INTRODUCTION

Becoming the mother of a medically fragile infant is an exceptionally stressful and challenging life event. Social support can be a critical resource in helping mothers cope and alleviating the isolation that can result from this experience. Addressing the needs of this population is important considering that almost one out of every ten babies in North Carolina is placed in a Neonatal Intensive Care Unit at birth.¹ These medically fragile infants have a diverse range of conditions including prematurity, low birthweight, birth defects, or an overlapping combination of these. Thirteen percent of infants in North Carolina are born preterm (<37 weeks);² 2.6% are born very preterm, at less than 32 weeks of gestation.¹ 9.1% are born at a low birth weight (<2500 grams).³ About one in thirty-three babies are born with a serious birth defect.⁴ Rates of birth defects have remained stable over the past few decades,⁵ while rates of late preterm birth have begun to fall very recently, following a dramatic rise since the early 1980’s.⁶ Major advances in neonatal care since the early 1990’s have resulted in both improved
infant survival and long term outcomes. However, the saving of extremely small or sick infants has also increased long term morbidity, sometimes continuing into childhood and adulthood, among medically fragile babies who live past the neonatal period. Medically fragile infants have different long term health trajectories; many eventually recover while others are faced with a lifetime of challenges. Each infant’s course is unique and not always predictable.

From birth, medically fragile infants have special needs that require extraordinary support from health systems, health care providers, and most of all, their families. Mothers of medically fragile infants face a host of challenges and emotions in the NICU and after they bring their babies home. They must cope not only with making difficult decisions about their baby’s care and learning how to meet their baby’s special needs, but also how to construct their new identity as the mother of a medically fragile child and access new sources of social support.

The unexpected experience of spending weeks or months in the NICU and returning home with a fragile infant has the potential to change the social, familial and economic dynamics in a woman’s life, creating new relationships and both straining and strengthening existing ones. For the primary caregiver of a baby with special needs, experiences of isolation and limited mobility are common. Social support has been widely acknowledged as an important component of good overall health, and as a potential source of protection against the harmful health effects of stress and stressful life events. Supportive and tailored interconception health care (i.e., care between pregnancies) for high-risk women is an important component of improving birth outcomes and ensuring better health for mothers, children and families. This paper uses a grounded theory approach to examine how having
a medically fragile infant shaped mothers’ experiences of isolation and social support in this study.

BACKGROUND

A seminal article on the role of social support in moderating life stress defines social support as interactions that make us feel cared for, valued, and part of a social network involving mutual obligation and communication.\textsuperscript{11} The existence and experience of social support can provide a buffer against the damaging effects of psychosocial stress on our health.\textsuperscript{13} The literature on social support and health frequently shows the potential for a strong protective effect. Both the existence and perception of supportive social relationships are associated with better health outcomes, while social loss and loneliness can have harmful effects on health. The research regarding social support and health is convincing, but correlational rather than causal and often inconclusive.\textsuperscript{11-13} This is partially due to inconsistent definitions of social support, weak study design and difficulty replicating results, and the need to recognize that social support will be operational only “when the type of support provided matches the coping requirements elicited by a particular stressor or stress experience.”\textsuperscript{13, p261} In other words, social support must be tailored to the needs of the individual or situation in order to be effective.

This is particularly relevant to the social support requirements of mothers of medically fragile infants. Becoming a new mother is a stressful experience; social support can help mediate anxiety and depression and enable a positive transition to motherhood.\textsuperscript{16,17} It is well established that mothers caring for children with special needs are at particular risk for social and spatial isolation.\textsuperscript{18} Mothers of infants in the NICU develop new support needs during this
time, and may find some types of assistance more important than anticipated.\textsuperscript{10} One study of NICU parents found that lack of perceived social support, as measured subjectively using a scale that measured support from family, friends, and significant others, was associated with anxiety and depression among other poor psychosocial health outcomes, a finding that was identified as especially relevant for women.\textsuperscript{19} A review of the literature on isolation, social support, and mothers of medically fragile infants and children with special health care needs suggests four main types of social support which are discussed in this paper.

The first type of support is material support,\textsuperscript{20,21} also referred to as instrumental support\textsuperscript{10} or tangible support.\textsuperscript{13} This form of support includes providing financial resources, assisting with routine tasks and chores, or taking on another person’s responsibilities to enable that person to perform a different role.\textsuperscript{10} In a discussion of infants with special needs, this category may also include unpaid respite services, where someone else steps in to provide care for the infant for a short time, to free the child’s primary caregiver to rest, care for herself, spend time with friends or other family members, and accomplish other tasks.\textsuperscript{18} This is a particularly vital category of support for mothers caring for babies with special needs. One study interviewed mothers of preterm infants about their expectations of social support shortly before hospital discharge, and one month later. The category of material support showed the greatest increase in importance between the two time points, indicating this type of support to be even more significant than the mothers anticipated.\textsuperscript{10} Caring for infants with special needs in the home can be especially isolating for mothers; the physical, emotional and logistic work involved in leaving the house, particularly for mothers of technology-dependent children, can become a major impediment to participating in activities outside of the home.\textsuperscript{18} If material
support is offered, it is also important that this support is both seen as appropriate by the recipient\textsuperscript{13} and trusted as quality care. Inadequate or inaccessible care can further contribute to stress and isolation.\textsuperscript{22} Trusted and appropriate material support is a key component in facilitating a healthy caregiving relationship between a mother and her infant.

Material support often makes the difference in whether a woman is able to pursue economic or educational opportunities while acting as the primary caregiver for a medically fragile infant. The issue of whether a mother is able to work or pursue education is deeply integrated with both her ability to access various sources of support, and her general experience of stress and isolation. Participating in career or educational endeavors outside the home has the potential to expand a mother’s social network and increase her feelings of self-efficacy. Additionally, being able to financially meet their families’ needs is a major stressor for parents of young children with developmental disabilities.\textsuperscript{23} A meta-synthesis of qualitative research on mothering special needs children found that, unsurprisingly, caring for such children had a dramatic impact on mothers’ employment status. Many women chose to work fewer hours or stop working outside the home; those who continued to work questioned their decision or experienced negative effects on their career goals and work life.\textsuperscript{24} For some women, paid work was perceived as a break or respite from their role as a caregiver, and even identified as helping to lessen spatial isolation in certain cases. Others were grateful for the flexibility to leave work and become a full-time parent.\textsuperscript{18} Experiences of pursuing economic or educational opportunities while caring for a child with special needs are diverse and vital to understanding the overall context of support in each individual mother’s experience. As such, this aspect of the women’s lives is essential to understanding how they experience isolation.
and support following the birth of a medically fragile infant; given the diversity of outcomes among these babies, some mothers face a short interruption to work and school while others will be affected for much longer.

Two related types of support are emotional support and comparison support.\textsuperscript{20,21} Emotional support is a broad concept that includes “encouragement, affection, approval, and feelings of ‘togetherness.”\textsuperscript{10} Comparison support is emotional support provided by someone in a similar situation or undergoing a similar experience, who can provide a unique source of camaraderie, useful information, and credible advice.\textsuperscript{10} Given the distinctive experience of having an infant in the NICU, comparison support is particularly important for mothers during this stressful time. One study created a parent buddy program by matching experienced NICU parents with new NICU mothers to provide support; the mothers participating in this buddy system reported less stress, anxiety, and depression.\textsuperscript{25} Another study found social support (intimate, friendship, and community) to have a significant positive effect on the behavior and attitudes of mothers of both preterm and full-term infants, with intimate (partner/spouse) support showing the strongest effect. The same study found indications that maternal social support may even improve the development of social competence among infants.\textsuperscript{26} It is important to reiterate that provision of emotional support is not one-size-fits-all and support needs to be tailored. One study of a support intervention among mothers of high-risk infants transitioning from the hospital to the home found that the intervention improved self-efficacy among mothers needing a high level of support. However, among mothers needing less support the same intervention actually had a negative impact, possibly due to interrupting the mothers’ optimistic views of their children’s progress and
disrupting their processes of adaptation. Experiences of emotional support are highly individual and complex.

Finally, information and interactions with health systems are a critical part of mothers’ experiences caring for medically fragile infants. Informational support, a traditional support construct, consists of sharing knowledge or helping others access information. With regard to mothers of medically fragile infants, this type of support can include informational support related to interactions with the health care system. Navigating health systems and accessing services can be challenging even under the best circumstances, and these interactions take on a new meaning and weight as a mother with a medically fragile infant advocates for her child and herself. In one study of parents of preterm infants in the hospital, mothers in particular expressed a desire to participate in their baby’s care but found negotiating this participation a stressful and uncertain process. Several studies of mothers parenting children with developmental disabilities found that early interactions with health systems were often characterized by naiveté, passivity and trust in their health care providers. However, as mothers became more confident in caring for their children, they took on a more proactive, protective role. Individual experiences with health care providers were, predictably, both positive and negative. Supportive provider relationships were characterized by “acknowledgement of maternal effort and knowledge, and a willingness to listen.”

Negotiating respite services was another challenge for mothers; while this type of care has the potential to increase a mother’s mobility and appease spatial isolation, this is not always the reality. Financial constraints, particularly for mothers receiving publicly funded services, mean that respite care is often only available on a set and limited schedule, allowing
mothers to attend to other tasks but not physically leave the house. Another major concern is the ability of the paid caregiver to meet the child’s medical needs; many home health workers are not trained to provide the level of medical care a child requires. This mismatch between needs and expertise, along with not being able to build a consistent relationship with the same worker, suggests that respite services do not always provide a meaningful source of support and mobility to mothers.18

It is well established that mothers of medically fragile infants often experience stress and isolation as they adjust to their new role. Social support can help with this transition but must be tailored to individual needs and desires. Little qualitative evidence exists on how mothers of medically fragile infants experience isolation and social support as their babies transition out of infancy and into toddlerhood. Social support is best understood within the greater context of a woman’s life. Our understanding is enriched by considering the many unique aspects of a mother’s environment that contribute to her experiences of support, and hearing these stories in her own words. Social support has great potential to improve the health and wellness of mothers and families of medically fragile infants; more comprehensive studies on this topic are needed to inform efforts to provide effective, individualized support.

METHODS

Data

The data analyzed in this paper come from the Postpartum Plus Prevention Program (P4) Study, a longitudinal, prospective cohort study focusing on interconception health and health care for high-risk women. This study was approved by the Institutional Review Board (IRB) at the University of North Carolina at Chapel Hill. Between October 2007 and January
2009, a convenience sample of 44 women was enrolled in the P4 study. Women were eligible to be included if they: were above 18 years of age; had an infant receiving care in the UNC Hospitals’ NICU; had a living infant at the time of enrollment; and consented to be a part of the study. Mothers were self-referred or referred by a NICU nurse or physician, and recruited by a nurse midwife who had prior medical contact with most (87%) of the women in the study. As participants in the study, the women were offered a postpartum visit, a wellness kit at 3 months postpartum, and were interviewed by the nurse midwife at 3, 6, 9 and 12 months postpartum, and at the end of the study (18 months). At each time point, the nurse midwife covered a standard set of questions related to the study, and offered tailored support and medical information to each participant as needed. Contacts were recorded using either transcribed phone conversations or structured notes from in-person interviews. The nurse midwife was also available to the study participants for additional contacts over the phone and in person, and had an average of 15 contacts with each woman. It is worth nothing that the nurse midwife became a substantial source of social support for many of the women.

Sample Characteristics

For the purposes of consistency in this data analysis, only transcribed interviews were included. Structured notes were collected during in person interviews, while phone interviews were transcribed. As a result, all of the transcribed interviews collected in this study took place after discharge from the NICU, most at 9 months postpartum and beyond. Thirty-one women had transcribed interviews for one or more of the study contacts. Of the 31 women included in this analysis, eight of the women are black; the remainder (23) are white. The average age of the women in this analysis, as of May 2010, was 30 years old, with ages ranging from 20 to 42
years. The women represent 18 North Carolina counties and five US states in addition to North Carolina (several women moved away from North Carolina but remained in the study).

Seventeen of the women were insured by Medicaid, eight by private insurance, and six by Tricare (health benefits for military personnel and their dependents.) The infants in this analysis spent an average of 64 days in the NICU, ranging from stays of 3 to 145 days. Twenty-two of the infants were diagnosed with birth defects and the remaining nine were in the NICU for prematurity and related consequences. By the end of the study, two of the infants were deceased; seven were severely disabled; six were making progress but still coping with long term sequelae; and 16 were either fully recovered or progressing toward a full recovery.

**Analysis**

Analysis was performed using ATLAS.ti 6.2. The analysis involved selective coding informed by a grounded theory approach. Grounded theory involves approaching the data without a preconceived research question or hypothesis, and observing themes or trends that surface through the process of data analysis. The aim of this analysis is to understand and describe the lived experience of women in a particular situation (as mothers of medically fragile infants). For this analysis, coding was targeted to quotations involving the concepts of isolation and social support. The codes used are outlined in Table 1 below.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>Material support</td>
<td><strong>Definition:</strong> Help consisting of “performing household tasks, financial support, or taking over one’s duties so as to free that person to perform another role.”&lt;sup&gt;10&lt;/sup&gt;</td>
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<tr>
<td></td>
<td><strong>Includes:</strong> Mobility, ability to participate in self-care such as exercise or leisure time, financial/housing support, availability and acceptability of caregivers besides the mother</td>
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### Economic/educational opportunity

**Definition:** The ability or inability to pursue paid work and/or educational endeavors related to baby’s needs/condition  
**Includes:** Mother’s current work/education situation with regard to caregiving responsibilities, mother’s future plans and aspirations

### Emotional support

**Definition:** “Encouragement, affection, approval, and feelings of ‘togetherness’,“

**Includes:** Emotional availability and care from family, friends and community, comparison support (support from someone in a similar situation), stress due to lack of emotional/comparison support

### Informational/health systems support

**Definition:** Interactions with the health care system regarding mom and/or baby’s health; information provided by or regarding health care providers and health systems  
**Includes:** Interactions with health care providers, consequences of inadequate information from providers, feelings of trust or lack thereof with health systems, experiences with paid medical caregivers (i.e. home health care) for baby

Once the data was coded, the quotations fitting under each code were extracted and analyzed for recurrent and notable themes. The codes provided an organizational structure to the analysis but were intentionally broad and inclusive to facilitate the natural emergence of themes among a very diverse set of experiences.

**FINDINGS**

The infants of the women in this analysis have diagnoses ranging from extreme prematurity (birth at less than 28 weeks) to severe and often overlapping congenital anomalies. Throughout their babies’ first year of life, the mothers dealt with the experience and aftermath of their stay in the NICU. Some infants were on the path to full recovery by the time they were toddlers; others will require a multitude of special services and care for life. Two mothers experienced the death of their babies. Having a medically fragile infant is only one piece of the women’s lives throughout this time; they are also managing work, school, financial insecurity, marriage and relationships, family, other children, and often their own health issues.
The supposition that caring for a medically fragile infant often causes isolation among mothers was borne out in the experiences of the women in the P4 study. As one woman remarked, “I’m tired of not being able to have a life... I can’t go anywhere. I can’t do anything.” The degree and perception of isolation was impacted by the severity of the infant’s condition, the availability of support from partners, extended family, friends and community as well as a woman’s involvement in work or school outside of the home and diverse other factors. Likewise, there were many sources of social support discussed and more often than not they were complex and not entirely positive or negative in nature. Given that the subject of this analysis is the women’s experiences of isolation, a state characterized by solitude and often lack of voice, the analytical approach prioritized sharing the women’s stories in their own words as much as possible, both to express their experiences with integrity and let their stories be heard. The following subsections identify the most pervasive themes that emerged throughout the women’s interviews.

**Family support**

The role of extended family (family members outside of a woman’s intimate partner and children) was a significant theme running throughout the interviews. Grandmothers especially were often involved in providing childcare. In addition to caring for their infants, several women had accounts of their mothers providing unique and perceptive care for them, even when they did not ask for it or recognize they needed it, as described in these examples from two different women.

Mom came in the day after I had [my baby] and said do you want to go to the bathroom? I said yes mother, I do. ‘Well get up.’ ‘What?’ She said get up. She said use your legs and arms to get up and I was like yeah but I was like, mom, and she said it’s
going to hurt no matter what. She said you’ve got to get through the pain... See [my husband] went and stayed with his mother and my mom stayed with me. And it’s probably a good thing he did go stay with his mom because other than that, I wouldn’t have been up walking on my feet like that.

My mom told me that we needed a night out. I said well, no. I said no. She’s like, yeah. So I think me and my husband, see we went to, it’s a comedy club where comedians stand up and, you know, tell jokes and all that... it was really good.

Other family members also provided support and encouragement to get out of the house for self-care and to engage in exercise and other healthy behaviors. Physical activity is particularly important for these women given the high prevalence in this sample of medical conditions that could be improved with exercise (overweight and obesity, high blood pressure, diabetes, depression and anxiety). One example of a family member facilitating healthy behavior is illustrated in this mother’s description of a conversation with a sister who plans to move in with her.

We actually were talking last night for about an hour or so about how we were both excited and she’s excited because we can take little walks with [my baby] and go work out at the gym and this and that... And I’m like yeah! I’m so excited because I want that too. She’s definitely going to be, I think we’re kind of going to like have an unspoken support for each other.

Family also provided much needed emotional support to one of the women who lost her baby, in the form of solidarity and recognition. She describes her family, who live in different parts of the country, participating in a ritual to memorialize her daughter on what would have been her first birthday.

It’s going to be like the three of us and plus the grandparents and stuff, you know, and all my family down in [the South] is going to have like a lot of balloons and they’re going to throw, you know, throw them up in the air too all at the same time.

However, while many experiences of family support were positive or uneventful, interactions with family were also a source of strain and mixed emotions. Some of the women described a
lack of trust in the ability of family members to properly care for their infant, negating the 
benefits of having someone else available to care for the baby. As one mother explained, “I 
didn’t do a whole lot of resting because I really didn’t trust [my sister-in-law] a whole lot.” 
Interactions with family members also brought up insecurities; sibling rivalry was mentioned 
more than once. This mother describes how it feels to compare herself with her younger sister. 
Um, because [my sister]’ll start graduate school in the fall... She’s younger than me. And 
she’s about to go to graduate school. Isn’t that like a kick in the face?

Another woman described the mixed experience of having her sister come to live with her, 
noting that living with her sister is a source of stress as well as a valuable resource who can 
provide quality, familial care for her infant daughter.

You know, right now I have my sister living with me... You know, sometimes it can be 
frustrating and I’m like ughh...

**Interviewer:** *Is it helpful having her there? I mean does she help out with [the baby]*?
Yeah. In fact, she and [my daughter] are really, really close... Sometimes I think that [my 
daughter] would rather have her but then again she’ll yell momma, momma, momma.

A few of the women described very negative family situations that were exacerbated by 
poverty and the special childcare needs of their medically fragile infant. The following situation 
represents a critical case among the women in the analysis, in which a woman is facing a 
severely hostile family situation compounded by housing insecurity, poverty and an 
incarcerated partner.

You know, where I’m at now it’s really uncomfortable and it’s really bad because there, 
it’s arguing and fighting all the time. [My mother and I] just don’t get along. We’ve 
never lived together. I’ve been on my own since I was seventeen... It is terrible. It’s a 
terrible, it’s a terrible situation. **Interviewer:** *Does [your mother] help out with the kids?*
Um – Not really because [my son] still goes to his [other] grandmother and I, I have to 
pay her a hundred dollars a week to put my son on a bus. So, you know, this situation 
really ain’t getting no better.
In this case, on one hand, the baby’s paternal grandmother enables the mother to continue working by caring for her son during the week; yet with her partner incarcerated she is unable to fully support her children and herself, and is forced to turn to her own mother, with whom she has a very strained relationship, for housing. This experience, while certainly atypical throughout the women’s stories, represents one end of the spectrum and highlights the additional strain that occurs when a medically fragile infant becomes one piece in the downward spiral of a family in crisis.

**Immediate family**

Intimate partners and other children were often closest to the mothers throughout their experiences in the NICU and bringing their babies home. Some of the women described their partners as strong sources of support, both emotionally and materially. As expected, even within supportive, functional couples each parent handled the situation in his or her own way. In the following example, a mother who is pregnant again after giving birth to a baby at 29 weeks describes her need to be practical and realistic about the birth of her second baby, compared with her husband’s optimism.

I told him, I was like, you know I have to think, I can’t always think positive. I know too much. And he doesn’t understand that. He’s like you need to think positive. I was like well if she comes now, I’m sorry honey, I love you but she’s not going to live.

While many of the couples remained supportive and unified, many also experienced significant strain. Five couples split during the study; another five of the infants’ fathers were deployed at some point during the study. The loss of an infant had, predictably, a far-reaching and profound impact on both parents, as described by one mother.
I would say the biggest problem has been, um, our marriage has really suffered from everything that happened... We’ve had a lot of fights... It’s kind of day to day with us now. We don’t really make a lot of future plans because we’re just – we’ve gone through so much and it’s just kind of like right now we’re on survival mode.

Other children also constituted a potential source of distraction and stress for parents. Yet older siblings were also described as caring sweetly for the baby, as described by this mother who lost her infant after several NICU stays.

And with [the baby’s big sister] like we couldn’t, like sometimes I would go all day without talking to her because like I had, you know, just him, I had to focus on him. You know? Because I was always scared is this the day he’s going to pass, like you know and I was like, and she did so good. She did not care. She did not whine. She did not, you know, act like she was jealous... She was just glad to have him.

**Support from friends and community**

Affirmative support from friends, community and to a lesser extent, religious organizations appeared to have a very positive effect where it was available, and to be noticeably missed where it was not. Many of the women, particularly those in military families, spoke in detail about the social support available in their communities. The women often described the value of particular friendships, indicating that just one or two strong sources of support can make a huge difference in quality of life. One mother describes unexpectedly finding comparison support among two of her neighbors, and how this encouraged her to try becoming pregnant again after losing a baby.

Both of my neighbors, they have lost children. And they’re the same age as me... One of my neighbors, she lost two babies, a boy and a girl and my other one she lost her first born son... The one that lost the boy and the girl, she has a boy and a girl now. And the other one has a son... I’m like well if they can do it so can I... We talk about it all the time and like they’ve helped me through so much.

Another woman describes her neighborhood as a place where she and her child both easily find social interaction and support.
We’ve got some great new neighbors, um, lots of kids in our neighborhood so [my child] always got somebody to play with. We, you know, anywhere you go around the block you usually run into somebody... There’s two other ladies that we go for a walk with every morning and we tote the three strollers along with us so we’re able to go for about a two and a half mile walk.

The above neighborhood sounds like an ideal location for this mother and her family. She describes the availability of other neighbors with infants in a very positive light and, by saying that you can interact with someone just by going around the block, she gives the impression that both spatial and social isolation can be easily remedied in this environment.

**Daycare**

A major theme arising from the interviews was the relationship between mothers, infants, and daycare. Even though daycare would be a necessity for many of the women in order to return to work or pursue further education, mothers were overwhelmingly ambivalent about this step. Their reluctance was often rooted directly in their child’s current or earlier health issues.

I don’t like to have daycare with everything he’s got... I’d be afraid. You know? He’s not like somebody you know you can just let him play on the floor... You’ve got to watch him.

I never leave her by herself. I always have my eye on her. And you know for a long time I was worried about her breathing and things and I just can’t imagine right now just putting her in the hands of somebody else.

In addition to concern about letting others care for their child, mothers often expressed not wanting to miss out on time with their child after getting off to a rocky start and spending so much time in the NICU.

I just ain’t quite ready to let go of her yet. And I told, I told the therapist, you know, that I guess for all we went through last year I wanted time with her. Good time with her because, you know, we were back and forth all the time.
Understandably, mothers felt more comfortable with daycare if other special needs children were already enrolled or if the staff was willing to make special provisions. One mother describes her enthusiasm at finding a daycare that she liked.

It’s a home daycare... There’s another little boy that is, was also premature and he was twenty-four weeks and he’s a month older than [my son]. That was very exciting when I went and I found that out. I’m still very, very excited about that and it’s walking distance to our house so... we were just, we were thrilled on that one.

This is an especially important theme with relation to experiences of isolation; for mothers whose infants do not require round the clock medical care, but may have more specialized needs than normally developed infants, it can be hard to locate a daycare that inspires confidence. For women without trustworthy and available family members nearby to provide care, they may feel no choice than to remain at home even if they had originally planned to return to work or school.

Mobility

One common theme was the role of seasons and weather in mobility. While it is intuitive that people tend to stay inside during the colder winter months and spend more time outside once the weather starts to warm up, this appeared to aggravate difficulties getting out of the house and concerns for infant health among the mothers.

When it got warm weather I started getting out a little more. But the winter I sat in.

I’m like I don’t want to take her anywhere because I don’t want to risk her getting a cold. I don’t need two things to deal with.

While this association is obvious, it also highlights a time of particular risk for isolation, and the need for other options for exercise and social interaction. A couple of the mothers mention organizations where they can leave their children in daycare for a couple of hours while they
work out in the same building, or where indoor play spaces are provided for children. However, as discussed above with daycare, these spaces may not be equipped for infants with special needs.

An important point that arose in the data is that isolation and social support cannot be measured solely by proximity to social interaction. Sometimes the support and stress relief a woman needs most is to get out on her own and have some time to herself. One mother describes the importance of a brief weekly outing.

[My husband] gets mad at me because the doctor allows me to drive myself to the doctor’s office every week. That’s like my one outing that I get by myself and it’s like yeah I’m so excited. And I noticed even just going to the doctor it’s like wooo I get to drive and I get to go. And it’s always ‘do you want me to drive you to your doctor? I want to go to the doctor with you.’ I’m like no. [Laughter]. I know that sounds so ugly but I’m like no. I kind of want to go by myself.

Throughout the data family played a very important role in enabling mobility, with grandparents and to a lesser extent partners and other families members often stepping in to take care of the infant when a mother needed to return to work or school. In the absence of adequate, available daycare this often made the difference in whether a woman was able to get out of the house to pursue career and educational opportunities, and engage in self-care activities.

**Home health care**

A small subset of the infants required consistent support from home health workers or nurses. One of the women talked at length about her experience with home health care, which was overwhelmingly negative. Both the mother and her husband worked in the healthcare field and felt fairly health literate. She described deep disappointment with the quality of most
home health nurses who cared for her daughter, both their medical skills and their ability to provide emotionally engaged, quality care.

Poor [baby] don’t know what it’s like to be in the dark or not have the TV running. She’s never slept in the dark. The lights are always on and the TV is always going... They don’t do nothing but watch TV. I have a couple of good ones now that will get down on the floor and they’ll play with her and read to her and sing to her and, you know, they’re not the ones who have the TV on all day but now there’s some that from the time they get here to the time they leave that’s all they do is watch TV... And [my husband] and I, you know, we make her bottles and we, um, change her trach\textsuperscript{1} and supposedly we’re doing more than what we’re supposed to be doing but some of them I, I don’t know. I don’t feel like they’re capable.

She also described feeling that many of the nurses wound up in home health care because they were not competent enough to work in a hospital or doctor’s office. She said many of them had health issues and that led to their decision to work in home health. In addition to her disappointment, she described feeling deep betrayal at the way home health care had been portrayed when she met with the nursing company while in the NICU, compared with the reality of the situation once she took her baby home.

I just think there’s people out there that are given the wrong impression from these nursing companies and they think that they can handle it. I said because you all made us go back [home] with a new light. I mean we went with our head on our shoulders like we can do this, we can do this. I said and now I just want to have a private meeting with everyone who’s going home with home health care and say look, let me really tell you what it’s going to be like. Let me just forewarn you right now.

While not a theme described by many of the women (only seven of the infants had severe long term disabilities), the depth of disappointment and betrayal described by this mother indicate a critical need to examine the quality of home health services available. In this example, these health services are not only not alleviating the isolation of caring for a technology-dependent infant, but are in fact aggravating the stress experienced by these two parents. The infant is

\textsuperscript{1} Tracheostomy tube, a tube placed through a surgical opening through the neck into the windpipe to provide an airway and to remove secretions from the lungs.\textsuperscript{33}
not receiving an acceptable level of care, and so her parents are forced to step in. As described by the mother above, it is essential that parents have an accurate idea of what awaits them when they leave the NICU so they can plan accordingly. Receiving inadequate medical care for their daughter is clearly a source of stress, and potentially a contributor to isolation, for this mother and her husband.

**Women’s health care**

A subset of the women described troubling interactions with health care providers and health systems after returning home from the NICU to their respective communities. As a caveat, many of these contacts took place at one particular medical center, and may not represent the quality of care available in the state overall. These negative interactions often had to do with receiving inadequate information. As illustrated by the following quotes, some women found their own health care interactions lacking in satisfactory informational support, leading to potentially harmful medical outcomes. Two mothers describe receiving highly inadequate information from their providers:

And they just [said] oh it’ll go away, it’ll go away, it’ll go away. They never told me that it was HPV.\(^i\) They’re just like oh you got, you know, mild lesions on your cervix and everything and then when I went back for my six week check-up with the midwife that did my IUI\(^ii\) she referred me to [an outside OB/GYN] and she’s the one that explained to me and instead of it being a mild case, it went up to moderate so I had to have a LEEP\(^iv\) done... And see she told me she’s like well, you know, do you and your husband have, you know, protected sex? I’m like no. I mean you know we’re, she’s like well that’s how it’s transferred. Again well [the medical center] never told me this.

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\(^i\) Human Papillomaviruses (HPV) are common sexually transmitted viruses. Low-risk HPV can cause genital warts; high-risk HPV can lead to several types of cancer.\(^34\)

\(^ii\) Intrauterine insemination (a type of fertility treatment)\(^35\)

\(^iv\) Loop electrocautery excision procedure, a treatment for early cervical cancer that uses electricity to remove abnormal tissue (cancerous or precancerous) from the cervix\(^36\)
So he gave me this medicine but then when they gave it to me I didn’t read the little labels on it until after I left. And then on it, on the little label it says in third trimester it can cause defects... So it kind of concerned me because I mean I am in my seventh month now.

One woman describes her experience of seeking medical attention when it was warranted and receiving unacceptably insufficient care. This health system failure had a huge impact on the early health of her baby and the outcome of her pregnancy.

I was actually healthy throughout my pregnancy. But I went into pre-term labor. My water broke and [the medical center] didn’t catch it for three weeks. And you know had they caught it that very first time, I think things would have went a lot different.

Feeling supported by health systems and health care providers – through receiving accurate and adequate health information, feeling that concerns are acknowledged and addressed, and getting quality treatment when needed – is particularly important for mothers of fragile infants. These women have frequent contact with health care providers, and supportive interactions promote trust and continued utilization of health systems, helping to facilitate better health outcomes for mothers and their infants. Positive, effective interactions ensure that women are receiving screening and treatment for mental and psychosocial health issues. It is especially important for this population of women, who may be at risk for additional high-risk pregnancies, to receive quality interconception care.

**Infants’ health care**

Some interactions around infant health also indicated cracks or inconsistencies in health systems that can lead mothers to feel stressed and worry that their child is not receiving optimal care. The following mothers describe experiences of not feeling that their infant’s health was being taken seriously and prioritized.
I took her to the local emergency room and they told me they’re like oh it’s going to be a five hour wait. I was like you’re kidding me, right? My child can’t breathe all that well and you’re telling me it’s a five hour wait. So I waited like three hours and I asked them and she said oh well it could be another five. I’m like you know I can take her to the doctor tomorrow. I was like just forget it.

I don’t think she got any shots until she was two months. And, um, then I had to, you know, I had to remind them then and they’re like yeah she’s two months. She needs some shots.

Despite a theme emerging of dissatisfactory interactions with health systems, not all experiences were negative; several women described having great trust in and appreciation for the providers they met in the NICU in particular.

[The doctor] is wonderful... I mean he really is and I tell all the doctors around here, I say look, if there’s something wrong with her, I said I have his number and I can contact anybody in [the hospital where the NICU is located] and I’m pretty sure I can get some answers.

There were also accounts of some dedicated individuals providing valuable developmental support services, such as the physical therapist described in the following quote.

But either way everyone wants to do what’s best for [my daughter]. You know? As long as she has good physical therapy. That’s what matters is as long as she’s getting her good physical therapy. Her physical therapist said even if, even if she has to turn her over, she said she’s still going to come see her even, you know, for free. She said that she just wants to help [my daughter] so she’s wonderful.

This individual is contributing to the mother’s sense that her child will be well-cared for and receive the services she needs, despite barriers within the health system. While this is not a sufficient sample to draw conclusions about the availability of quality health care for medically fragile infants and their mothers, several themes emerged that indicate the need to further examine these interactions and ensure that high-risk women and their children are receiving adequate medical care, a critical component of feeling supported as the parent of a child with special needs.
Military life

A substantial subset of the women (six) are members of military families; all of these women’s husbands were deployed at some time during the study. Within the topics of isolation and social support, the experiences of military wives are distinct: partners are gone for months at a time, families move frequently, and women are often entirely dependent on the military for all of their needs from housing and health care to friendship. One woman describes her experience of social relationships that are easily formed but more difficult to sustain:

Actually as we go along you know we’ve met quite a few other people so – We’re a military community so people come and go all the time. It’s hard to find people who stay.

Living on post can provide a strong sense of community, but for military wives, this camaraderie is linked to their husbands’ positions. Cliquishness between different divisions can lead to a complicated hierarchy that carries over into social and neighborhood interactions. As such, women are very dependent on the military to provide entrance into appropriate social groups. One woman describes, first, her experience living on post and second, how she must wait until a pre-deployment event before meeting the other wives in her husband’s division:

Interviewer: And you like being on base? Is that good?
I do. I feel more safe here... except for people don’t like us around here... they don’t like [my husband’s division]... they don’t really care for them because they think they’re special. One of my neighbors already has talked junk about [my husband]... They don’t even know us.

Well I talked to this lady... She said once [the husbands] get on the team you’ll meet all the wives and everything. You know? She said you’ll love it. I was like yeah I hope so because I’m bored. I hate sitting at home all the time.

Deployment and moving frequently are key experiences in the lives of military wives. Living far away from family and friends who would normally form a woman’s long-term social network
can compound the absence of a partner. For one mother of a severely disabled infant, this means relying mainly on herself, with sporadic visits from friends and family:

My husband is not coming home but for fifteen days and that’s probably in November. And then he’ll go back out until April.

**Interviewer:** What are you going to do out there all by yourself? Are you going to be okay?

I just, I’ve been by myself all along until I got the friend of the family to come in for a month.

Another mother, whose baby was born at 29 weeks and was progressing to a full recovery by the end of the study, describes exhausting her material support resources and not knowing where to turn next:

And then his mom is coming the following week and then we don’t have anybody else... I’m like well did we use our resources too soon? But you know the doctor was like you need to make preparations [so] do it now.

**Interviewer:** Well how about the army? I thought they were going to [help provide care for the baby].

Oh they were but then they changed their mind... Well they said that my situation was not critical enough...

**Interviewer:** That is too bad. I really thought that they were going to help you guys out because it seems like they often do a good job of, you know, providing that kind of support for people, but.

Yeah. Well, not too much.

Military families enjoy guaranteed health insurance (Tricare) and in some cases, may have access to an accessible and well-structured system of social resources on post. However, military wives cope with unique challenges that put them at great risk for isolation, making consistent social support even more essential but harder to maintain.

**Overall experience**

Not all of the mothers were in the position to look back and reflect on their experience as a whole. Many, especially those with more severely disabled infants, were still in the trenches, figuring out the details of care, support, and their new reality. However, some of the
women reflected on what social support meant to them throughout their time in the NICU and afterward. One mother who lost her baby after several hospital stays discussed what the support of the health care providers in the NICU meant to her:

I was so glad to meet you guys. I mean I couldn’t have asked for a better you know, people to take care of me and [my baby]. Like you guys were really there for us and everything and I appreciate everything you guys did.

Another mother, whose baby made a full recovery by the end of the study, discussed how the experience actually had a positive outcome:

You know what, it made us, it made us stronger and made us appreciate [my daughter] a lot more. **Interviewer:** Yup. And you made some good friends. You met [another NICU mom?] and some other people there at the hospital so that was all good. I guess everything happens for some reason.

Oh exactly. Exactly. So I mean I wouldn’t trade it. Would I change it? I would probably make her a bit further along. But as far as the experience, it just makes me appreciate her a bit more.

Both of these women were able to reflect with a kind of closure; while these experiences will shape their lives forever, their time as mothers actively caring for medically fragile infants had ended. In these two examples, the women’s positive reflections of this very painful time related directly to memories of good social support.

**DISCUSSION**

The themes that emerged through this grounded theory analysis paint a picture of social support among the mothers that is highly individual and complex. The arrival of a healthy new baby can be expected to test a woman’s coping skills and the support available to her from family, friends, communities and health systems. The birth of a medically fragile infant changes expectations and creates new needs. Following the birth, often early and unexpected, of a fragile infant, parents suddenly have to arrange their lives around caring for their baby in an
unfamiliar hospital setting, sometimes far away from their homes and other responsibilities, for weeks or months at a time. After bringing their babies home, mothers handle the emotional aftermath of this experience while trying to meet the ongoing special care needs of their new infants. Having a medically fragile infant seems to test the limits and quality of social support available to the mothers in this study. Black et al. describe a pattern among mothers of medically fragile preterm infants of mothers intentionally narrowing their social networks immediately following the baby’s birth, and then beginning to widen their social circle after “mothers perceived their infants as less vulnerable and their confidence increased in their ability to manage infant care.”\textsuperscript{28, p47}

Women in this study who already had strong marriages, supportive friends and family members, or positive neighborhood and community involvement often experienced an affirmation of these ties, even if the support provided was not always a perfect fit. Women who were already in precarious family and financial situations found these circumstances exacerbated by the arrival of a medically fragile infant. Docherty et al. describe the multiple pathways through which poverty shapes the experience of mothering a medically fragile infant. Lack of maternal resources, housing instability, living in a community with high rates of drug and alcohol abuse, single parenting, stigmatization by health care providers, and chaotic family situations all had a profound effect on women’s ability to care for their infant and develop as mothers: “the context of poverty directly affected the maternal developmental trajectory... However, despite the distress and negative developmental impact of the infant's birth and illness, most mothers did grow intrapersonally.”\textsuperscript{29, p368} Similar to the findings of this study, some mothers of medically fragile infants increase self-efficacy and are inspired to pursue
educational and career opportunities as a direct result of caring for their infant. Families of the most severely disabled infants in this study sometimes found support from health systems insufficient to restore some sense of normalcy to their lives. This was expressed through lack of trust in the care provided by home health nursing companies and a sense of betrayal at the stark difference between the level of care expected and the kind of care received.

One of the major findings throughout the literature on social support and fragile children is the necessity of appropriate, tailored support. The importance of this kind of support was confirmed throughout the themes that arose in this study. This was especially apparent among themes related to care for the baby. Care from family members, daycare, and home health workers were a source of stress if the mother perceived the care as inadequate or untrustworthy. As would be expected, someone else caring for the baby only alleviated stress if the caregiver was a trusted family member or had specific experience and demonstrated competency caring for medically fragile infants. This theme continued into emotional support provided by friends and family. The mothers in the study had individual methods of processing the emotional trauma of having their infant in the NICU after they returned home. Optimism might not be an appropriate type of emotional support for a woman who wants to acknowledge the likely outcome of another child born extremely preterm. Likewise, support from family and friends is most effective when it directly addresses a particular need. Tailoring support becomes more complicated when it takes the form of a reciprocal relationship. This was a fairly common situation throughout this study. Support becomes more complicated as time goes on, because it is no longer a matter of providing targeted support for several days or weeks while the mother and baby are in the hospital. As the baby grows up and the mother
often must return to work or school, the limits of her social network’s ability to help meet her needs on top of their own is tested. Sometimes this threshold is crossed before a family has figured out how to provide care for the infant on their own, as vocalized by one woman who wondered if they had used their resources too soon. Poverty and unstable or crowded housing can add to the strain placed on a mother’s kinship network when they must step in to provide for her and her infant while she is unable to return to work due to her infant’s medical needs.29

This is where interactions with paid caregivers come into the picture, and these relationships can fall short of their potential to lighten the stress and isolation experienced by mothers. While not a major theme throughout the data, one mother described very disheartening experiences with home health nurses and expressed a sense of betrayal after being given confidence by this option while in the NICU. Contact with health systems and health care providers arose as a theme throughout the data and as a distinct area of need for some these mothers. Some health care providers inspired confidence and seemed to be acting in the best interests of the mother and child while others left the mothers feeling confused and seriously shook their faith in health systems. Some women left interactions with providers, both theirs and their child’s, with inadequate information, feeling that their concerns were not taken seriously, and receiving insufficient care for their medical needs. While only a subset of women discussed these kinds of experiences, this is of great concern given the importance of interconceptional care, particularly for the high-risk women included in this study. Interconception care is an important opportunity to screen and refer women for psychosocial and mental health or substance abuse concerns, promote positive nutrition and physical activity habits, counsel women on family planning and help them access contraceptives, and
treat conditions that could lead to future negative birth outcomes (such as high blood pressure or diabetes). This is also a chance to assist with service coordination for mothers with chronic conditions, and/or mothers of children requiring special medical and developmental support services. To help mothers effectively utilize their interconception health care interactions, providers should actively listen to their patients, be aware of women’s social and environmental circumstances, and help them to make positive behavior changes that fit their lifestyle.

Parent buddy systems in the NICU have been shown effective at reducing stress and anxiety, and providing valuable informational support among families who may find it culturally or linguistically difficult to interact with hospital staff. This may be a method to consider in the future when planning programs to support mothers as they transition home from the hospital and begin navigating the maze of home health care services and developmental therapies available. Sensitive care and support for parents who experience the perinatal death of their child is also an essential consideration. Perinatal loss is a highly traumatic experience that leaves parents at risk for numerous negative psychosocial outcomes, including post traumatic stress disorder (PTSD), in the short and long term. The grief following a perinatal loss often contributes to marital strain. Perceived inadequate social support has been identified as a factor in poor psychosocial outcomes among parents experiencing the death of their infant.

The original purpose of the P4 study was to evaluate the interconception health care needs of high-risk women and how to best care for this population. Exploring isolation and social support in this study adds to our understanding of what happens when families of medically fragile infants leave the NICU and return home. While experiences of social support
are highly complex and dependent on myriad factors including pre-existing social networks, poverty, and health systems, this study identifies needs that are well within the scope of public health research and interventions. These needs should be acknowledged in efforts to establish best practices in providing interconception care to high-risk women.

Limitations

One main limitation to this study is that only transcribed interviews were included, thus excluding a substantial number of women (13) who were in the original P4 sample. This reduced linguistic and ethnic/racial diversity in the sample, and made the sample less representative of the general population seen in this NICU. It also reduced the diversity in time points represented; there were no transcripts for interviews at the 3-month time point, for example, and all interviews took place after hospital discharge.

Another limitation is that the interviewer was acting in the capacity of a health care provider and source of social support to the women as well as a researcher. Interviews were unstructured and frequently conversational in nature. Each contact was tailored to the woman’s individual life and needs. Questions were not uniform and were sometimes leading. While this resulted in interviews that were unstandardized, the nurse midwife’s close relationship with the women could also be viewed as a strength, as it likely promoted their level of comfort and disclosure in discussing their lives.

This study is exploratory and descriptive. While not intended to be representative of all mothers of medically fragile infants in the state, this research can help inform efforts to provide interconception care and support to high-risk women in North Carolina.
NEXT STEPS

Our challenge as public health professionals is to translate the complex needs revealed in this study into concrete strategies to support mothers of medically fragile infants. Social support is a challenging concept to incorporate into programs and practices, but there is promising evidence that interventions such as parent buddy systems in the NICU are desirable and effective at reducing stress and increasing informational support.\textsuperscript{25,31} This study shows that support services available to families with medically fragile infants have significant room for improvement. Health care systems, social services, public health programs, maternal and child health services, faith and community organizations all have an important role in supporting and caring for this population. Incorporating the development of social support into the recognized needs of these families can improve our ability to effectively serve them and improve their holistic wellbeing.

Regarding interconception care, programs should focus on assessing social support among new mothers of medically fragile infants, and recognizing the importance of this support for their mental and physical wellbeing. Tailored support was a major theme throughout this study. This can be accomplished, above all, by asking women and families what they need. Future research to help NICU providers and programs care for these families should focus on how to effectively facilitate social support as families transition out of the NICU and back into their communities. For example, it would be helpful to understand how mothers negotiate asking for support from informal sources once they return home. Is this a process that could be improved if mothers received advice and encouragement about how to manage this process before their baby was discharged from the NICU? For mothers without an existing strong social
network, interventions could focus on helping them identify community or faith organizations and other resources to provide social support once they return home. Comparison support emerged as one of the most helpful forms of support in both the literature and this study; connections with others who have shared in a similar experience can be an exceptionally valuable resource for both emotional and informational support. Creating an accessible venue (an online forum, for example) to help NICU parents stay connected, exchange stories and advice, and share resources, could be a feasible and self-sustaining intervention to provide continuity of support throughout and after the transition home. With the challenges of isolation, particularly among military families who move frequently, web-based support could be an effective tool that merits testing and evaluating. Building on the findings of this study, future research should focus on how women access social support and what the health community can do to facilitate these connections. Many interesting subthemes emerged in this study that warrant further analysis. The experiences of military wives with medically fragile infants, the challenge of finding adequate daycare arrangements, and the effect of having a fragile infant on marriage and intimate relationships all merit further exploration.

In summary, each woman in this study faced distinct challenges and accessed social support in her own way. Isolation was a fairly common consequence of caring for a medically fragile infant, but many of the mothers reached out to their support networks and found individual ways to cope. Social support interventions in this population have the potential to improve mental, physical and psychosocial health among these women and improve quality of life for medically fragile infants and their families.
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